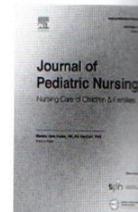




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Perceptions of children with cancer and their parents regarding illness: A qualitative study



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ABSTRACT

Purpose: The current study aims to understand inter-generational differences and similarities in the perception of illness and the available resources employed by children with cancer and their parents.

Methods: A qualitative descriptive research design was utilized, including face-to-face interviews with 108 parent-child dyads where the children had been diagnosed with cancer, by means of a semi-structured questionnaire. The participants were recruited from two pediatric hematology-oncology wards in two different hospitals in Israel. The data were analyzed using conventional qualitative content analysis. Debriefing and inter-rater reliability methods were utilized.

Findings: Similarities were found between the coping of children and parents with the illness. Children with cancer and their parents can find bright sides and support for coping, such as different perspectives on life, faith, positive thoughts, and family assistance. Most of the differences between the perceptions of children and parents relate to the difficulties encountered. While parents are mainly concerned about the long-term impact, children contend with ordeals involving the here-and-now.

Conclusions: Parents and children demonstrate a dual process in their challenging journey. Positive and facilitating factors are intertwined with the aggravating aspects, which exist side by side.

Practice implications: Nursing staff should advise children and their parents to attain and use external and internal sources of support found in this study to help them deal with cancer.

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Introduction

Every year approximately 300,000 children aged 0 to 19 are diagnosed with cancer worldwide (Steliarova-Foucher et al., 2017), generating fear, anxiety, and distress among their families. Along with the difficulties, evidence has shown that children with cancer and their parents can also experience positive emotions throughout the illness trajectory (Straehla et al., 2017). Only a limited number of studies have examined inter-generational perceptions of cancer among children and their parents. The current study explored inter-generational perceptions of difficulties and alleviating factors among both parents and their children. The findings can provide a broad portrayal of factors that could offer support for the duration of the cancer trajectory.

Background

Difficulties impairing the capacity of sick children and their parents to cope with cancer

A diagnosis of childhood cancer might have varying effects on the sick child as well as on the parents and family. The parents of a child with cancer might experience many difficulties, from the moment of diagnosis and many years after conclusion of the treatment (Ljungman et al., 2015). From the emotional respect, studies show that parents experience a wide range of feelings, including anxiety, fatigue, loneliness, helplessness, and stress (Demirtepe-Saygılı & Bozo, 2020; Gurtovenko et al., 2021; Lewandowska, 2021). Stressors are related primarily to the sick child's suffering as a result of the illness and treatments, recurring hospital admissions, and uncertainty concerning the future (Cox, 2018; Eche et al., 2019).

From interpersonal respect, childhood cancer may affect the relationships between family members. A study conducted by Lewandowska (2021) among 800 parents of children with cancer found that 47%

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reported difficulty with finding a balance between caring for the sick child and for the child's siblings and the lack of opportunity to spend quality time with the healthy children. Also, the relationship between the parents might be harmed by the child's illness. A study conducted among 90 parents of children diagnosed with leukemia found that half the participants reported that their spousal intimacy had been negatively affected (Barruscio-Higa & Valdés, 2022). In addition, the financial aspect might be a stressor burdening parents of children with cancer primarily due to job termination or leaving one's job following the child's illness (Roser et al., 2019).

The child diagnosed with cancer also experiences many physical and emotional difficulties while coping with the illness, including pain, nausea, vomiting, lack of appetite, tiredness, harm to body image (Linder & Hooke, 2019; Miller et al., 2011), sadness (Linder & Hooke, 2019), stress, and fear (Compas et al., 2014). Studies that examined the fears of children with cancer found different sources of fear, including pain related to pricking, removing bandaging, and inserting feeding tubes (Leibring & Anderzén-Carlsson, 2019).

One major resource for dealing with all occurrences is social support, defined by Cohen et al. (1985) as a state where a person belongs to a group that provides mutual relationships, commitment, and responsibility. Social rejection and loneliness are linked to various negative emotional experiences, including anxiety, depression, anger, and shame (MacDonald & Leary, 2005). A study conducted in Canada found that according to parent reports, children with cancer experience loneliness and social alienation as a result of missing school, the concern of contracting infections when their blood count is low, and concerns involving body image, which make it hard to maintain continuous social relationships (Tsimicalis et al., 2018). Family and social support allow one to share fears and concerns, receive support from others, consult, and express feelings. One's belief that supportive elements will be available in times of crisis improves the individual's ability to cope. Moreover, social support can reduce or eliminate the negative consequences of a stressor for the individual's behavior and health (Cohen et al., 2000). Thus, social support can serve as a "buffer" against stressors. According to Lakey and Cohen (2000), when the type of support provided is well adapted to the stressor, it can serve as a defense mechanism. It can also affect one's perception and evaluation of one's ability to deal with a stressful situation.

Social relationships have a powerful effect on one's happiness (Argyle & Lu, 1990; Hills & Argyle, 2001). Bradburn (1969), in his early work on personal well-being, found a strong correlation between social relationships and positive feelings. This leads to the main question of this study: Do parents and children experience similar difficulties and hardships? In addition: Can parents and children experience positive feelings alongside the difficulties? Positive and negative feelings are described as two different mechanisms that operate concurrently, where the existence of one does not detract from that of the other (Fredrickson, 2013, 2016). Fredrickson (2013) indicates the ability of positive feelings to constitute an immunizing mechanism responsible both for fighting negative emotions and helping the body develop, as positive feelings are perceived as a major component of one's ability to experience a high level of well-being. The study of well-being in general, or of positive feelings that constitute a main component, focuses on the question of which elements facilitate positive feelings.

Elements that make it easier for sick children and their parents to cope with cancer

Studies conducted among children with cancer and their parents found that, side by side with factors that hamper coping, there are also factors that help and increase well-being, such as social support, optimism, spirituality, faith, gratitude, changing one's perspective on life, resilience, knowledge, and others (Bally et al., 2014; Chien et al., 2020; Gise & Cohen, 2022; Mahayati & Happy, 2018; Wehdizadeh et al., 2019).

Pargament (2011) investigated the role of faith in coping and in the human capacity to reach positive feelings and high psychological well-being. He found that irrespective of the type of faith, one's very ability to believe in something and to strive for it constitutes an element that facilitates coping. In the case of parents of a child with cancer, maintaining faith might contribute positively to coping with fear and to mental fortification (Schneider & Mannell, 2006; Vitorino et al., 2018). A similar resource that assists with coping is hope, which gives one the ability to achieve goals in various ways in times of routine or sickness (Snyder, 2000). Studies have found that this resource helps both sick children and their parents find hope and manage the stressful situation, reduce anxiety, and improve their quality of life (Bally et al., 2018; Martins et al., 2018).

The research literature emphasizes factors that make it harder or easier to cope with cancer from the perspective of parents and of sick children. Nonetheless, the literature contains insufficient information on the similar and dissimilar components in the perceived experience of illness among children and parents and whether and how they experience these feelings and events positively.

Aim

The aim of the study was to understand the similarities and differences between parents and children in their perception of illness in the context of a child's cancer regarding three aspects: difficulties, the coping experience, and available sources of strength employed by children with cancer and their parents.

Methods

Design

The present study is a report on the qualitative part of a larger study conducted with a mixed methods design. The study used a descriptive qualitative design. This methodology makes it possible to describe phenomena that are hard to quantify based on the narrative of the person experiencing them (Shkedi, 2007). Descriptive qualitative studies allow the participants to present their experiences with their own words, language, and meanings (Sandelowski, 2000). The descriptive qualitative method grounded from a naturalistic inquiry approach. The naturalistic inquiry approach aims to locate the truth as it is reflected in the eyes of the individual in his natural environment without the researcher's interpretation (Colorafi & Evans, 2016). Regarding the research aims, the descriptive qualitative approach allows researchers to deeply understand the similarities and differences in the coping journey of parents and their children with cancer and the resources that support this complex coping.

The study was designed in the form of face-to-face interviews guided by a semi-structured questionnaire.

Setting and sample

The interviews were conducted among 108 parent-child dyads recruited from two pediatric hematology-oncology wards in two different hospitals in central Israel with 60 beds altogether.

The inclusion criteria were as follows: (a) Children aged 7–18 years; (b) children who had been diagnosed with cancer at least 6 months before the study began, and no more than one year after the end of treatments; (c) ability to communicate in Hebrew; (d) free of pain and with no analgesia at the time of the interview; (e) parental informed consent to participate in study; (f) child willingness to participate in the study.

In each hospital ward, data were collected from the child's computerized records to assess the children who met the criteria for inclusion in the study. Initial contact was made with the parent in order to explain the aims of the study.

Research tools

The interview in the current study was guided by a semi-structured questionnaire based on three open-ended questions. Two questions

address factors that cause difficulty and relief when dealing with the illness. The third asked the participants about positive consequences of the illness. Additional questions were raised depending on the participants' answers

The questionnaire was developed by the research team based on the literature review (e.g., Bally et al., 2014; Eiser et al., 2000) and according to the aims of the study.

Data collection

The interviews were conducted by two expert pediatric-oncology nurses who were trained to conduct the interviews. Data collection was carried out from 2014 to 2017

The interviews took place in a private room in the ward. Each of the interviews, with the child and parent separately, took 45 min. When the parent was being interviewed, the child was with a volunteer or another family member. The child was interviewed in the presence of a parent unless he/she agreed to be interviewed alone. The interviewer asked the participant each question and gave him/her time to think before answering. Additional queries, clarifications, and probing were utilized during the interview, depending on the participants' answers. The interviews were manually transcribed by the interviewers, including gestures and reactions.

Analysis

The data were analyzed using conventional qualitative content analysis, following the recommendations of Hsieh and Shannon (2005). In conventional content analysis, coding categories are derived directly from the text data. Thus the transcripts of the interviews were first read by two research teams, for an initial coding scheme. Next, the researchers discussed the agreed criteria codes and organized them into a tree diagram with a hierarchical structure of categories, sub-categories, and codes. A discussion was held to identify inter-generational child-parent associations regarding categories and codes.

To determine the rigor and quality of the data analysis, debriefing and inter-rater reliability methods were utilized as recommended by Morse (2015). The research team met three times for two hours each to complete the process.

Ethical consideration

Approval for conducting the study was obtained from the Helsinki Committees at the two hospitals (# 0178–13-RMC, # 0611–14-TLV, respectively).

All parents provided oral and written informed consent. The children were asked separately for their consent to participate in the study. Parents and children participated in the study only with their consent and willingness. It was clarified to the participants that they could choose whether to answer the questions and that they could add information that matters to them even if not requested. The parents and children could stop the interview at any time or request a break. They were assured that there would be no consequences for withdrawing from the interview.

Findings

Participants

The participants' characteristics are shown in Table 1. Altogether, 108 child-parent pairs were interviewed. The children had been diagnosed with various types of cancer, from common diseases such as leukemia to rare childhood diseases such as carcinoma of the colon. About one third of the children were under intensive treatment and the others had already completed their intensive treatment

Themes

The findings below reflect the themes, codes, and sub-codes shared by the children and parents, although sometimes the meaning or translation attached to the contents differed between the child and the

Table 1
Parents' and children's characteristics.

Characteristic		Parents (N = 108)	Children (N = 108)
Sex	Female	70.4%	40.7%
	Male	29.6%	59.3%
Age in years	Range	30–62	7–18
	M	44.46	13.10
	SD	6.10	3.62
Parent's marital status	Married	82.4%	–
	Single	0.9%	–
	Divorced	13.0%	–
	Widowed	3.7%	–
Parent's religious observance	Traditional	49%	–
	Secular	34.3%	–
	Ultra-orthodox	16.7%	–
Child's treatment phase	Active treatment phase	–	29.6%
	1 month since treatment ended	–	10.2%
	2 months since treatment ended	–	10.2%
	3–12 months since treatment ended	–	50.0%
Child's diagnosis	Acute lymphoblastic leukemia	–	39%
	Bone cancer	–	23%
	Lymphoma	–	16%
	Acute myeloid leukemia	–	8%
	Rhabdomyosarcoma	–	3%
	Neuroblastoma	–	3%
	Wilms tumor	–	2%
Rare oncology disease	–	6%	

parent. The three themes are related to the three main research questions: factors that cause difficulty, factors that provide relief when dealing with the illness, and positive consequences of the illness

Table 2 presents the themes, codes, and sub-codes that emerged from the data by the similarity and dissimilarity between parents and children. The names of the participants have been removed in order to protect their confidentiality. The age of the participants is indicated.

Theme: Difficulties involved in coping with the illness

The first theme addresses difficulties involved in coping with the illness.

In this theme there seems to be a reference to the perceptual, physical, and emotional aspects. The perceptual aspect has a significant role, especially among parents who feel anxiety regarding possible recurrence of the disease or death. The physical aspect relates to the suffering, the side effects, and the disability that the disease brings with it, while the emotional aspect refers to the change in oneself, one's functioning, and the emotional consequences of insufficient support.

The three codes identified among parents and children were: nagging thoughts about the future, physical suffering, and emotional difficulties.

Nagging thoughts about the future

About half the parents (45%; $n = 49$) noted thoughts about the future as extremely disturbing. The disturbing thoughts they raised were related to uncertainty, as well as to fear of recurrence, of the possibility of death, and regarding their financial security. Only five of the adolescents referred to living in a state of uncertainty. The other concerns regarding the future did not arise among the children.

Living in a state of uncertainty

It is very hard for the parents to cope with uncertainty regarding the child's future. They are busy thinking about when and whether the illness will be resolved. A 36-year-old mother said: "The uncertainty is killing me. It's the hardest thing for me to deal with. What will we do if it is not resolved?!"

Table 2

The difficulties, alleviating factors, and positive factors derived from the cancer journey, similarities and dissimilarities between parents and children.

Theme	Codes	Sub-codes	Parent ⁺	Child ⁺
Difficulties involved in coping	Nagging thoughts about the future	Living in uncertainty	●	●
		Anxiety regarding possible recurrence of the disease	●	○
		Fear of possible death	●	○
	Suffering	Financial security	●	○
		Helplessness and harm to their protective defenses	●	○
		Dealing with the side effects, medications & functioning difficulties	○	●
		Suboptimal parents	●	○
	Emotional difficulties	I can't recognize myself	○	●
		Lack of support by the surroundings	●	●
		Support by family and friends	●	●
The alleviating factors involved in coping	Support resources	Support by the healthcare staff	●	●
		Support by parents/children who have had a similar experience	●	●
		Support by organizations	●	●
		The child's ability to become enlisted in the process	●	○
		Exposure to positive traits	●	●
	Positive thoughts	Faith in God	●	●
		belief in oneself	●	●
	Change of perspective	A new perspective	●	●
		Living in the present and understanding that we have limited control	●	●
		A change in priorities	●	○
Enhancing the relationship with the sick child		●	○	
Strengthening relationships with others		●	●	
Positive factors deriving from the cancer journey	Strengthening interpersonal relationships		●	●
			●	●

● yes, ○ no.

Only five children related to the difficulty posed by uncertainty regarding their future and all were from the older age group, above age 16.5. As noted by a 17-year-old adolescent: "It is hard for me to live in a state of uncertainty, there are lots of thoughts that are bothering me, I'm also afraid of being exposed to negative situations."

Anxiety regarding possible recurrence of the disease

The parents raised thoughts about the future, fears related to the possibility that the illness would recur. Some described a fear of the "eternal alliance" with the cancer and the concern that it would not end. Some of the parents claimed that the fear is endless and is constantly with them. As described by a 44-year-old mother: "The paralyzing fear that maybe it will recur, that it is endless, that it is a vicious circle, that this is it, if you're in you can never leave. Endless fear".

Fear of possible death

Some parents said that the thoughts about the possibility of death are the hardest for them. They described being unable to imagine their life without their child. The thoughts about such a potential future constitute a huge difficulty for them. As described by a 43-year-old mother: "I'm afraid to think about it [death], afraid to think about the most terrible, what will happen if he were to die of the illness? The thoughts of death immobilize me".

Financial security

Some of the parents (15%; $n = 16$) spoke about financial difficulties resulting mainly from the need to leave their jobs. Some had been single breadwinners and their child's illness does not allow them to work. A 40-year-old mother shared: "The financial difficulty is considerable. I can't run the business I built because I devote all my time to being with my child. I have to make sacrifices".

Suffering

Analysis of the findings shows that suffering is a considerable aggravation for both parents and children. About one third of the parents reported that it is hard for them to be exposed to the child's suffering and most of the children reported physical torments due to the illness and treatments. Analysis of subcodes in the parents' group shows that the

child's suffering is a source of difficulty primarily due to the parents' sense of helplessness

Helplessness and harm to their protective defenses

Helplessness due to exposure to suffering was found only among the parents. The parents expressed a sense of helplessness as a result of seeing their child suffering. As described by a 55-year-old mother: "The treatment ordeal, the side effects, the child's harsh references to his condition, the sense of pain and suffering, are the hardest for me". Another mother (aged 43) said: "Seeing my child suffering [is the hardest]. The hospital is both hell and heaven".

The helplessness voiced by the parents was found related to the fact that they are witnesses to the suffering but can't fulfill the most natural duty of a parent – to protect their child. The parents would like to take their child's place and it is clear to everyone that this is not possible. As one of the fathers (aged 38) shared: "The inability to control my child's health, I truly feel helpless. As a parent you feel the need to cure your child, as an obligation, not as an option and often, the feeling that it is unfair, why can't I take his place – I should be sick and he healthy".

The children also referred to suffering, but unlike the parents where the reference was to the suffering of another, the orientation in the children's group was to their own suffering. Nearly two-thirds of the children saw their personal suffering as the most common difficult element. The causes of suffering were found to include side effects, difficulty functioning physically, and insecurity.

Dealing with the side effects, medications, and functioning difficulties

The children spoke of suffering from the side effects that affected their functioning, mainly pain, nausea, vomiting, and hair loss. The children reported side effects and physical difficulty with injections and swallowing medicine. Some noted a difficulty related to their responsibility for taking medications, as reported by an 18-year-old boy:

[It is hard for me] to take pills continuously. I'm less strong, and that makes it hard. I constantly have to take responsibility not to forget the medications, and it's hard". The fear of injections and of tests arose in all age groups. An 18-year-old girl said: "The pricking is hard for me psychologically. I am traumatized by the needle pricks". A 7.5-year-old boy noted in a similar context: "It is hard for me to swallow the pills. My mother threatened me with a feeding tube".

Beyond the suffering related to the side effects, the children reported difficulty functioning and executing tasks they had been capable of doing in the past. This difficulty affected their self-confidence. A 14-year-old boy shared: *"It is hard for me mainly as a result of the very strong pain, I can't go places because of the treatments, or I am unable to do things because of the illness."*

Emotional difficulties

Emotional difficulties were found in both groups, but the difference was in the causes. Forty percent of the parents ($n = 43$) reported that emotional difficulties arose mainly surrounding the guilt regarding their functioning as parents, the consequences of the illness for the entire family, and the lack of support by the close environment. In the children's group, emotional difficulties arose, mainly surrounding coping with unpleasant feelings that made them feel that they do not know themselves, resulting from the social isolation and how they are seen by those in their surroundings.

Suboptimal parents

The parents reported feeling guilty for not being "optimal" parents of their healthy children at home. Their intensive care of the sick child prevents them from devoting attention to their healthy children. As they see it, their functioning as parents has been severely affected, as noted by one of the mothers (aged 54): *"I have a hard time with my feelings of guilt towards the other children as a result of being absent from home"*.

In addition, the parents shared how the illness affects the entire family in many ways and as parents they take responsibility for the situation, leading them to feel guilt, as a 41-year-old mother shared: *"The greatest difficulty is the issue of the children in the family. Everyone has emotional consequences as a result of X's illness"*.

I can't recognize myself

More than a quarter of the children reported that unpleasant feelings such as anger, sadness, concern, and uncertainty make it hard for them to cope. Some of the children related that these feelings are unfamiliar to them. A 16.5-year-old boy said: *"The hardest for me is the sadness, crying, and depression that assault me during treatments"*. A 7.5-year-old girl shared: *"It's hard for me that I become annoyed quickly. I wasn't like that in the past"*.

Lack of support by the surroundings

About one fifth of the parents reported that the most significant difficulty for them is related to the lack of support from those in their surroundings while caring for the child. According to the parents, there was a particular lack of significant support from their close surroundings. Some of the parents who raised this difficulty were divorced or widowed. *The lack of support led to a feeling of loneliness and manifested in a lack of help with household chores or caring for the sick child and being with the sick child with no ability to take a breather.* A 51-year-old mother shared: *"I carry most of the burden and care, I have no assistance with household chores. It's very burdening for me, I feel lonely"*.

The group of children raised no difficulty with regard to the lack of support from their close surroundings, but they did speak of the sense of social isolation as a result of social separation due to the concern of catching infectious diseases, as described by an 11.5-year-old girl: *"It is hard for me emotionally to be absent from school, the separation from my friends, friends who participated in ceremonies [at school] that I missed because I couldn't be there"*. Some of the children shared how the illness had caused them to be separated from others, which made the others feel sorry for them. In some situations, for example, certain people did not have any contact with them, and suddenly, following the illness, they formed contact, which the children perceived as pity. The children want to be treated as they had been before the diagnosis and, most important, not to be pitied, as described by a 17.5-year-old girl: *"It is hard*

for me to be absent from school and the social disconnection. It is also hard for me emotionally when I am pitied; people who had not spoken to me in the past suddenly talk to me because I'm sick".

Theme: Factors capable of alleviating coping with the illness

This theme describes the codes that address factors capable of alleviating coping with the illness, divided by parents and children. In this theme as well there is a reference to three main aspects: emotional, perceptual, and spiritual. The emotional aspect is a result of the varied support, the perceptual aspect comes from exposure to thoughts and the discovery of positive traits that they were not necessarily aware of before the illness, and spiritual aspects relate to faith in God or in oneself.

Unlike the factors that make it hard to cope, here there is more similarity between the groups.

Support resources

The support resource was identified as the strongest alleviating factor in both research groups and the differences found were in the prevalence of the support sources in each group. In both groups, support by family and friends was found to be the first and most significant alleviating factor, however support by organizations was found to be the second alleviating factor in the category of support among the children, whereas the parents perceived this source of support as less fundamental.

Support by family and friends

More than half the parents and children reported that support by members of their community, close friends, and relatives, makes it easier for them to cope. As related by a 36-year-old mother: *"The knowledge that an entire town has our back as a family makes it much easier and relieves a lot of the burden, gives us confidence and makes it easier for us"*. Another mother (aged 42) said: *"My amazing friends enveloped me in endless love and helped me throughout the ordeal. It makes it much easier for us"*. In the group of children, the support received from this source was found to strengthen them and help them maintain a routine within their other life routine, which helps them remain updated regarding happenings in their absence. As one of the boys (aged 11.5) related: *"The support of my family gave me lots of strength. In the midst of the treatments I also received a new brother and that made me happy and helped me cope"*. A 13-year-old girl shared: *"My friends tell me about everything I'm missing at school. It helps me, I understand that I know what's happening, I don't miss out on anything"*. Some children see this support as a good and efficient way of holding an emotional discourse and airing feelings that emerge following the ordeal, as related by an 18-year-old boy: *"The fact that I always have someone to talk to, to vent, is very helpful and makes things easier. [I] love my friends and family"*.

Support by the healthcare staff

About one fourth of the parents and children see the healthcare staff as a significant source of support. The parents claimed that supportive and caring staff help them cope better and strengthen their sense of security. One of the fathers (aged 53) related: *"The humaneness of the staff, the explanations they provide with unending patience, their trustworthiness, the kindness, the love with which they envelope is, helps us and lets us feel that we are in good hands"*. In a similar context, a 45-year-old mother related: *"I never felt alone. The hospital staff is always with me [and I] trust them. I feel that it is the best place that she [the sick daughter] can be"*. The children shared that the good attitude and sense of security that they received from the staff ease their coping. They related to being seen "at eye level", which gives them a sense of belonging and control, as one of the girls (aged 18) related: *"The outstanding attitude of the staff helped me very much. I am treated at eye level, everything I say and any opinion I have. It gives you a good feeling"*. The support by the staff is also relevant for young patients, as related by a 9.5-year-old girl: *"*

well developed and loved by the entire staff. It is a good thing that there is such a wonderful team who care for me, it is very helpful”.

Support by parents/children who had a similar experience

Support by this source constituted an alleviating factor for both groups, however not at a high prevalence. Participants who saw this as an alleviating factor claimed that it strengthens their sense of hope, as if others managed to overcome it they would too. A 44-year-old mother said: “Conversations with people who went through similar things and now have a healthy normal life help me cope. Seeing them and talking to them gives me lots of hope. If they did it, I can too”. Another mother (aged 48) said: “Meeting parents at a more advanced stage or recovering adults who come to visit after the illness is very helpful. It fills me with optimism”. The group of children too related to this source of support as fortifying, as shared by an 18-year-old girl: “Seeing someone in my condition is strengthening and connecting. This means deep conversations with someone who understands what I’m talking about. It is strengthening to share your thoughts with such a person”. In younger ages as well this source of support was found to be helpful, as shared by one of the 10-year-old boys: “It is very helpful for me to talk to other children in my condition, we understand each other”.

Support by organizations

This source of support was perceived as most meaningful by the children compared to the parents. About a third of the children saw this resource as one that alleviates and helps coping. The children related mainly to the fact that it helps them pass time at the hospital when they are with volunteers of whom some are of a similar age, as well as the good atmosphere that these volunteers create in their vicinity, as a 15-year-old boy related: “The national service volunteers in the organizations and the other volunteers always come and cheer me up. They help me pass the time. They are almost my age, it’s fun”. A 13-year-old boy also mentioned: “The volunteers from the organizations cheer us up, it helps pass the time. I laugh a lot with them”. With regard to this source of support, there also seems to be a material aspect that helps them cope, through gifts and trips. This aspect is particularly characteristic of children in younger ages, as related by a 7-year-old boy: “It was very helpful for me to get gifts from everyone. It helps me pass the time and makes me happy”. Another boy (aged 8) related in a similar context: “The most fun was when I got an i-pad, I was so excited. It made me feel wonderful”. A 12-year-old boy shared in a similar context: “The trips abroad with the organizations are very helpful for me. I wait for it and it helps me pass the time and gives me the hope that something positive will happen”. The parents related to the organizations as alleviating coping and spoke mainly about the volunteers who help the sick child pass the time, make him smile, and give him a sense of belonging to a group, denied him by the illness and treatments, as related by one of the mothers (aged 43) who represents the group of parents: “The amazing volunteers who made my child smile, that’s what made it easier for him and for me. There is nothing better than seeing your child in moments of joy and happiness in the midst of the greatest crisis in life”.

Positive thoughts

Positive thoughts of the sick child were found to be a source of relief for both parents and children. Among parents, the positive thoughts of their child and the child’s resiliency resources eased their experience. Parents who found that their child had sources of resilience found the strength to continue coping. The children as well related to their own positive thoughts as an alleviating resource.

The child’s ability to become enlisted in the process

The parents related to the child’s ability to become enlisted in the therapeutic process and to make every effort to fight the disease, as

shared by a 40-year-old father: *It helped me that [my] child accepts the illness, understands it, and agrees to fight it with all his might”.*

Exposure to positive traits

The fact that the parents are exposed to the child’s positive traits is a relief for them. This type of exposure gives them a sense of satisfaction and pride, encourages them to forge on and fight, and arouses their inspiration. One of the mothers (aged 41) related: “My child gives me lots of strength and encouragement. I see her courage and fortitude, her positive thoughts. If she can get through it, then certainly I can?!” Another mother (aged 53) too related, in a similar context: “What gives me relief is my sick son – [he’s] optimistic, smiling, forms a good atmosphere even if it is hard for him. We have the privilege of having raised a charming son who encourages all of us”. Similar to the parents who saw the positive traits of their child as helpful, the children saw their own positive traits as helping them cope. They related to their optimism, humor, seeing the bright sides, and courage, as related by a 17-year-old girl when asked what makes things easier for her: “My courage, the faith that things will always work out, my strength, that no matter what I will go through, I will always be victorious”. Another girl (aged 18) said in a similar context: “I am encouraged by the thought that it could always be worse. The motto: Live life as though every day is the last. I also use humor. It always helps me”. A 14-year-old boy also spoke about humor and about the ability to see life in its entirety, of which the illness is only one part: “The thought that the illness is a small part of life – not to treat it as the main thing. Laughing helped me a lot”. One of the girls (aged 14) said: “I mainly think about my good friend who died of cancer after fighting for 8 years and it gives me strength. Also thinking about my future helps me, it strengthens my optimism and the desire to proceed and to achieve the life goals that I have set myself”. Exposure to positive traits was also found in the young age group, but at a lower prevalence than in the older ages, as related by a 7-year-old boy despite his young age: “What helps me is to think positively, it really helps me avoid fear”.

Faith

Faith in God or in oneself was found to be an alleviating factor in both groups, however with a greater prevalence in the group of parents.

Faith in God

Faith helps parents understand that not everything is under their control and that with the power of faith they will manage to overcome any obstacle posed by life, as a 39-year-old mother described: “I always have faith that everything is from God and that everything is to our benefit”. Another mother (aged 50) related in a similar context: “Faith in God strengthens me. It makes me feel that everything is only a trial for us and that it will pass just as it appeared”. In addition, it seemed from the parents’ responses that prayers manage to revive their sense of control over reality, which is not always under their control. As one of the mothers (aged 35) said: “I am not always able to do anything about the circumstances and prayers help do something, it is where I may be able to have some impact”.

In the group of children as well, it seemed that prayers and faith in God are a relief and help them think positively about their condition, as noted by a 17-year-old girl: “Following the illness, my faith in God became enhanced. I discovered that it helps me and advances me. I am much more positive due to my faith”.

Belief in oneself

Belief in oneself helps parents and children discover in themselves forces of which they were unaware. The participants in the two groups related that if in the past they had been told they would have to cope with such life circumstances they would never have believed themselves capable, but life taught them otherwise. It taught them that

they have the strength and the ability to deal with any obstacle they encounter in the present or future. A 43-year-old mother related: “I discovered in myself incredible mental force. I believe in myself and it helps me cope”. Another mother (aged 48) said in a similar context: “I learned that I am much stronger than I had thought. I thought that aside from crying and fainting I could do nothing [but I can]”. A 50-year-old mother also shared: “I became a stronger person. A lot less sensitive. I used to be very fragile, today I am strong and not easily hurt. I know how to take care of myself”. One of the mothers (aged 43) also spoke about the strength and intensities she discovered in herself: “The most positive thing I learned was to discover that I am strong, I can deal with it. I became tougher, I discovered in myself strength that was previously unknown to me”.

Half of the children claimed that the illness had strengthened their belief in themselves, caused them to mature and to understand that they have the strength to overcome obstacles and difficulties. A 17-year-old girl related: “I discovered my courage, I have faith that things will always turn out well because of my strength. Whatever I go through, I will always be victorious”. In a similar context a 12-year-old boy related that he had found strength in himself following the illness: “I used to think that cancer is not a grave illness and today I understand what it is and how severe it is. If you haven't had it you won't understand... But I learned about myself that I am good at coping with ordeals”. There were children such as one of the 11-year-old boys who see their illness experience as a story of bravery: “If a child were to come to me and tell me about his difficulties, I would tell him how I dealt with the illness and show him that his problem is small in comparison. I'm brave and I have the strength to deal with anything”.

Theme: The positive elements derived from the cancer journey

This part will describe themes that involve the positive elements that arose as a result of coping with the illness, divided by parents and children.

This theme refers to perceptual aspects related to the change of perspective as a result of dealing with the disease and to social-emotional aspects that shed light on the child and his family, the texture of the relationship between them, and the close, dear, and caring environment.

Change of perspective

More than a third of the parents and children reported seeing life from a new perspective as a result of their experience with cancer. In addition, they managed to understand that it is necessary to live in the present, in the knowledge that they have limited control over circumstances, and to maintain a different order of priorities.

A new perspective

Some of the parents claimed that they had learned, unlike the past, to stay calm and not become excited about unimportant things. One of the mothers (aged 41) related: “I see life differently. Things that used to be important are less important now. Not to pay attention to silly things, [it is important] to proceed with life”. A 40-year-old mother too shared that she had learned to see life differently. She lives with the right perspective: “To see things in a different light, to take things in the right proportion and understand that everything is marginal in life and that everything is insignificant compared to health.” Among the children as well, a new perspective emerged following the illness and the treatments, which enhanced their recognition of the value of life, health, and support. As described by an 11.5-year-old girl: “Now I look at the positive parts of life. During the treatments, my grandmother taught me to see the positive elements even when I was aggravated, and I apply that to my life”. A 17-year-old boy related in a similar context: “I learned to appreciate life. I used to live in a bubble – I didn't know that ordeals and illnesses existed. Now I understand that the most important thing in the world

is health. Beauty and money are not everything. Happiness comes from good health and supportive surroundings”. A 7.5-year-old girl too noted that it is possible to overcome difficulties and that positive elements can be found in any predicament: “I learned that I can do anything, deal with pain [pain should not be concealed]. Not to be stubborn. I learned that in any situation I encounter I will do well and the family will support and help me. I learned that cancer can be positive. Cancer is not the end of the world!”.

Living in the present and understanding that we have limited control

Some parents learned, following the illness, to live in the present, enjoy a simple life and routine. This insight was found in the group of children mainly among the older ages.

One of the fathers (aged 38) related in this context: “[Following the illness] I changed my perspective. My motto at present is *carpe diem*, seize the day”. Another mother (aged 47) related to a similar aspect: “I learned to find happiness in the small things that I manage to do, things to which I ascribed no significance in the past”. A 37-year-old father related: “I learned that even if we think that we are in control, life surprises us and we find out that we do not run the world. To put things that challenge us in daily life in the right perspective”. Among the children similar insights were found, as described by an 18-year-old girl: “I learned to appreciate life and my friends, my surroundings. To live in the here and now”.

A change in priorities

Some parents changed their priorities in life following the child's illness. Where in the past they saw their achievements and those of their children as their ultimate goal, the illness made them understand that the family should receive precedence, that it is necessary to put efforts into other things, and that nothing is to be taken for granted. As related by a 42-year-old mother: “Following the illness I changed my perspective, my entire order of priorities changed. I used to be very achievement-oriented, work is the most important thing, and then I acquired a different perspective. Nothing will happen if I'm absent from work, my children are the most important for me. Also the requirements made of the children changed. Today I understand that grades are not the most important thing”.

Strengthening interpersonal relationships

One fifth of the parents shared that the positive element they took from the illness is related to strengthening their relationship with the sick child, due to the quality family time they received, which was not possible before the diagnosis. A similar proportion of the children noted that the positive element they derived from the illness is getting to know new, good, and caring people, and the understanding that family is a supreme value in their life.

Enhancing the relationship with the sick child

The parents reported that following the illness their relationship with the sick child was enhanced and they managed to become closer. They received a deeper connection with their child and saw this as a great privilege. As related by one of the mothers (aged 44): “It sounds funny, but it was precisely the fact that I received my child anew. Until the diagnosis, if I look back, I don't remember deep conversations with my son that go on for hours. I don't remember any strong interest on my part in his social life and hobbies. I don't remember watching television series that we both like together, or movies. Since the illness was discovered, we do that together all the time and even more. The feeling is that I discovered him anew, otherwise he would have grown up and I would have missed out on everything”.

Strengthening relationships with others

The parents and children related that following the illness they learned who are their true friends, the power of family, and how the family is their anchor, as described by a 50-year-old mother: "I learned how close my family is and how this is the most important thing in life". Another mother (aged 47) shared in a similar context: "The family underwent an important process together. It strengthened us". The children described similar insights. As a 15-year-old girl related: "I learned who are my best friends who will stay with me forever. The family became united and connected and I got to know amazing people along the way. I learned that there are people with a truly good heart in life". Her description represents other interviewees who related similar things. Another girl (aged 13) also described the insight that the family is a supreme value: "I learned that my family is the best thing in the world".

Discussion

The purpose of the current study was to portray similar and dissimilar elements in the perceptions and insights of children with cancer and their parents with regard to the illness and coping with it. The study revealed the elements that form a burden and those that provide relief, as well as the positive aspects related to cancer, as manifested in the personal narrative of both the children and their parents. With regard to the elements that form a burden, a significant difference can be seen between the difficulties of the parents and those of the sick child. With regard to the alleviating and positive elements, however, it can be seen that these two groups are more compatible.

Perception of the difficulties –similarities and differences between the sick children and their parents

In the perceived difficulties, there is a difference between the parents and children in their perception of the situation and in their perspective. While the parents reported difficulties related to a cherished other, whether the sick child, their spouse, or the healthy children, the children expressed difficulties related mainly to their own experience, such as difficulties swallowing medication, side effects, and loneliness. These findings are consistent with the professional literature. Studies show that parents experience fear of the unknown, concern that the illness will recur, and difficulty finding time for their healthy children (Demirtepe-Saygılı & Bozo, 2020; Lewandowska, 2021). The children, in contrast, focus on difficulties related to the physical consequences of the illness for their life in the "here and now" (Leibring & Anderzén-Carlsson, 2019). The adult thinking is characterized by future-oriented thinking (prospective bias) (Grant & Walsh, 2016), while the children tend to think about the past and present and thus give less weight to concerns regarding the implications of the illness for their future (Coughlin et al., 2014; McCormack et al., 2019). The parents and children have a different role in the family's existence. In the wish to defend their child, the parents choose not to share their worries with the child (Rosenberg et al., 2017). The parents keep their concerns to themselves and some of the children may also not wish to burden their parents and keep their fear and difficulties to themselves. Aamotsmo and Bugge (2013) found in their study among parents with cancer that the parents found it hard to talk to their children about their illness in the concern of harming their children, causing panic, and taking away their hope. Although the current findings show that few children expressed concerns related to uncertainty regarding the future, the children certainly expressed various difficulties that if discussed with their parents could ease their coping with the illness.

Finding strength when coping with a life-threatening illness

The current study found that, beside the difficulties, children with cancer and their parents also find positive points and reinforcement of

their coping. It seems that following the illness the children and parents received a different perspective on life, their faith in themselves or in God was strengthened, they see the family as a supreme value and appreciate the good they have in their life. Hobfoll (1998) theory of conservation of resources can provide an explanation of this phenomenon. According to the theory, people constantly seek a state of balance. The moment a certain resource is taken from them, in this case the health resource, they seek other resources such as faith in themselves, family support, and others.

Another finding arising from the study relates to the importance of support in times of crisis. It is evident from the study that in both groups support is the most significant alleviating resource. This finding reinforces that which is known about the support resource as an alleviating and helping factor at any age in states of health and sickness (Pahl et al., 2021) and is consistent with the qualitative study conducted by Tan et al. (2020) among ten mothers of children with cancer. Their study shows that side by side with the difficulties, the mothers found in the resources of support and faith a buffer against the stress that exists in this complex ordeal. In the current study, the importance of the support provided by organizations can be noted as a supportive factor that helps cope with illness. This support is important particularly for the children; specifically, the trips and young volunteers who come to have a good time and help children in the hospital pass the time make it much easier for them, where these experiences might manage to divert their attention to positive and enjoyable experiences. This may be a type of "compensation" which they need following the loss of their routine. To the best of our knowledge, the topic of the organizations' contribution to the well-being of children with cancer has yet to be empirically investigated.

Beyond the environmental resources, the study indicates the importance of an internal resource – faith in oneself – among the parents and children. The interviews show that the children and their parents found in themselves abilities and strength of which they had been unaware, and these help them proceed in the complex and complicated oncological trajectory. Studies show that after exposure to a traumatic event, people can see themselves as stronger and as having the self-efficacy to cope in grave life situations (Behzadi et al., 2018; Tan et al., 2020; Tedeschi & Calhoun, 2006).

The current study portrays a considerable similarity between the sick children and their parents with regard to the alleviating and positive factors derived from the illness. On these topics there may be open communication and sharing between the parent and child, giving the child an opportunity to identify supportive elements, manage feelings well, and acquire hope (Sisk et al., 2020).

Implications for pediatric nursing practice

Accompanying the child and his family throughout the cancer trajectory is an ongoing challenge for the healthcare team. The study has applied consequences related to how difficulties are handled. The nursing staff should advise the sick children and their parents to expand their view of reality, focus on the alleviating and positive elements in their life, encourage them to use the existing support resources, and direct them to find inner strength. There is room to instruct parents on the importance of emotional sharing with the sick child and thus legitimize fear and pain, but also of the helpful and alleviating elements in their life. The emotional discourse must be adapted to one's age and emotional condition and it has positive implications for the sick child (Sisk et al., 2020). Avoiding this discourse might lead to a sense of loneliness, anxiety, depression, and guilt (Meriggi et al., 2017). Following these tasks requires a special training program emphasizing the bio-psychosocial consequences of childhood cancer. The training program for nurses should provide practical tools through which they can help these families reduce stress levels and increase subjective well-being alongside the disease. Nurses who undergo this training can provide effective psychosocial support and refine the nursing process, including

identification, evaluation, and decision making. Such training programs should emphasize the importance of social and emotional support, open communication, and interpersonal relationships during the illness.

In addition, nurses can direct the parents to maintain open communication with the sick child and his siblings through shared experiences such as trips, games, and books. For example, as a result of the current study a family card game was developed, and a children's book was written that allows an emotional conversation regarding the difficult and alleviating factors involved in dealing with illness.

The study found that support by voluntary organizations alleviates the coping of sick children and their parents. It is recommended that the healthcare system utilize volunteer organizations that operate in the oncological wards and spend quality time with sick children to support their well-being.

The study's strengths and limitations

The current study included interviews with 108 parent-child dyads, reinforcing the validity of the findings. Thickening the data by conducting a large number of interviews is one way of revealing recurring phenomena and increasing the credibility of qualitative research (Yossiphon, 2001). The study expands the existing knowledge concerning the considerable significance of resources such as support and hope for the ability to develop positive feelings among parents and children even during a crisis. These positive factors may mitigate the cancer journey that the parent and child experience together. The study supplements the insufficient knowledge regarding the inter-generational connection between parents and children and makes it possible to clarify the similarities and dissimilarities between their manners of coping.

The first limitation is related to the fact that the study was conducted at two medical centers in central Israel. The fact that no current patients from peripheral areas were included might affect the generalizability of the research findings. Another limitation is that the study was conducted in Hebrew, and there is insufficient representation of minorities who do not speak Hebrew. Finally, when the children were interviewed in the presence of their parents, this may have affected the child's degree of openness. Albeit, the parent's presence was essential for the child's sense of security, particularly among the younger ages.

Conclusions

Side by side with the difficulties involved in coping with cancer, children with cancer and their parents find positive aspects and resources that they can utilize. While the parents refer to difficulties related to significant others and the future, the children experience difficulties that involve themselves as well as the here and now. Regarding the positive and alleviating factors, a greater similarity was found between the reports of the children and of their parents. The alleviating factors found include support by various sources, positive thoughts, and faith in God and in oneself. Embracing a new perspective regarding life, changing one's order of priorities, and perceiving the family as a supreme value were found to be meaningful insights derived as a consequence of the illness. The research findings illuminate the perception of resilience factors as well as of factors that form a burden on sick children and their parents and may help the healthcare staff direct and instruct families in this complex process.

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Irit Schwartz-Attias: Project administration, Conceptualization, Investigation, Methodology, Formal analysis, Writing – original draft,

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Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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