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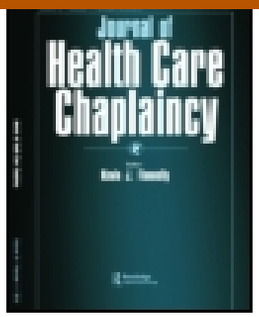

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# The fragile spirituality of parents whose children died in the pediatric intensive care unit

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**ABSTRACT**

Spiritual care is recognized as a relevant dimension of health care. In the context of pediatric palliative end-of-life care, spirituality entails more than adhering to a spiritual worldview or religion. Interviews with parents whose critically ill child died in the pediatric intensive care unit revealed features of a spirituality that is fragmentary and full of contradictions. This type of spirituality, which we refer to as fragile, speaks of parents' connectedness with the deceased child and the hope of some kind of reuniting after one's own death. Acknowledging that fragments of spirituality can be part of parents' experiences in their child's end-of-life stage can be a meaningful contribution to compassionate care.

**KEYWORDS**

End-of-life care; pediatric intensive care; spirituality

## Introduction

*Pediatrician, having learned about research on spirituality in the pediatric ward:* "How very interesting! Well actually, you know, spirituality doesn't appeal to me. However, what I have experienced …" *And next followed an extraordinary anecdote about a happening in his professional life that had left him without an explanation.*

This quote illustrates the ambivalent place of spirituality in (pediatric) health care in a modern western society like the Netherlands. It reflects on the one hand interest in spirituality, but on the other hand denial of personal affiliation to it. A personal unexplainable experience however can easily follow such denial.

The rejection of spirituality seems a legacy of the changed attitude towards faith, religion and spirituality in the second half of the twentieth century. In a rapidly dechristianized society like that of the Netherlands, religion and spirituality no longer seemed relevant. The term spirituality was mostly associated with esoteric and new age movements (Van de Geer & Leget, 2012). In health care, however, the rise of palliative

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care brought a new interest in spirituality. In the World Health Organization (WHO) definition of palliative care, spirituality has been recognized as a relevant dimension of care (World Health Organization, 2018). International conferences have worked towards consensus on definitions of spirituality that best suit the medical context (Puchalski, Vitillo, Hull, & Reller, 2014). The International Consensus Conference of 2009 in the USA defined it as follows: "Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred" (Puchalski et al., 2009). The European Association for Palliative Care (EAPC) has adapted this definition by stressing the dynamic character of spirituality, the role of the community and the importance of experiences and transcendence (Nolan, Saltmarsh, & Leget, 2011). Spirituality, then, is no longer confined to faith and religion. Its multidimensional character is reflected by attention to existential challenges, value-based considerations and attitudes (what is important to a person) and religious considerations and foundations (Nolan et al., 2011).

It has also become evident that spiritual care is no longer the exclusive area of chaplaincy. Spiritual care is multidisciplinary care, with a role for doctors and nurses as well, and is considered a component of relationship-centered compassionate care (Puchalski et al., 2014). As spirituality becomes an integral part of the medical structure, it is important to help caregivers identify spiritual themes and needs. Diagnostic models have been developed to give insight in the spiritual dimension of health care in clinical practice, and to help caregivers respond to patients' spiritual needs and desires (Cobb, Dowrick, & Lloyd-Williams, 2012; Körver, 2013; Kruizinga et al., 2017; van de Geer et al., 2017). Nevertheless, the possibility that spirituality might also involve an *unconscious* process of connectedness, is hardly considered. It is taken for granted that "spirituality is expressed through beliefs, values, traditions and practices" (Puchalski et al., 2014). Yet, in a secular society like the Netherlands, spiritual meaning-making is often an implicit rather than explicit affair. In our pluralist world belief and unbelief jostle in many ways (Taylor, 2007).

Spirituality can acquire meaning in the confrontation with contingent life experiences – those that happen out of the blue and shake us to the core (Kruizinga, 2017). Attributing meaning and experiencing connections to what transcends our natural (tangible) world can be a natural response to the impact of life-changing events. To learn how people deal with existential and possible spiritual issues today, we should listen to their stories, and note the way in which they describe and give meaning to traumatic events. The narrative approach makes it possible to reflect upon the subjective understanding of different dimensions of empirical life (Ganzevoort, 2011).

The present research on existential and spiritual issues in health care relates to the experiences of parents whose critically ill child died in a pediatric intensive care unit (PICU). Life-threatening ailments and possible nearness of the child's death evoke existential questions of life and death that may touch upon spiritual aspects of life. Faith and spirituality can help parents when their child's end of life is near (Hexem, Mollen, Carroll, Lanctot, & Feudtner, 2011; Knapp et al., 2011; Rosenbaum, Smith, & Zollfrank, 2011). Spirituality has been found a considerable factor in the mourning process of grieving parents (Talbot, 2002). Spirituality in end-of-life care becomes explicit in

expressions of faith, such as prayers and rituals and contact with clergy. Research among parents whose child died in the PICU has shown that maintaining connection to the child proved essential (Meert, Thurston, & Briller, 2005) and that the transcendent quality of the parent-child relationship endures beyond death (Robinson, Thiel, Backus, & Meyer, 2006). These findings refer mostly to the USA, where almost 90% of the population believe in God or a higher power (Houskamp, Fisher, & Stuber, 2004). Still, we encounter manifestations of lasting connections to the dead child also in the Netherlands, where faith and religion no longer have a prominent place in the lives of most citizens (van der Geest et al., 2015).

In a previous study, we investigated how after-death communication affected the search for meaning of parents who lost their child to cancer (Ganzevoort & Falkenburg, 2012).

The aim of our present research was to learn more – again from the stories of bereaved parents – about the specific features and function of the spirituality that is part of the confrontation with death. Our point of departure is the existential dimension of life that becomes manifest in the exposure to death, grief and loss.

We investigated whether the often sudden and traumatic confrontation with life's finitude evoked experiences that transcend the perception of a rational-empirical world and whether such experiences refer to another ontological realm or are to be understood metaphorically. At the end of this article we turn to the concrete world of medicine, to consider the relevance of our research findings for end-of-life care and caregivers.

## Methods

Our research project consisted of a qualitative interview study with 36 parents of 20 children who had died some 5years earlier in the 34-bed multidisciplinary tertiary care PICU of the Erasmus MC-Sophia Children's Hospital, Rotterdam, the Netherlands. We contacted parents 5 years after the death of their child to understand what experiences were so meaningful that they remained branded in their minds even after such a lapse of time. The choice for 5 years was related to the idea that we wanted them to be more distanced to the raw grief of the first few years and to have found some balance in their lives again while still connected to what had happened to their child in the intensive care. Our intention was to learn how these parents look back upon that period in their life and how their memories affect their present emotions.

In view of the delicate topic, we considered it best to interview the parents at home, rather than by telephone. Face-to-face interviews give the narrator the opportunity to tell the story with little interference of the interviewer. We could pace the interview to the parents' situation and pay attention to nonverbal signs of discomfort or distress. They sometimes needed time to overcome emotions; we could look at significant photographs or mementoes they wanted to show and give them our full and undivided attention. The interviewer followed the flow of the narrative upon the parents' response to the opening question: "What happened to your child?" The interview was unstructured, but if key issues did not come up spontaneously, the interviewer asked questions like: "*Do you still feel connected to your child in some way*?"; "*Do you live with the idea that*

*your child is still somewhere*?"; and "*Has your vision on life and death changed by all you have experienced*?".

Parents were selected randomly. The interviewer (JLF) is a health care chaplain in the department and we wanted to ascertain that the selection was not biased by her foreknowledge of the participants. We excluded those parents who were thought to be mentally or physically too unstable to again be confronted with their traumatic stay at the hospital or when there were language barriers. Patients were assigned a random number (1–85 eligible patients) from a random table generator from internet to select numbers to be given an invitation to participate. Thirty-eight children were thus selected and their parents approached. Twenty invitations were accepted. After these 20 interviews data saturation had been reached. It turned out that the interviewer knew the parents of three of the selected children from the time their child had been admitted to the PICU.

The interviews were held in Dutch. The anonymized transcripts of the interviews were analyzed using Atlas-Ti 7.0 for the coding and selection of themes.

Further details on design, setting, participants and data analysis have been published previously (Falkenburg et al., 2016; Falkenburg, Tibboel, Ganzevoort, Gischler, & van Dijk, 2018). The presented quotes in this article were translated into English by an independent translator. The numbers (N) attached to the quotes represent the different children.

## Results

*Participant characteristics.* Sixteen couples, and three mothers and one father individually, participated. All but one were native Dutch; the exceptional case was a mother of Pakistan origin. The children's age at the time of death varied from 2 weeks to 14 years. Length of stay in the PICU varied from 2 h to over 5 months. Four children had been hospitalized from birth until death. Some of the mothers never held the baby until the moment he or she died.

### *Background*

All narratives made clear that the child's death had made an inexpressible impact on the parents' lives. Even after 5 years they thought about their child every day and still felt grief, pain and longing.

### *Parental interpretations of the child's condition in the PICU*

Feelings of pain and desolation originated during the child's PICU stay, when they had been confronted with the child's imminent death. The narratives of parents' experiences showed a palette of different, sometimes simultaneous reactions to events revealing how they interpreted the happenings on a different level from the harsh reality of the child's medical condition. For instance, parents had highly appreciated being told the truth about their child's condition. Many, however, at the same time had maintained hope of cure. One of the mothers described how she was convinced until the very end that her son would survive. "*Until the moment they said: 'We will stop treatment', I still thought: no*

*way, it will turn out right. A miracle will happen and he'll survive*" (N6). This was what many parents described: How they kept hope until the very last moment, even though they knew exactly what the medical prognosis was.

Many parents felt they were in touch with their son or daughter in the final hours, even when the child was deeply sedated or suffered severe brain damage. Parents could somehow 'read' their child, even when apparently no communication seemed possible. Internally they interacted with their child, were aware of his or her needs, made promises to fight side by side, knew when their child was still fighting, but also felt when the moment had come for the child to let go. Many parents had the impression that it was the child who decided 'it was time to go'. It was not the withdrawal of the respiratory support that ended the child's life, but he or she 'chose' to go before machines were switched off. For them it signified that their child steered the process, which was very important to parents. Another highly significant feature of life's ending was the final physical contact. Even when the child's brain was so heavily damaged that caregivers said no contact was possible, parents were convinced the child 'said goodbye' to them; mostly through eye contact. The meaning the parents found in these experiences was that the child had accepted the outcome, death. The child had made the choice; the child was ready to die.

Other descriptions of experiences in the PICU were contradictory. The mother who gave birth to a son known to have a life-threatening congenital anomaly, described the childbirth as the moment of farewell. To many parents the moment of death was terrible and beautiful at the same time.

### Spiritual features of connectedness: transcending ordinary events

Expressions of this connectedness were largely in line with our previous research project (Ganzevoort & Falkenburg, 2012). Parents gave transcendent meaning to ordinary events. Their experiences involved sensations like cold, smells, sounds, sights, and symbols like birds and butterflies, flickering lights and music. Examples are given in Table 1. These events, which are commonly encountered in daily life, were not coincidental to the parents. They occurred at emotionally difficult times and were ascribed deeper meaning, referring to the child that had died. These sensations were too ordinary to be labeled as paranormal or supernatural or of a numinous kind. Yet they were certainly transcending a rational interpretation of these happenings. Many parents did not share these experiences with family or friends, as they had received negative reactions like "*you need a psychiatrist*" (N8). They carefully chose whom to talk to about these special moments; often persons with similar loss and experience (N1, N3).

In essence, these moments signified that the *relationship* still existed. The child was still part of and sometimes present in the parents' lives. To some parents it was as if the child was literally 'there'; to others, these sensations were more indirect references to the child.

### Belief in a transcendent world?

To learn how the parents understood such connection, we explicitly asked whether they believed their son or daughter was still at some place and not just 'around'. Most of

Table 1. Examples of spiritual connections between parents and their children.

| | |
|---|---|
| Child's decision | **N1** Son died in operation room:<br>Mother: "I am actually at peace with that. That he doesn't have to wait to die until I'm there. That's not necessary for me. He just chooses his moment. We ourselves are like: he had already chosen that moment himself. In advance." |
| Peri-death contact | **N16** Father: "The most wonderful thing I found was the day of death. That we would stop the ventilation. Then she was still looking at us with big eyes … She looked at us both again, closed her eyes and just like: 'Dad, Mom, I'm ready for it'. Really." |
| Still near | Question: "Do you still feel connected to him/her"<br>**N6** Mother: "Yes, yes. I do have the feeling the idea of, well, that he is just with me. It is not at all that I'm into the spiritual world and so on, but simply the feeling."<br>Question: "Do you live with the idea that she still is somewhere?"<br>**N4** Mother: "Yes, around us. Yes. Yes."<br>Father: "Yes, you feel that very strongly, don't you?"<br>M: "She is around us, and there at the cemetery, can be everywhere at the same time."<br>**N19** Mother: "Yes, she is just/simply here. And it is not like I see her, but it feels like that." |
| Senses | **N13** Mother: "Everywhere you look, you feel him, sometimes you smell his odor pass by and sometimes you feel suddenly his hand going through your face when you have a hard time. And then you just know, he is there." |
| Toys making spontaneous sounds | **N3** Father: "And we have experienced more. Music from toys that are constantly going off. Then you think: somewhere a button is stuck, but when it does nothing for two hours and then suddenly starts playing again, and then again not and then again starts … Such things just happen … " |
| Flickering lights | **N4** Mother:"And also again while on holiday: the ceiling lamp went on and off, on and off … I said: 'Ivette has come along! Yes, yes."<br>**N8** Mother: "In the beginning it was mainly the light, the light he was playing with. We really say: he was playing with that. Because then it was switched on/off. Or you were talking about something, and he disagreed."<br>Father: "Then something fell.."<br>Mother: "Something fell, or that light".<br>Father: "It can be coincidence. But it happened so regularly that I thought: no, that's not possible." |
| Music | **N13** Mother "When things don't go well with mums, she gets music again via the radio. All very appropriate lyrics that exactly fit the situation<br>And at a certain point also that music, it just said as it where: 'what are you doing? It seemed as if you were being talked to" |
| Symbols | **N16** Mother ( talking about seeing a butterfly): "But then I had something like it was a sign: you just let me know that you're there."<br>**N17** Mother: "We actually from the moment Jimmy passed away that whole winter, it was a very harsh winter, we had those whole winter ladybirds in our house and at the moment that you felt down or so or that you really thought of him, then one came out again." |
| Interventions | **N1** Mother: "As if he says: I'm still there. Yes. But I do experience it myself: that he is always with me. And also with certain things that he kind of sends me , helps or … yes, I do notice that."<br>**N16** Mother: "Because there was a good chance that I was pregnant again with a sick child of course. So. Then I had something like, she must have somehow made sure that Jens is healthy..". |
| Premonition | (N9) Shortly before her sudden death a daughter had drawn a black heart in her agenda on the day she was to die and had crossed out her name, symbolizing unmistakingly to parents some subconscious preknowledge. |

them said they did not know. Others replied hesitantly. It was clearly easier to answer that the child was 'here', rather than (maybe) at some place. Some (N1) said: "*I hope in heaven*". One couple (N16) said they did not believe their son was somewhere, but did attribute special signs and signals to their son. A mother (N11) said (searchingly):

"*Maybe, with family?*" From the narrative of a few of the parents emerged a spatial notion of some realm, like that of the Islamic mother who believed that her son was in paradise. Yet, belief in something like heaven was not conditional for the spiritual connectedness. The space where the child was 'found' was primarily 'around me'. The presence of the child was expressed in terms of a relational connection, to which the indication of a possible spatial reality was subordinate.

### Receptiveness

Experiences that surpassed the logical immanent meaning of events were not consciously sought for but *encountered* in daily life. The signs and signals that parents connected to the deceased son or daughter were interpreted as initiatives of the child to interfere with the parents.

The transcending momentum was felt to come from the outside, but included movement from the inside out, as meaning was attributed to these events surpassing the boundaries of life (Ganzevoort, 2006). Our findings suggest that receptiveness is an important condition in this spirituality, as mentioned in other research in which the concept of receptivity is even considered to be decisive for spirituality (Walton, 2013).

Some parents, however, experienced these connecting features 'despite themselves'. They said they were not open to spirituality, yet mentioned strange happenings. One of the couples explicitly rejected a transcendent dimension of life but told humorously that they had failed to scatter their son's ashes at sea. Up to four times they had arranged to go out on a boat, but every time a storm prevented setting sail. Father: *"Then you think somehow: he does it again"*. Mother: *"Yes, that is typically R"*. *Father: "Yes, so that's the joke now. Every time we want to do something with the ashes, we look outside: 'O no, there's a wind blowing, so … "* (N14). After 5 years the ashes were still at home.

### Ambivalence

As we have seen so far, ambivalence is manifest in different aspects of parental confrontation with the loss. In our previous research (Ganzevoort & Falkenburg, 2012), the notion of ambivalence was encountered in the attribution of meaning; now we noted it again in the parents' interpretation of spiritual events. Though parents experienced connectedness to the deceased child, many of them at the same time conveyed doubts and reservations. Most parents put these experiences in perspective by voicing 'common sense' (N3, N6). They said not to believe in heaven, or spirituality, or God, or mediums (but visited them all the same). They had doubts about the rationality of the 'non-accidental' happenings of contact and at the same time, they cherished them. They did not seek for a meaningful frame to give meaning to the loss or the experiences of connectedness. In fact, most parents said 'no' to a belief or coherent story. And yet, after denying the logic of their experience they virtually let it follow by: "And yet … ". Although parents valued logic and rational thought, they also embraced its opposite: the unexplainable. Unexplainable experiences and cognitive reservations went effortlessly together in the personal narratives. Parents did not try to find explanations for these contradictions; they moved between the cognitive and affective, between transcendence

and immanence, between the ontological and metaphorical and between presence and absence. The "Yes he is here with me" and the "No I don't know if he is somewhere" was not perceived as conflicting.

Ambivalence was also found in the narratives of parents who had a religious background but said that faith was no longer meaningful (N4, N6, N11, N19). God was mentioned as representing a religious truth, to which many parents referred to in terms of doubt and anger. Yet, at the same time affective attributions to God were not completely absent. One could be deeply touched by a picture of Maria, or of Christ on the cross. Other parents made use of grandparents' or friends' religious or spiritual interpretation of events without making it their own. Two couples (N10, N17) were comforted by family members' views on life (Rosicrucian and Buddhist, respectively). These parents explicitly said that they did not feel the urge to subscribe to these views; they just 'borrowed' the interpretation, but did not proclaim to it.

Parents also had a dual vision of life and death. The death of the child constituted a major rupture, after which every aspect of life fundamentally changed (N2, N11). Death now belonged to life. Yet, the lesson they learned from it is that they must live consciously (N11, N17, N19,) and intensely (N 19). Death put many things into perspective (N14, N15). Most remarkably, many parents insisted they had learned to *enjoy* life, the little things, relationships. Personal contact, family and friends were most valuable, whereas concerns about material things still (after 5 years) were dismissed as not important.

### *Vision on death*

To many parents, their own death had initially been an attractive alternative to living without the child. This perception had changed over time. After 5 years, they no longer longed for death. Yet they were sharply aware that death can appear at any moment. "*It can be over any time*" (N2). Not all parents found it easy to define their own concept of death. "*If you ask me: 'Do you believe in an afterlife?' I would say on the one hand: 'I don't have a clue', but on the other hand I do think there is more*" (N3). Most parents had lost all fear of death. For many, death provided the opportunity of reuniting: "*Every new day is a day sooner with I*" (N9). 'I am not afraid of death. I will go to my child', is what many parents said (N1, N3, N8, N9, N12, N13, N17).

One of the fathers who had no affiliation with spirituality declared: "*I am still convinced that we know so little about how it all works, all those dimensions and I don't know what, that it might well be like that, that what stops here, lives parallel elsewhere. We know so very little, [ … ] in a physics sense we know so little. It might well be that what is material here lives on elsewhere in another form. Not in the religious sense. At least I never had that feeling. But it might well be that it lives on somewhere else; yes. I do believe so" (N2).*

Not the existence of a place where the dead dwell, but the relational continuation in death was what mattered for the majority of parents. In many narratives the child was thought to be with family (mostly grandparents) (N1, N2, N5, N6, N9, N11, N15) or friends (N19).

Parents of three children explicitly rejected the possibility to meet again (N10, N14, N20). Yet one of these parents (N10) sighed: "*I find it very, very bizarre that he knows how it is to be dead*", thus hinting that there could still be some form of consciousness after death.

### *Affinity to spirituality and faith*

We investigated if these parents explained their experiences in terms of spirituality or faith. The words spirituality and spiritual were not often used, in contrast to "*strange*", "*amazing*", (N16) "*bizarre*", (N3) "*Well say it, make it up, I don't know*", (N8) "*Things about which you say: how is that possible*" *(N18).* Some parents explicitly linked the experiences to a form of transcendence. They referred to it with open phrases like 'there is more' or 'there is more between heaven and earth', indicating awareness of deeper dimensions in life.

The Christian and Islamic believers spoke not of spirituality but of their faith. Two of the Christian couples did not speak of experiences of contact with their deceased child; they rather ascribed signals as coming from God. One of the couples made clear that God had placed meaningful events on their path that were not coincidental but came out of His hand (N18). The other mother saw the appearance of a butterfly as a message from God (N12). Both said that God sent people to help them in difficult situations.

### *Other connections*

Mention was also made of special experiences not directly linked to the child but to some form of spiritual dimension. One parent couple (N10) did not feel contact with their son, but told of special energies, of a different relationship with nature and life itself. The mother had felt "*lifted up*" several times. The father felt connected to the "*memory of water.*" A very religious father had also experienced new depths in life itself (N18).

## Discussion

The interviews with parents whose critically ill child had died in our PICU 5 years previously, brought out special moments of connectedness to their child that transcend rational, empirical facts of life and belong to the spiritual domain. Through signs and signals they sometimes felt connectedness with God, but in most cases with the deceased child itself. People who do not necessarily adhere to or seek for a spiritual worldview – let alone use terms like 'spiritual' to describe their experiences – may still foster a sense of spirituality. What emerged was a pattern of fragmentary moments of experiencing contact. These moments signify a remaining connection to the deceased child. We define this fragmentary-connectional spirituality as 'fragile spirituality' as it is encountered in people who are existentially affected by a major rupture in their lives. It is full of contradictions and ambivalence and not incorporated in a coherent worldview. The fragile character of this form of spirituality also manifests itself in being reluctant

to speak openly of these experiences. The intimate character of the connecting experiences is protected against potentially negative reactions suggesting parents' psychological weakness. There is also a vagueness surrounding the interpretation of events. The fragile spirituality we discovered does not depend on (prior) spiritual or religious affinity; the transcending meaning of lasting connectedness suffices to parents.

The parents described events that as such were not exceptional but interpreted them as not being coincidental. These events were not paranormal or supernatural phenomena, as described in research in which religious experiences and manifestations were associated with non-natural, preternatural events (Körver, 2013; Kwilecki, 2004). These moments of perceived connectedness were considered extraordinary, but they did not resemble the numinous experiences of the sacred (in a *mysterium tremendum*) as investigated by Rudolf Otto (Otto, 2012) or the transformative mystic religious experiences described by William James (2005).

We recognize the vagueness that Superdock and colleagues encountered when they investigated the role of religion and spirituality in complex pediatric decision-making. It appeared that the parents' vagueness and contradictions helped them to bear the anguish and uncertainty (Superdock, Barfield, Brandon, & Docherty, 2018). Parents' expressions of religion and spirituality can present alternatives to a harsh reality, without denying this reality.

From a psychological point of view, this type of spirituality shows similarity to Winnicott's description of a *potential space* between an individual's inner life and his environment, which originates in the gradual separation from the mother after birth (Winnicott, 1971). In this process, the child uses transitional objects and phenomena in an intermediate area to initiate the relationship between itself and the world. This "area of playing is not inner psychic reality. It is outside the individual, but it is not the external world", says Winnicott (p. 51). This playing is linked to cultural experiences – and in our case: spiritual experiences.

Similar to the early days of mother-child separation, transitional objects and phenomena can help to accept the paradox that objects can be both joined and separated. Translating this to grieving parents, we can say that the transcending experiences of connectedness are transitional as they help parents accept the separation, which also gives hope for continuation of the relationship.

Thus, spiritual notions can create a 'playing ground' of conflicting notions and ideas in which not rationality rules but possibilities of lasting contact jostle.

## Significance

The moments of experiencing connectedness, however fragmentary, signify that the experience of loss is not total and indefinite; an inkling of hope of contact remains – like the hope of the child's recovery in the PICU – even if it is unlikely, even to the parents themselves.

In the present study, the parent's need for logic, consistency and coherence was not dominant and often explicitly rejected. Few of the parents adjusted their (global) meaning system to the changed situation, although such adjustment may be important for dealing with the loss (Park, 2010). The fragile spirituality we encountered was related to

not understanding on the one side, yet finding significance on the other side. This significance was found in relational continuation; in other words, the deceased child was still part of the parents' life.

### Function of this spirituality: creating perspectives

Even to people who do not declare themselves to be religious or spiritual, experiences of connectedness create the possibility of perspective in their loss. There is a 'beyond'. As Ganzevoort put it: "It is not so much the conviction about a transcendent reality but the entrustment to a transcendent possibility" (Ganzevoort, 2004). Spirituality is significant in its capacity to open meaningful horizons. In the case of grieving parents in the present study, it transformed expectations of the continuation of life after death. Death is on the one hand the final limit to life. Pain and longing due to a child's absence are parents' daily reality. On the other hand, death consists of a porous boundary that makes some form of connection and relationship possible (Chidester, 2002). This transcendence transforms the signature of death, in that it leaves open a future reuniting.

### Caregivers' role in the spiritual dimension

We return to the question how spirituality can be approached in health care. Chaplains or spiritual caregivers are specialized in supporting people when they are confronted with the depth of existential experiences and help them connect to the spiritual. In their methodological approach the experience of connectedness is intrinsically explored (Smit, 2015). But the spiritual dimension is also touched in the encounter with other helpers like health care professionals, when patients (or their families) feel personally noticed in what they endure (Weiher, 2014). Especially in aftercare, an important but often disregarded part of palliative care, all caregivers could pay attention to spirituality even though the spiritual dimension shows little structure and is often more implicit than explicit.

Pediatric intensive care treats vulnerable children in a life-threatening situation, which makes parents experience existential anguish. Understanding spirituality as an important life experience means to be open to the diverse experiences and multi-voiced connections and meanings parents of critically ill children attribute to the situation. It does not suffice to ask parents if they relate to some religious meaning system. The answer will in many cases be negative (Kruizinga et al., 2017; van der Geest et al., 2015) while the impact of spiritual connectedness to the child, to life, and to transcendence is not recognized at all. Spirituality is more than the adherence to a particular view of life.

Health care professionals would do well to acknowledge the existential dimension which is part of the human condition. The hope that people cherish both in sickness and in the confrontation with death is not a denial of reality, as is often thought (Sisk, Kang, & Mack, 2018). When in end-of-life care parents voice their hope of a miracle, health care professionals often keep telling them how desperate the child's condition is (Superdock et al., 2018). In line with findings from Kamihara and coworkers on hope in the context of childhood cancer, our findings show that the contradiction between reality and meaningful experiences that transmit hope, is not problematic to parents (Kamihara, Nyborn, Olcese, Nickerson, & Mack, 2015). Physicians and nurses who are

conscious of the fact that families interpret the situation on a different level, are better able to support parents. This underlines the relevance of the concept of Patient and Family Centered Care, in which the perspective of the family is important. Health care professionals are really to listen to what is important to families in their anguish (Meert, Clark, & Eggly, 2013).

### *Strengths and limitations*

A strength of our research is that it reveals expressions of spirituality that so far have received little attention. The fact that spirituality can be discovered in people's stories, even when they do not adhere to a belief or religion, contributes to better understanding of the relevance of spirituality in health care. We realize that our findings may not be generalizable to all bereaved parents. The special spirituality we discovered may be especially found in secularized societies in which belief in a Higher power of God is no longer dominant. A limitation of the study is that the participants were predominantly native Dutch parents, with only one parent from another cultural background.

Administering an interview in parents' home environment can be considered both a strength and a limitation. The strength is that parents felt at ease and could set the pace of the interview. A possible limitation is that of researcher bias. In the interaction between parents and the interviewer, elements of parents' stories could have been consciously or subconsciously stressed or neglected. In other circumstances or with another interviewer their stories might have been narrated differently. In addition, we cannot rule out certain social desirable responses. For instance, we asked open questions about parents' experiences and their personal interpretation but when we asked a question like "Do you still feel connected to your child?", parents might have interpreted this as something they should feel.

### *Conclusions*

In the confrontation with the loss of their child, parents encounter special experiences of a transcending kind, which help them stay connected to their child during the end-of-life stage (in the PICU) and after death. We consider these experiences manifestations of a 'fragile spirituality', which is a form of spirituality that is fragmentary, unbound, ambivalent, and referring to another dimension in this life. This spirituality is significant in the perspective it offers in the existentially disrupting reality of loss. Thus, the spiritual dimension is part of end-of-life care, and all caregivers should be aware of its relevance and consider offering appropriate compassionate care.

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