

Parent views: decision-making in paediatric palliative care

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The Holmes family





From Henry's story: decision-making*

- Relationship with the health care team: qualities & behaviours
- Decision-making: roles, process, content, factors, interconnected, layered, complex

**so much more that could be spoken about*



Relationship with the health care team: qualities

The way he is, the way he talks, the way he takes time, his love, ... just him as a person. Now you can't put [that] into everybody. Some of it is the person themselves and you can't do that with everybody. (Parent 21)

So we were lucky that we had good doctors. Like good key people that made it easier for us ... The paediatrician that we've still got for our other children, he's very laid back. He's not condescending and patronizing. He tells it like it is and doesn't make a fuss. And he would also say 'hello Sara' and treat her like a person but a normal person. Not over the top. And he was respectful. I think respect is the key. They were respectful of us. (Parent 3)

"I like them ... their personalities"



Relationship with the healthcare team: actions

Parents reported how clinicians could help them to be “*good parents*” to their dying child (study by Hinds et al., 2009)

15 behaviours

- Assuring all that can be done is being done, staff respect me and my decisions, staff continue to comfort my child and me, staff know our special needs, staff like my child, give us facts, staff do not quit on us, give time, do not forget us, are pleasant, ask about faith, tell us we are good parents, keep including our child, provide more material items and support options, staff give us time to decide

‘Clinicians respect and support parent’s wishes, decisions, and efforts to advocate for their ill child, thus allowing the parent to retain full parental role at end of the child’s life’ (Hinds et al. 2009 p.5982-3)



Relationship with the healthcare team: actions (Orioles et al., 2013)

- empathy (critical)
- availability
- treating child as an individual
- respecting parents' knowledge of the child
- allowing room for hope
- body language
- thoroughness
- going beyond the call of duty
- accountability
- willingness to accept being questioned
- attention to the suffering of the child



Relationship with the healthcare team

... it's much nicer coming from someone that you are familiar with and knows your child than some specialist you've never met ... I think we were lucky that we made it at a time that wasn't critical. We weren't in ICU ... with five minutes to make, to decide you know, how to end his life. I think we were lucky that we had a really good paediatrician who, while we were discussing [it] amongst ourselves, brought it out in the open and made it a process and a legal document, something when we had plenty of time to think about it. (Parent 11)

Jess and the care team: “built a relationship over time”, “consistency”, the meaning of *being there* over time (not being abandoned) reflected in follow-up support



Boo and Monkey are going on a special journey up into the mountains. Monkey is so excited about the beautiful surprise he just can't wait for Boo! Boo goes "Boo-plee!" Boo goes impetuously and Boo-plee off!

But soon Monkey finds he needs his friend much more than he thought.

A Friend Like You



End-of-life decisions: parents' roles

'The importance of involving parents is recognised by ethical guidelines in numerous countries ... results from studies exploring caregivers' and parents' opinions on this topic are far from unequivocal' (Caeymaex et al., 2011)

'Our findings show that both parents and health-care professionals are ambivalent with regard to the question of who should decide. Parents who have experienced life and death discussions concerning their premature infants emphasized that the physician's ability to communicate and to include them as decision-making partners was more important than the parents' right to autonomous choice' (Brinchmann & Vik 2005)

'... most parents, independent of country of origin, seem to prefer a shared approach by their physicians over a paternalistic approach or an informed approach' (de Vos et al., 2015)

'many parents find it valuable to express their opinion in the EOL DMP of their child' (Caeymaex et al., 2011)

I felt that it was our job and our responsibility and our responsibility as parents but I thought it was also what we owed to 'Sadie', to make the decisions for her (Parent 23)



Research studies: mixed outcomes

'... parents demonstrate an impressive ability to understand issues and weigh up the consequences for their own child. The parents' lack of subsequent guilt or doubt seems to underline their confidence and their capacity to bear this burden.' (McHaffie et al., 2001)

'... the American parents in this study did not react well to deciding the fate of their children ... The lack of an active choice for the French parents appeared to lessen the psychological distress associated with the death of their babies.' (Botti et al., 2009)

'Three years after the death of their child, the type of EoL DM perceived by parents affects their present grief. The perception of shared DM is correlated with less grief, compared with the other types of DM' (Caeymaex et al., 2011)

'Found regret and guilt in parents who had been the decision-makers and those who had not'. (Carnevale et al., 2007)



The nature of decision-making involvement:

‘It can be concluded then that parents ought to be given the *opportunity* to take this responsibility even though a significant number of our respondents declined to do so, indicating that they should not be *obliged* to make the ultimate decision themselves’. (McHaffie et al., 2001)

‘Most parents in our study made an effort to actively participate in the decision-making process ...’
(Caeymaex et al., 2011)

‘Shared, joint, partnership decision-making recommended in end-of-life care by local & overseas professional codes of practice’ (RACP, AMA, AAP, RCPCH, GMC)

“You’ve done this before and I haven’t”



Decision-making: parents' role

'As involvement preferences and associated feelings can vary, parents should be able to decide what role they want to play.' (Caeymaex et al., 2011)

'... recent studies have concluded that the way parents are involved should be highly tailored to their individual preferences and needs'. (de Vos et al., 2015)

Jess & the doctors *worked out* their decision-making areas: medications & feeds



Decision-making preference

In none of the cases did the physicians ask the parents how they preferred to be involved in the decision-making process. (de Vos et al., 2015)

On the whole, parents did not report the existence of an explicit discussion with the physicians on the distribution of roles in the DM. (Caeymaex et al., 2011)



Decision-making: communication:

- in emotionally charged context but effective discussions can happen
- interpersonal behaviours of doctors important to parents in difficult conversations
- ... in most cases intense emotions of anxiety, grief, and distress did not hinder them from asking relevant questions and from explaining their considerations and preferences. (Caeymaex et al., 2011)
- positive features:
compassionate, informative, timely, respectful, an exchange of information, willingness to accept being questioned, –can be brief, repeated. (Orioles et al., 2013 Hinds & Kelly, 2010, Jones et al., 2014, Bright et al., 2009)



Decision-making: content

It's got to be factual. So, I saw his x-rays and I thought oh my goodness. This is it...You need the evidence. (Parent 1)

[message to healthcare professionals] Sit down with them and take the time to explain in graphic detail what is going on to them. Even if they are not processing it right then and there, they will go home, they'll think about it, they'll ask questions. (Parent 18)

Because you are just thrown into world of doctors and they talk double Dutch doctors. They really don't speak in a language that any person off the street can understand. (Parent 25)

clear, full information, no euphemisms/jargon, written, different sources, asking questions is difficult, revisit, medical opinion



Decision-making: process

You need to be informed on it. I look back now, I think things looked black and white in a lot of circumstances when they weren't really ... There was multiple aspects to stuff. That unless you asked the right question or you didn't necessarily get [the information]. And that could change your decision ... You know, I had in my mind that at some point we would have to turn off something. (Parent 23)

It's so confronting to people. Even if it's a bit of information now, look we'll let you mull that over and we'll come back in a number of hours ... I know they don't have time to come and go like that but there are obviously some situations where it's just required ... (Parent 15)





Decision-making: factors

- child centred
- multiple factors
- ‘not just one decision’: kinds of interventions, place for end-of-life care, timing, who should be there
- knowing *“not ready yet”*

“I got to observe a lot”

- quality of life, suffering, loss of capacities, being able to interact, doing the right thing, observing/witnessing their child, medical recommendation (Basu, 2013; Hinds et al., 2009; Hinds & Kelly, 2010; McHaffie et al., 2001; Sharman et al. 2005)

Henry ran out of puff



Decision-making: factors

Existential and moral considerations: dominated by child-related factors:

We didn't want him to have any less capacity to function than the day he was born, pretty much. We thought it wasn't fair for him. I mean you can just go on forever. We didn't want anything like that ... I think it was quality of life. (Parent 11)

I think at that stage I could see that I was no longer doing it for him that I was doing it for me ... And that was not appropriate. (Parent 15)

'Parents' greatest concern is that their child might suffer' (de Vos et al. 2015)



Henry died with the dignity and love he deserved

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The study

- Twenty-five parents who are bereaved
- 6 fathers and 19 mothers - 15 individuals and 5 couples
- Parents aged between 30 years and early 50s
- Time since their child's death ranged from 4 months to 16 years (average was $5\frac{3}{4}$ years)
- Children with life-limiting conditions - 12 boys & 9 girls aged from 3 months to 10.5 years when they died
- One parent had two children who had died

The children's medical conditions

Child's form of life-limiting condition	Diagnosis	Number of Children
Incurable	neurological disorder, cardiac abnormality, metabolic disease, chromosomal abnormality, neuromuscular disorder, muscle disorder	10
Potentially curable	cancer (neuroblastoma, neurofibrosarcoma)	6
Severe disability	spina bifida, brain damage, cerebral palsy	5

Communication: content

- It's got to be factual. So, I saw his xrays and I thought, oh my goodness. This is it ... you need the evidence (Parent 1)
-
- [message to healthcare professionals]: Sit down with them and take the time to explain in graphic detail what is going on to them. Even if they are not processing it right there and then, they will go home, they'll think about it, they'll ask questions (Parent 18)

Messages to healthcare professionals

What would I say to them? ... listen to what the parents have to say. It may not be medical knowledge or it may be, but listen to everything the parents have to say ... I think a decision like that needs to be made with as much input from both sides as possible, without either side saying I don't want to hear that or overlooking things. Really giving each, professionals and families, [space] and having as many opportunities to meet face to face, as often as it takes to get the full picture.

(Parent 20)

