

Original Article

The Spiritual Dimension of Parents' Experiences Caring for a Seriously Ill Child: An Interview Study



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Abstract

Background. Parents of children with life-threatening conditions may have to balance their personal, family, and professional lives in the anticipation of child loss and the demands of providing medical care for their child. The challenges these parents are confronted with may lead to specific care needs. In this paper we explore the spiritual dimension of caring for a child with a life-threatening condition from the parents perspective.

Methods. We held an exploratory qualitative study with in-depth interviews with parents of children (0–21) with life-threatening conditions. Interviews were transcribed and subsequently thematically analyzed.

Results. Twenty-four parents of 21 children participated in the interviews. The spiritual dimension is an important, although not always visible, aspect of the experience of parents dealing with their child's illness. The main domains with regard to spirituality were: 1) identity; 2) parenthood; 3) connectedness; 4) loss or adjustment of goals; 5) agency; 6) navigating beliefs and uncertainties; and 7) decision-making. Parents also reflected on their spiritual care needs.

Conclusion. The spiritual dimension plays a central role in the experiences of parents who care for children with life-threatening conditions, but they receive little support in this dimension, and care needs often go unnoticed. If we want to provide high-quality pediatric palliative care including adequate spiritual support for parents, we should focus on the wide range of their spiritual experiences, and provide support that focuses both on loss of meaning as well as on where parents find growth, joy or meaning. *J Pain Symptom Manage* 2024;68:360–368. © 2024 The Authors. Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine. This is an open access article under the CC BY license (<http://creativecommons.org/licenses/by/4.0/>)

Keywords

spiritual care, pediatrics, palliative care, family care, existential care

Key Message

This article describes a qualitative interview study exploring how parents of children (0–21) with a life-threatening condition experience the spiritual dimension. The results indicate that spiritual aspects play a central role in parental caregiving, however their spiritual needs often go unnoticed. Parents need more adequate spiritual care.

Introduction

When parents are confronted with a life-threatening condition of their child, it affects their lives in many ways. Annually, approximately 5000–7500 children in the Netherlands are diagnosed with a life-threatening condition.¹ Over the last years, developments in medical treatment have increased the life-expectancy for these children. As a consequence, children with

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life-threatening conditions spend increasing periods of time at their family homes, where parents play a major role in the medical care for their child.²

Care for children with life-threatening conditions comes with many challenges. Parents may have to balance their personal, family, and professional lives with the demands of providing medical care for their child,^{2,3} may face feelings of guilt over their role as a parent with regard to optimizing their child's condition,^{4–6} and they may have to face and deal with the loss of their child.^{4,6–8} The challenges these parents are confronted with may lead to spiritual care needs.^{7–14} Parents often feel isolated in dealing with their challenges.^{15–18} Supporting parents in their spiritual care needs is an important aspect of care, as spiritually is one of the four dimensions of the concept of "total pain"^{19,20} and of the four dimensions of (pediatric) palliative care: the physical, psychological, social and spiritual dimension.^{21,22} Nevertheless, issues in the spiritual dimension remain largely unaddressed in daily care.

In this study, we adhere to the overarching definition of Spirituality as defined by the European Association for Palliative Care (EAPC) Reference Group on Spiritual Care that does not differ significantly from other important international consensus definitions²³: "Spirituality is the dynamic dimension of human life that relates to the way persons (individual and community) experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred."²⁴

Although gradually more studies explore the spiritual dimension of parents caring for a child with a life-threatening condition, literature is still scarce and many studies mainly focus on religious aspects or lack a clear definition of spirituality.¹⁴ Also, most studies focus on oncology.^{3–9,13,17,18} Therefore, the research question of this study was: how do parents experience the spiritual dimension of caring for a child with a life-threatening condition?

Methods

Design

In order to explore the ways in which parents experience the spiritual dimension of caring for a child with a life-threatening condition, we held an exploratory qualitative study with in-depth interviews with parents of children with life-threatening conditions.^{25,26}

Study Population

We recruited a purposive sample of bereaved and nonbereaved parents of children (aged 0–21 years) diagnosed with a life-threatening condition who (had) received the majority of their care in a home-setting

and were Dutch-speaking. Parents were excluded when their child had died more than three years prior to the interview. Recruitment was tailored to yield maximum variety in terms of condition and age of the child, and religious background of the parents. Recruitment continued until data saturation was achieved.

Recruitment

Participants were recruited through open recruitment via online parent support groups and pediatric palliative care teams in the period from October 2020 to May 2021. Interested participants contacted the research team and received full information about the study. They were given an opportunity to ask questions before participation, and all participants provided written informed consent prior to the interview.

Data collection

A single in-depth interview was held with parents (average duration: 1, 5 hours). Interviews were conducted by MAB (researcher, female, PhD) and BBD (researcher, female, MA), who had undergone formal training for this purpose. An interview guide was constructed based on existing literature and expert knowledge to structure the interview.²⁶ During the interviews, parents were asked about their experiences regarding caring for their child, and were subsequently asked in-depth questions about themes related to spirituality. The interviews were held in Dutch, audio recorded and subsequently transcribed verbatim. An English translation of the interview guide is presented in [supplemental file 1](#). Since the interview study took place during the COVID-19 pandemic, interviews were held through video-conferencing software (Webex, Teams) or by telephone (N=2) if participants were unable to use videoconferencing software. When both parents participated (couples, N=3), they were free to choose to be interviewed individually (N=2) or as a couple (N=1). Parents did not receive monetary compensation for participating.

Analysis

A thematic analysis was performed.^{25–27} First, MAB, ME and MCK reread five transcripts together to become familiar with the data. Next, themes were identified by a reiterative process of comparing and contrasting interview sections relevant to the research question, which were further specified using Nvivo 12, a software program for analyzing qualitative data.²⁸ Coding and categorizing was performed by MAB and reviewed by ME and MCK. Discrepancies in interpretation were discussed until consensus was achieved. This resulted in a code tree rooted in the data and constructed by all authors. Regular meetings with an advisory group of parents and professionals working in the

field of pediatric palliative care were held to critically review the results.

Results

Twenty-four parents of 21 children participated in the interviews. The details of the participants can be found in [table 1](#).

When exploring their experiences regarding spirituality, the experiences of parents centered around the following main themes: the way they 1) connect to their own identity and who they are as persons; 2) give meaning to being a parent and the way parenthood changes as a result of the illness of their child; 3) connect to the people around them; 4) adjust to the loss of their goals and expectations; 5) experience a sense of (loss of) agency and control throughout their child's illness; 6) relate to their own beliefs and (un)certainities about the world around them, and; 7) give meaning to care-

Table 1
Characteristics of Parents

Characteristics	Number of parents (N=24)
Gender parent	
Male	6 (25%)
Female	18 (75%)
Age parent	
<35	7 (29%)
35–45	11 (46%)
>45	6 (25%)
Marital status	
Married/ living together	22(92%)
Single/ not living together	2 (8%)
Education	
High school	2 (8%)
Practical education	6 (25%)
Vocational education	12 (50%)
Academic education	5 (21%)
Religious beliefs	
None / Not practicing	12 (50%)
Christian	6 (25%)
Muslim	3 (13%)
Other	3 (13%)
	Number of their children (N=21)
Age child	
0–5	6 (29%)
5–10	10 (47%)
10–15	2 (10%)
15+	3 (14%)
Status child at time of interview	
Alive	14 (67%)
Deceased	7 (33%)
Gender child	
Female	11 (53%)
Male	10 (47%)
Diagnosis child	
Malignancies	8 (38%)
Neurological / metabolic conditions	7 (7%)
Cardiovascular conditions	4 (19%)
Other	2 (10%)
Family composition	
1 child	5 (24%)
2 children	9 (43%)
3 children	6 (29%)
>3 children	1 (4%)

decisions. Finally, parents reflected on their care needs and the support they wished to receive regarding spiritual care. These themes describe the width and variety of how parents experience the spiritual dimension of caring for a child with a life-threatening condition. Quotes for all themes are presented in [table 2](#).

Identity; Connecting to Who They are as a Person

Parents reported how they often put their personal, social and professional lives on the back burner when providing medical care for an extended period of time. Especially when children were young when they received a life-threatening diagnosis, parents themselves were in a transitional phase in their lives where they were developing themselves as parents, partners, friends and professionals. When confronted with the dismal diagnosis of their child, a situation that was in many cases accompanied by much uncertainty about the child's prognosis, parents had to adapt to the way that the care for their child became part of their lives. The way in which parents coordinated care tasks had a major impact on the way in which they continued to develop themselves as people alongside their role as parent/care provider. Especially mothers often put their careers, social lives and personal development on hold in order to care for their child. In this process parents aligned their own identity to a large extent to that of their child and saw a unity between who they were as people, and who their child was.

But as time progressed, several parents began to wonder who they were outside their role as caregiver, and how they could reconnect with their social lives, passions, and professional development. Others emphasized that caring for their child had also helped them in finding themselves, and developing as a person. Caring provided them with a purpose in life and finding a new identity in their role as carer.

Parenthood; Giving Meaning to Parenting and Connectedness to Their Child

Many participants described their role as a parent as a pivotal part of their identity. There was a significant relation between parents' identity and their role as parents and carer. Some described that in a way, being a parent became their identity. From the moment of pregnancy, parents described how they developed a bond with their child and had started to give meaning to their parental role. However, the parental role drastically altered when their child was diagnosed with a life-threatening condition. Next to their relation of parent and child, they developed a bond as carer and patient. In some cases with adolescent children, this created tension, as children were at an age of gaining independence, while their illness reestablished their dependency of their parents. Many parents felt that they owed it to their child to take on this role as care

Table 2
Illustrative Quotes

Theme	Subtheme	Quote ^a
1. Identity; connecting to who they are as a person.	Alignment of own identity with role of carer.	Mother of daughter with metabolic condition, interview 21. "I am [Lizzie], my husband is Lizzie, Lizzie's brother and sister are also Lizzie. We as a family, we have all become Lizzie."
	Loss of identity.	Mother of son with cardiovascular condition, interview 18. "I had put my life on hold, intentionally. So that I could care for ... I had to be available at all times. But now that he is stable, I can suddenly think about: who was I, what did I use to do and enjoy? Who am I as a wife, a friend, a daughter, a sister?"
	(Re)building their identity in the role as parent.	Mother of son with rare condition, interview 3. "I am quite proud of who I have become. Being able to manage his care (...) being able to stand up for him, and speak up, I would never have dared that before. I have learned that because of him."
2. Parenthood; giving meaning to parenting and connectedness to their child.	Experiencing togetherness.	Father of daughter with metabolic condition, interview 1. "At one moment I thought: "You are a father too, you are also a dad and you can enjoy your child instead of just arranging things."
	Giving meaning to parenthood after bereavement.	Father of son with malignancy, interview 15. "I write a lot about him, and often talk about what would he think about something, what would he do during the COVID pandemic, or.. (...) I find it very important to make new memories with him, so that he is not only part of our past."
3. Social connectedness; loneliness and connection within the framework of medical care.	Loss of social connectedness.	Mother of son with metabolic condition, interview 9. "Sometimes I sit in the park with my friends, who are all busy with their healthy children, and I just feel so alone. They have no idea what it is like. My son can never join those children, we will never be able to do that."
	Disconnect from the world around you.	Mother of son with rare condition, interview 3. "After the diagnosis, I felt like I was living in another world. You know, time just goes on, but it's as if you yourself are standing still."
4. Goals and expectations; embracing and letting go.	Letting go of expectations.	Mother of son with rare condition, interview 3. "I had pretty much plotted out what my life would look like; being married, having a job, raising children. But all those beautiful dreams of what it would be like to be a mother completely fell away. And I had to find out new ways to give my life a new meaning"
	Embracing new goals and expectations.	Mother of deceased son with malignancy, interview 12. "Even when he was ill, everything went on as usual. And this... the important thing for [Steven] was that he kept in living his own world. By creating a bucket list [making special memories] you keep pulling him out of that. You're doing something you normally don't do because you're sick, because you're dying, that is confirming that something will soon no longer be there."
5. Sense of agency: dealing with loss of control.	Loss of control.	Mother of a daughter with rare condition, interview 2. "You just have no control. I put a perfectly healthy child to bed with her rucksack all ready for her in the hallway, and the next day she was in a coma. You can plan as much as you want, but life goes its own way."
	Searching for agency.	Mother of son with cardiovascular condition, interview 18. "I was a new mom, and I couldn't decide anything for him. So, the little things you can control become extra important. (...) There is very little you can control, I could control what he wore, and that was it. For Christmas I had chosen a little sweater for him, and then the nurse dressed him in something different. And I got a bit angry about that. Because that is the only thing you can control."

(Continued)

Table 2
Continued

Theme	Subtheme	Quote ^a
6. Beliefs and (un)certainities: finding a framework of understanding.	Living with uncertainties.	Mother of son with cardiovascular condition, interview 18. "The knowledge is always there, in the back of your head. It is like having a blue sky overhead, but there is always this little thundercloud in the background. You know that something will happen, but you don't know when. And you know it will get hard. That's the knowledge you always carry with you."
	Finding strength in beliefs.	Mother of daughter with malignancy, interview 7. "The death of my daughter had brought me a lot of pain, but it has also showed me that I can't live without my faith. (...) The fact that she is in paradise gives me the strength to go on. With ups and downs, but also with the knowledge that Allah doesn't put more burden on a human being than he or she can bear."
7. Care-decisions: doing what is right.	Weighing values.	Father of son with malignancy, interview 16. "He didn't finish his chemotherapy. He said: I just can't do any more of these. (...) What do you say as a parent in that situation? If he really can't bear it, then we just have to stop and hope it was enough. But it was very tough because you'll always know you didn't finish the treatment. But we saw he couldn't take any more, so should you just push him through it?"
	Giving meaning to decisions.	Mother of deceased son with malignancy, interview 12. "As parents, you continue to struggle with questions. The first question: why is this happening? And then: did I do the right thing? And I think that, as a parent, I have found my peace with this, because I know that my child has made me a better mother. And we have done our best for him."

^aQuotes were edited for readability. Names are fictitious.

provider. They related how they had welcomed their child into the world, and felt that with that decision, they not only had embraced the responsibility but also felt a need to be there as a parent for their child and to give it the best care, and life possible. While some parents saw their roles as parent and carer as interwoven with each other, others struggled to unify both roles, and felt ambiguity in how they related to their child. They wanted to connect with their child as a parent, instead of connecting as carer and patient. The need to experience togetherness with their child became almost tangible.

Bereaved parents emphasized that their connectedness with their child continued after their child had passed away. By involving their child into their daily lives, the relation with their child was not something only to be remembered, but something that they carried with them into the future.

Social Connectedness; Loneliness and Connection Within the Framework of Medical Care

While caring for a child with a life-threatening condition, a large part of the parents' perception of the world was focused on their ill child. Much of their energy, efforts and social relationships were focused on being there for their child and organizing medical care. Several parents mentioned how the illness made

them feel like living inside a bubble; a small reality that had formed around their child, that was only partially attached to the outside world. Some parents experienced dissonance between these realities; they were no longer able to give the everyday worries of the outside world a place within their lives and felt misunderstood by the people around them. The confrontation with healthy families could evoke experiences of loss, because it made visible what parents were trying to suppress; the extent to which their situation deviated from what they consider a 'normal life'.

In many interviews, parents emphasized dealing with their child's illness as a lonely process. They felt like they could not connect with people around them, and their experiences were lost in the translation. Even amidst others, several parents reported to feel alone and misunderstood.

Some parents were hesitant about opening up to others because sharing their fears and insecurities with others left them vulnerable. There also seemed to be a divide in their social connections: there was an inner circle of contacts where their child's illness was a central aspect of their connection (family, but also medical staff and peers), but parents also tried to find meaningful connections with people who were not privy to the child's illness. While several parents described difficulties in their attempts to find connection especially with people outside their inner circle, other parents

described their social network as a safe haven, where they could escape their worries, get support and feel connected to others.

Goals and Expectations; Embracing and Letting Go

For many parents, the confrontation with a life-threatening diagnosis initially meant a sudden loss of many spoken and unspoken dreams, hopes and expectations they had for their future.

Especially shortly after learning the prognosis parents reported experiencing a great loss of meaning in their lives; all the goals they previously worked towards turned out to be no longer achievable; expectations about what their family life would look like and hopes for the future and development of their child became uncertain. Goals set in their professional careers or other aspects of their life had to be let go, or seemed of less importance in the light of their child's illness.

However, after an initial period that was dominated by loss, many parents were able to find new goals, often rooted in focusing on their family, finding moments of happiness or quality of life in everyday life. Especially bereaved parents used their experiences to reevaluate on what was truly important to them, to let go of goals that had no real value to them (success in work, stressing over futilities), and instead pursue more substantial values.

For several parents refocusing on what they saw as "normal" family life became a goal that was pursued. They emphasized that normality itself gained a new value, as an anchor that kept families connected to the world around them and emphasized their bond as a family.

Sense of Agency: Dealing With Loss of Control

For many parents, the confrontation with life-threatening illness of their child was a confrontation with lack of control. Several parents recalled that their child's illness confronted them with the fact that ultimately, they were not in control of their own future. This gave many an initial sense of powerlessness. Not only the illness, but also the rigor of hospital stays made several parents feel powerless; some felt that in the hospital they were visiting someone else's world, where their lives were determined by the rules and schedules of the hospital staff instead of their own.

Being able to provide care at home or finding alternative ways to express a sense of agency, was for many of these parents a way to regain some control and find meaning in their lives again.

Beliefs and (Un)Certainties: Finding a Framework of Understanding

Having to incorporate knowledge and uncertainties about their child's illness and prognosis into their own

lives, had a significant impact on how parents perceived the world around them. When parents recalled how they dealt with the (lack of) knowledge regarding their child's illness, living with uncertainty was a major theme. For some uncertainty provided a beacon of hope, a way to keep perspective in the face of a serious illness, but for others the uncertainties meant that parents were denied the opportunity to make sense of their child's illness. This was especially felt when parents had the impression that health care professionals withheld information from them with the intention to keep parents hopeful.

Parents tried to understand the facts and uncertainties of their child's prognosis within their own world views. Religious and spiritual beliefs of the participants varied. A few felt let down by their religion, as they found the idea of a benevolent God incompatible with their reality of a suffering child. Others however, felt strengthened in their beliefs, as it provided them with an inner anchorage and a framework to understand their child's illness. Regardless of religious views, most bereaved parents expressed a sense of presence of their child after death: through notions of an afterlife, or in a more abstract feeling that the child was with them.

Care-Decisions: Doing What is Right

Doing what was right for their child was a major motivation for parents to keep going, and provide their child with the best care, even if it demanded great efforts of parents. All parents were actively involved in the decision-making process. It was sometimes difficult for them to speak up and question decisions of the care team, but they felt that they owed it to their child to do so, and they found meaning in being involved and being able to do the right thing for their child.

However, what "doing the right thing" actually meant for them depended on their situation and values. In this process, some parents were torn between pursuing invasive treatments that increased the child's prospects or reducing life sustaining treatments and focusing on quality of life at that moment. Navigating such decisions required effort and time to evaluate what was truly important for them and their child.

Experiences and Needs With Regard to Spiritual Support

When asked about the support they had received, most parents reported that attention for spiritual care needs was very scarce. Referral to a spiritual counsellor was offered in a few cases, usually in the early stages of the diagnosis, while the child was admitted to hospital care, or around end-of-life decisions. During these tumultuous times, parent often lacked the energy and mental space to use these services, and care needs related to a changed life and future often arose later on in the process. Most had little knowledge of available sources of support and stated that reaching out

themselves to find such professionals, was too demanding in a time where so much of their effort was focused on caring for their child or mourning the loss of a child.

Some parents also sought support within their own social networks, through meaningful connections they shared with health care professionals, and through parent support groups, where they found peers who understood what they were going through. Parents especially valued people who were able to listen without judgement and without downplaying their feelings. They found it difficult when their search for meaning was answered by instant advice or answers, because they did not feel their experiences were acknowledged.

Discussion

This study shows the nature and presence of the spiritual dimension as an aspect of parents' life when caring for a child with a life-threatening condition. The spiritual dimension of care is often associated with religious and transcendental questions. However, when prompted to explore their own experiences a bit further, it shows that the spiritual dimension plays a pivotal role in how parents experience caring for a child with a life-threatening condition.

The confrontation of a life-threatening condition disrupts parents' personal, social and professional lives, as well as their fundamental views. This can lead to an initial sense of disconnect: to themselves, others, or the world around them. This can result in them feeling swept away by their circumstances. For parents, spirituality relates both to everyday experiences as well as bigger questions regarding life, such as who they are as persons and as parents, what motivates them, and what is important for them. In previous studies on spirituality, religious beliefs are a prominent theme, and are regarded as both a source of strength for parents as well as a source of doubt.^{11,29} Other studies describe the serious illness as a period of reevaluation and personal development.^{3,5,30} Studies have also described the way that parenthood changes during the illness of their child, and how parents search to express their role as parents.^{10,13,31,32}

Despite the reality of their child's serious illness, parents' experiences of the spiritual dimension are not solely negative. The results also show how parents are able to find new meaning, purpose or connection. Seeing for example their own resilience and strength, experiencing connectedness with their child or as a family, and experiencing personal growth helped them to ascribe positive meaning to the reality of their child's illness, or regaining a sense of connection to themselves or the world around them. The way many parents are able to adapt their lives to the demands and uncertainty of their child's illness, is significant, as

it highlights that spiritual support should not only focus on loss of meaning, but also on aspects where parents are able to experience strength, growth and joy.^{7,18,29,33,34} The studies that are cited did not provide exact findings along the same line, but they focused on positive aspects of spirituality, sometimes in terms of religious or spiritual coping.³³ Our study, however, is the first to provide an overview on how parents experience spirituality in the context of parenting and caring for a child with a life limiting disease.

The results of this study highlight the dynamic nature of spirituality, where parents navigate a new reality where they can both lose and find meaning. They have to redefine their relationship with themselves, with their child, their goals, and to whom they are as parents or as social beings. That process comes with loss and growth. This process can be understood in terms of connectedness to a person's "inner space", a concept that lies at the heart of several approaches of spirituality.³⁵⁻³⁷ Finding meaning helps parents experience more inner space for reflection, and relate to the changes in their lives. Understanding the variety and tensions that are present in parents' experiences of spirituality, can help us to further develop support that suits their needs.

Strengths and Limitations

This study has some strengths and limitations. A strength is the variety of age and religious beliefs of the parents in our study, and the varieties in diagnosis and number of siblings of the children which ensured variety within the themes. A limitation was the fact that the majority of participants were mothers, whose experiences may be very different from fathers. A large proportion of participating parents had children between the age of five and 10, which is notable given the fact that the majority of pediatric deaths occurs in children under the age of one. The digital setting due to COVID-19 restrictions may have limited the interaction with participants, although, when asked after the interviews, participants indicated that they had not found the online setting problematic. Because of this, we hypothesize that live interviews with parents would not have given (very) different results. Finally, as the inclusion of parents with migration backgrounds was limited in this study, a future study focusing specifically on parents with migration-backgrounds might give further insights into how they deal with spiritual care needs, and what their specific support needs are. Future studies on comparing the differences between bereaved and nonbereaved parents might also further develop our understanding on how to provide suitable support.

Conclusion

The way parents experience spirituality is a relevant topic in pediatric palliative care and emphasizes the

need for accessible and suitable spiritual support. The experiences of parents relate to the way they connect with their own identity and who they are as parents, how they connect to people and the world around them, how they deal with letting go of, or changing goals and expectations, how they experience a sense of (loss of) agency during their child's illness, and how they understand their child's illness from their own framework of knowledge and belief. The way that parents experience the spiritual dimension is important for the well-being of parents and can help to clarify what is important to them when making care decisions. If we want to provide high-quality pediatric palliative care including adequate spiritual support for parents, we should focus on this wide range of spiritual experiences, and provide support that focuses both on loss of meaning as well as on positive aspects of their experiences: the potential where parents find growth, joy and meaning.

Disclosures

Ethics Approval and Consent to Participate

This study was submitted for an independent quality check to ensure compliance with legislation and regulation requirements, including informed consent procedures, data management, and privacy and legal conditions. This confirmed that this type of study does not require approval from an accredited ethics committee in The Netherlands, as according to the Central Committee on Research involving Human Subjects (CCMO) this type of study does not fall under the scope of the Medical Research Involving Human Subjects Act (WMO). The research protocol for this study was registered under number 20/533.

Consent for Participation

All participants provided written informed consent prior to their interview.

Availability of Data and Materials

The datasets generated and/or analyzed during the current study are not publicly available to protect the privacy of participants and other persons mentioned in the interviews. The data of this study are kept by Marijke Kars in the University Medical Center Utrecht and are available upon reasonable request.

Authors' Contributions

Dr. Marije Brouwer designed the study, carried out data collection, carried out the analysis, drafted the initial manuscript, critically reviewed and revised the manuscript. Dr. Marijanne Engel critically reviewed the analysis, and critically reviewed and revised the

manuscript. Prof. Carlo Leget and Prof. Saskia Teunissen conceptualized the study, critically reviewed the analysis, and critically reviewed and revised the manuscript. Dr. Marijke Kars conceptualized and designed the study, coordinated and supervised data collection, critically reviewed the analysis, and critically reviewed and revised the manuscript. All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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Supplemental file 1

Interview Guide CONNECT-Study: Parent Interviews

Related to the article “The spiritual dimension of parents’ experiences caring for a seriously ill child: an interview study.”

Introduction to the Interview Guide

This interview guide is created to explore the (potentially) broad range of experiences of parents connected to spirituality. In order to do so, a more extensive interview guide was created, and tailored in each interview to suit the experiences of the participant.

The interview guide was based on existing literature and expert knowledge. It helped to recognize, explore and deepen the wide variety of related aspects. All interviews started with an open invitation to parents’ to share their stories. We used the guide to explore their experiences and perceptions more in-depth.

Please note that the interview guide is translated, as interviews were conducted in Dutch. As such, slight nuances may differ depending on cultural context and the limitations of translation.

Theme 1. Illness Narrative

- I would like to interview you about your experiences as a parent of a child with a life-threatening condition. In this interview we will focus on spirituality. But before we focus deeper onto topics related to spirituality, I would like to ask you to share the story of your child’s illness.

- Can you tell me more about who your child is/was?
- How would you describe the care for [name child]? (curative/ comfort oriented?)

Is [name child] receiving palliative care?

- What were crucial moments for you during your child’s illness? Have there been moments that meant a lot to you as a parent?

Theme 2. Identity

How does their child’s illness influence the way parents perceive themselves and their own identity?

Subthemes: change, reflectivity, autonomy, sense of normality

- What is it like to be a parent of [name child]?
- [Change] Do you feel that you have changed as a person because of your experiences with [name child]?

How has it changed you/ your life?

Can you tell me about who you were before the illness of [name child]?

- [Reflectivity] Do you often reflect on/ think about the way that your experiences with [name child] have influenced who you are as a person?

- [Autonomy] To what extent does caring for [name child] affect your ability to live your life according to your own views and preferences?

To what extent does it change your sense of autonomy or being in control?

- What does it mean for you to be in control?

Can you tell me about moments where you feel like having a having/losing control?

What helps you to keep/regain a sense of control?

-[Sense of normality] When you look at your life at this moment, do you perceive it as a “normal life” ?

If not: how does it feel to you? (state of emergency? Feeling lost?)

Is there something that helps you regain a sense of normality?

- Do you often compare your own life to that of others? If so: how?

Do you feel different from families without a seriously ill child?

Thema 3. Goals

How do parents reflect on their own priorities and goals?

Subthemes: values, goals

- (Values): Can you tell me about the things that are most important to you?

- Has your role as a parent and carer for [name child] changed what is most valuable to you?

And conversely: do your values also influence the way that you deal with your child’s illness?

- (Goals): Do you have goals for yourself, your family of child, or not at all?

- Has your child’s illness, aside from the limitations, also given you new goals or opportunities?

Where there goals that you had to let go?

- What are you proud of?

Thema 4. Social Environment

How do parents reflect on their (changing) social relations?

Subthemes: valuing relationships, openness, receiving/giving support

- (Valuing relationships): Who is most important in your life? And can you tell me what these relationships mean to you?

Who is close to you, and who isn’t?

What has changed in your social environment?

What is it like for you to maintain social contacts in your life, in light of [name child]’s illness?

What do you value most and least in your social environment?

- (Relation with child) How do you experience your relationship with your child?

What meaning do you give to being a parent of [name child]?

What kind of parent do you aspire to be for [name child]? In what ways do you succeed or fail?

- (Openness): How do you feel about talking to others about what you are going through with the illness of [name child]?

Are there people with whom you would like to talk about your experiences?

- (Receiving/giving support): Can you tell something about how dependent, or indeed independent you feel?

- What is it like for you to ask for support or help from those around you?

- What is it like for you to give support to others?

Thema 5. Rationality

How do parents they give meaning to (lack of) knowledge about their child's situation?

- (Information): an illness and medical treatment can bring information and certainties that you as a parent may have to deal with. Can you tell something about how do deal with information about [name child]'s illness?

- Do you feel like you have sufficient knowledge about [name child]'s illness?

How do you cope with uncertainties?

Is there information you miss, or perhaps things you'd rather not have known?

- In some cases, parents may also have to deal with information about a chance that their child might not survive. Is that something that plays a role for you?

Can you share what that means to you?

Thema 6. Coping

How do parents cope/ what keeps them going on?

Subthemes: emotions, hope, holding on and letting go.

- (Emotions): Can you tell something about how [name child]'s illness affects you on an emotional level?

How do you deal with these emotions?

- What helps you to keep going?

- What makes a day a good day?

- (Hope): What does hope mean to you?

Are there things you hope for?

Have you ever felt like there was no hope?

(Holding on and letting go): What do you hold on to?

Are there things that you had to let go of?

What do you let go of? How do you let go?

Thema 7. Spirituality and Religion

What spiritual/ religious beliefs do parents hold, and how to they influence the way that parents give meaning to their life?

Subthemes: beliefs, community, rituals

- (Beliefs): Can you share something about your outlook on life?

Are religious or spiritual beliefs part of that outlook?

In what way do these beliefs play a role in giving meaning to [name child]'s illness?

(How) have your beliefs/outlook on life changed because of the illness of [name child]?

-(Community): Do you share your beliefs/ outlook on life in a (religious) community? What role does that community play for you?

-(Rituals): Do you ever create moments to stand still and reflect on your child's illness (or passing)?

What do these moments look like?

- Do you create moments to experience closeness to your child?

- Are there other rituals, or objects that are important to you?

- Have healthcare professionals ever helped you/ enabled moments to reflect/remember/experience closeness? If so: what was it like?

Thema 8. Future

How do parents reflect on the future and/or (possible) dying of their child, and what meaning does it hold for them?

Future, dying, afterlife

-(Future): Can you share something about how you look at [name child]'s future?

Do you often think about what the future may bring? How?

-(End of life, if applicable): Have you ever reflected on what would be important for you if you were to be confronted with a possible end of life?

Do you have any wishes for that phase?

-(Afterlife, if applicable) Have you ever reflected on what 'dying' means to you? Have you thoughts on for example an afterlife?

Is that view or belief important to you? Does it influence the way you look at [name child]'s illness?

Do you ever talk with others about your views on death/afterlife?

- What is a meaningful life for you?

- Have you ever reflected on what would be a meaningful farewell for you?

Thema 9. Care Needs

An exploration of spiritual care needs of parents.

In the final phase of this interview, I would like to explore with you how we can support parents with spiritual care needs. Have you ever talked about spirituality with a (healthcare) professional?

If so, can you share how that conversation went?

- Have you ever received spiritual support? If so, by whom, and what kind of help was offered?

If so, what were your experiences?

- Would you have liked more support with regard to spirituality? And what kind of support would have been helpful to you?

What kind of professional/person would have been most helpful to you?

What is needed to make spiritual support successful?

- Do you think parents have enough information about who can help them when they have spiritual care needs, or want to talk about what their child's illness means to them?

- Have you ever been offered support from a chaplain, or from a grief/bereavement counsellor?

What kind of associations do you have with these professions?

Do you think these professionals might offer suitable support to parents?

- What advice do you have to better support parents when dealing with the spiritual dimension of caring for a seriously ill child?

Closing Questions

Do you have any advice for health care professionals?

Is there anything you want to share in the context of this interview?