Seeking an Adjustment from the Unnatural to the Supernatural: The Experience of Losing a Child from Cancer in Colombia

Sonia Carreño-Moreno, Mauricio Arias-Rojas, Lorena Chaparro-Díaz
Research Group Nursing Care for the Chronic Patient, Facultad de Enfermería, Universidad Nacional de Colombia, Bogotá, 1Department of Vocational Training, Faculty of Nursing, Universidad de Antioquia, Antioquia, Colombia

Abstract

Aims: The death of a child with cancer can be devastating for his or her parents. This study sought to understand the way in which the process of parental grief develops after the death of a child with cancer. Methods: The research used a grounded theory approach, in which 18 participants were enrolled including parents whose child died from cancer 5 months to 5 years before. In-depth interviews were conducted, which were analyzed using constant comparisons until theoretical saturation was reached. Results: Fifteen subcategories were identified and grouped into three categories that explain what the grieving process represents to the parents over time (a) crossing a desert, (b) dying while alive, and (c) coming back to life. From the emerging relationships among the categories, the core category “seeking adjustment from the unnatural to the supernatural” arises. The results show that grief begins from the moment of diagnosis until long after the child’s death. For parents, it entails understanding the disruption in the natural course of life, going through indescribable pain, and being spiritually reconnected with their child. Conclusions: These results enable nurses to design comprehensive interventions that meet the described needs of these parents.

Keywords: Cancer, caregivers, child, grief, grounded theory

Introduction

According to the World Health Organization,[1] more than 150,000 children are diagnosed with cancer each year, and about 90% of them do not survive because they live in low- and middle-income countries, which represents a barrier to receiving or completing treatment. In a Colombian context, according to the Ministry of Health,[2] there are 1,322 new cases of cancer in children under 18 years of age occur annually, with approximately 500 deaths from cancer per year in children under 14 years of age.

Childhood cancer is not only considered a chronic disease, but it also presents a potential threat to a child’s life. This arouses feelings of uncertainty and deep sorrow in parents who are facing a situation that symbolizes a backward course in life, in which their child’s wishes and life plans come to an abrupt end.[3,4] In many cases, after a difficult, prolonged, and ineffective treatment, the parents face their child’s death, one of the most traumatic and stressful events not only because of the loss itself but also because of the impact of the physical absence and the removal of a part of the parents’ life plan.[5]

The response to the loss of a child is often complicated. It is characterized by different forms of expressing sorrow and grief as the reflections of triggered emotions, and the belief system adopted by the parents.[5] Some studies have shown a potential risk of hospitalization after this event, mainly caused by mental disorders[6,7] and a mortality increase of 133% after the death of the child.[8]

Since bereaved parents share their pain and grief after this significant loss, the dynamics of emotions at home are filled with sadness as they engage in conducts of negligence, isolation, and living with their own pain.[9] This is an experience that has been compared to the physical pain of dismemberment.[9] In addition to this, there are family function problems, little marital satisfaction, reduced sexual intimacy,
and increased thoughts of separation along with high divorce rates.\textsuperscript{[10],[11]}

All in all, most of the research has been done mainly using qualitative methods, phenomenological approaches, trying to try looking at the meaning the parents give to the loss,\textsuperscript{[12]} and from the quantitative studies, looking for the medium and long-term effects of grief in these parents.\textsuperscript{[17]} Most of these studies have been carried out in developed countries where the health-care system provides comprehensive accompaniment through social support services in mourning.\textsuperscript{[13]} The results of these studies cannot be extrapolated to developing countries where the context, resources, and needs are different. To date, there are not studies that describe the experience of these parents in Latin American countries. Investigating the experience of parents who lose their child due to cancer in a developing country serves to document and make their needs visible to decision makers in the health-care system.

Qualitative studies address the phenomenon of mourning in parents once the child dies.\textsuperscript{[14-16]} However, this study addresses parental grief as a lived process over a period of time, in which the experience is studied even before the child’s death, until long after it. This research responds to a call to understand the nature of grief in parents whose children died from cancer, inquiring into their needs, beliefs, resources, and abilities to face adversity and achieve personal growth over time. Conducting this type of study helps to understand the experience and enables health professionals to provide human care throughout the disease of the child and bereavement support during the parents’ grief.\textsuperscript{[16,17]} Thus, the aim of this qualitative study was to understand the way in which the process of parental grief develops at the death of a child with cancer by describing emerging concepts and relationships from the findings.

\section*{Methods}

\subsection*{Design}

This qualitative study was conducted using the method of grounded theory.\textsuperscript{[18]} The study attempts to understand the experience of losing a child with cancer in Colombia through an constant comparison, epistemologically based on the principles of symbolic interactionism which seeks the understanding of basic social processes.\textsuperscript{[19]} This methodological approach recognizes that the interaction between the researcher and the participant is a fundamental factor in the research process and that it has an impact on the analysis and the interpretation of the experience that are developed. Parents whose children died from cancer were enrolled between January and August 2019.

\subsection*{Ethics}

The study obtained ethical approval by the health-care institution, and all participants agreed to participate voluntarily. Doubts about the study were solved, and the participants signed the informed consent.

\subsection*{Participants}

Eighteen parents of children who died from cancer in a public hospital for cancer control in Bogota-Colombia during the first semester of 2019 participated in the study. They were located by checking the medical records of the children who died at the hospitals’ pediatric ward and invited to participate in the study on a telephone call made by the researchers, all parents who were approach agree to participate. The following inclusion criteria were met: (1) Parents whose child died from cancer, (2) their child died 5 months to 5 years before, (3) parents living in Bogotá, Colombia, after the death of their child, and (4) parents over 18 years of age. Parents with hospitalized children at the time of the study were excluded. Table 1 shows the participants’ demographic characteristics.

\subsection*{Interviews}

After agreeing to participate and checking the inclusion criteria, the parents chose between being interviewed at home or at the hospital office. In-depth interviews were used for data collection\textsuperscript{[19]} since they were considered appropriate to explore meaningful data for participants about the grieving process. All the interviews were audio recorded and done individually, each of the two researchers interviewed nine participants. The two researchers were experts in in-depth interviews and grounded theory studies and also had experience in oncology pediatric nursing. For the interviews, a trustworthy atmosphere was created so that the interviewees could freely express their opinions, no judgments were made about the ideas or feelings expressed and therapeutic strategies were used to manage the emotions triggered due to remembering the experience of losing their children. The interviews were structured to have a therapeutic approach since it was a difficult and painful experience for the participants.\textsuperscript{[20]} The research team created the following questions based on their experience in this area and also based on the interviews of studies involving grief. The questions were: What has your life experience been like since your child passed away? How has the process of facing your child’s passing been? After these two initial questions, the researchers asked other questions to further complement the answers given by the participants. Interviews lasted between 30 and 60 min.

\subsection*{Data analysis}

Grounded theory was the method used to address the phenomenon of the study because it enables the researchers to identify the patterns and critical points in the grieving process that can offer guidance to nursing on developing concepts and explanatory theories of the phenomenon. The data were collected following theoretical sampling and analyzed through constant comparisons until theoretical saturation was achieved.\textsuperscript{[18]} The interviews were transcribed completely word by word, and then stored in ATLAS.ti.

In order to conduct the analysis, the Corbin and Strauss\textsuperscript{[18]} approach was used. These authors consider a nonlinear process consisting of (a) open coding (line-by-line creation of codes), (b) axial coding (grouping of several codes with similar characteristics), and (c) selective coding (integration
in a single category and validation of relationships among categories). Both data collection and data analysis took place simultaneously. This way, each interview that was conducted was analyzed before starting the next interview. Data analysis was carried out continuously from the first interview until saturation was reached, by the two researchers (Sonia Carreño and Lorena Chaparro). While analyzing the interviews, the researchers began to see a constant repetition of the attributes of the categories, which showed that there was no new information emerging from the data. When differences in the analysis arose, the third researcher (Mauricio Arias) helped to resolve them. During the analysis and coding process, codes were categorized and interpreted within the context, and the research team validated and defined the core category. When the analysis concluded, a validation of findings that included the participants was carried out.

In addition, considering that this research was conducted in Colombia, by Spanish speakers, data were collected and analyzed in Spanish and then translated into English by a certified translator. As previously mentioned, the credibility criteria were followed when including in the results extracts from interviews that reflect the proposed category, auditability by giving a detailed account of the method with which the research was carried out, transferability when making a clear description of the research context and the sociodemographic characteristics of the study participants. In this way, the criteria to maintain the methodological rigor of the study were met.\(^{[21]}\)

**Results**

Fifteen subcategories emerged from the data, which were grouped into three categories named as follows: (1) Crossing a desert, (2) dying while alive, and (3) coming back to life. Each category includes five subcategories. Finally, these three categories were connected to each other and the core category seeking adjustment from the unnatural to the supernatural was described. The process is illustrated in Figure 1.

---

### Table 1: Characteristics of participants and deceased children

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Percentage (n=18)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Data of parents</strong></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>11</td>
</tr>
<tr>
<td>Female</td>
<td>89</td>
</tr>
<tr>
<td>Educational attainment</td>
<td></td>
</tr>
<tr>
<td>Elementary School</td>
<td>50</td>
</tr>
<tr>
<td>High School</td>
<td>38.8</td>
</tr>
<tr>
<td>Higher education</td>
<td>11.1</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>22</td>
</tr>
<tr>
<td>Single</td>
<td>16.6</td>
</tr>
<tr>
<td>Nonmarital cohabitation</td>
<td>61.1</td>
</tr>
<tr>
<td>Religion</td>
<td></td>
</tr>
<tr>
<td>Roman catholic</td>
<td>88.9</td>
</tr>
<tr>
<td>Evangelical</td>
<td>11.1</td>
</tr>
<tr>
<td>Sole caregiver</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>61.1</td>
</tr>
<tr>
<td>No</td>
<td>38.8</td>
</tr>
<tr>
<td><strong>Data of deceased children</strong></td>
<td></td>
</tr>
<tr>
<td>Oncological diagnosis</td>
<td></td>
</tr>
<tr>
<td>ALL</td>
<td>44.4</td>
</tr>
<tr>
<td>AML</td>
<td>16.6</td>
</tr>
<tr>
<td>Osteosarcoma</td>
<td>16.6</td>
</tr>
<tr>
<td>Other cancers</td>
<td>16.6</td>
</tr>
<tr>
<td>LBL</td>
<td>5.5</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>50</td>
</tr>
<tr>
<td>Female</td>
<td>50</td>
</tr>
</tbody>
</table>

### Descriptive statistics

<table>
<thead>
<tr>
<th></th>
<th>Minimum</th>
<th>Maximum</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age of the child at the time of death (years)</td>
<td>0.6</td>
<td>18</td>
<td>10.7</td>
<td>5.05</td>
</tr>
<tr>
<td>Length of time the child had the disease (years)</td>
<td>0.2</td>
<td>4.8</td>
<td>1.8</td>
<td>1.2</td>
</tr>
<tr>
<td>Caregiver’s age (years)</td>
<td>19</td>
<td>69</td>
<td>38.8</td>
<td>11.6</td>
</tr>
<tr>
<td>Length of time as a caregiver (years)</td>
<td>0.11</td>
<td>13</td>
<td>2.4</td>
<td>2.9</td>
</tr>
</tbody>
</table>

Carreño-Moreno, et al.: Experience of losing a child

Indian Journal of Palliative Care ¦ Volume 27 ¦ Issue 1 ¦ January-March 2021

What

Figure 1: Grieving process representation of parents whose children died from cancer

Crossing a desert
Crossing a desert includes the bereavement experience from the moment the parents learn of the cancer diagnosis of their child, which is when the feeling of loss begins. The subcategories describe the coping process, impact, and expectations of the parents at the beginning of the experience, when they face an impossible situation they refer to as “unnatural.”

Discovering the unnatural
This is the moment when the parents, after carrying out the necessary tests to know what is going on with their child, receive the cancer diagnosis. A moment that they describe as an instant where everything collapses. The parents go through an emotional shock when they hear the word cancer, due to all the cultural beliefs around this disease. Moreover, parents acknowledge the feelings of anger and bewilderment; they do not understand the reasons behind this situation, and consider it unfair and unnatural because it does not follow the normal course of the life cycle in human nature. For instance, a participant compares death between adults and children: “...My father died, then my mother died, okay? Eight months after my mother’s death, my daughter died. So, I said, the comparison is... yes, all of them hurt, but the pain of having lost a child has no comparison. Yes, I miss my mother and that’s painful, but maybe she’s already completed her life cycle; but losing a child and at that age is very hard.” P09

Imagining the worst
After the shocking news of their child’s condition, the parents try to process all the information around this situation, looking for reasons behind an awful reality they do not understand. This is how they enter a stage characterized by uncertainty, fear, and lack of control where they try to make sense of the news about the disease and consider the options they have. While some of them are skeptical of the diagnosis and ask for second opinions, others accept it with resignation and receive recommendations from the healthcare team or are eager to go through treatment, even knowing that its results may be unpredictable. This caregiver discusses his constant feelings while he imagined the worst: “I got up every night worried to look at him and see if he was okay if he was breathing because I was more afraid that I would get up and he would no longer be with us.” P18

Changing one’s life completely
Chronic diseases generally involve a change of life. However, cancer entails a greater change, effort, and dedication for its management and care, triggering alterations in family and work aspects that are perceived negatively because all the attention is focused on the child. Thus, the child’s disease thwarts the plans the parents had for themselves, their family, and their child.

At work, some parents experience isolation, and in some cases, the loss of their job, because they spend most of their time with their child. This may lead to bankruptcy when there are no other sources of economic income. At home, family life is significantly affected, because the child’s siblings are left aside at that moment, not by the parents’ choice, but because the complexity of the situation demands it. Furthermore, the parents set aside their couple’s relationship and shut themselves off, leading to marital problems by negligence and increasing family dysfunction. This mother explains how her child’s disease changed their family life: “As for family, it was completely destroyed. There were no more family lunches or gatherings. In December, it’s a complete disaster... a complete disaster. My Christmas was ruined.” P02

Clinging to hope
As a way to deal with this difficult, uncertain, and painful situation, parents seek support, guidance, and information to hold on to. On the one hand, they focus on learning about treatment alternatives and scientific developments in cancer management, pinning their hopes on it. On the other hand, they look for relief in friends and relatives on whom they rely to face the situation. Similarly, through spiritual support, some parents try to keep the faith. They make promises to a superior being waiting for divine messages and answers, even though some parents think their circumstances are divine retribution. This mother shares the promises she made to God to heal her son: “My child said to me, ‘Mommy, it says I’ll heal you’. I said to him, ‘Well darling, then believe God’. And later I said to myself, ‘Dear Lord, if you are going to heal my son, I thank you infinitely, you know that I would give my life for him.’” P18

Getting what you don’t deserve
As they try to adapt to the changes brought on by the disease, parents start to question themselves and allow themselves time to feel their emotions. They perceive this experience as tortuous, as an inner burial procession that causes an indescribable pain, and makes them feel constantly worried and numb as if they were the spectators of their own tragedy. That is when they wonder why this has happened to them and call God unfair and selfish. A father put it as follows: “What do I have to talk to Him [God] about? I was blinded by pain and rage. ‘Well, then you tell Him to let you stay with me, ask Him why he is so unfair, why He brought you to me if He was going to take you back when you were seven? What for.’” P05

Dying while alive
This category and its subcategories describe the expression and management of feelings and emotions that frame parents’ experience when they realize their child has no
options of curative treatment, their child loses the battle with cancer, and dies. This situation is called by them as dying while alive.

**Fighting a losing battle**

In this part of the grieving process, parents face the fact that the treatment has been unsuccessful. They say that although they have followed all the recommendations, there is no improvement; therefore, they assume the situation is a victory for the disease. For parents, this is a desperate struggle in which they are not in control and inevitably feel powerless against the progression of the disease, especially because the children are in a vulnerable state in which they need their parents’ care and protection. As one parent puts it: “When you realize it, you can imagine. So much struggle, so much hurry, so much effort, not just from me, but especially from her: You know who my girl was: A fighter. She deserved to win.” P13

**Clinging to a miracle**

With the situation out of their control and given the lack of improvement in their child’s health, parents do not lose hope that the whole treatment would have a positive effect and cancer would go into remission. They do not give up and seek the strength to go on through their faith and beliefs that the impossible may be possible, if they cling to God, waiting for divine intervention that will bring their child back to health. They also resort to extraordinary treatments, and even to their spiritual beliefs for getting answers. A participant expresses this situation as follows: “Oh good Lord, will this struggle be any good? Sometimes he’d get better, then our hopes would rise again, and when they told us there was nothing to do… in that moment… oh… that was very hard. It was very hard for me. Those days were terrible.” P08

**Wishing to stop time**

When parent realize that their child’s treatment is no longer curative, they feel aimless and start fantasizing about going back in time and having done something differently. Parents miss how their children were and how their lives worked before cancer. When envisioning the situation of losing the child, parents say they would never be ready for their child’s final moment and would wish to stop time. A girl’s mother puts it this way: “Because you always say that maybe you’re fully ready, but if anything should happen, you weren’t fully ready. Those are things that amaze you, that leave you at that moment, like, aimless, in darkness.” P06

**Falling into a hole**

The moment when the child dies is traumatizing for parents. They describe it as an unbearable pain and compare it to a shipwreck where they lose faith to be rescued. They feel shattered and incomplete because a part of them dies with their children. All feelings of guilt, despair, disappointment, and anger come together at this moment. Bereaved parents feel like they were dying, they shut themselves off, isolate themselves, become aggressive, and go through depression. This is how a mother describes her negative feelings: “Imagine me, staying at home. That was terrible for me. On my days off I cried and looked for my girl’s stuff. It was a terrible pain, and then, the most terrible thing that could have happened to me was that my relatives left me alone.” P13

**Wishing to die**

With their child’s death, bereaved parents feel their life is an arid and dry desert where they are lost, and it makes no sense to continue living. Emotionally, bereaved parents are heartbroken, so they fall into a self-destructive, self-punishing routine in which they isolate themselves. The difficulty of letting go their beloved child makes them wish to die and have suicidal ideas and even suicidal attempts because they cannot otherwise cope with grief. A father describes his longing for death to come as follows: “Before what happened with Alejo, talking about death scared the wits out of me. Now… I await death, without fear, even with longing … longing for the moment I meet my son, and when death comes, then it would simply be a step, to meet him.” P04

**Coming back to life**

This category and its subcategories describe what grieving parents do, feel, and think in order to overcome gradually the loss of their child. It includes reorganizing their lives, cherishing good memories, and transforming the experience to help other bereaved parents. Constantly remembering the child and the hope of life after death gives this category the meaning of “supernatural.”

**Rising up to fight new battles**

For parents, the struggle does not end when the child dies. It persists for a long time, because it does not represent the loss of any loved one, but that of a child, and despite the pain, they understand at some point that life goes on and does not stop. It is for this reason that they look for the strength and motivation to move forward, take up the things they had put aside and try to reorganize their work and family lives. Although it is almost impossible for them to move forward, bereaved parents endeavor to rise up and stay motivated by their child’s memories. An example of it is told by a participant: “No, you don’t have like enough strength, I mean, this is a ‘get over it, because she’s gone’… it’s not easy, but yes, I did focus a lot on the dream that the two of us [mother and daughter] always had.” P05

**Valuing what you have experienced**

Along with the memory of their deceased child, bereaved parents begin to cling to the good moments they lived with their child, as a strategy to accept what happened and try to heal internally. To do that, bereaved parents fill their minds with positive thoughts such as “my child finally rested from suffering” or “my child is in a better place.” They place great value in the life they shared with their children and remember small details about them and the teachings they received from them. Bereaved parents also try to recall anecdotes and precious moments that help them to carry on with life. The mother of a girl who died at the age of 9 relives a happy memory as follows: “A week before her passing, she was very upset and her arm hurt a lot. To soothe it, she sang and turned
on music and we pretended that she performed in a concert and we were spectators. She sang a song that said ‘...and I already won this battle...’ and looked at us and said ‘And you must believe so because I already won this battle’, that’s how the song ends. So, that’s also useful to you. It gives you strength, all those videos she left, the photos, the memories...’” P10

Reestablishing bonds
For grieving parents, reestablishing affective bonds is a way of reorganizing their lives after their child’s death. So, they try to take part again of the social life they had left aside during their child’s disease and they start to connect with their partner, their other children, and their friends again. Reestablishing relationships allows bereaved parents to feel accompanied during grief. It also allows them space to express their feelings, strengthen family ties, and even welcome new family members, such as a baby. With the learnings from this experience, bereaved parents who managed to go beyond their grief busy themselves with sharing with others and even establishing new relationships with a new partner or new friends. This is how a father talked about reestablishing relationships: “Well I think that, for us, more than anything else, I think what’s helped us is how united we’ve always been, do you know what I mean? We have been united all along, more united, closer every day, more and more, I mean, we’ve never separated in any way. We’ve always been as united and supporting each other that it has been the most important thing that has helped us a lot.” P06

Keeping with love the memory of the child
The grief after a child’s death is not completely overcome; it is accepted, but bereaved parents never forget their child. They understand that the child’s physical presence is no longer there, but his or her spiritual presence prevails. Bereaved parents evoke the memory of their children and remember them as virtuous, unique, and incomparable beings. Such parent-child bond is unbreakable. Remembering is used as an action to relive beautiful moments they shared with their child when they were alive and this motivates them to go on and reorganize their lives. For example, a father told how he remembers his son through videos he made on his phone: “I took a photo of him sick and it was to see all that process before. And I said this to my wife ‘That’s what we have to remember about Alejandro: Those beautiful moments, those games we played, outings we went on, what we shared together, right?’ Those were beautiful things and it’s nice to remember because he is... he was our prince charming.” P04

Getting ready to help
The other way for beareved parents to overcome grief is by serving others who have gone through similar experiences, that is, they use everything they learned from the experience with their children, and even what they learned from their children themselves to go along with other families and provide them with counsel and support. For bereaved parents, helping others is part of a mission they should accomplish and it is a way to leave a legacy of what they went through with their children. This is a strategy that enables parents to be empathic and supportive without expecting anything in return, they just want to transcend and achieve spiritual well-being. A participant put it as follows: “In my heart I have every little thing kept as a treasure. When I talk about Sharon with other people, it’s like a breath of life for them and they say to me that I should go there and help others. We want to start an organization that would be called ‘Heart and a Half’.” P05

Seeking adjustment from the unnatural to the supernatural
The grieving process in bereaved parents does not have a specific starting point, for parents the bereavement experience is complete and begins at the very moment the child is diagnosed. The child’s passing is not regarded as a specific period of time, but rather is described from the whole experience of the disease. The grieving process is especially complex and begins when the parents face the diagnosis of their child. At that moment, the situation is perceived as contrary to the natural course of life, as “unnatural.” In spite of all efforts, faith in treatment and care, and the waiting for a miracle, many parents lose the battle against the disease, and with their child’s death, they think they are getting what they do not deserve, wishing at this point to be dead. After their child’s death, bereaved parents in search of a meaning consider reorganizing their lives, and to do so, they turn to the memories of their child and what they lived together. At this point, an unbreakable bond of love is created, a bond that goes beyond the physical, a “supernatural” bond that helps parents move forward.

DISCUSSION
This study described the grieving process of parents whose children died from cancer. For parents, grief begins long before the death of the child. Experiences with health professionals, painful and uncomfortable treatments, hospitalizations, and difficulties with the health system lead parents to look for ways to cope with a situation that brings about countless changes in their lives. Coping strategies that parents resort to can be negatives, for example, getting involved in regular arguments with health-care staff and feeling anger against God or, contrary, they can be positive, for example, when parents maintain faith and hope in God. These findings are similar to those made in other researches that also demonstrated that such aspects will be related to grief resolution.[14,15,22]

Regarding the process preceding the child’s death, the present study highlights the importance of active accompaniment by health-care staff, as part of the bereavement experience, since as other studies confirm[23-26] bad experiences before the death such as poor communication between health-care staff and family, inadequate symptom approach, signs of suffering in the last days of the child, lack of information about nearness to death, and perceived indifference from healthcare staff are related to a complicated, long-term parental grief. In this study, we found that parents feel like they were falling into a hole when they realize that the treatment does not have curative effects anymore; however, they cling to the hope of a miracle.

28

Carreño-Moreno, et al.: Experience of losing a child
as evidenced by Lockwood and Humphrey[27] who describe in their study that abandoning the goal of a cure and moving toward the idea of a peaceful death is an extremely difficult transition for all those involved. At this time, it is a priority for health professionals to inform parents at the beginning of the treatment about the possible outcomes.[28]

The present study made an interesting finding: In the early stages of grief, before the child’s death, parents come into conflict with God and feel angry because they think their circumstances are a punishment they do not deserve. However, after the child’s death, it changes, because at that moment they need to believe in God and believe that thanks to divine laws the child will live spiritually and be in a better place.

Previous research[29] has described that the parents who lost adult children to cancer have feelings of guilt for being alive. They also think that developing the disease was unfair and that the death of children goes against the logical course of life. In this regard, the results of the present study complement these statements and show that regardless of the age of the children, their losses are always devastating for their parents.

Furthermore, rituals that facilitate grief resolution in the present study show similar findings to those reported by literature, in which actions such as continuing bonds with the child through memories, sharing stories, participating in rituals in honor of the deceased child, keeping some personal belongings, going to places where the child used to be, and doing activities the child would have liked to do are helpful for parents to resolve grief.[10,11] However, an important element for grief resolution in the present study was to be willing to help and share with others the experience of losing a child. This is a very interesting finding because bereaved parents and society in general commonly avoid talking about losing a child for fear of addressing sensitive topics that may hurt the people involved.[32] It is important for parents and health professionals to acknowledge that helping and sharing with others their experience may be a helpful strategy for grief resolution and should be taken into account in interventions that address this issue. For instance, strategies such as counseling and support groups that promote constructive remembrance, personal growth awareness, normalcy reconfiguration, keeping busy, and present centeredness might help grief resolution.

This study succeeded in capturing thoroughly the experience of the parents who participated, given the researchers’ expertise in the area and in interviewing, the interviews took place in a setting that resulted to be healing for the participants. Future research should focus on understanding bereavement experience from the parents’ perspective in other regions of Colombia, as well as from the perspective of people who may not be parents but are principal caregivers of the child, for example, uncles, aunts, grandparents, or friends, and in this sense to be able to describe the implications for the entire family nucleus of the loss of a child with cancer. Furthermore, given the influence of the Catholic culture in Colombia, further research is important to go deeply into the concepts of spirituality and religiosity as coping strategies for bereaved parent, as well as understanding the ways through which parental care can be strengthened taking into account these two concepts. Among the limitations of this study, it is important to note that the children of the parents who participated in this study received treatment in a high-quality cancer control center at the capital city; therefore, the findings may not be comparable with the circumstances from other regions where the access to health care is limited.

Implications for practice

The results from this research allow health professionals to understand thoughts, emotions, and sensations experienced by parents when their child dies from cancer. It should be noted that parents highlight the important role of health-care staff in keeping honest, constant, and assertive communication with them, in which they are willing to discuss the implications of the end-of-life care and the death.[10]

Therefore, health professionals who care for this population must be emotionally prepared to establish a genuine relationship with the child and his or her parents, helping to provide opportunities for creating memories, special moments, and provide spiritual or religious assistance. Likewise, interpersonal relationships should be developed to enable health professionals to be empathetic and forge bonds of trust, which are highly valued by caregivers.[11] Finally, these results help to understand and prioritize parents’ needs during grief, which will enable the development of interventions in which bereaved parents are continuously accompanied and empowered to share their experiences.[33]

Conclusions

The grieving process of parents who lose their child to cancer is long and complex given the significant bond they have with their child. Parental grief is described as a search for adjustment between the unnatural and the supernatural. Parents go through moments of uncertainty in illness and disruption of daily life. After the child’s weakening and following death, bereaved parents feel they lost the battle against cancer and wish to die with their children. As time goes by, living seems more complicated because bereaved parents have to adapt to a new life; however, with family and friends support along with the spiritual belief that their child is with them, they manage to carry on and continue without ever forgetting what they lived through.

The process derived from this theory allows nursing professionals to address parental grief from the beginning of the child’s diagnosis until the parents regain motivation to move forward and establish a bond with the child that transcends the physical.
Financial support and sponsorship
Nil.

Conflicts of interest
There are no conflicts of interest.

REFERENCES
23. Albuquerque S, Narciso I, Pereira M. Dyadic coping mediates the relationship between parents’ grief and dyadic adjustment following the loss of a child. Anxiety Stress Coping 2018;31:93-106.