

Home or hospital as the place of end-of-life care and death: A grounded theory study of parents' decision-making

Palliative Medicine

1–12

© The Author(s) 2020



Article reuse guidelines:

sagepub.com/journals-permissions

DOI: 10.1177/0269216320967547

journals.sagepub.com/home/pmj

Danai Papadatou¹, Vasiliki Kalliani², Eleni Karakosta²,
Panagiota Liakopoulou² and Myra Bluebond-Langner³

Abstract

Background: While several studies have examined ‘what’ families want with regard to the place of a child’s end-of-life care and death, few have explored ‘how’ parents reach a decision.

Aims: (1) to develop a model explaining how parents of a child with a life-threatening illness in Greece decide about the place of end-of-life care and death; (2) to identify the factors affecting decision-making; (3) to consider the implications for clinical practice.

Design: Grounded theory study of bereaved parents using semi-structured open-ended interviews following Strauss and Corbin’s principles of data collection and analysis.

Setting/participants: Semi-structured interviews with 36 bereaved parents of 22 children who died at home ($n = 9$) or in a paediatric hospital ($n = 13$) in Athens, Greece.

Results: (1) Decisions regarding place of care and death were reached in one of four ways: consensus, accommodation, imposition of professional decisions on parents or imposition of parents’ decisions without including professionals. (2) Six factors were identified as affecting decisions: awareness of dying, perceived parental caregiving competence, perceived professional competence, parents’ view of symptom management, timing of decision-making, and being a ‘good parent’. (3) Decisions were clear-cut or shifting. Few parents did not engage in decisions.

Conclusion: Parents’ decisions about place of end-of-life care and death are affected by personal, interpersonal, timing and disease-related factors. Parents are best supported in decision-making when information is presented clearly and honestly with recognition of what acting as ‘good parents’ means to them, and opportunities to enhance their caregiving competence to care for their child at home, if they choose so.

Keywords

Decision-making, end-of-life, hospital, home care, grounded theory, place of death

What is already known about the topic?

- Despite the fact that home is often advocated as the preferred place of death and as a ‘marker’ of a ‘good death’ for children, this is not supported by robust evidence.
- Research on location of end-of-life care and death has been more outcome-focused, documenting parents’ and clinicians’ preferences or epidemiological trends with regard to the achieved place of death.
- Studies focus on ‘what’ decisions parents make at the end of the child’s life, rather than ‘how’ these decisions are reached.

¹Faculty of Nursing, School of Health Sciences, National and Kapodistrian University of Athens, Athens, Greece

²“Merimna” Society for the Care of Children and Families Facing Illness and Death, Athens, Greece

³UCL-School of Life and Medical Sciences, Faculty of Population Health Sciences Great Ormond Street Institute of Child Health, Population, Policy and Practice Research and Teaching Department, Louis Dundas Centre for Children’s Palliative Care, UK

Corresponding author:

Danai Papadatou, Department of Clinical Psychology, Faculty of Nursing, School of Health Sciences, National and Kapodistrian University of Athens, 123, Papadiamandopoulou Street, Goudi, 11527 Athens, Greece.

Email: dpap@nurs.uoa.gr

What this paper add?

- Identification of six salient factors affecting decision-making about place of care and place of death: awareness of dying, perceived professionals competence, parents' perceived competence to deliver care at home, parents' view of symptom management, timing of decision-making, and being a 'good parent'.
- Identification of four distinct processes through which decisions are made: mutual consensus, accommodation, acceding to professional decisions and imposing decisions by excluding professionals.
- Articulation of an explanatory model of parents' decision-making for the place of care at the end-of-life and death, derived from empirical findings, situated in current context of care in Greece that has relevance beyond Greece.

What are the implications for practice, theory and policy?

- Parents should be helped to make decisions about place of end-of-life care and place of death in such a way that they are not only truly informed by caring professionals but also presented timely with options so as to develop competence to deliver care at home, should they choose to do so.
- Perceptions of what 'good parenting' entails, should be explored in deliberations with parents as decisions are reached.
- Policy makers should improve end-of-life care at all sites since home and hospital are desirable to different families, for different reasons, at different times.

Background

Ida Martinson, in her pioneering work '*Home Care Project for the Dying Child*', was the first to explore the feasibility, desirability, and effectiveness of home care as an alternative to hospitalisation.^{1,2} Since then, several studies have been undertaken to document family and clinicians' preferences,³⁻⁶ epidemiological trends with regard to the achieved place of death,⁷⁻¹⁴ variables, such as socioeconomic status or type of disease, associated with different outcomes,^{15,16} and bereaved family's adjustment following home or hospital end-of-life care.¹⁷⁻²⁰

A review of the literature suggests that while home is often perceived as the preferred place of death, this view is not supported by robust evidence.⁶ According to Dussel et al.²¹ 'the actual place of death may be less important than argued', whereas 'the opportunity to plan the location of death may be a better proxy for high-quality end-of-life care, one that is more inclusive and better aligned with palliative care principles' (pp. 34, 40). Moreover, a 'good death' is not achieved in a linear or univocal way. Attention needs to be given not just to what parents want, but also to 'how' parents reach a decision when given a choice about the place of the child's dying and death.

To date, only two studies, one conducted in England²² and one in France,²³ have addressed the issue, both with families of children with cancer. Their findings suggest that decision-making is culturally and country specific and as such decision-making about place of care at the end-of-life should be studied in several contexts before drawing conclusions across contexts. The aim of this study was (1) to develop a theoretical framework grounded in empirical data to explain how parents in Greece decide on the location of their child's end-of-life care and death, and (2) to explore how choices and service delivery affect bereavement. This article addresses the first aim.

Method*Study design*

The larger study had a *quantitative component* comprising a structured questionnaire to explore parents' perceptions of service effectiveness at the end-of-life and impact upon bereavement, and a *qualitative component*, following the principles of grounded theory articulated by Strauss and Corbin.²⁴ Two research questions guided the qualitative study: (1) how do parents decide where the child will be cared for at the end-of-life and die, and (2) what factors impact their decision?

In adopting a grounded theory methodology, we recognise that our study is underpinned by a post-positivist philosophical approach to the study of decision-making; acknowledging the researcher's subjectivity, while striving to ensure maximum objectivity through a systematic approach to data analysis and the use of triangulation.

Population and setting

Bereaved parents were invited to participate. Their children had received end-of-life care services from 'Merimna',²⁵ the only Paediatric Palliative Home Care Service in Greece, or hospital services in specialised units located in a 400-bed public paediatric hospital of Athens. Paediatric hospice care is not available in Greece.

Sampling and eligibility criteria

Families who participated in the study met the eligibility criteria outlined in Table 1. Theoretical sampling was adopted to ensure maximum variation in terms of disease, age, site of death (home, hospital specialised unit vs intensive care unit).

Table 1. Inclusion and exclusion sample criteria.*Inclusion criteria*

- Bereaved mothers and fathers of a child (0–18 years old), who died from a life-threatening or life-limiting illness
- End-of-life care and death occurred at home following enrollment in a paediatric palliative home care service or in a unit of a large paediatric hospital in Athens
- Interview took place 6–30 months since child's death
- Resident in Athens
- Fluent and literate in Greek

Exclusion criteria

- End-of-life care and death occurred in another country or outside Athens
- Child's death occurred less than 6 or more than 30 months before the interview
- Bereaved parents neither fluent nor literate in Greek.

Data collection

Data were collected over 2 years (2015–2016). Bereaved parents were contacted and informed about the study by the hospital's or Merimna's staff. Those who consented were invited to an interview with their spouse at a time and place that was most convenient to them. They signed a consent form and were informed that confidentiality would be preserved with data being anonymised.

The semi-structured interview was conducted in Greek with one or both parents. Interviews, which lasted from 45 to 180 minutes, were conducted by two psychologists and one social worker with post-graduate training in research and palliative care experience. Translation was not needed for Albanian parents, who read and spoke Greek fluently, having lived in Greece for over 10 years.

As per principles of grounded theory, data collection and analysis occurred concurrently and when new information emerged additional questions were added to the interview guide and new categories were refined in the analysis (e.g. shifting decisions, last minute change of place, communication patterns such as exaggerated prognostication).

Data analysis

Transcripts were analysed with attention to parents' points of view on their decision-making. Data were initially broken down into small segments (codes) which were reassembled into categories and subcategories along the lines of their properties and dimensions (axial coding). Codes were raised to a higher level of abstraction (selective coding) through further refinement of categories, subcategories and their interrelations.

Regular meetings were held among three coders (V.K., E.K., P.L.) and the principal investigator (D.P.), throughout the analysis process, to minimise biases. When alternative codes and categories were proposed, consensus was

reached through repeated data examination and the collection of additional accounts. This also enriched the theory that was progressively emerging. Data collection ended when data saturation was achieved and an empirically based model could be put forward.

Ethical issues

Ethical approval was obtained from the Scientific Committee of the Children's Hospital P & A Kyriakou, and from the Ethics Committee of the Faculty of Nursing of the National and Kapodistrian University of Athens.

Results*Participants' characteristics*

Twenty-seven families were invited to participate in the study; 22 consented (81% response rate) with 36 parents of 11 boys and 11 girls, attending the interview (Table 2). About 6 fathers and 2 mothers declined participation. About 28 were of Greek origin; 6 of Albanian origin. Children's age at death ranged from 5 months to 18 years.

Analysis of parents' accounts revealed three core categories: (1) the decision-making process about the place of end-of-life care and death, (2) factors affecting parents' decisions, and (3) types of decisions reached.

1. The decision-making process

According to participants' reports, discussions about the place of the child's care and death were held among parents and clinicians, including an adult sibling. While children were not included in these discussions parents took their preferences into consideration. Decisions about the place of care were reached in four distinct ways (Table 3).

- 1.1. By mutual consensus.** Options about the place of end-of-life care were thoroughly explored by parents and professionals who came to a mutual agreement.

After discussing with Dr. X the option of home care, I told her: 'I am interested but I want first to meet the home care physician. Then, Dr. Z (paediatric palliative care specialist) came home. Along with my wife, we had a thorough discussion about the option of home care. When the physician left, I asked her: 'What do you want?' She replied: 'I prefer home care', and I said 'Me too'. We came to a unanimous decision and that's how it happened. (F13)

- 1.2. By accommodation.** Decision-making occurred between spouses and among professionals and parents. In some cases, one spouse, usually the mother, assumed a leading role, and her partner willingly consented.

Table 2. Parent, deceased child characteristics, place of end-of-life care and place of death.

Parent's characteristics			Child's characteristics					
Family ID	Participants	Ethnicity	Interview (months since death)	Gender	Diagnosis	Age at death (years)	Place of end-of-life care	Place of death
F1	Mother Father	Greek	8	F	Malignant	4	Hospital	Hospital
F2	Mother Father	Greek	9	F	Malignant	7	Hospital	Hospital
F3	Mother Father	Greek	18	M	Malignant	12	Hospital	Hospital
F4	Mother <i>Father refused</i>	Greek	9	M	Malignant	15	Hospital	Hospital
F5	Mother Father	Greek	13	F	Malignant	2	Hospital	Hospital
F6	Mother <i>Father unavailable</i>	Greek	6	M	Malignant	13	Home	Hospital
F7	Mother <i>Father unavailable</i>	Greek	24	F	Non-malignant	20 months	Hospital	Hospital
F8	<i>Mother unavailable</i> Father	Greek	17	M	Malignant	10	Home	Home
F9	Mother Father	Greek	16	F	Malignant	2	Home	Home
F10	Mother Father	Greek	6	M	Non-malignant	5 months	Home	Home
F11	Mother <i>Father unavailable</i>	Albanian	30	M	Malignant	10	Home	Hospital
F12	Mother <i>Father refused</i>	Albanian	18	M	Malignant	6	Home	Hospital
F13	Mother Father	Greek	8	M	Malignant	4	Home	Home
F14	Mother Father	Greek	9	F	Non-malignant	2	Hospital	Hospital
F15	Mother Father	Greek	8	F	Non-malignant	2.5 months	Home	Home
F16	Mother <i>Father refused</i>	Greek	9	F	Non-malignant	7	Home	Home
F17	Mother Father	Greek	12	M	Malignant	8	Home	Home
F18	Mother Father	Albanian	11	F	Malignant	16	Hospital	Home
F19	Mother <i>Father refused</i>	Greek	10	M	Malignant	9	Home/ Hospital	Hospital
F20	<i>Mother refused</i> Father	Albania	9	M	Malignant	11	Hospital	Hospital
F21	Mother Father	Greek	12	F	Malignant	3	Home	Home
F22	Mother Father	Greek	11	M	Non-malignant	7 months	Home/ Hospital	Hospital

Table 3. Decision-making process about the place of child's end-of-life care and death.

Decision-making process	Dynamics among parents and professionals
By mutual consensus	Parents and professionals consider options and mutually agree upon a decision for home or hospital care at the child's end-of-life and death
By accommodation	<i>Within the couple:</i> One parent assumes a leading role in the decision-making process and the other willingly accommodates <i>Among professionals and the couple:</i> Parents or professionals make a decision, which is respected and embraced by others
By acceding to professionals decisions	No options offered. Professionals make a decision to which parents abide
By imposing decisions and excluding professionals	Professionals disregard parents' expressed preferences Parents exclude professionals from decisions and act independently

He (husband) is a reserved person, holds everything inside. In few words, he let me make all the decisions. (M12)

In other cases, professionals assumed a leading role and parents accommodated to the proposed option, which was in line with their preference. When parents refused the staff's option, they offered an alternative proposal which was embraced by professionals who accommodated to their desires.

They (German professionals who were asked for a second opinion) proposed a medication which was at an experimental stage. We refused and told them: 'Our desire is to go back to

Greece and let her rest and sleep at home'. Deeply touched, these professionals realised we were determined; they showed respect, gave us a hug, and asked: 'Where do you find such strength?' (M9)

1.3. **By acceding to professionals decisions.** In some cases parents were not offered any options. The physician told them what was going to happen and parents acceded to clinicians' decision.

Interviewer: *Did the clinicians propose Merimna's pediatric palliative care service?*

- Parent: *No they didn't suggest it. They [oncologists] told us: 'Our job is finished. From now on, the home care team will help you until the end of her life'. That was all. Nothing else.*
- Interviewer: *Did you have difficulty deciding about palliative home care?*
- Parent: *No, we had no difficulty, because they did not give us a choice. (F21)*

Some parents welcomed the clinician making the decision, expressing relief from the burden of responsibility of making a choice.

- 1.4. **By imposing decisions and excluding professionals.** When parents' desires were ignored and professionals wanted to impose their preference, participants excluded physicians from decisions and followed their own course of action.

We went back to Dr X and she told us about a new treatment (requiring hospitalisation), and I asked if it was experimental, and she replied: 'No'. I asked about the success percentage and she replied they had no indications, so I assumed it was a clinical trial. 'We will think about it, and we will let you know', I told her. This lady thought she was dealing with idiots and said to us: 'You know, I have the power and capacity to impose my decision, if I believe that this (treatment) is what your son should get'. It was the last time we saw her. We opted for home care. (M17)

2. Factors affecting parental decisions about the place of end-of-life care and death

We identified six factors affecting parents' decisions: (1) awareness of child's dying, (2) perceived professional competence, (3) parents' perceived competence to deliver care at home, (4) parents' view of symptom management, (5) timing of decision-making, and (6) being a 'good parent' (Figure 1).

- 2.1. **Awareness of child's dying.** For some parents, awareness increased as the child's condition deteriorated whereas for others awareness came suddenly after a critical incident (e.g. heart arrest, trachyostomy). Analysis of accounts revealed three levels of awareness.

Open awareness involved the realisation of the child's imminent death, even though it did not always imply acceptance. Decisions of parents who were both aware and accepting of the child's terminal condition, aimed at ensuring a dignified dying process according to their own and the child's preferences.

I nursed, breast fed him, and told myself: 'At some point this kid will leave this life'. I tried to make him laugh, sung, danced for him and he laughed. . . . When I was alone, I would let go and cry. It was difficult to come to terms that in one year, six

or nine months, he will die. You tend to push the thought at the corner of your mind and tell yourself: 'Now, I will make him laugh, now I will tickle him, now I will sing to him, now I will tell him stories'. (M10)

Open awareness was often facilitated by the children themselves, enabling parents to exchange direct or symbolic farewells.

'He used three motorbike toys and told me: 'The black is mine because I drive far ahead of you, and I am gone'. I replied: 'I will reach you, and pass ahead of you'. 'You can't because I will be gone. You will stay behind me, to look after my young brother'. . . . I couldn't hold my tears, and asked him: 'What do you mean?' He said: 'I won't say it again: I will leave'. (F13)

Compartmentalised awareness reflected a conscious or intuitive awareness of the child's inevitable death, which was put to the side or 'back of one's mind' as hope for a miracle came forward; resurfacing when the child's condition deteriorated. Parents moved in and out of the realisation that their child was dying.

Even though she was in a terrible condition, I said to myself: 'We will fight this and move on'. I didn't want to consider the thought that this child would die in the future. I didn't think about it. I believed in a miracle, yet in the back of my mind, the thought (of her death) was there. (M21)

While for some parents compartmentalisation led to choosing home care, for others it led to choosing hospitalisation in pursuit of a cure.

Hope never fades away. Until the very last minute, we believed that he wouldn't die. I had read many things. . . . I was fully aware that scientifically he would not survive, but along with his mother, we couldn't accept it; we hold on hope until the last moment. (F20)

Closed awareness persisted even when parents were exposed to the child's health deterioration and imminent death. These parents reported coming to an awareness only during the very last hours of his or her life.

They (palliative care staff) tried to prepare us. We didn't accept it. . . . My husband didn't want to be told such things. . . . and I simply thought they would be disconfirmed. I realised he was dying at the very moment of death. Until then, I believed in a miracle. (M19)

Even when children were aware of their terminal condition and tried to say goodbye, parents were unable to return the farewell.

She told me: 'You are my favourite person in the world'. It was the last thing she said and never spoke again. I didn't understand that she was going to leave'. (M18)

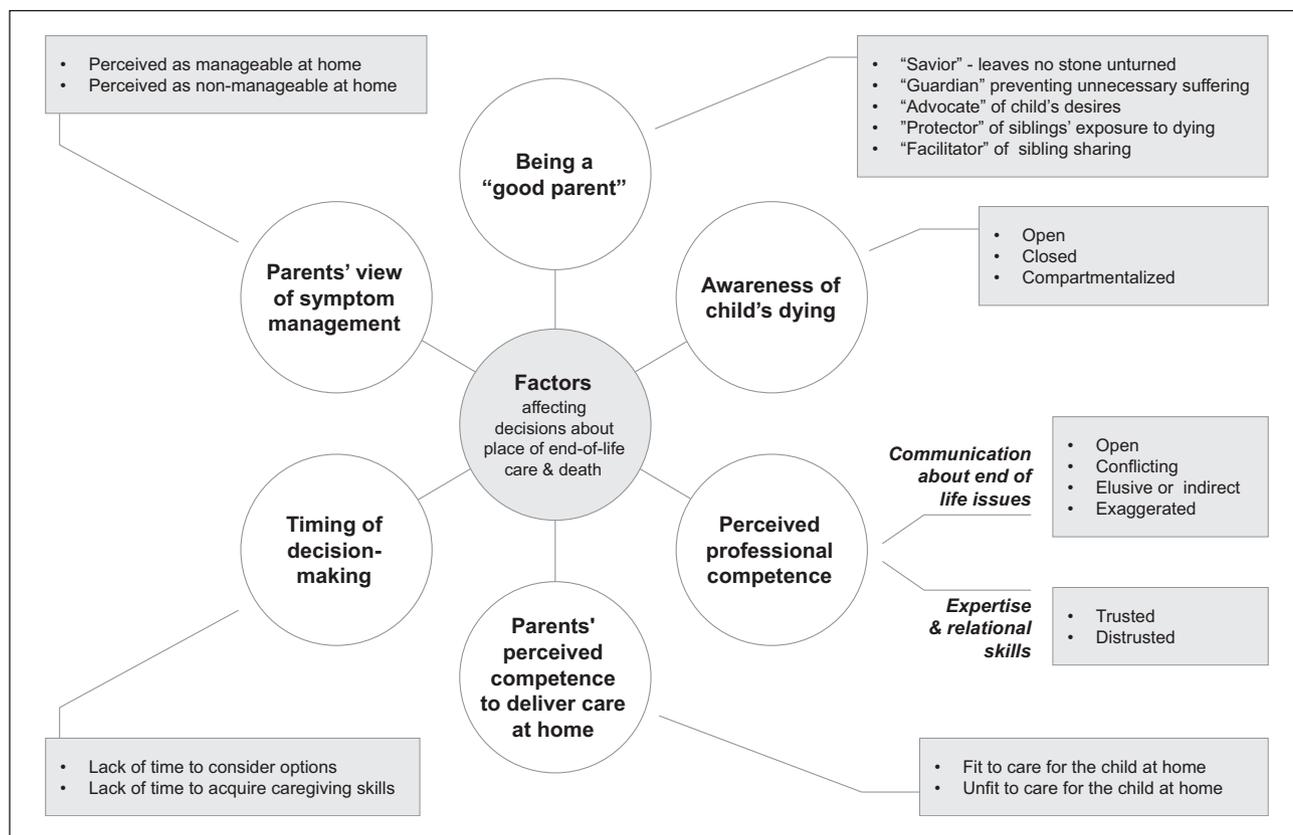


Figure 1. Categories and sub-categories associated to the factors affecting parents' decisions.

Parents' decisions about place of care at the end of life varied by their awareness of the child's terminal condition. For parents with compartmentalised or closed awareness their preference shifted from home to hospital, and vice-versa.

2.2. Perceived professional competence. Decision-making was affected by their perceptions of the professionals' (a) ability to communicate about end-of-life issues and (b) skills in negotiating interpersonal relationships.

2.2.1. Communication about end-of-life issues. All parents reported having been informed about the child's deteriorating condition however *what* they were told and *how* information was imparted affected their decisions.

Open communication involved imparting straightforward information about the child's terminal condition and end-of-life care options. It affected parents' perceptions of professionals' competence and by extension, their decision about the place of end-of-life care.

They explained very clearly the negative and positive aspects of care. This was very helpful because they were straightforward. In other words, they did not leave us with 'yes, but', 'may be', 'it could turn out this or that way'. (F7)

Conflicting communication occurred when one or several staff members gave contradictory messages, which confused parents as to death's imminence.

The key doctors didn't tell us, 'go home', but the intern said to me, 'there is no point staying here'. (M16)

Elusive or indirect communication was vague and evoked uncertainty and anxiety. Expressions such as 'the situation is difficult', 'you will give birth to another child', 'do you have another child?' confused parents who were reluctant to clarify what had been insinuated.

He (child) was asking to go home and Dr Y suggested: 'Don't bring him to the hospital. I will send a physician to your home, who is a friend of mine, to help you. It is better to avoid tiring him with hospital visits and exams every 10 days'. I never imagined that the child would become bedridden at home and never get up again. (M11)

Exaggerated communication accounted for what parents described as 'dramatic prognostication' which desensitised and prevented them from realizing the imminence of death.

The physicians' attitude was to include 'difficulties' in all their prognostications. . . Their prognoses and diagnoses were nightmarish. I didn't believe them. I thought they would fight the disease and everything would turn out fine. (F3)

Just as awareness was associated with more or less stability in parents' decisions regarding place of care, so too was clinicians' communication. Conflicting or elusive communication was associated with vacillating decisions whereas open communication was associated with stability in decisions.

2.2.2. Professional expertise and relational skills.

Decisions were affected by parents' perceptions of professional expertise and competence to support their child and family. 'Humane' qualities, such as loving concern, empathy, compassion, and psychological availability, were reported as critical in affecting decisions.

At the hospital they all took special care of us and loved him very much. I received a lot of love from everybody. (M22)

They (palliative home care team) were interested in her as a 'person' and did not perceive her as a clinical case. The nurse and paediatrician became indispensable to her. I was in peace because I had next to me, my own trusted people. (M21)

Parents who maintained trusted relationships with hospital personnel, were more likely to opt for hospital care whereas those who questioned the professionals' competence, decided for home care and death.

We (spouses) agreed that our child wouldn't die in a hospital setting where some nurses treated her adequately, whereas others put tape on her pacifier to prevent her from crying. . . . When I saw this, at a time she was actually dying, I decided to take her home, and hold her in my arms before she goes. (F15)

2.3. Parents' perceived competence to deliver care at home. Parents who chose hospital for end-of-life care, were uncertain of their ability to provide effective care and felt insecure about managing a health crisis or the actual death at home.

We didn't know. . . We couldn't manage anything on our own. (M7)

By contrast, those who felt competent in assuming care and were supported by a palliative care team they trusted, opted for home care.

You just become more 'hardened' than a parent with a healthy child; you see the blood and you know you must stop it. And you do it. You gain experience inevitably. . . . At home, you are not limited to a parental role, but you also assume a nursing role. (F13)

2.4. Parents' view of symptom management.

When clinical symptoms were perceived as uncontrollable or requiring intrusive or aggressive interventions not available outside

the hospital, parents decided to hospitalise their child.

We wouldn't be able to offer at home what professionals could offer at the hospital. I have no doubt about it. She underwent two mini surgeries at the end of her life, because she couldn't urinate. . . . I couldn't listen to her being in pain. She received a lot of morphine to prevent the suffering. (M2)

2.5. Timing of decision-making. Parents objected to home care when the child's condition suddenly deteriorated or when they felt they had no time to develop the skills and confidence to care for the child and cope with eventual emergencies at home.

Things developed very fast and we didn't know how to assume the care at home. (F7)

I didn't expect this turnout. He died so suddenly, like in a road traffic accident. (F3)

2.6. Being a 'good parent'. Decisions were affected by the parents' values, priorities, and sense of duty to act on behalf of their dying child. Some perceived themselves as a 'saviour' who left no stone unturned in the face of death. Others described themselves as 'guardians' by preventing unnecessary suffering or as 'advocates' of the child's desires who sought to remain or return home. All verbally competent children ($n = 16$) except one, expressed a preference to die at home.

We should do what needs to be done, with nothing weighing on our conscience, with no regret that we may have left 1/100 or 1/1000 possibility unexplored. (F14)

- (father): *He perceived the hospital as a prison for the sick,*
 - (mother): *so we decided to return home.*
 - (father): *If we would keep him in the hospital, he would have felt deserted by us, and we didn't want this to happen. (F-M17)*

Hospital care was also chosen by parents who perceived good parenting as 'sibling(s) protector' from exposure to dying and death, whereas home care was chosen by parents whose good-parent beliefs involved being a 'facilitator of sibling sharing'.

They (brother and sister) interacted until the end, exchanged wishes and their love to each other. . . . Is there anything more beautiful, and more powerful? He was a bit more distressed after her death, but now feels better that he was at the bedside of his sister until the end. Both children would have been deprived of something precious if they were apart. (F8)

3. Types of decisions reached

Decision-making led to two types of decisions. Few parents did not decide.

- 3.1. Clear-cut decisions.** Fully aware of the child's terminal condition, most parents had a clear preference as to the place of care and death, which was in line with their values and priorities. Some reported reaching decisions spontaneously and instantaneously.

There was NO chance to take the child home, since his care was too demanding. (M4)

Our child should be in her environment with everything that is familiar to her; this was 'magic' to her at the very end of her life. (M9)

Yet other parents reported reaching a decision only after lengthy deliberation.

I knew nothing about home care. The day the oncologist informed me about this option, we met with the palliative care physician. I told the oncologist that I am interested in this option, but I want first to meet the physician. So, she came along with her colleagues, and we had a meeting with my wife and the oncologist. She explained how they provide home care services, what were the steps for enrolling to their palliative care service. . . . and gained my trust. They had an answer for everything. I appreciated that very much. After this initial meeting, I discussed with my wife, and we both agreed to opt for home care. (F13)

- 3.2. Shifting decisions.** Some parents vacillated between two options, both of which were desirable for different reasons at different times. They moved in and out of the awareness that the child was dying, shifted locations, changed care teams or transferred the child from home to hospital or vice-versa few hours before death. Four families made a shift during the very last hours, three from home to hospital, and one from hospital to home.

What I experienced at home was beautiful. I wouldn't have experienced all these special moments and family farewells in the hospital. . . . But at the very last moment, I do not know what I felt, but I had to do something, and called for an ambulance. The hospital physician warned me that the child could die on the road, and asked me if I was certain about my decision. And I said: 'yes, I want to do that'. (M12)

- 3.3. No decision.** When physicians imposed a decision about home or hospital, or when parents maintained a closed awareness, they did not engage in decisions, feeling they had no options.

I believed that we would give a fight. . . . and I was optimistic. . . . That is why it all came so suddenly and I was unprepared. I couldn't imagine that things would develop in such a way. . . . Physicians informed us, but I didn't want to believe them. I didn't expect this evolution, and I realised only the very last day that we had come to the end. (F3)

4. The derived model of parents' decision-making

The derived model (Figure 2) depicts the interrelation between (1) decision-making processes, (2) types of decisions reached, and (3) factors affecting the choice of place for end-of-life care and death.

Decisions for *hospital* end-of-life care and death were most likely when (1) physical symptoms were perceived as uncontrollable, (2) parents felt they lacked the time to develop skills, (3) doubted their ability to care for the child at home, and (4) defined 'good parenting' as an act of leaving no stone unturned and of protecting siblings from exposure to death.

Decisions for *home* were most likely when parents (1) maintained open awareness of the child's dying condition, (2) felt competent in caring for their child at home, (3) perceived good parenting to be 'guardians' by making decisions -to prevent unnecessary suffering, 'advocates' by fulfilling the child's wish to be at home, and/or 'facilitators' of sibling sharing of a dignified death. Although painful, parents described their experience as unique and meaningful.

Clear-cut decisions for home or hospital were reached by mutual consensus, by accommodation, or by imposition of parental decisions on professionals who were in conflict with parents' preferences. By contrast, *shifting decisions* were typical of parents with closed or compartmentalised awareness of the child's dying, whose belief of being a good parent involved acting as 'saviours' of the child's life or as 'advocates' of his or her wish to return home. Clinicians accommodated to these shifting decisions. *No decision* was typical of parents who maintained a closed awareness and acceded to professionals' decisions.

Discussion

Main findings

The proposed model suggests that the decision to pursue home or hospital as the place of end-of-life care and death is complex and multidimensional. Six factors are involved: awareness of child's impending death, parents' perceived competence to deliver care at home, perceived professional competence, view of symptom management, timing of decision-making, and being a 'good parent'. The salience of each of these factors differs in the choice of home versus hospital.

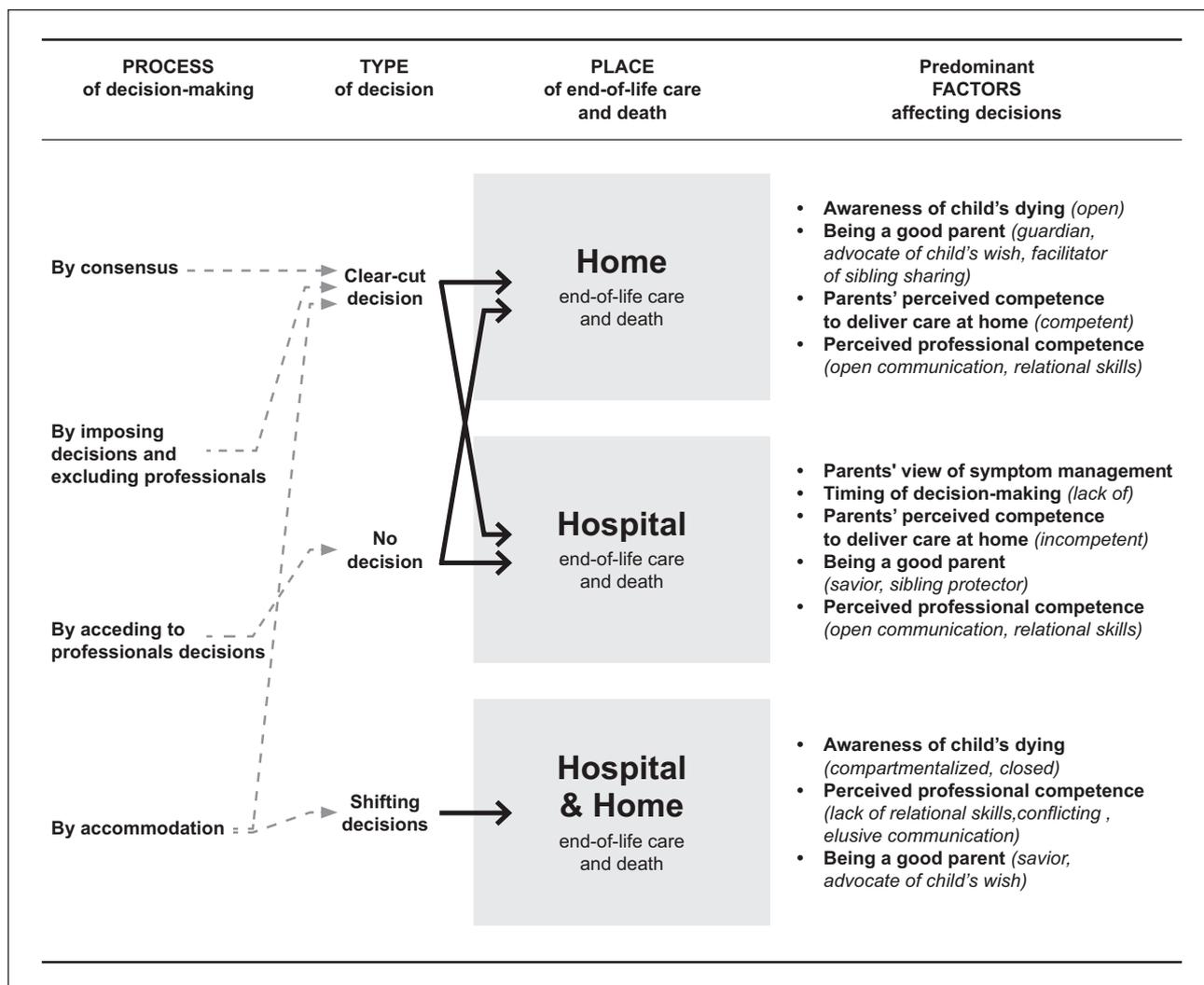


Figure 2. Model on parents' decision-making about place of end-of-life care and death.

In the decision to go home, beliefs about what it is to be a 'good parent' emerges as the primary factor affecting choice among parents who were aware of death's imminence; whereas in the decision to be in hospital parents' views of symptom management is primary and affected by the severity of the child's condition, the timing of decision-making – not long enough to become competent and confident in delivering care at home. 'Perceived professional competence' cross cuts both decisions suggesting that the clinicians' ability to communicate honestly and relate with compassion affects parents' decisions about the place of their child's dying and death regardless of the chosen place.

Our findings also support four distinct processes through which decisions are made or avoided: 'mutual consensus', 'accommodation', 'acceding to professional decisions' or 'imposition of parental decisions and exclusion of professionals'. Most parents eventually reach a

clear-cut decision as to the place of dying and death; fewer vacillate between possible courses of action and change preferences as death becomes imminent. Parents who maintain closed awareness are unable to consider alternative options and avoid decisions altogether.

Several factors identified in this study have not been as prominent in other studies of parents' end-of-life experiences^{26–28} or decision-making.^{29–38} Particularly, the parents' perceptions of their competence and confidence in delivering care at home, suggests a new area deserving our attention in end-of-life decision-making theory and practice about place of care and death.

In contrast to the Hannan and Gibson²² study which supports that parents *react* to places where their family feels safe or unsafe rather than *decide*, and to Montel's et al.²³ findings which refer to parental *motivations* for home or hospital death, the present findings suggest that

parents actively engage in decision-making, with the majority reaching, spontaneously or after deliberations a clear-cut decision for home or hospital. Parents are active agents in the care of their children, not passive recipients.

The identified perceptions of 'good parenting', resonate with some of the predominant explicit heuristics used in parents' end-of-life decision-making.³⁹ These heuristics act as mental short-cuts that reduce parents' cognitive burden associated with decision-making,⁴⁰ thus preventing a lingering on dilemmas over the location of care at the terminal phase. It further explains the parents' increased reports of clear-cut decisions.

Definitions of 'good parenting' at the end-of-life⁴¹ as well as changes over time in the 'good parent belief system' have been documented.⁴² In the present study five definitions have been identified in parents' reports: 'saviour', 'guardian', 'advocate', 'sibling protector' and 'facilitator of sibling sharing'. These definitions both confirm and enlarge prior evidence.

Compared to a Greek study conducted 25 years ago,⁴³ when hospital was the only option available for children dying of cancer, the present findings highlight how the introduction of palliative home care services may affect practices and decisions among parents and clinicians. Choosing to return home then meant that parents were on their own in caring for their dying child, whereas now the burden and responsibility for decision-making is shared with professionals and often achieved by consensus or accommodation.

Not surprisingly, parents who are overwhelmed by the child's dying or the burden of decision-making value that clinicians decide on their behalf. However, the majority opt for a process described in the literature as 'shared decision-making'^{44,45} and 'collaborative communication' at the end-of-life,⁴⁶ with the maintenance of the clinician-parent relationship as of utmost importance.⁴⁷ The proposed decision-making model further enriches the current evidence-based international mapping of end-of-life decision-making styles.^{36,48,49}

Strengths and limitations

Methodological strengths include researcher triangulation in data collection and analysis, and theoretical sampling to ensure maximum variation and heterogeneity among mothers and fathers of children of different ages, with malignant and non-malignant diseases. However, the study shares some problems common to retrospective studies on bereaved parents, who may cope with the loss of their child by constructing a narrative they can live with. While questions about generalisability of findings to other cultures and health care systems beyond Greece can be raised, the articulation of an explanatory model derived from empirical findings has relevance beyond

Greece, particularly in countries which are in the process of developing paediatric home care services. Helping professionals become knowledgeable of the complexity of factors and processes affecting parental decision-making, will enhance the quality of end-of-life care and positively affect the family's adjustment to the child's loss.

What this study adds

Findings illuminate for the first time how different *decision-making processes*, affected by a variety of interrelated *factors*, lead to distinct *types of decisions* about the place of a child's end-of-life care and death.

Findings have clinical implications for health professionals who, in addition to providing clear and honest information, should explore options about the place of end-of-life care and death in a timely way so as to allow parents to develop competence and confidence to assume care at home, should they choose so. Policy makers should improve end-of-life care at all sites, since home and hospital are desirable to different families, for different reasons, at different times.

Authors' contributions

All authors have approved the final version of the manuscript for publication. They have actively participated through the entire process in the design of the work, analysis and interpretation of data. D.P. was the principle investigator and was involved in the methodological design of the study, in data analysis and in the writing of article. V.K. and P.L. conducted the interviews with parents whose child received palliative care at home and were involved in the coding and data analysis. E.K. conducted the interviews with the parents whose child was cared for at the hospital. All researchers were clinicians and experienced in providing adult or paediatric palliative care. M.B-L. was involved in the design and data analysis, development of core categories and sub categories, drafting and redrafting of paper.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article: The authors' contribution was funded by their posts- Danai Papadatou by the National and Kapodistrian University of Athens, Vasiliki Kalliani, Eleni Karakosta, and Panagiota Liakopoulou by Merimna, and Myra Bluebond-Langner by the True Colours Trust and her research at GOS-ICH that is supported by NIHR Great Ormond Street Hospital Biomedical Research Centre.

Ethical approval

Approval to conduct the study was obtained by the Scientific Committee of the Children's Hospital 'P & A Kyriakou'

(667/17.01.2014), the Ethic Committee of the Faculty of Nursing of the National and Kapodistrian University of Athens (128/8.05.2014). Data collection and analysis began in 2015. All participants received information about the study, and provided written consent. Data was securely stored per regulation of the National and Kapodistrian University of Athens.

ORCID iDs

Danai Papadatou  <https://orcid.org/0000-0002-2743-0241>

Myra Bluebond-Langner  <https://orcid.org/0000-0001-9281-5431>

References

- Martinson IM, Moldow DG, Armstrong GD, et al. Home care for children dying of cancer. *Res Nurs Health* 1986; 9(1): 11–16.
- Martinson IM, Moldow DG and Henry WF. Home care for the child with cancer. In: Christ AE and Flomenhaft K (eds) *Childhood cancer*. Boston, MA: Springer, 1984, pp.177–198.
- Kassam A, Skiadareis J, Alexander S, et al. Parent and clinician preferences for location of end-of-life care: home, hospital or freestanding hospice? *Pediatr Blood Cancer* 2014; 61(5): 859–864.
- Vickers JL and Carlisle C. Choices and control: parental experiences in pediatric terminal home care. *J Pediatr Oncol Nurs* 2000; 17(1): 12–21.
- Grinyer A and Thomas C. The importance of place of death in young adults with terminal cancer. *Mortality* 2004; 9(2): 114–131.
- Bluebond-Langner M, Beecham E, Candy B, et al. Preferred place of death for children and young people with life-limiting and life-threatening conditions: a systematic review of the literature and recommendations for future inquiry and policy. *Palliat Med* 2013; 27(8): 705–713.
- Feudtner C, Feinstein JA, Satchell M, et al. Shifting place of death among children with complex chronic conditions in the United States, 1989–2003. *JAMA* 2007; 297(24): 2725–2732.
- Feudtner C, Silveira MJ and Christakis DA. Where do children with complex chronic conditions die? Patterns in Washington State, 1980–1998. *Pediatrics* 2002; 109(4): 656–660.
- Leuthner SR, Boldt AM and Kirby RS. Where infants die: examination of place of death and hospice/home health care options in the state of Wisconsin. *J Palliat Med* 2004; 7(2): 269–277.
- Håkanson C, Öhlén J, Kreicbergs U, et al. Place of death of children with complex chronic conditions: cross-national study of 11 countries. *Eur J Pediatr* 2017; 176(3): 327–335.
- Gao W, Verne J, Peacock J, et al. Place of death in children and young people with cancer and implications for end of life care: a population-based study in England, 1993–2014. *BMC Cancer* 2016; 16(1): 727.
- Zernikow B, Szybalski K, Hübner-Möhler B, et al. Specialized pediatric palliative care services for children dying from cancer: a repeated cohort study on the developments of symptom management and quality of care over a 10-year period. *Palliat Med* 2019; 33(3): 381–391.
- Fraser LK, Fleming S and Parslow R. Changing place of death in children who died after discharge from paediatric intensive care units: a national, data linkage study. *Palliat Med* 2018; 32(2): 337–346.
- Higginson IJ and Thompson M. Children and young people who die from cancer: epidemiology and place of death in England (1995–9). *BMJ* 2003; 327(7413): 478–479.
- Cawkwell PB, Gardner SL and Weitzman M. Persistent racial and ethnic differences in location of death for children with cancer. *Pediatr Blood Cancer* 2015; 62(8): 1403–1408.
- Siden H, Miller M, Straatman L, et al. A report on location of death in paediatric palliative care between home, hospice and hospital. *Palliat Med* 2008; 22(7): 831–834.
- Lauer ME, Mulhern RK, Wallskog JM, et al. A comparison study of parental adaptation following a child's death at home or in the hospital. *Pediatrics* 1983; 71(1): 107–112.
- Lauer ME, Mulhern RK, Schell MJ, et al. Long-term follow-up of parental adjustment following a child's death at home or hospital. *Cancer* 1989; 63(5): 988–994.
- Mulhern RK, Lauer ME and Hoffmann RG. Death of a child at home or in the hospital: subsequent psychological adjustment of the family. *Pediatrics* 1983; 71(5): 743–747.
- Goodenough B, Drew D, Higgins S, et al. Bereavement outcomes for parents who lose a child to cancer: are place of death and sex of parent associated with differences in psychological functioning? *Psychooncology* 2004; 13(11): 779–791.
- Dussel V, Kreicbergs U, Hilden JM, et al. Looking beyond where children die: determinants and effects of planning a child's location of death. *J Pain Symptom Manage* 2009; 37(1): 33–43.
- Hannan J and Gibson F. Advanced cancer in children: how parents decide on final place of care for their dying child. *Int J Palliat Nurs* 2005; 11(6): 284–291.
- Montel S, Laurence V, Copel L, et al. Place of death of adolescents and young adults with cancer: first study in a French population. *Palliat Support Care* 2009; 7(1): 27–35.
- Strauss A and Corbin J. *Basics of qualitative research: techniques and procedures for developing grounded theory*, 2nd ed. Thousand Oaks, CA: SAGE, 1998.
- Papadatou D. Merimna: the society for the care of children and families facing illness and death. *Grief Matters* 2012; 15(3): 64–68.
- Mack JW, Hilden JM, Watterson J, et al. Parent and physician perspectives on quality of care at the end of life in children with cancer. *J Clin Oncol* 2005; 23(36): 9155–9161.
- Aschenbrenner AP, Winters JM and Belknap RA. Integrative review: parent perspectives on care of their child at the end of life. *J Pediatr Nurs* 2012; 27(5): 514–522.
- Hechler T, Blankenburg M, Friedrichsdorf SJ, et al. Parents' perspective on symptoms, quality of life, characteristics of death and end-of-life decisions for children dying from cancer. *Klin Padiatr* 2008; 220(3): 166–174.
- Heinze KE and Nolan MT. Parental decision making for children with cancer at the end of life: a meta-ethnography. *J Pediatr Oncol Nurs* 2012; 29(6): 337–345.
- Hinds PS, Oakes L, Furman W, et al. End-of-life decision making by adolescents, parents, and healthcare providers in pediatric oncology: research to evidence-based practice guidelines. *Cancer Nurs* 2001; 24(2): 122–134.
- Lipstein EA, Brinkman WB and Britto MT. What is known about parents' treatment decisions? a narrative review of

- pediatric decision making. *Med Decis Making* 2012; 32(2): 246–258.
32. Pyke-Grimm KA, Stewart JL, Kelly KP, et al. Parents of children with cancer: factors influencing their treatment decision making roles. *J Pediatr Nurs* 2006; 21(5): 350–361.
 33. Sharman M, Meert KL and Sarnaik AP. What influences parents' decisions to limit or withdraw life support? *Pediatr Crit Care Med* 2005; 6(5): 513–518.
 34. Stewart JL, Pyke-Grimm KA and Kelly KP. Parental treatment decision making in pediatric oncology. *Semin Oncol Nurs* 2005; 21(2): 89–97.
 35. Carroll KW, Mollen CJ, Aldridge S, et al. Influences on decision making identified by parents of children receiving pediatric palliative care. *AJOB Prim Res* 2012; 3(1): 1–7.
 36. de Vos MA, Bos AP, Plötz FB, et al. Talking with parents about end-of-life decisions for their children. *Pediatrics* 2015; 135(2): e465–e476.
 37. Bellali T and Papadatou D. The decision-making process of parents regarding organ donation of their brain dead child: a Greek study. *Soc Sci Med* 2007; 64(2): 439–450.
 38. Santoro JD and Bennett M. Ethics of end of life decisions in pediatrics: a narrative review of the roles of caregivers, shared decision-making, and patient centered values. *Behav Sci (Basel)* 2018; 8(5): 42.
 39. Renjilian CB, Womer JW, Carroll KW, et al. Parental explicit heuristics in decision-making for children with life-threatening illnesses. *Pediatrics* 2013; 131(2): e566–e572.
 40. Dietrich C. Decision making: factors that influence decision making, heuristics used, and decision outcomes. *Inquiries Journal/Student Pulse*, 2(2): 1–3, <http://www.inquiriesjournal.com/a?id=180> (accessed 29 October 2020).
 41. Hinds PS, Oakes LL, Hicks J, et al. "Trying to be a good parent" as defined by interviews with parents who made phase I, terminal care, and resuscitation decisions for their children. *J Clin Oncol* 2009; 27(35): 5979–5985.
 42. Hill DL, Faerber JA, Li Y, et al. Changes over time in good-parent beliefs among parents of children with serious illness: a two-year cohort study. *J Pain Symptom Manage* 2019; 58(2): 190–197.
 43. Papadatou D, Yfantopoulos J and Kosmidis HV. Death of a child at home or in hospital: experiences of Greek mothers. *Death Stud* 1996; 20(3): 215–235.
 44. Barry MJ and Edgman-Levitan S. Shared decision making – pinnacle of patient-centered care. *N Engl J Med* 2012; 366(9): 780–781.
 45. Kon AA. The shared decision-making continuum. *JAMA* 2010; 304(8): 903–904.
 46. Feudtner C. Collaborative communication in pediatric palliative care: a foundation for problem-solving and decision-making. *Pediatr Clin North Am* 2007; 54(5): 583–607.
 47. Bluebond-Langner M, Hargrave D, Henderson EM, et al. 'I have to live with the decisions I make': laying a foundation for decision-making for children with life-limiting conditions and life-threatening illnesses. *Arch Dis Child* 2017; 102(5): 468–471.
 48. de Vos MA, van der Heide A, Maurice-Stam H, et al. The process of end-of-life decision-making in pediatrics: a national survey in the Netherlands. *Pediatrics* 2011; 127(4): e1004–e1012.
 49. Carnevale FA, Canoui P, Cremer R, et al. Parental involvement in treatment decisions regarding their critically ill child: a comparative study of France and Quebec. *Pediatr Crit Care Med* 2007; 8(4): 337–342.