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The psychological experience of pediatric oncology patients facing life-threatening situations: A systematic review with narrative synthesis

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Review Article

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Abstract

Objective. The purpose of this systematic review is to describe the elements of the psychological experience of pediatric oncology patients facing life-threatening situations and the corresponding care needs.

Methods. The study design is a systematic review following the PRISMA standard of qualitative, quantitative, and mixed-methods research. The review was conducted using multiple databases, including Scopus, Web of Science, PubMed, and PsycINFO. The risk of bias of the articles was evaluated with the "Critical Appraisal Skills Programme."

Results. A total of 21 articles met inclusion criteria. The analysis of the evidence revealed that the psychological experience involves changes in relationships, thoughts about death, emotional changes, physical symptoms, spiritual changes, and feelings of uncertainty.

Significance of results. The care needs identified are maintaining normality, controlling physical and psychological symptoms, and that maintaining hope is an important aspect for children. Whether or not the children want to talk about death is another important aspect that needs to be reflected upon, and it would be appropriate to consider, on an individual level, involving patients in the discussion on the diagnosis and treatment of the illness. Future research should be conducted from the children's perspective since most existing research is from the perspective of the family members or health professionals. Furthermore, it is recommended to take into account qualitative approaches that provide more detailed information on the patients' subjectivity.

Introduction

During the year 2012, an estimated 163,000 children were diagnosed with cancer worldwide (American Cancer Society, 2015); approximately 80% of children diagnosed with cancer in high-income countries survived for 5 years or more after the diagnosis, a survival rate that decreases in low-income countries (World Health Organization (WHO), 2017). Cancer is the second leading cause of death globally (World Health Organization (WHO), 2018a), and as Laubmeier and Zakowski (2004) expose, there is a potential life threat associated with the disease. The term "life-threatening condition" in childhood is defined as any illness or condition developed in childhood whereby the child is likely to die prematurely (Lenton et al., 2001), as it is cancer. As Fernandes and Souza (2019) point out, children with cancer are faced with impending death at all times; therefore, life-threatening situations can appear at the time of diagnosis (Laubmeier and Zakowski, 2004; Kazak et al., 2006), during difficult moments in the treatment as a relapse (Koocher, 1986), or in the end-of-life process. Indeed, it is known that the life-threatening perception is more related to psychological aspects than to objective measures such as the stage of the illness (Laubmeier and Zakowski, 2004).

Most studies that have been carried out in relation to psychological aspects of pediatric oncology patients facing life-threatening situations are about how communication with the pediatric patient should be (Lannen et al., 2010; Jalmsell et al., 2015; Kaye et al., 2018; Lövgren et al., 2019; Montgomery et al., 2020), about making necessary decisions during the illness and who should be involved in them (Day et al., 2016; Badarau et al., 2017; Yamaji et al., 2020), and about the quality of life of the children and adolescents in the dying process and their needs (Tomlinson et al., 2011; Avoine-Blondin et al., 2017). The studies mentioned above are relevant, but they do not address the personal experience of the pediatric oncology patient facing life-threatening situations.

The psychological experience of children and adolescents facing life-threatening situations is complex, as it involves emotional, relational, physical, cognitive, and spiritual aspects. To understand it, we cannot infer from the experience of an adult, and hence, we need to identify studies that analyze their own experience. As the American Psychological Association (APA, 2005) points out, children are not adults in miniature. Therefore, the evolution and maturity of children can condition aspects of the illness, the treatment, or the prognosis. It can also condition ethical aspects, such as decision-making process or the communication with patients and their families.

In the field of psychological care, knowing how the child or adolescent experiences life-threatening situations due to an oncological illness is crucial if we are to offer appropriate care. The main objective of this study is to explore and synthesize through a systematic review what has been published on the subject to date. The goals of the review are as follows: (1) to describe the elements of the psychological experience of pediatric oncology patients facing life-threatening situations and (2) to identify the corresponding care needs.

Methods

Selection criteria

The review included the following studies: quantitative, qualitative, and mixed-methods studies that analyzed the psychological experience of children and adolescents facing life-threatening situations; studies that referred to children and adolescents between 6 and 18 years of age; and research where the subjects under study were children or adolescents, their families, or the health professionals that cared for them. The review excluded studies that described the experience of children and adolescents due to a nononcological illness or other circumstances because cancer is a leading cause of death for children and adolescents around the world (World Health Organization (WHO), 2018b), as well as nonscientific studies or those with low methodological quality.

Search strategy

A search in the Scopus, Web of Science, PubMed, and PsycINFO databases was carried out to identify articles published on the psychological experience of pediatric oncology patients facing life-threatening situations. The search was done including all the studies published until June 2020 and was restricted to articles written in English, French, and Spanish. The following keywords were used for the search:

> "Near death experience," Death*, "Life threatening illness," "Pediatric palliative care," "Adolescent palliative care," End-of-life, Palliative phase, Palliative care
>
> Child*, Adolescent*, Youth*, "Pediatric patients"
>
> "Child cancer," "Pediatric oncology," "Terminally ill child," "Children with cancer," "Dying with cancer," "Adolescent cancer"

The PRISMA standard was followed. The duplicates of articles identified in the databases were eliminated; criteria created by the three authors were followed to screen these articles. One reviewer (ECC) independently proceeded by eliminating those studies that were clearly irrelevant from reading the titles, and from the abstracts selected those that needed to be read in full in order to decide their inclusion. The three authors discussed the selected articles to make sure that the selection was in line with the objectives of the review. Two authors (ECC and DMO) then independently collected the full text of the selected articles to evaluate their possible inclusion in the review. If no agreement was reached between the two reviewers, the third reviewer was consulted (EBA).

Evaluation of the risk of bias

The "Critical Appraisal Skills Programme" (CASP) (2018) was used to evaluate the risk of bias of the articles included in the review. The CASP consists of 10 questions that are designed to think systemically on three general aspects: the validity, the content, and the applicability of the results. Each study was given a score based on the number of questions that were answered positively, and those articles that had a score of less than 50% of the total number of questions were excluded. Each study was assessed independently by two reviewers, and any disagreements were resolved through discussion.

Extraction and synthesis of the data

The extraction of the data was carried out with the help of a standard format table that gathered together information about the authors, year, and country; methodology and method of data collection; quality assessment; sample and study area; and results.

A narrative synthesis of the data using the Popay et al. (2006) guide was carried out. As Popay et al. (2006) assert, narrative synthesis is a way of telling stories; it permits the gathering of evidence and the construction of a convincing story as to why one needs to act, or stop acting, in a certain way. To bring forward the narrative synthesis, the following adapted steps of Popay et al. (2006) were applied: (1) extracting the data of the studies on a table, (2) exploring the relations in each study and between the different studies, (3) describing the central topics brought from the data, (4) critically reflecting on the process of the synthesis, and (5) elaborating the conclusion of the narrative synthesis.

Results

Once the duplicates were eliminated, 3,910 articles were identified in the database. Those studies that failed to fulfill the selection criteria were excluded. Many of these were eliminated since they lacked results in the area of psychology. This exclusion left 124 articles whose full texts were read, and of these, 21 were included in the review. The reasons to exclude articles are that they do not deal with the experience of the child or adolescent, they are not scientific articles, the information on the experience of children is a collateral result of the study, and they are written in a language other than the selected ones. Six articles were excluded due to a risk of bias once their quality had been assessed by the CASP (2018; Figure 1). The details of the final articles analyzed and the quality assessment of each one are described in Table 1.

The 15 studies synthesized in this article are heterogeneous in their methodology: 11 are qualitative, 3 quantitative, and 1 mixed. Most of them are studies from the perspective of family members, and the ages of the patients are varied, although there is a predominance of studies focused on patients over 12. Studies from the perspective of the patient are practically nonexistent with the 0–7 age group (Table 2), which is understandable taking

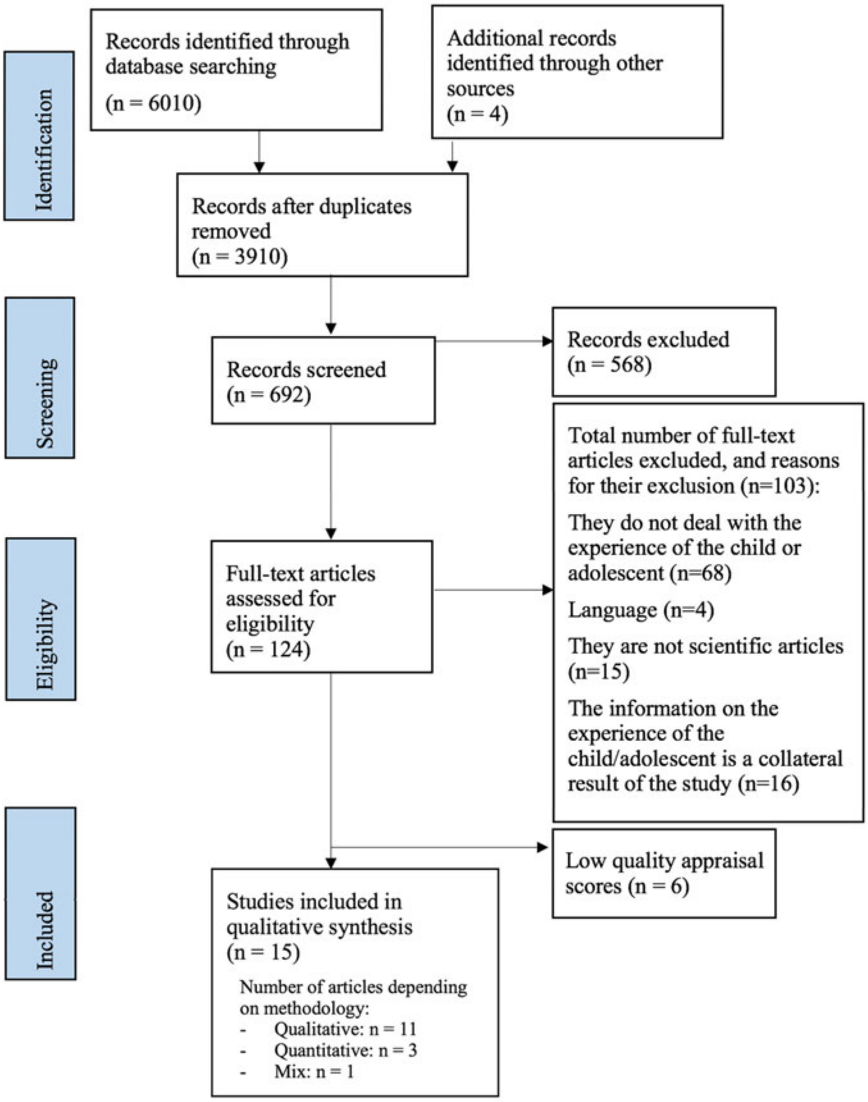

Fig. 1. PRISMA diagram.

into account that at this stage children have not developed the mental capacities of logic thought, which is an impediment to the generation of an explanation of his own experience (Piaget and Inhelder, 2007).

After carrying out the narrative synthesis, six key elements in the literature on the psychological experience of children and adolescents facing life-threatening situations were identified. These are (1) changes in relationships, (2) thoughts about death, (3) emotional changes, (4) physical symptoms that are a source of suffering, (5) changes on a spiritual level, and (6) feelings of uncertainty. The conceptual map of the synthesis of the results shows the elements of the psychological experience of the pediatric oncology patient, the consequences of these elements on them, and the related care needs (see Figure 2).

Change in relationships

The aspect that appeared in 50% of the articles reviewed is a change in the relationships experienced by children and adolescents with cancer. These changes are identified, in general, as negative, despite the detection of certain positive aspects as well (Callaghan, 2007; Hechler et al., 2008; Flavelle, 2011; Gaab et al., 2013; Montoya-Juárez et al., 2013; Eilertsen et al., 2017; Kavas, 2018).

Gaab et al. (2013) describe that pediatric oncology patients feel that they are treated differently and this disturbs them. The social isolation experienced due to the limitations resulting from the illness and the confusion that friends may feel with respect to the illness and physical limitations are factors that facilitate this change in the relationship with their peers (Callaghan, 2007; Hechler et al., 2008; Montoya-Juárez et al., 2013). This can make them feel dependent on others, distanced from their friends, and fearful of being disregarded or judged, all of which increases the distance between them (Kavas, 2018). Some studies show that relationships can change leading to family conflict: sadness, anxiety, and pain cause the family to argue and become frustrated, despite needing to be together (Eilertsen et al., 2017).

At the same time, other authors point out that this complex situation also leads to a strengthening of family bonds, a feeling of being closer to each other, and placing more importance on love and their relationships. The children and adolescents emphasize the loving care, comfort, and affection that they receive (Flavelle, 2011; Gaab et al., 2013; Eilertsen et al., 2017), but also the worry they feel for their carers and their need to protect them (Flavelle, 2011).

Table 1. Description of the articles

Authors and publication year	Country	Methodology and method for collecting information	Quality assessment (%)	Sample and area	Main results
Callaghan (2007)	Canada	Qualitative case study Method: case study	50	Sample: a 14-year-old boy with cancer receiving pediatric palliative care Area: Children's Health Program and IWK Health Centre	The adolescent wishes to maintain a normal relationship with his peers and family, who facilitate his perception of independence and reduce his feeling of isolation; to have a good control over the symptoms, which keeps him feeling balanced; to have more independence from his parents, but at the same time, he requires care due to his illness; to take part in the decisions related to his care, which makes him feel more competent and independent. The adolescent also uses the mechanism of denial to process the information he receives and hope as an adaptive mechanism, based on the hope of his parents. The adolescent has not shared his thoughts about death with anyone; to do so, he will need somebody he trusts due to the need adolescents feel to protect their parents from emotional pain.
Cataudella and Zelcer (2012)	Canada	Qualitative Method: focus groups	95	Sample: 24 parents of children that died of a brain tumor Area: patients that appear in the registry of brain tumors in South East Ontario	Parents identify with the psychological experience of their children: intrapsychic changes that include emotional and cognitive change, and the fact that the children were conscious of their imminent death and expressed this indirectly. With respect to interpersonal relations, the parents said that their children wished to be treated like normal (not ill) children by others and wanted to continue being connected to them. And posttraumatic growth, a wisdom in children that does not correspond to their age, that helped them accept their circumstances and to be close to others, being more worried about them than about themselves.
De Clercq et al. (2017)	Switzerland	Qualitative (narrative approach) Method: interviews	80	Sample: six children with cancer receiving pediatric palliative care, their parents (five), and health professionals (five) Area: oncology centers in Switzerland	The children feel that the illness has robbed them of their everyday life. Uncertainty is a common aspect in children, and most of them wish to be involved in the discussions about the treatment. Feeling the competence of the health professionals and the support of others is important for them. Some mention having found meaning in their lives.
De Graves and Aranda (2008)	Australia	Qualitative, ethnography Method: in-depth interviews and observations	80	Sample: 13 families with a child who has cancer Area: families with a child who has cancer and has had a relapse in the last 6 months	The families say that when the relapse occurs, what most characterizes their experience is uncertainty (with anxiety). They live between two realities: hope of cure and fear of death. Having hope and fighting for the cure enable them to manage this uncertainty and, at the same time, to be aware that the treatment might fail. The strategies used against uncertainty are maintaining normality and living in the moment.
Eilertsen et al. (2017)	Sweden	Qualitative Method: open questions	75	Sample: 124 siblings of children with cancer Area: siblings of children with cancer registered in the Swedish Childhood Cancer Registry and who died between 2000 and 2007	The siblings identify four key topics: the resistance vs. vulnerability experienced by the ill children during the end-of-life process, the family cohesion vs. family conflict that occurs during the experience, the growth vs. the lack of growth that the siblings experienced during this process, and the emotional support vs. the lack of such support.

Flavelle (2011)	Canada	Qualitative case study Method: analysis of a personal diary	95	Sample: one 15-year-old boy with advanced cancer Area: Izaak Walton Killam Health Centre, Halifax, Nova Scotia, Canada	The adolescent writes about issues related to adolescent growth, the need to escape from the illness, changes in relationships, physical symptoms, and spirituality.
França et al. (2018)	Brazil	Qualitative study based on the humanistic nursing theory Method: technique of drawing-history	65	Sample: 11 children, between 7 and 11 years old, with cancer under palliative care Area: non-governmental institution, in Joao Pessoa	Children with cancer under palliative care go through: (1) fear, sadness, anguish, and insecurity about their diagnosis and (2) the fear of their family falling apart because of the possibility of dying.
Gaab et al. (2013)	New Zealand	Qualitative, ethnography Method: analysis of a personal diary	85	Sample: 16 young people involved in palliative care (patients and siblings) Area: pediatric palliative care in Starship Children's Hospital, Child Cancer Foundation, Heart Children Foundation, and True Colours	The children express their concerns about five main areas in pediatric palliative care: they note that they receive special treatment and detect both negative and positive aspects of this; most say that they want to spend as much time as possible with their family; they describe feelings of having felt judged or discriminated; they also explain feeling understood by others and having shared feelings and perceptions with them; and, finally, the topic of death is a topic that arises intertwined with others but few share it explicitly.
Hechler et al. (2008)	Germany	Retrospective study Methods: questionnaires	83	Sample: father of 48 children who died of cancer Area: families of North Rhine-Westphalia that lost a child due to cancer	The parents said that the most frequent symptoms that their children had during the end-of-life period were fatigue and pain, and that the ones that made them suffer most were difficulty in breathing (dyspnea) and anxiety. The symptoms treated successfully were pain, constipation, and nausea. Fatigue, the loss of appetite, dyspnea, and anxiety were not treated successfully. With respect to the children's quality of life, only a minority could go to school and meets their friends; but even then, most were seen as happy, in good humor, and calm. Half the children did not have negative emotions.
Holge-Hazelton et al. (2016)	Denmark	Mixed study Method: questionnaires with an open question	83	Sample: 822 adolescents and young adults Area: people between 15 and 29 who appear in the Danish Cancer Registry	21% of adolescents and young adults with cancer worried a lot about death, and 18% quite a lot. 22% never spoke to anyone about this concern, and 19% said they had no need to do so. For 25%, these concerns did not affect their life much; for over half, the fears affected them in various ways, both positively and negatively; and for less than 25%, they affected them negatively.
Hongo et al. (2003)	Japan	Retrospective study Method: analysis of medical reports	79	Sample: 28 medical reports of children with cancer who died between 1994 and 2000 Area: University Hospital of Hamamatsu	The medical reports show that the children in the end-of-life process present the following signs and symptoms: little appetite (100%); dyspnea (82.1%), pain (75%), fatigue (71.4%), nausea/vomiting (57.1%), constipation (46.4%), diarrhea (21.4%), anxiety (53.6%), and alteration in consciousness (35.7%). 32.1% verbally expressed being aware of their imminent death, fear, or acceptance of it; of those children, the majority had anxiety.
Kavas (2018)	Turkey	Qualitative, phenomenological Method: analysis of a personal diary	85	Sample: one girl with advanced cancer Area: Department of Medical History and Ethics (Ankara University School of Medicine)	The adolescent shares that throughout her illness and during the end-of-life process, she felt alone, isolated, dependent, limited, and with uncertainty. She details aspects of her identity, her activities, her self-image, her perception of time, and contextual aspects such as the hospital, the health professionals, and the experiences she has gone through.

(Continued)

Table 1. (*Continued.*)

Authors and publication year	Country	Methodology and method for collecting information	Quality assessment (%)	Sample and area	Main results
Keim-Malpass et al. (2016)	USA	Qualitative, descriptive Method: analysis of blogs	100	Sample: seven adolescents with cancer Area: adolescents with cancer between 13 and 18 and authors of blogs about the illness	The adolescents normalize the bad news; confronted with the possibility of dying, they describe the process of the illness in detail, with humor, gratitude, and with great acceptance and empowerment. They share the moment of facing the failure of the treatment as a moment of uncertainty and of feeling blocked or stuck. They express the feeling of not having enough time.
Montoya-Juárez et al. (2013)	Spain	Qualitative, descriptive Method: semi-structured interviews	85	Sample: 13 parents of children with an advanced illness Area: pediatric units in the University Hospital "Virgen de las Nieves" and the University Hospital "San Cecilio"	It is difficult for the parents to describe what the suffering is. Some indicate physical aspects, others emotional ones, visible or invisible ones, etc. The signs of suffering that they detect in their children are sadness, apathy, and rage; of these, sadness is better understood and tolerated by the parents than apathy and rage. They see pain and anticipation of pain, isolation, and uncertainty about the future as causal elements of the suffering.
Theunissen et al. (2007)	The Netherlands	Retrospective study Method: questionnaires	79	Sample: 59 parents of children who died due to cancer Area: pediatrics department, hematology/oncology, and Radboud University Nijmegen Medical Centre (RUNMC)	The physical symptoms most pointed to by the parents were pain, little appetite, fatigue, lack of mobility, and vomiting; of these, 82% were attended to by the health professionals. The psychological symptoms most pointed to were sadness, difficulty in talking to their parents about their feelings with respect to the illness and death, fear of being alone, loss of perspective, and loss of independence; 43% of these symptoms were attended to by the health professionals. Children over 12 suffered more psychological symptoms than those under 7; the 7–12 age group found it more difficult to talk about their feelings with respect to the illness and death.

Table 2. Number of studies according to their characteristics

		Number of studies based on who the informants are		
		Parents or other family members	Health professionals	Pediatric patients
Number of studies according to age group	0–7 years	5 (Theunissen et al., 2007; De Graves and Aranda, 2008; Hechler et al., 2008; Cataudella and Zelcer, 2012; Montoya-Juárez et al., 2013)	1 (Hongo et al., 2003)	1 (De Graves and Aranda, 2008)
	7–12 years	7 (Theunissen et al., 2007; De Graves and Aranda, 2008; Hechler et al., 2008; Cataudella and Zelcer, 2012; Gaab et al., 2013; Montoya-Juárez et al., 2013; De Clercq et al., 2017)	2 (Hongo et al., 2003; De Clercq et al., 2017)	4 (De Graves and Aranda, 2008; Gaab et al., 2013; De Clercq et al., 2017; França et al., 2018)
	>12 years	8 (Theunissen et al., 2007; De Graves and Aranda, 2008; Hechler et al., 2008; Cataudella and Zelcer, 2012; Gaab et al., 2013; Montoya-Juárez et al., 2013; De Clercq et al., 2017; Eilertsen et al., 2017)	2 (Hongo et al., 2003; Callaghan, 2007)	7 (De Graves and Aranda, 2008; Flavelle, 2011; Gaab et al., 2013; Holge-Hazelton et al., 2016; Keim-Malpass et al., 2016; De Clercq et al., 2017; Kavas, 2018)

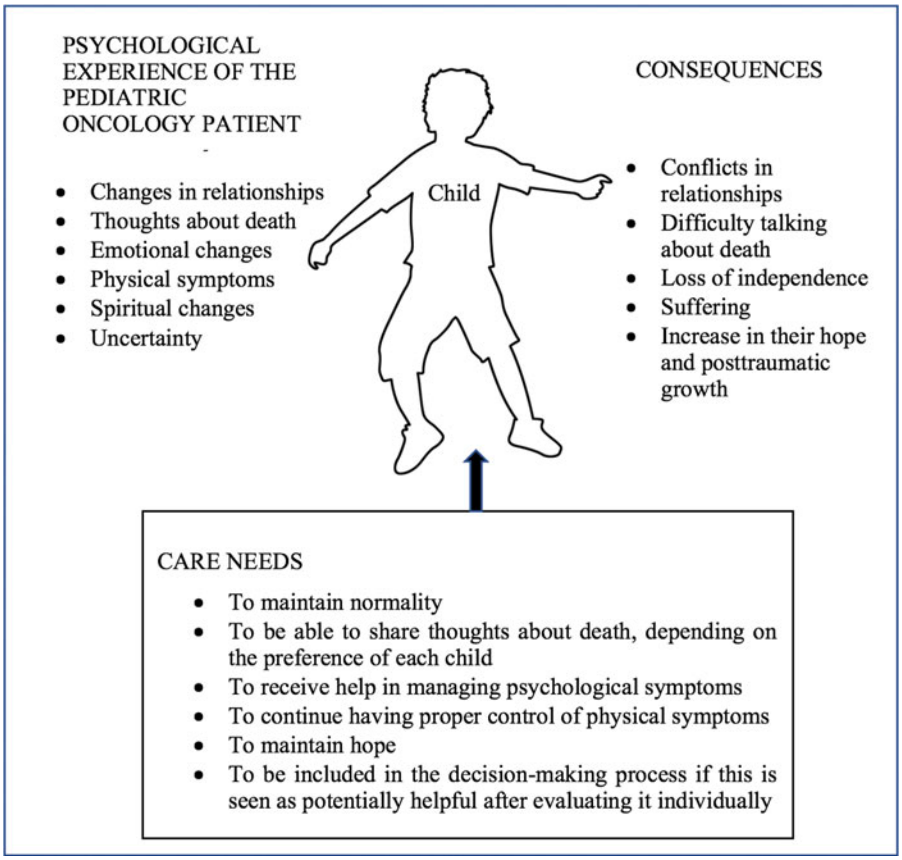

Fig. 2. Conceptual map of the synthesis of results.

Of the 15 studies included in the synthesis, 4 show that pediatric oncology patients wish to maintain *normality*: they wish to be treated like their healthy friends or siblings, to feel as "normal" as possible, and they want to lead the life they led before the illness. Maintaining normality can reduce the feeling of impotence and desperation (Callaghan, 2007; De Graves and Aranda, 2008; Cataudella and Zelcer, 2012; Kavas, 2018). One article points out that the "normal" treatment of children or adolescents facing life-threatening situations involves avoiding overprotection (De Graves and Aranda, 2008). Kavas (2018) points out that, despite the children's need to resume their daily activities, to be accepted by their classmates, and to be treated like a healthy child, they can distance themselves out of fear of being judged, which makes the process more challenging.

Thoughts about death

All the studies that deal with the topic of thoughts about death show that children and adolescents with cancer worry about death, and they express this awareness of their possible imminent death verbally or indirectly through certain comments, behavior, or gestures (Hongo et al., 2003; Callaghan, 2007; Theunissen et al., 2007; Cataudella and Zelcer, 2012; Gaab et al., 2013; Holge-Hazelton et al., 2016).

There are studies with different results regarding whether this population *talks or does not talk about death* with someone. Gaab et al. (2013) say that the topic of death arises in children with advanced illnesses and that some of them talk about it openly. Holge-Hazelton et al. (2016), on the other hand, explain that although a majority of the patients express their desire to talk about death with someone, a third of them do not. Another article explains the situation of an adolescent who has not shared his thoughts about death with anybody. According to the author, this behavior is justified by the tendency of adolescents to protect their parents from emotional pain (Callaghan, 2007). Theunissen et al. (2007) corroborate the results discussed earlier, indicating that the difficulty of children in palliative care to talk about their feelings with respect to the illness and death is the second most common symptom after sadness, especially for children between 7 and 12.

Emotional changes

All the children and adolescents facing life-threatening situations feel most of the following emotions or moods: sadness, rage or frustration, anxiety, fear, and guilt (Hongo et al., 2003; Theunissen et al., 2007; Hechler et al., 2008; Cataudella and Zelcer, 2012; Montoya-Juárez et al., 2013; França et al., 2018). Some studies emphasize some emotions over others. Hongo et al. (2003) point out that approximately half of the children feel anxious and a third fear death, whereas Theunissen et al. (2007) say that the most prevalent emotions are sadness and fear, although they also identify rage and feelings of guilt.

As Montoya-Juárez et al. (2013) point out, sadness is observed through the tears or facial expression of the child, apathy is perceived when the patient does not want anything, does not want to speak, etc., and rage is shown via hostile or aggressive behavior toward the parents or health professionals. Of these emotions, sadness is better understood and tolerated by the parents than apathy or rage due to the feelings of impotence and suffering that generate them (Montoya-Juárez et al., 2013). According to Cataudella and Zelcer (2012), the causes of these emotions are sadness due to not being able to do pleasant activities, frustration at the progressive loss of communication, mood change, and the progressive loss of self-esteem due to the physical changes produced by the treatment and anxiety due to the pain. Anxiety is considered to be one of the symptoms that cause most suffering and that it is not treated successfully (Hechler et al., 2008). According to França et al. (2018), when children are going through a process of severe and uncertain disease, they perceive death itself, which generates fear. This causes them anguish and suffering, especially for the treatment and the separation from their parents and siblings when hospitalization is necessary.

One aspect that is connected to emotional changes and the change in relationships mentioned earlier is the *loss of independence* (Callaghan, 2007; Theunissen et al., 2007; Flavelle, 2011; Kavas, 2018). This independence is demanded more strongly by adolescents since they want independence from their parents, but the limitations of the illness make becoming independent more challenging (Callaghan, 2007; Flavelle, 2011; Kavas, 2018). If the adolescents are involved in the *decision-making process* during the illness, their feelings of competence and independence increase (Callaghan, 2007; Flavelle, 2011).

Physical symptoms

Physical symptoms are another important aspect of the psychological experience of children or adolescents facing life-threatening situations; five articles describe them. The main symptoms that cause *suffering* are pain, fatigue, little appetite, lack of mobility, vomiting, constipation, and diarrhea (Hongo et al., 2003; Theunissen et al., 2007; Hechler et al., 2008; Flavelle, 2011; Montoya-Juárez et al., 2013). The physical symptoms are attended to more frequently and better managed than the psychological symptoms (Theunissen et al., 2007), although fatigue, loss of appetite, and dyspnea are not always treated successfully (Hechler et al., 2008). Pain is one of the symptoms that affect the quality of relationships: patients can show anger with their loved ones due to the pain and feel bad for having this reaction (Flavelle, 2011).

Spiritual changes

Five articles of the review detect changes on a spiritual level (Flavelle, 2011; Cataudella and Zelcer, 2012; Holge-Hazelton et al., 2016; De Clercq et al., 2017; Kavas, 2018). The search for meaning and purpose in life is the most common aspect with respect to the spirituality of children and adolescents (Flavelle, 2011; De Clercq et al., 2017; Kavas, 2018). Kavas (2018) describes an adolescent who goes through an existential crisis due to having faced life-threatening situations, questioning the meaning of her life, going over her past errors and early relationships, and thinking about the future and the person that she would have liked to become.

Maintaining *hope* in spite of being aware of the diminishing probability of surviving is another common element of the spiritual needs of these children and adolescents (Flavelle, 2011; Cataudella and Zelcer, 2012; Kavas, 2018). More specifically, one article explains how one adolescent shares her recognition of faith as a source of strength and makes the use of prayer (Flavelle, 2011).

The last aspect of spiritual change is *posttraumatic growth*, detected by some parents who see a wisdom in these children that does not correspond to their age. This helps them accept their circumstances and to be close to others, being more concerned about them than about themselves. Their personal strength increases, and this is seen in their capacity to cope with unpleasant treatments, to accept help, and to find meaning in the normal things of life (Cataudella and Zelcer, 2012). Another study shows that the adolescents' concern about death can cause fear or other negative aspects, but they also experience a process of transition, feel more mature, and, as a result of this, lead a fuller life emphasizing the positive aspects of existence (Holge-Hazelton et al., 2016). A final article describes one person who speaks of having matured and learnt to be happier than before falling ill, happier with the little things of life (De Clercq et al., 2017).

Uncertainty

Uncertainty about the effectiveness of the treatment, or when it has not been successful, is a difficult moment and one of feeling stuck or blocked in which the children and adolescents live between two realities: the hope of being cured and the fear of death (De Graves and Aranda, 2008; Montoya-Juárez et al., 2013; Keim-Malpass et al., 2016; De Clercq et al., 2017; Kavas, 2018).

Maintaining *hope* and fighting to become cured enables them to manage this uncertainty and, at the same time, to be aware that the treatment may fail (De Graves and Aranda, 2008). Hope becomes modified during the process of the illness, and when the end-of-life process begins, the hope of being cured can become the hope of spending more quality time with the family; pediatric patients tend to adopt the hope of their parents as their own (Callaghan, 2007).

To counteract the feeling of uncertainty, most patients wish to be *involved in the discussions* on diagnosis and treatment, although some prefer not to think about it (De Clercq et al., 2017). During these periods of uncertainty, the health professionals might adopt a paternalistic attitude, which can later change into a relationship where the adolescent participates and is committed to the discussions of the treatment. If this occurs, the patients feel better and their rumination decreases (Keim-Malpass et al., 2016).

The main adaptation strategies for dealing with uncertainty are living for the moment adopting a “day by day” attitude and maintaining *normality* in the patients’ lives, a factor analyzed above (De Graves and Aranda, 2008).

Discussion

The systematic literature review suggests that children and adolescents that go through life-threatening situations experience relational and emotional changes (Hongo et al., 2003; Callaghan, 2007; Theunissen et al., 2007; Hechler et al., 2008; Flavelle, 2011; Cataudella and Zelcer, 2012; Gaab et al., 2013; Montoya-Juárez et al., 2013; Eilertsen et al., 2017; França et al., 2018; Kavas, 2018), which are intertwined and entail a loss of independence of the patient. The most outstanding relational aspect is the feeling that the children and adolescents with cancer have of being treated differently from other people (Gaab et al., 2013; Kavas, 2018), along with the unease that goes with this. This is triggered by the loss of their routine and social life that results from the illness, and by the impact that this has on others (Callaghan, 2007; Hechler et al., 2008; Montoya-Juárez et al., 2013). The most common emotions or moods in pediatric oncology patients facing these situations are sadness (Theunissen et al., 2007; Montoya-Juárez et al., 2013), fear of death or of being alone (Hongo et al., 2003; Theunissen et al., 2007; França et al., 2018), anxiety (Hongo et al., 2003; Hechler et al., 2008), rage (Theunissen et al., 2007; Montoya-Juárez et al., 2013), and guilt (Theunissen et al., 2007). These arise as a consequence of the illness, the threat to life that it represents, and the physical symptoms that can create or strengthen some of these emotions affecting, at the same time, the quality of the relationships that the child or adolescent has with his or her loved ones (Flavelle, 2011).

Thoughts about death are another prominent element that emerge from the synthesis of the articles. Children and adolescents facing life-threatening situations due to cancer worry about death and express this directly or indirectly (Hongo et al., 2003; Callaghan, 2007; Theunissen et al., 2007; Cataudella and Zelcer, 2012; Gaab et al., 2013; Holge-Hazelton et al., 2016). The results obtained show that talking about death tends to be difficult for children and adolescents, especially children between 7 and 12, although it is not clear whether they do speak about death with someone or not, nor whether they need to do so. These findings make us wonder whether this difficulty is due to problems of understanding on the part of the children and adolescents; because they are worried about causing suffering to their family; because they cannot find an appropriate interlocutor; because they do not have the communicative resources or for other reasons. These questions become more relevant once we know that the capacity of a child to understand the concept of death does not depend only on their cognitive capacity but also on their lived experiences. As Bluebond-Langner (1978) points out, a child of 4 can understand the illness and its prognosis better than a child of 10 depending on their lived experiences.

Another significant source of suffering for children and adolescents is the uncertainty that they experience on not knowing what is going to happen, whether the treatment will or will not work. According to Callaghan (2007) and De Graves and Aranda (2008), hope provides the balance to manage the uncertainty and to be aware of the possibility that there might be no cure. In fact, the articles reviewed identified that pediatric patients experience hope as one of the elements of spiritual change when facing life-threatening situations. Other spiritual elements found are the search for meaning and purpose in life and posttraumatic growth (Flavelle, 2011; Cataudella and Zelcer, 2012; De Clercq et al., 2017; Kavas, 2018).

Finally, we would like to highlight some of the protective factors in this same experience: the strengthening of family bonds, shared affection, and the valuing of love (Flavelle, 2011; Gaab et al., 2013; Eilertsen et al., 2017); constructive cope mechanisms of the children and adolescents, like playing an active role and having a sense of humor (Cataudella and Zelcer, 2012); and resources developed by them like the capacity to normalize bad news in order to cope with this experience (Keim-Malpass et al., 2016). All these are protective factors identified by Haase et al. (2014) that, as these authors assert, can promote resilience and contribute to a better psychosocial adjustment.

The results of the review allow to identify the pediatric oncology patients’ care needs. What these patients value the most is normality: to be treated as “normal” children or adolescents and to carry on with their habitual routines and activities (Callaghan, 2007; De Graves and Aranda, 2008; Cataudella and Zelcer, 2012; Holge-Hazelton et al., 2016; Kavas, 2018). Normality helps in three different ways: to reduce the relational changes that take place, to decrease the feeling of uncertainty, and to facilitate the independence of the adolescents. Another aspect that helps reduce uncertainty is involving the patients in the discussions on the diagnosis and treatment of the illness (Keim-Malpass et al., 2016; De Clercq et al., 2017), which, at the same time, increases their feeling of independence (Callaghan, 2007; Flavelle, 2011). Holge-Hazelton et al. (2016) suggest that one aspect that would help to meet the needs of the children and adolescents is to offer them the possibility of sharing their thoughts on death, provided that such a concern is detected in the patient. According to the synthesis of the review, fostering hope (Callaghan, 2007; De Graves and Aranda, 2008) is another crucial element to accompany the experience of the children or adolescents that feel their life is threatened.

Strengths and limitations of the review

The review conducted in this article includes studies of different methodologies — qualitative, quantitative, and mixed — which provides a broad perspective of the topic being studied. The risk of bias of all the research included has been assessed, and those studies that failed to present sufficient methodological quality were discarded. The narrative synthesis carried out has enabled us to present the evidence clearly and concisely.

One limitation of this review is the inclusion of studies on populations of very different ages, which may mean that the assertions made are not valid for all age groups. It should be pointed out that, given the dearth of studies from the perspective of the children or adolescents, we have included and compared studies done from the perspective of the pediatric patient, of their family members, and of the health professionals, as well as studies using different methodologies, which could weaken the results. Furthermore, one aspect that might hinder the generalization of the results is that most of the studies analyzed were conducted in the USA or Europe (10 out of 15). Consequently, the results cannot be generalized since there is not enough socio-cultural variety. Finally, it should be pointed out that restricting the articles searched to those written in English, Spanish, and French could entail an additional limitation of this review.

In spite of these limitations, this literature review provides crucial information on the psychological experience of the pediatric oncology patient facing life-threatening situations. There is another review on the experience of pediatric oncology patients facing the end-of-life process (Montgomery et al., 2016), but it does not go deeply into their psychological experience. The results obtained enable us to get a little closer to what the children or adolescents think, what they feel, and what they do when they face life-threatening situations.

Conclusions

To know which are the main elements involved in the psychological experience of pediatric oncology patients facing life-threatening situations can guide health professionals on what aspects are worth considering when caring for these children.

The main elements that pediatric oncology patients can experience in these situations are (1) changes in relationships: identified, in general, as negative; (2) thoughts about death, which can be expressed verbally or indirectly; (3) emotional changes: most of them feel sadness, rage or frustration, anxiety, fear, and guilt; (4) physical symptoms: pain, fatigue, little appetite, lack of mobility, vomiting, constipation, and diarrhea; (5) spiritual changes: searching for meaning and purpose in life and posttraumatic growth; and (6) feelings of uncertainty about the effectiveness of the treatment.

The analysis of these elements shows that there are six main domains of care needs that can be considered as guidelines for interventions with these children: (1) The children express a wish to be treated like their peers, to feel as "normal" as possible. Maintaining this normality also helps to manage feelings of uncertainty (Callaghan, 2007; De Graves and Aranda, 2008; Cataudella and Zelcer, 2012; Kavas, 2018). (2) Talking about death is an important element (Callaghan, 2007; Theunissen et al., 2007; Gaab et al., 2013), although it should be noted that some results indicate that while a majority of the patients express their desire to talk about death, a third of them do not (Holge-Hazelton et al., 2016). (3) A full psychological assessment and a proper control of the psychological symptoms are necessary. Hechler et al. (2008) show that anxiety is considered to be one of the symptoms that cause most suffering and that it is not treated successfully. Furthermore, Theunissen et al. (2007) point out that, in general, physical symptoms are attended to more frequently and better managed than psychological symptoms. (4) To continue ensuring the proper control of physical symptoms, since it is shown that they are generally well attended (Theunissen et al., 2007), although fatigue, loss of appetite, and dyspnea are not always treated successfully (Hechler et al., 2008). (5) Maintaining hope seems to be an important aspect for children. In this regard, some authors (Flavelle, 2011; Cataudella and Zelcer, 2012; Kavas, 2018) found that maintaining hope in spite of being aware of the diminishing probability of surviving is a spiritual need of these children and adolescents. In addition, De Graves and Aranda (2008) found that hope enables them to manage uncertainty. (6) Finally, considering including patients in the decision-making process during the illness would be recommendable, given that there are studies that show that doing so increases their feelings of competence and independence and reduces rumination (Callaghan, 2007; Flavelle, 2011; Keim-Malpass et al., 2016). Individualized care is shown to be important for this type of patient. In this regard, De Clercq et al. (2017) indicate that while most patients wish to take part in the decision-making process because it reduces the sense of uncertainty, there are some who prefer not to think about it.

The literature review showed that studies from the perspective of the patient are practically nonexistent with the 7–12 age group, which is surprising if we bear in mind that at this age, children are capable of expressing themselves and explaining their personal experiences. Furthermore, the qualitative studies can offer more detailed information and consider it appropriate to continue along these lines. It also emphasizes the need to conduct more studies from the perspective of the pediatric patient since, in this population, many of the studies are done from the perspective of the parents, and we know that the perception of the parents is not always the same as the one of the children, especially with respect to subjective aspects of the experience (Janse et al., 2008). Future research should continue to deepen our knowledge of the psychological experience of children or adolescents facing life-threatening situations since there is little evidence on the subject.

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