

# Parents' Faith and Hope during the Pediatric Palliative Phase and the Association with Long-Term Parental Adjustment

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## Abstract

**Background:** The loss of a child is associated with an increased risk for developing psychological problems. However, studies investigating the impact of parents' faith and hope for a cure during the palliative phase on long-term parental psychological functioning are limited.

**Objective:** The study's objective was to explore the role of faith and hope as a source of coping and indicator of long-term parental adjustment.

**Methods:** Eighty-nine parents of 57 children who died of cancer completed questionnaires retrospectively, exploring faith, hope, and sources of coping, and measuring parents' current level of grief and depression.

**Results:** For 19 parents (21%) faith was very important during the palliative phase. The majority of parents remained hopeful for a meaningful time with their child ( $n=68$ , 76%); a pain-free death ( $n=58$ , 65%); and a cure ( $n=30$ , 34%). Their child ( $n=70$ , 79%) was parents' main source of coping. Twelve parents (14%) suffered from traumatic grief, and 22 parents (25%) showed symptoms of depression. Parents' faith was not associated with less long-term traumatic grief (OR=0.86,  $p=0.51$ ) or symptoms of depression (OR=0.95,  $p=0.74$ ), and parents' hope for a cure was not related to more long-term traumatic grief (OR=1.07,  $p=0.71$ ) or symptoms of depression (OR=1.12,  $p=0.47$ ).

**Conclusions:** Faith was important for a minority of parents and was not associated with less long-term traumatic grief or symptoms of depression. The majority of parents remained hopeful. Hope for a cure was not associated with more long-term traumatic grief or symptoms of depression.

## Introduction

ALTHOUGH SURVIVAL RATES of childhood cancer have increased in the past decades, approximately 25% of all children diagnosed with cancer will ultimately die.<sup>1</sup> Pediatric palliative care is aimed at achieving the best possible quality of life for children with life-threatening conditions and their family, and encompasses not only attention to the child's physical well-being, but also involves spiritual care for the child and family.<sup>2</sup> Spirituality includes themes like hope, faith, sense of empowerment and confidence, relationships and connectedness with others, and comprises the most existential questions about meaning and purpose in life.<sup>3,4</sup> The current study focuses on two aspects of spirituality, faith and hope, both as a source of coping during the palliative phase as

well as a determinant of long-term parental psychological adjustment after the child's death, including traumatic grief and symptoms of depression.

Bereaved parents often acknowledge that faith was important to them when they were faced with the imminent death of their child.<sup>5-9</sup> For example, faith supported parents in the process of creating meaning,<sup>7</sup> providing comfort,<sup>7,8</sup> and aiding in managing difficult decisions.<sup>10,11</sup> However, to date, mostly qualitative research has been carried out,<sup>6-11</sup> predominantly in the United States.<sup>5-9</sup> While faith includes "an evolving pattern of believing which grounds and guides authentic living and gives meaning to the present moment of inter-relating,"<sup>12</sup> in the current study we conceptualized faith as the beliefs and practices that make up an enduring relationship with a God.

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An aligned construct which seems important for parents is hope.<sup>2,7,13</sup> The term hope is however ambiguous as there is no clear definition<sup>14</sup> and is subject to change.<sup>15,16</sup> As hope can be framed in a wider context than just survival,<sup>17</sup> we have made use of the following definition: Hope is the anticipation of something positive, while at the same time accepting the inevitable. From the perspective of parents, hope is 'a cornerstone of decision making'<sup>13</sup> and important for parents in decision making around either continuing intensive treatment or opting for supportive care alone during the palliative phase.<sup>18,19</sup> However, less is known about how important dimensions of hope are for parents during the palliative phase, such as hope for a cure, hope for a meaningful time, and hope for a death without pain.

Research has identified sources that help parents during the palliative phase, such as faith, prayer, health care professionals, family and friends, and the belief in a lasting relationship with their child.<sup>5-7,20-22</sup> Yet, the value of faith and prayer has not been extensively investigated in a secular society.

Although it is well known that the loss of a child is associated with an increased risk for developing psychological problems,<sup>23</sup> studies investigating the impact of faith and hope for a cure during the palliative phase on long-term parental psychological functioning are limited.<sup>24,25</sup> Only one study specifically focused on parents' faith and showed that, as it was referred to in the study, 'religious faith' does not protect bereaved parents from psychological symptoms, compared with nonbereaved parents.<sup>25</sup> However, it is worth exploring this relationship between parents' faith and long-term parental psychological adjustment in more depth, as previous studies showed that in other settings, religiousness may protect people from depressive symptoms.<sup>26,27</sup> No studies have investigated the association between hope for a cure and long-term parental psychological adjustment after the child's death. Conversely, the need for such a study is highlighted by results of previous reports, showing that some health care professionals may consider hope for a cure during the palliative phase as 'false' or 'unrealistic'<sup>28,29</sup> and inhibiting patients' acceptance.<sup>30</sup>

The aims of this study are to develop better insights into the importance of faith and several dimensions of hope during the palliative phase (i.e., hope for a cure, hope for a death without pain, and hope for a meaningful time with their child); to explore parents' sources of coping during the palliative phase; and to unravel the impact of faith and hope for a cure on parents' long-term adjustment, i.e., grief and symptoms of depression.

## Methods

### Parent recruitment procedure

Participants in this study were parents who lost a child to cancer between January 2000 and December 2004, during or after treatment at the Erasmus Medical Centre – Sophia Children's Hospital, Department of Pediatric Oncology/Hematology. In total, parents of 123 of 135 children were eligible for this study. Parents of 12 children were not approached to participate in this study, as it was thought too burdensome ( $n=5$ ), because their child died in the diagnostic phase of childhood cancer ( $n=2$ ), or their child died because of a sudden toxic death during treatment ( $n=2$ ). In addition, parents of two prematurely born infants were not approached,

as both infants had multiple organ problems and died very shortly after birth. One family was seeking asylum at the time of their child's death.

Mothers and fathers were asked to separately complete the (1) Inventory of Traumatic Grief (ITG), (2) the depression subscale of the Brief Symptom Inventory (BSI), and (3) a questionnaire investigating parents' experiences of palliative care. Demographic characteristics of the child were collected: gender, diagnosis (categorized as hematological malignancy, non-CNS solid tumor, or brain tumor), age at death, and place of death. In addition, parents' gender, age, satisfaction with place of death, and self-reported religious affiliation were assessed.

This study was approved by the Medical Ethical Committee of the Erasmus Medical Centre, Rotterdam, the Netherlands (MEC number 2007–362).

### Measurement instruments

**Inventory of Traumatic Grief.** The ITG measures current parental grief. Twenty-nine items such as 'I can't accept his/her death' are rated on a five-point Likert scale ranging from 'never' (1) to 'always' (5). Possible scores range from 29 to 145. Higher ITG scores indicate more grief. The reliability of the ITG is good; internal consistency is Cronbach's alpha 0.94, and test-retest correlation for the ITG total score is 0.92.<sup>31</sup> In order to explore the number of parents with clinically relevant traumatic grief, scores were dichotomized, based on a provided cut-off score for traumatic grief (i.e., a total grief score >90).<sup>31</sup>

**Depression subscale of the Brief Symptom Inventory.** The depression subscale of the BSI measures parental depression. Six items such as 'I feel lonely' are rated on a five-point Likert scale ranging from 'not at all' (0) to 'a lot' (4). Possible scores range from 0 to 4, as the mean score of the six items was used to calculate the depression subscale. Higher scores on the depression subscale of the BSI indicate more symptoms of depression. Internal consistency is 0.87 and test-retest correlation 0.84.<sup>32</sup> In order to explore the number of parents with symptoms of depression, scores were dichotomized, based on provided cut-offs scored for males (>0.71) and females (>0.80).<sup>33</sup>

**Questionnaire designed for this study.** A questionnaire was developed to assess parents' experience of palliative care, which was part of a larger study.<sup>34</sup> The questionnaire was developed on the basis of an extensive study of the literature; clinical experience; and a pilot study interviewing three bereaved mothers (Vereniging 'Ouders, Kinderen en Kanker' (VOKK), the Dutch Childhood Cancer Parent Organization), which was carried out to establish content and face validity of the questions, with emphasis on the sensitive nature of the items. In the current study, questions relating to parents' perception of faith and hope during the palliative phase and factors that helped parents to cope while facing the death of their child were investigated. The two elements of faith explored in this study were: the extent to which parents have faith in a God or a higher power, and whether parents' faith has been strengthened because of their child's disease. The three elements of hope explored in this study were: hope for a cure, hope for a pain-free death, and hope for a

meaningful time with their child. Moreover, we measured which factors and/or people supported parents during the palliative phase of their child's illness (see Table 1).

### Data analysis

Data were analyzed using SPSS 21.0 (SPSS, Inc., Chicago, IL). Descriptive analyses were generated for all variables. Continuous data are presented as median and range; categorical data are presented as numbers and percentages. To explore the importance of faith, hope, and sources of coping during the palliative phase, parents' level of agreement with statements are presented as the number and percentage for each statement (1 = disagree, 2 = somewhat disagree, 3 = neutral, 4 = somewhat agree, 5 = agree). The number of parents with traumatic grief and symptoms of depression was calculated by using the cut-off scores. To unravel the impact of faith and hope for a cure on parents' long-term adjustment, i.e., grief and symptoms of depression, unadjusted logistic regression analyses were performed. Results were considered statistically significant when the *p*-value was <0.05, two-tailed.

### Results

Of the 246 fathers and mothers who received the questionnaires (all families received two questionnaires), 89 parents of 57 deceased children completed the questionnaires. For 32 children, both parents returned the questionnaires. No significant differences were found between children of parents who completed the questionnaires com-

pared with children whose parents did not respond in terms of gender, diagnosis, age at death, and place of death.

A higher number of mothers responded than fathers (63% versus 37%). Median age of fathers at time of the study was 45 years (31–55 years); median age of mothers at time of the study was 42 years (25–59 years). Median time between completion of the questionnaires and date of death of the child was five years (range 3–8 years). Of the 57 children, 41 were boys (72%). Median age at death was seven years (range 1–17 years). The majority of children died at home (*n* = 39, 68%). In total, 80 parents (90%) were satisfied with the place of death. Twenty-one children (37%) had died of a hematological malignancy, 20 children (35%) of a brain tumor, and 16 children (28%) of another solid tumor.

### Faith and hope

Thirty-five parents (39%) reported a religious affiliation, including Christian (*n* = 31), Muslim (*n* = 1), Buddhist (*n* = 1), Jehovah's Witness (*n* = 1), and 'other' (*n* = 1). Of the parents who reported they were Christian, 18 were Protestant and 13 were Roman Catholic (belonging to a variety of churches). Nineteen parents (21%) indicated that faith was very important for them in the palliative phase, while 45 parents (51%) disagreed. Thirteen parents (15%) revealed that their faith had become stronger, while the majority of parents disagreed with that statement (*n* = 52, 58%). Most parents remained hopeful during the pediatric palliative phase. Sixty-eight parents (76%) had hope for a meaningful time with their child, 58 parents (65%) had hope for a death without pain,

TABLE 1. LEVEL OF AGREEMENT WITH STATEMENTS ON FAITH, HOPE, AND SOURCES OF COPING<sup>a</sup>

	No. of parents who completed question	1	2	3	4	5
<b>First element (1 = disagree; 5 = agree)</b>						
<b>Faith</b>						
'In the period my child was incurably ill, faith was very important to me.'	86	45 (51%)	2 (2%)	14 (16%)	6 (7%)	19 (21%)
'My faith has been strengthened because of the disease of my child.'	87	52 (58%)	3 (3%)	14 (16%)	5 (6%)	13 (15%)
<b>Hope</b>						
'I hoped that my child would be cured.'	79	26 (29%)	6 (7%)	5 (6%)	12 (14%)	30 (34%)
'I hoped for a meaningful time with my child.'	83	2 (2%)	-	4 (5%)	9 (10%)	68 (76%)
'I hoped for a death without pain.'	78	2 (2%)	1 (1%)	9 (10%)	8 (9%)	58 (65%)
<b>Second element (1 = disagree; 5 = agree)</b>						
<b>To what extent have the following helped you cope, from the time you were told your child was incurably ill to the moment your child passed away:</b>						
My child	82	1 (1%)	-	7 (8%)	4 (5%)	70 (79%)
Health care professionals	76	3 (3%)	2 (2%)	10 (11%)	15 (17%)	46 (52%)
Hope in general	74	19 (21%)	3 (3%)	11 (12%)	14 (16%)	27 (30%)
Prayer	70	42 (47%)	3 (3%)	7 (8%)	6 (7%)	12 (14%)
Faith in a God/Allah	69	40 (45%)	2 (2%)	8 (9%)	3 (3%)	16 (18%)
The belief that there is more 'between heaven and earth'	70	19 (21%)	5 (6%)	16 (18%)	11 (12%)	19 (21%)
The belief in a lasting relationship with my child	73	21 (24%)	3 (3%)	13 (15%)	14 (16%)	22 (25%)
Family and friends	79	1 (1%)	2 (2%)	8 (9%)	23 (26%)	45 (51%)

<sup>a</sup>Questionnaire consisted of two elements: (1) the role of faith and hope and (2) exploration of factors that helped parents cope with the palliative phase. Level of agreement is presented as a number (frequency): 1 = disagree; 2 = somewhat disagree; 3 = neutral; 4 = somewhat agree; 5 = agree.

Number of parents and percentages are presented (percentage calculated from total [*n* = 89]).

and 30 parents (34%) had hope that their child would be cured. Parents' levels of agreement with the individual statements regarding faith and hope are outlined in Table 1.

### Parents' sources of coping

Most parents stated that the child helped them cope during the palliative phase ( $n=70$ , 79%), and more than half of the parents agreed that health care professionals ( $n=46$ , 52%) and family and friends ( $n=45$ , 51%) helped them cope. Factors mentioned less often by parents were hope in general ( $n=27$ , 30%), the belief in a lasting relationship with their child ( $n=22$ , 25%), the belief that there is more 'between heaven and earth' ( $n=19$ , 21%), faith in a God/Allah ( $n=16$ , 18%), and prayer ( $n=12$ , 14%) (see Table 1).

### Long-term parental adjustment

Median ITG score was 55.0 (range 32.0–116.0); median score for the depression subscale of the BSI was 0.2 (range 0.0–3.5). Using published cut-off scores, 12 parents (14%) could be categorized as having traumatic grief and 22 parents (25%) showed symptoms of depression. Nine parents (10%) showed symptoms of both traumatic grief and depression.

### Impact of faith and hope for a cure

Neither faith nor strengthening of faith were associated with less long-term traumatic grief ( $OR=0.86$ ,  $p=0.51$ ;  $OR=0.58$ ,  $p=0.11$ ) or symptoms of depression ( $OR=0.95$ ,  $p=0.74$ ;  $OR=0.90$ ,  $p=0.52$ ). Likewise, remaining hopeful for a cure during the palliative phase was not related to increased levels of traumatic grief ( $OR=1.07$ ,  $p=0.71$ ) or symptoms of depression ( $OR=1.12$ ,  $p=0.47$ ) (see Table 2).

### Discussion

The current study set out to explore the importance of two aspects of spirituality, faith and hope; parents' sources of coping; and to unravel the impact of faith and hope for a cure on parents' long-term adjustment, i.e., grief and symptoms of depression. In the present study, faith was important for a small number of parents during the palliative phase. In addition, both faith and prayer were reported as important for a minority of parents as a source of coping. These findings are not in line with previous studies, all performed with parents

of incurable children in the United States.<sup>5–9</sup> It is conceivable that this is due to the fact that in the United States nearly 70% of people believe in a God or a universal spirit.<sup>35</sup> In contrast, a profound process of secularization is ongoing in the Netherlands.<sup>36</sup> Our results add to the literature by demonstrating that faith is less prominent in a secular society such as the Netherlands, which is likely to be of interest to other secular societies.<sup>15,28,29</sup>

In general, the majority of parents retained wide-ranging hopes. About three-quarters of parents hoped for a meaningful time with their child, and almost half of parents remained hopeful for a cure, despite awareness of their child's poor prognosis. Although the existence of parents' hope for a cure concurrently with the child's poor prognosis may seem incompatible, this phenomenon has previously been acknowledged in adult studies.<sup>14,37–41</sup> Moreover, in clinical practice, honest communication of physicians does not impede sustaining hope, and in some cases, this can make families even feel more hopeful.<sup>40–43</sup>

Regarding the question around what or who helped parents to cope with the child's nearing death, 80% of parents indicated their child as being pivotal. Although we can only speculate why their child was important in coping at the end of the child's life, this finding emphasises the importance of parents being involved in care for their child and being physically close to their child.<sup>20,44</sup> While it has been previously reported that some parents find comfort in the belief that the connection with the child will extend after the child's death,<sup>6,7</sup> the belief in 'a lasting relationship' with their child was helpful only for a quarter of parents in the current study. Similar to previous reports, our results showed that family, friends, and health care professionals were important for parents in helping them cope at the end of the child's life.<sup>5,6,8,21,45</sup> Our findings indicate a minor role for spiritual aspects for parents as a source of coping, with relationships with the child, family and friends, and health care professionals being instrumental in providing support.

The current study showed that the extent to which parents had faith was not associated with traumatic grief or symptoms of depression in the long-term, which is in line with a previous study of parents of an incurable child.<sup>25</sup> The reason we did not find an association could be that in a secular society faith is less often used by parents as a coping factor. In addition, it is possible that some parents use their faith as a negative coping factor, for instance by interpreting their

TABLE 2. IMPACT OF FAITH AND HOPE ON LONG-TERM TRAUMATIC GRIEF AND SYMPTOMS OF DEPRESSION (OUTCOME MEASURES)<sup>a</sup>

	Traumatic grief <sup>b</sup>				Symptoms of depression <sup>c</sup>			
	OR	B	P	95% CI	OR	B	P	95% CI
<b>Faith</b>								
'In the period my child was incurably ill, faith was very important to me.'	0.86	-0.15	0.51	0.56; 1.33	0.95	-0.05	0.74	0.70; 1.29
'My faith has been strengthened because of the disease of my child.'	0.58	-0.55	0.11	0.30; 1.13	0.90	-0.11	0.52	0.64; 1.26
<b>Hope</b>								
'I hoped that my child would be cured.'	1.07	0.07	0.71	0.74; 1.56	1.12	0.11	0.47	0.83; 1.51

<sup>a</sup>Unadjusted logistic regression analyses.

<sup>b</sup>Dichotomized (clinical cut-off >90) (Boelen et al.).

<sup>c</sup>Dichotomized (clinical cut-off >0.80 females; clinical area >0.71 males) (De Beurs et al.).

B, beta; CI, confidence interval; OR, odds ratio; P, p-value.

child's death as a punishment.<sup>46–48</sup> Moreover, a previous study showed that some parents might start questioning their faith, feeling anger and blaming God, or rejecting their faith or communities.<sup>10</sup> On the other hand, as we did not find a negative association between faith and long-term parental psychological functioning, our finding does not preclude the possibility that for some parents faith might have a positive influence on long-term adjustment.

In our cohort, those parents who remained hopeful for a cure did not report more traumatic grief or symptoms of depression five years after the child's death, showing that hope for a cure may not necessarily mean that parents are not able to accept their child's situation. This finding is supported by Kwon and colleagues, who showed that having hope, irrespective of whether this hope is realistic, is associated with positive adjustment.<sup>49</sup>

The dual approach of supporting hope and honest communication about the child's prognosis can be difficult.<sup>39,41,50,51</sup> A questionnaire among health care professionals in the field of oncology revealed that about half of all participants believed that they lack the skills to sustain hope in patients,<sup>52</sup> whereas health care professionals have an important role in giving hope.<sup>53</sup> Moreover, some health care professionals worry when parents remain hopeful, as they might associate this with 'not accepting' the child's death, or the possibility that parents want to carry on with unsuccessful potentially harmful treatment.<sup>13</sup> The approach of hope may differ between individuals: for parents, hope is considered as a protector of their child, while for health care professionals, hope is associated with positive health-related outcomes.<sup>13,54</sup> Current evidence would suggest that in clinical practice it is necessary to be honest, but there is no need to discourage parents from hoping for a cure.<sup>39,41,55,56</sup>

We acknowledge that this study has some limitations. A small number of parents of different religious affiliations completed our questionnaire, which excludes the possibility to explore and draw conclusions on variations between religious affiliations. Moreover, the possibility of recall bias should be taken into consideration, as we asked parents to describe their feelings in a time period on average five years later. Another limitation is that for the purpose of this study we defined faith as a part of religion. However, faith can be considered as a much broader concept.<sup>12</sup> This could potentially bias our results regarding the importance of faith. Lastly, the response rate, which was 35%, is a limitation of our study, as this could bias our established number of parents with traumatic grief and/or symptoms of depression. Further research should explore the association between traumatic grief, depression, and faith among parents with different religious affiliations<sup>57</sup> and stronger beliefs.<sup>24</sup>

In summary, in our Dutch cohort, faith was important for only a minority of parents during the palliative phase. The majority of parents retained wide-ranging hopes. Their child, family and friends, and health care professionals, were the main sources of coping for parents during the palliative phase. Faith was not associated with less traumatic grief or symptoms of depression, and hope for a cure was not associated with more traumatic grief or symptoms of depression.

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### Author Disclosure Statement

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