Sullivan Jane (Orcid ID: 0000-0001-8723-1917)

Title page

(i) **Title: After an end-of-life decision: parents' reflections on living with an end-of-life decision for their child**

(ii) **Original article**

(iii) **Authors:** Jane Elizabeth Sullivan[1,2], BSW (Melb), BA (Monash), Grad Dip Adol & Ch Psych (Melb), BTHEOL (MCD), MSW, PhD (Melb)
Lynn Heather Gillam,MA[1,2] (Oxon.), PhD, Monash.
Paul Terence Monagle[3,4,5,] MBBS (Hons) M.Sc.(Health Research Methodology, McMaster) M.D.

Affiliations:
1. The Children's Bioethics Centre, The Royal Children's Hospital, Parkville, Australia,
2. Centre for Health Equity, The University of Melbourne, Melbourne, Australia
3. The Royal Children's Hospital, Melbourne, Australia
4. Department of Paediatrics, The University of Melbourne, Melbourne, Australia
5. Critical Care and Neurosciences Theme, Murdoch Children's, Research Institute, Melbourne,
Australia

(iv) **Corresponding author:** Dr Jane Sullivan, The Children's Bioethics Centre, Royal Children's Hospital, Flemington Road, Parkville 3052, Australia.
sulj@unimelb.edu.au telephone: 00 61 03 98599105
Reprints: Will not be available

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Abstract

Aims

Parents’ role as end-of-life decision-makers for their child has become largely accepted Western healthcare practice. How parents subsequently view and live with the end-of-life decision they made has not been extensively examined.

To help extend understanding of this phenomenon and contribute to care, as a part of a study on end-of-life decision-making, bereaved parents were asked about the aftermath of their decision-making.

Methods

A qualitative methodology was used. Semi-structured interviews were conducted with parents who had discussed end-of-life decisions for their child who had a life-limiting condition and had died. Data were thematically analysed.

Results

Twenty-five bereaved parents participated. Results indicate that parents hold multi-facetted views about their decision-making experiences. An end-of-life decision was viewed as weighty in nature, with decisions judged against the circumstances that the child and parents found themselves in. Despite the weightiness, parents reflected positively on their decisions, regarding themselves as making the right decision. Consequently, parents’comments demonstrated being able to live with their decision.

When expressed, regret related to needing an end-of-life decision, rather than the actual decision. The few parents who didn't perceive themselves as their child's decision-maker subsequently articulated negative reactions. Enduring concerns held by some parents mostly related to non-decisional matters, such as the child's suffering or not knowing cause of death.

Conclusion

Results suggest that parents can live well with the end-of-life decisions they made for their child. End-of-life decision-making knowledge is confirmed and extended, and clinical support for parents informed.

Key words: ethics, end-of-life decision-making, parents, adjustment, support

What is known:

End–of-life decision-making for children is a profound complex phenomenon. In Western societies, parents typically want to be the end-of-life decision maker for their child. Particular aspects of end-o-life decision-making especially the aftermath have not been extensively examined.

What is added: Provides parental insight on living with an end-of-life decision. Confirms parents can live with having made an end-of-life decision for their child. Offers a way to help parents understand the end-of-life decision they have made for their child.

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Briefpoints

What is known:

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What is added: Provides parental insight on living with an end-of-life decision.
Confirms parents can live with having made an end-of-life decision for their child. Offers a way to help parents understand the end-of-life decision they have made for their child and identifies implications for clinical and bereavement care. In particular, the potential subsequent benefits for grieving parents are discussed.

Introduction

In contemporary Western healthcare practice, it is generally accepted that parents will make or at least be involved in making end-of-life decisions for their child[1-5]. An end-of-life decision (ELD) is understood as a decision to either withhold or withdraw life-sustaining medical treatment. Justification for parents taking this decision-making role has been supported by reference to principle[4,5-7] and the positive outcomes shown in empirical studies[8-10]. Understanding the possible long-term psychosocial impacts of fulfilling this relatively new role has become an important clinical issue. However, few studies have examined in depth how parents later view and live with their ELD[8-11]. Studies reporting on this phenomenon generally demonstrate that parents are not adversely affected by their participation in end-of-life decision-making (ELDM)[10-12]. However, negative outcomes such as guilt have been also identified[3,8,12,13]. Indeed, anticipated future guilt about possible adverse outcomes for their child has been identified by some parents as a reason for not engaging in decision-making[**13**,14].

Paediatric studies[7,9,12] and a recent narrative review of ELDM recommend further research into this complex process[2], **parental grief and bereavement support[15, 16] and more generally into paediatric palliative care[17,18]**.

Further research into the psychosocial outcomes for parents making ELDs will contribute to a fuller appreciation of this significant phenomenon and help to inform health care policy, clinical and bereavement practices. As part of a study examining parents' views and experiences of end-of-life decision-making for their child, parents who were bereaved were asked about the aftermath of their ELDM. Results reported here relate to how parents subsequently reflected on and lived with their decision

METHOD

A qualitative methodology with semi-structured interviews was used. This methodology, considered ethically appropriate when participants may be vulnerable, **is** useful for exploring under-studied phenomenon[1,19]. This methodology is especially relevant for paediatric palliative care research[19,20].

With approval (30061A) of the Human Research Ethics Committee of The Royal Children's Hospital Melbourne, an invitation to participate in the study was placed in newsletters of three organizations caring for parents whose children had died from various causes. The inclusion criteria were: (1) their child had a life-limiting condition; (2) their child was aged between 3 months and 12 years at the time of their death; and (3) the parents had discussed end-of-life decisions and care for their child. There was no restriction on the child's diagnosis, other than it was a life-limiting condition. The study exhausted the recruitment strategy, the invitations in newsletter notices; that is, no other parents contacted the Principal Researcher (JS) to volunteer for the study. At this point theoretical saturation was being approached, with no new themes were emerging from the data[21,22].

Semi-structured interviews **were** conducted by the PR. Questions included asking parents to look on their decision, consider its nature and meaning and how they may have been affected by making it. Interviews were transcribed and thematically analysed using a four-stage analysis method that allows interpretations to emerge from the data, rather than being framed by pre-existing concepts or theories. Rigour of analysis was enhanced by use of a good practice guide[23]. Preliminary coding of the first group of transcripts was conducted by JS, and reviewed by LG. Differences in interpretation were discussed and resolved, and an agreed coding schema was created. JS then coded all remaining transcripts.

RESULTS

Participants: parents

Twenty-five parents who had discussed an end-of-life decision for their child with a life-limiting illness contributed to the study. One parent had two children who had died. Parents ranged in age from thirty to the mid-fifties. Nineteen parents were married, 1 was widowed, 1 was separated, 2 divorced and single, and 2 had re-partnered. Twenty-one parents were in paid employment and 4 were engaged in home duties.

The time since their child had died ranged from 4 months to 16 years, with an average of 5.75 years.

Interviews were conducted with 15 individuals and 5 couples, according to parents' preferences.

All parents were English-speaking. Parents were broadly culturally homogeneous, despite an intention to recruit from diverse cultural backgrounds.

The children

Twenty-one children, aged from three months to 10.5 years are represented in the study. The average age was 3.5 years. The conditions the children had are indicated in Table 1.

Table 1: Insert

The sample included children who had died in hospital (not only in intensive care units or neonatal intensive care units but in wards), in hospice, and at home.

In the study, six major themes were identified: (a) the nature of an end-of-life decision; (b) decision-making process; (c) factors in decision-making; (d) parents' roles; (e) doctors' roles and (f) the aftermath of an end-of-life decision. Findings reported here relate to (f), the aftermath of an ELDM, including the two closely interconnected sub-themes of looking back on the decision, and living with the decision now. To support the analysis, quotations from parents' interviews are provided.

Looking back on an end-of-life decision

Parents looked back on their ELDM with a fusion of thoughts and feelings, described by one as being “head and heart” and “hard and easy” by another. Some referred to decisions in ways that indicated their momentous and difficult quality:

> I’ve made the hardest decisions that I’ve ever made in my life ...Even when as a decision it was pretty clear about what we would do, it was still hard... (Parent 5)
>
> The most confronting individual question you could ask anyone...they’re the toughest decisions that one could ever make. (Parent 25)

Parents viewed their decisions as “a life choice”, a way to “protect [their child] from suffering”, and “ending life”. In reflecting on their decision some parents used emotive and blunt language, such as “murder’’, “virtually killed”, “choosing to let your child die” ,“to pull the plug, literally” and “basically giving-up on life”. However, such expressions did not preclude these parents commenting positively on the decision that was made. All these and the other decision-making parents considered that they had **mad**e the “right” decision for their child.

> ... you just need to think of it for a little bit and then [know] the decision was right. (Parent 5)
>
> As [daughter’s name] Mum, the most important thing was I was doing what was right for my daughter. (Parent 21)

Right was seen by parents in the context of the child's situation, their condition now and as anticipated. The decision was influenced by child-centred concerns such as their "suffering", and "quality of life" and avoiding being "cruel" to them:

> Would rather him have a life that was shorter, full of good stuff, than a longer life that on balance was kind of pretty crappy. (Parent 5)

> That a good life didn't necessarily have to be a long one...And I wanted it to be filled with a lot more joy. (Parent 25)

> I couldn't see myself with her disabled like that forever and [it] wasn't because I couldn't be bothered looking after a disabled child...it was more what quality would she get out of life? What would she be like at twenty? Would she hate me for putting her through all that and all that sort of stuff and that's what helped make those decisions and what helps me realize I did the right thing. (8)

> I'm looking at [her daughter] and thinking this is not quality of life. If this is the life she is going to live forever - it's not good enough. (Parent 19)

Parents did not articulate any regret about their decision. On the contrary, one parent even thought that regret would be caused by parents not being the decision-maker:

> Because they'll ultimately regret it if they let a doctor talk them into ending things without them. (Parent 3)

Another described how she thought that it was helpful in her grief to be taking personal "responsibility" and not having someone else to "blame".

Several parents explicitly said they would make the same decision if they had to:

> I would still make that same decision today and should something happen to my daughter, [I'd] make the same decision. Because that's my view on the whole thing. (Parent 14)

Regret, when articulated, related mostly to being in the situation where an end-of-life decision had to be considered for their child and for the child's death, rather than about the decision itself:

> Obviously, JS, I wish I wasn't sitting here talking with you...But I am. And I don't have any regrets, no I don't. Because the most important thing for me was knowing [child's name] was going to have quality of life. She wasn't going to get it in this life. (Parent 21)

Negative emotions such as self-anger, self-recrimination and selfishness relating to their decision were expressed by several parents. However, such emotions coincided with their overall positive appraisal of the decision:

> You always look back and think why didn't I do this, I could have done that, if only I'd done this or that and I think that's just human nature with everything. I mean I know we did the right thing to end her suffering. (Parent 3)

> At times you think maybe if we had have hung on a little longer, you get angry at yourself for making the decision and letting go. .. [later] I'm truly at peace about making that decision. (Parent 13).

Unlike the parents quoted here, one parent who did not consider herself the ultimate end-of-life decision-maker for her child, described the decision-making process as the most "horrific" and "painful" part of her experiences with her child.

Living with an end-of-life decision

The parents who had made the ELD for their child could live comfortably or happily with it, because it was judged by them as the right decision to make:

> But I guess once everything happened we were like: yes we made the choices we needed to make at the time and were very comfortable with the decisions we've made and we're ready just to move on from there. (Parent 4)

> I mean I know we did the right thing to end her suffering. (Parent 3)

> I felt content that we had made the right decision. (Parent 6)

> Absolutely we've had to live with that decision. It's ok because we thought we had made the right decision for [child's name] (Parent 20)

> It's in my head and my heart. And I can smile openly and look at you and know I made the right decision. Confidently ... I know and that helps me live. (Parent 21)

Living with an end-of-life decision: Talking about the decision

For the majority of parents, talking about their decision with others was not a significant aspect of living with the decision. However**,** all spoke about their child. Some parents spoke about their decision and decision-making a lot, most frequently to their partners, and others not all:

> It's such a huge personal thing that you do end up keeping it to yourself. Well [partner's name] and I at times talked about it but not to the degree that we have to-day [in the interview]. (Parent 1)

Other people to whom parents spoke about their decision included their child's grandparents, friends, work colleagues, and other bereaved parents. Formal discussion of the ELD was with community workers, social workers and counsellors with whom the parent had a relationship before their child's death and bereavement counsellors. Subsequent discussions with doctors about ELDs were not specifically noted in parents' narratives. Although, one parent had a letter from the doctor praising her decision.

The main reason that parents gave for not talking about their decision was their sense that other people could not "understand" their position:

> And until you're living our lives you can't understand exactly why we've had to make this decision (Parent 11)

> It’s difficult telling people ... It’s difficult not because we felt we made the wrong decision, we don’t, but wondering how to express it to someone who has no idea of being in that position. How they see you and quite frankly I don’t care. (Parent 20)

> I think it’s a very private decision, JS. That’s the precise way that I can put it. I would hate for anybody to make judgement about the most important decision I’ve ever made in my life. (Parent 8)

Concern about emotionally burdening other people was expressed by several parents as another reason they did not talk about their decisions:

> I guess we don’t want, necessarily, want to take them through it, to have the people we care about feel even a bit of what we felt. (Parent 5)

Living with the decision: enduring concerns

Enduring concerns were held by some parents. The majority of these parents were parents who did not perceive themselves as the decision-maker for their child. Enduring concerns did not relate, solely to ELDM roles or to the decision. They were about the child’s suffering (especially in their final moments of life), not understanding the physical process of the child’s death and lack of supportive follow-up**:**

> And I was shocked when we were told he was dying. Because I couldn’t understand how it [the cancer] would get ahead so quickly because I’m not a medical or scientific

> person and I don't understand how these things grow and operate. I couldn't understand how they operate on the body. (Parent 2)
>
> I don't even know what happened to her. How can you go from running around to dying? (Parent 7)

One decision-making parent held concerns about being unable to follow-through on her decision because of the attempts of others to prolong her child's life:

> And I also felt oh this is the hard part for me [tearful]...That I'd let him down because I'd always told him I wouldn't do anything horrible like that to him [CPR]...And I just hope, all the time **[**when the paramedics were tending to the child] that he was well and truly dead and that he didn't get any of that [suffering]. I'm sure he was [dead] but it was just a nightmare. (Parent 9)

Another parent, who like the previous parent was a decision-maker for her child, interpreted the absence of hospital follow up as a criticism of her decision to cease treatment for her child:

> And that was very disappointing [lack of hospital follow-up] because you kind of felt you've gone against what society expects of you, you know...: How dare you give up of life ... Because you don't give up on life. (Parent 8)

Discussion

In the aftermath of end-of-life decision-making for their child, parents live with their profound experiences and intricate reflections. This study found several close connections between the outcomes for parents. While articulating the significance of their decision, nearly all parents reflected positively and without regret, about the EOLD that they had made for their child.

Appraising their decision as right, these parents were able to live with their decision. This has been found in other studies [24,25]. Rightness was judged by parents against the child's circumstances. Similar to previous research[7], parents did not want to "prolong" their child's "suffering". A right decision was subsequently associated with having no regrets and effectively accommodating the experience. This is reflected in the expression of positive emotions by parents such as being *comfortable, happy* and *at peace.* Negative emotions about their decision were not articulated by parents. Nor was difficulty with living with their decision voiced by parents. Even when emotive language such as *killing* was used by some parents to describe the nature of the decision, they still viewed their decision as appropriate.

Results may suggest that doing the right thing or making the right decision for their child appears to make living with the decision less difficult for parents and helps them to integrate their experiences. Consistent with these findings, other ELDM studies and a research review have found the positive significance for parents of considering themselves a good parent, through their decision-making and their fulfilment of parental role[25-27]. Such perspectives could be understood as a meaning-making process by parents. Meaning-making in grief has been found to have benefits for bereaved parents [28]. Further**,** being able to view the *self* as a moral person has been associated with positive outcomes in parental bereavement[29]. Previous research has found that parents will try to regard their decision as moral and therefore "acceptable and morally praiseworthy"[29]. Such appraisal may help parents to maintain a moral integrity[30]. This in turn may help with their psychological wellbeing.

A significant novel finding is that some parents reported positive emotions, such as pride and feeling good about having been the decision-maker for their child. Being able to make the "hardest" "most important" decision was regarded as something of a personal achievement, something they could be "proud" of, a fulfilment of parental role**.** Several parents **spoke** about making the decision for their child as being their responsibility as a parent. Feelings of personal responsibility or blame for death, more typically associated with sudden or accidental deaths, have often been considered as a risk factor in grief[31,32]. In this study, however, decisional responsibility was identified as a possible protective factor. Findings imply then that understanding parents' decision-making as being responsible in a good way rather than being blameworthy better reflects parents' actual experiences. This re-conceptualizing of parents making a decision that will lead to their child's death as possible a protective factor in subsequent grief is a noteworthy finding. It may be related to the psychological benefits ascribed to taking control and self-efficacy[33], which previous studies have shown to be important for parents[4,10]. ELDM, curiously, may have been one of the few matters in their child's illness over which the parent had an element of control. Unlike other studies[3,8,13], feelings of guilt related to the decision were not expressed by parents who had made an end-of-life decision for their child, either as a self-determined or guided decision-maker. Being aware of these dimensions of parents' experience is useful for bereavement care. Potentially such a perspective enables assessment and interventions based on knowledge of post traumatic growth, risk and resilience leading to positive psychological outcomes[34, 35].

Another important finding was that generally, parents did not talk about their decision with other people. This came from apprehension about being judged or having to "defend" themselves, a phenomenon reported in other studies[13,29], rather than because they felt they had made the wrong decision. For parents who have made an ELD, anticipated negative social reactions may contribute to the sense of isolation and changed social relationships experienced often by bereaved parents [9,11,36,37,38]. The benefits of talking and of supportive connections for parents experiencing grief have been demonstrated. This study highlights the benefit of professional care and peer support from those who have made an end-of-life decision for their child, to fill a potential need for parents who feel unable to talk to family or friends. Professional care needs to be well informed about the process, outcomes and subsequent perceptions of ELDM for parents. It should also practically equip parents with ways to deal with encounters with other people who may be critical or uninformed about their ELD.

The value of hospital-based multifaceted bereavement programmes and of peer support have been previously demonstraterd[18],[39-42]. These interventions could be designed to incorporate the area of end-of-life decision-making, providing safe supported and constructive opportunities for grieving parents. To end this section with the voice of parents:

> I think it would be really good [if bereavement support programmes included discussion of end-of-life decisions] because there are probably parents who are out

> there who don't know how to feel about the decision that they may have made and it's an awful time, so many things happen when you lose a child ... (Parent 11)
>
> I think there needs to be access to people who understand- which is probably peers, other parents. (Parent 25)

Conclusion

In summary, this study suggests that parents are not adversely affected in the longer term by being the end-of-life decision-maker for their child. These findings are consistent with previous studies that have examined the psychological impact of ELDM on parents. One significant finding from this study was that being the decision-maker was actually beneficial, and not simply unharmful. This study demonstrates how parents **can** live well with their decision.

In this study end-of-life decision-making was identified by parents as a significant part of their experiences, but for most it does not seem to dominate their current life. It is difficult to extricate the role decision-making plays in parents' grief. Although a rare and arduous parenting task, we suggest that end-of-life decision-making should be regarded and supported as a parental responsibility. Given this, clinical support should recognize the positive meaning and potential for moral and psychological growth for parents of being their child's end-of-life decision-maker, affirm parents in undertaking this role and use this perspective and experience in subsequent bereavement support. In particular, the reasoning behind parents' decisions, the magnitude of their decision and significance of doing the "right thing" for their child given their situation should be drawn on in subsequent clinical and bereavement care. Providing peer support from parents who have made ELM could offer an additional resource to parents. Further research on how ELDM by parents could be constructed and used in bereavement care would be valuable**.**

Limitations and strengths

This study may be limited by being a self-selected sample and by not using an objective standardized measure of adjustment or grief. However, parents' own account supported the conclusion that end-of-life decision-making did not negatively impact on parents' future wellbeing. It could be argued that parents who did not view their decisions as right, had regrets, or were struggling in some way with the impacts of decision-making would not participate in the study as it **could be** psychologically too distressing to contemplate or articulate. However, it is not possible to know about non-participating parents. Additionally, the sample was not culturally diverse. The voices of parents from a range of cultures have not been heard. This may have distorted the findings. Specific recruitment strategies to encourage parents from CALD **backgrounds** to **participate** should be encouraged in future studies. This could strengthen the knowledge base and clarify the clinical implications for a multicultural community. Additionally, exploration of the impact of variables such as age of the child could also be useful.

A study's strength is that the qualitative design enabled the capturing of nuances of parents' views and experiences. An additional strength is that the average period of time since the child's death was over five years which meant parents had time to experience and reflect on the impacts of their decision.

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Table 1: Type of life-limiting condition

Child’s form of life-limiting condition	Diagnosis	Number of children
Incurable- irreversible, deteriorating	Neurological disorder, cardiac disorder, metabolic disease, chromosomal abnormality, neuromuscular disorder, muscular disorder	10
Potentially curable- curative treatment failed and/or discontinued	Cancer (neuroblastoma, neurofibrosarcoma	6
Severe disability- medically vulnerable	Spina bifida, brain damage, cerebral palsy	5

Title page

(i) **Title: After an end-of-life decision: parents' reflections on living with an end-of-life decision for their child**

(ii) **Original article**

(iii) **Authors:** Jane Elizabeth Sullivan[1,2], BSW (Melb), BA (Monash), Grad Dip Adol & Ch Psych (Melb), BTHEOL (MCD), MSW, PhD (Melb)
Lynn Heather Gillam,MA[1,2] (Oxon.), PhD, Monash.
Paul Terence Monagle[3,4,5,] MBBS (Hons) M.Sc.(Health Research Methodology, McMaster) M.D.

Affiliations:

1. The Children's Bioethics Centre, The Royal Children's Hospital, Parkville, Australia,

2. **Centre for Health Equity, The University of Melbourne, Melbourne, Australia**
3. The Royal Children's Hospital, Melbourne, Australia
4. Department of Paediatrics, The University of Melbourne, Melbourne, Australia
5. Critical Care and Neurosciences Theme, Murdoch Children's, Research Institute, Melbourne,
Australia

(iv) **Corresponding author:** Dr Jane Sullivan, The Children's Bioethics Centre, Royal Children's Hospital, Flemington Road, Parkville 3052, Australia.
sulj@unimelb.edu.au telephone: 00 61 03 98599105

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(v) **Institution for/Location of the work:**

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Abstract

Aims

Parents' role as end-of-life decision-makers for their child has become largely accepted Western healthcare practice. How parents subsequently view and live with the end-of-life decision they made has not been extensively examined.

To help extend understanding of this phenomenon and contribute to care, as a part of a study on end-of-life decision-making, bereaved parents were asked about the aftermath of their decision-making.

Methods

A qualitative methodology was used. Semi-structured interviews were conducted with parents who had discussed end-of-life decisions for their child who had a life-limiting condition and had died. Data were thematically analysed.

Results

Twenty-five bereaved parents participated. Results indicate that parents hold multi-facetted views about their decision-making experiences. An end-of-life decision was viewed as weighty in nature, with decisions judged against the circumstances that the child and parents found themselves in. Despite the weightiness, parents reflected positively on their decisions, regarding themselves as making the right decision. Consequently, parents'comments demonstrated being able to live with their decision.

When expressed, regret related to needing an end-of-life decision, rather than the actual decision. The few parents who didn't perceive themselves as their child's decision-maker subsequently articulated negative reactions. Enduring concerns held by some parents mostly related to non-decisional matters, such as the child's suffering or not knowing cause of death.

Conclusion

Results suggest that parents can live well with the end-of-life decisions they made for their child. End-of-life decision-making knowledge is confirmed and extended, and clinical support for parents informed.

Key words: ethics, end-of-life decision-making, parents, adjustment, support

What is known:

End–of-life decision-making for children is a profound complex phenomenon. In Western societies, parents typically want to be the end-of-life decision maker for their child. Particular aspects of end-o-life decision-making especially the aftermath have not been extensively examined.

What is added: Provides parental insight on living with an end-of-life decision. Confirms parents can live with having made an end-of-life decision for their child. Offers a way to help parents understand the end-of-life decision they have made for their child.