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What is Important to Families in Intensive Care Once a Decision has been Made to Withdraw Treatment

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Abstract

Objective: How doctors and nurses talk with families about decisions that lead to treatment withdrawal in intensive care is important and has been well explored. However less is known about what family members perceive as important once this decision has been made. This study explores the needs of family members during and after treatment has been withdrawn in intensive care.

Methods: An interpretive qualitative design was undertaken. Purposive sampling identified 112 deceased patients of whom 62 met the study criteria. From this sample, 17 in-depth interviews were conducted with 21 family members who had been bereaved in the previous 6-12 months. Thematic analysis was performed on the transcribed interviews.

Results: Whilst family members were able to broadly recollected conversations with doctors and nurses about the decision to withdraw treatment, there were detailed accounts of what was important to family members after that decision was made. In this, family members recalled wanting to: alleviate further suffering, re-establish identity of, and re-connect relationships with, the dying person. Bereaved family members spoke about the activities they undertook to realize these. At interview, family members demonstrated on-going distress about situations perceived as preventing achievement of these.

Conclusions: Families have existential and relational needs during and after treatment withdrawal in intensive care. Doctors and nurses must recognize the importance of assessing these family goals, identifying information that enables families to choose how such needs can be met, and developing skills to manage situations when these needs cannot be met.

Keywords: End of life; Withdrawal of treatment; Family experience; Family need; Intensive care; Palliative care

Objectives

It is important that patients have opportunity to make decisions about care at end of life [1]. However the environment and conditions encountered in the intensive care unit (ICU) often prohibits this due to physiological instability of critical illness and medical management therapies required. As a result, only a minority of patients is actively involved in discussions about care at this time [2] and family members, by default, become proxy decision makers about end-of-life treatment choices. The resultant burden on family members in intensive care has been recognized [3].

Much work to date has focused on how information is given to families during the transition from active intervention to palliation [4-6] as this can impact on health outcomes of the bereaved [7]. However less is known about what is important to families once the decision to withdraw treatment has been made.

Methods

An interpretative qualitative study was undertaken to understand the experiences and needs of bereaved families during and after treatment withdrawal in adult intensive care. Data were collected using in-depth interviews and thematic analysis was undertaken [8].

Setting and participants

Study setting was a 20 bedded tertiary adult ICU in the United Kingdom. Purposive sampling identified family members of deceased patients who received end of life care on the ICU during 2012. The patient notes were reviewed and cases excluded where contact with bereaved family members could have been problematic e.g. evidence of police involvement or family complaint. Every 10th case note was independently reviewed by an ICU Medical Consultant to ensure consistency and rigor.

Family members, who had all been bereaved in the previous 6-12 months, were recruited by letter. No follow up reminders were sent. Written consent was gained prior to commencement of the interview. Study approval was given by Hampshire and the Isle of Wight National Health Service Research Ethics Committee (11/SC/0338).

Interviews

A semi-structured interview guide was used. All interviews began with an introductory question inviting participants to talk about events leading up to the death of their family member on ICU. Topics explored included: admission to the ICU; events that lead to the decision to withdraw treatment; experiences during treatment withdrawal; events on the ICU after the family member had died. Probes such as 'What did that mean to you?' were used. Interviews took place at a time and place of convenience to participants. All interviews were digitally recorded and transcribed. Data saturation was reached.

Data analysis

Data analysis was an iterative process. Transcripts were thematically analysed using an interpretative phenomenological analysis approach [9]. Descriptive and interpretive notes were made during analysis to enable familiarity with the data and enhance interpretation. Codes and themes were developed from patterns and connections within each case. Group analysis across cases was then conducted using constant comparison. Developing themes were discussed and revised with other researchers (see Acknowledgements). Data management and coding was facilitated using a qualitative software package (Atlas Ti).

Findings

Sample: Of the 112 patients who died during the study review period62 met the inclusion criteria. From this sample, 17 interviews were conducted with 21 family members. 13 interviews took place with one family member, mainly the widowed spouse, sons or daughters. Four interviews occurred with two family members present. Mean duration of interviews was 49 minutes (range 28-86 minutes). The deceased patients from whom this sample was drawn were mainly older persons with only three patients under 55 years of age (Table 1). The majority of deaths occurred after emergency admissions to ICU. Whilst time on the ICU ranged from 6 hours to 21 days, the mean time from admission to death on the ICU short at under 2 days.

Case (n=17)	Age	Admission Type	Length of stay
Respiratory failure post gastric surgery	77	Elective	15 days
Intracerebral bleed	68	Emergency	24 hours
Multi-system failure Pneumonia	76	Emergency	24 hours
Multisystem failure post abdominal surgery	82	Emergency	12 hours
Cerebellar infarction	79	Emergency	36 hours
Out of hospital arrest	52	Emergency	12 hours
Multi-system failure post-surgery	51	Emergency	13 days
Respiratory failure post cardiac surgery	72	Emergency	4 days
Multisystem failure Lymphoma	55	Emergency	5 days
Respiratory failure post cardiac surgery	72	Emergency	21 days
Respiratory failure post sepsis	85	Emergency	48 hours
Pneumonia, Liposarcoma	68	Emergency	3 days
Sepsis post abdominal surgery	78	Emergency	24 hours
Pulmonary edema post sepsis	80	Emergency	4 days
Intracerebral bleed	77	Emergency	36 hours
Cardiac event with pulmonary fibrosis	79	Emergency	24 hours
Urosepsis	80	Emergency	6 hours

Table 1: Patient sample characteristics.

Meeting family need: Whilst all participants recalled the moment of realization that their family member was not going to survive ICU, detailed information was not recalled about medical interventions and procedures received by the deceased. Instead, bereaved family members remembered events that were important and meaningful during and after treatment withdrawal. Three themes were developed in this area focusing on: alleviating further suffering; re-establishing identity; and re-connecting with relationships.

Alleviating further suffering: An area of importance for bereaved families was to achieve a painless and comfortable death for the person. Once a decision to withdraw treatment had been made, delaying withdrawal of treatment was seen as increasing suffering and distress to the patient: 'by elongating it, it was just going to prolong his suffering...the longer we kept him the more pain he was going through and so just the knowledge of that and being told that, it was kind of an easy.' (Case 9) Therefore although discussions about treatment withdrawal were difficult and challenging for family members, decisions were more straightforward when families perceived that this would end suffering.

The fact that a decision had been made for the death to occur following withdrawal of treatment, as opposed to dying after unsuccessful resuscitation measures, was also perceived as minimizing any further suffering: 'Thank God she didn't have a cardiac arrest and then be jumping up and down or she had all sorts of other people around her, she died peacefully, which is what she would have wanted.' (Case 3) Indeed, withdrawal of treatment was often perceived as a more favorable option to end suffering rather than continuing to live incapacitated: 'and we thought, if he comes through this, what is there for him? He is going to know he's dying and he'll just have a horrible miserable downhill battle' (Case 2).

Re-establishing the identity of the person: An important issue for bereaved family members was how the dying person was remembered around the bedside during the final hours. This often involved bringing in personal items that held particular memories or importance and were connected to the dying person. These included the use of pictures (Case 18), religious artifacts holding significance (Case 14) or significant objects: 'It's a silly thing but he absolutely adored orangutans. We'd been adopting a chimp and an orangutan each year. And he had pictures up all over, all over the wall in that little corner there….He was like a big orangutan himself, the gentle giant you know (laughter) and his face, God bless him' (Case 8).

It was through such activities that family members appeared to re-connect to the dying person and remember the essence of who they were, especially if there had been a long history of declining health. Other family members recalled talking about the person and about their hobbies, including talking about the person's hobbies and singing football songs. Being able to undertake such activities and remembering the person was important for family members.

Whilst most family members recalled affirming experiences about remembering the person at this time, some family members held negative memories. In all such cases, this resulted from distressing memories of the physical state of the person as death approached and at the point of death:

'We walked in behind the curtains and they'd taken everything away and his eyes were still open, his mouth was all distorted and it was quite a horrific sight. To walk through the curtains and see that….that's our lasting image of him. I see it every day, every night when I go to bed I see that. I just thought that last little bit it was like a horror film.' (Case 6) Such distressing recollections made it difficult for families to remember who the person was with anything but continued distress.

Re-connecting relationships with the person: Family members spoke of activities undertaken to re-connect with the relationship held with that person as death approached. This often involved looking for a sign that the person knew they were there at the beside, for example, the opening of the eyes, speaking a few words, or a squeeze of the hand, or undertaking an activity, such as playing specific music that held a particular connection and meaning for the family member and the deceased: 'Music is something we've always shared. Our first courting day he got this record of Mozart's oboe and flute. We used to go out to concerts every night; we used to go to the opera. We had a mad life.' (Case 10)

The importance of social relationships included being there for the person up to the point of death. Therefore the moment of death and knowledge that the person's life had ended was significant for the majority of family members in this study. It was important for most family members to be present at the moment of death and so that the deceased did not feel on their own: 'I only went because I didn't want him to feel like he'd been abandoned. (Case 7). Others spoke of the importance of being there to say their goodbyes (Case 3, 4) and or having a choice to go and see the deceased one last time (Case 13). Those family members who, for whatever reason, chose not to stay until the moment of death were left with feelings of remorse: 'My one regret is that, they said they didn't think he would live much longer and we went to see him and then I said 'look I've got to go now' and I did regret not staying to the end.' (Case 11) Family members who expressed regret about decisions made during the time from treatment withdrawal through to the death in intensive care appeared more distressed during the interviews and less able to make sense of the death of the deceased.

Discussion

Families who are ill-equipped for death have higher risk of mental health disorders including depression, anxiety, complicated grief [10-13] and physical health complaints [14]. In addressing this, the ICU literature has focused on the importance of communication with families to inform decision making about treatment withdrawal [10,11]. Whilst this is key, it is naïve to think it is the only area that impacts on families [12]. Findings from this study highlight that bereaved families held detailed recall about events after treatment withdrawal and immediately prior to death. It is reasonable to suggest therefore that families must be prepared for the entire dying trajectory in ICU.

Identifying family need and expectation through use of proactive communication and open questioning to ascertain family goals and priorities at end of life [15]. During and after withdrawal of treatment this may include helping families recognize choices about activities that can be undertaken to honor the memory of the person or how best to organize their visiting time. This study highlights the importance that families place on timely withdrawal of treatment, once that decision has been made. It is clear that the 'wait and see' communication strategy [16] has no place here. Being close to the patient is important for families [17] and seen as one way to indicate love and care [18]. It is therefore important that families are given opportunity and choice about how to say 'goodbye' to the family member with guidance about predictability or unpredictability about time to death. Whilst personalizing care works to create rituals and legacies at the bedside during the dying process [19], doctors and nurses need to be aware of situations where family needs cannot or are unable to be met. As such situations can leave negative memories about the terminal events with family members, it is important that doctors and nurses address any such deficits using effective, structured and honest communication approaches as documented in the literature [7].

Generalization of findings is not possible from this small scale qualitative study. Furthermore, recall bias could result from family members remembering bereavement experiences and need after the death on ICU. Data could also be influenced by selection bias as bereaved relatives self-selected to participate in the study. Further prospective, longitudinal studies are required to inform interventions in this area.

Information seeking and communication with families does not stop after making a decision to withdraw treatment in intensive care. Families have continuing existential and relational needs to be met during and after the treatment withdrawal process. Doctors and nurses must recognize the importance of giving families opportunity to identify these needs, signpost information and support systems that enable families to choose how such needs can be met, and be aware of the impact on families when, due to specific circumstances, family requests and needs cannot be met.

Acknowledgements

References

1. Hall S, Petkova H, Agis D, Souros T, Massimo C, et al. (2011) Palliative Care for Older People: Better Practices 2011, World Health Organization, Europe.

2. Prendergast TJ, Luce JM (1997) Increasing incidence of withholding and withdrawal of life support from the critically ill. Am J Respir Crit Care Med 155: 15-20.

3. Kentish-Barnes N, Lemiale V, Chaize M, Pochard F, Azoulay E (2009) Assessing burden in families of critical care patients. Crit Care Med 37: S448-456.

4. Chambers-Evans J, Carnevale FA (2005) Dawning of awareness: the experience of surrogate decision making at the end of life. J Clin Ethics 16: 28-45.

5. Schenker Y, Crowley-Matoka M, Dohan D, Tiver GA, Arnold RM, et al. (2001) I donât want to be the one saying We should just let him die: intrapersonal tensions experienced by surrogate decision makers in the ICU. Journal of General Internal Medicine 27: 1657-1765.

6. Lautrette A, Darmon M, Megarbane B, Joly LM, Chevret S, et al. (2007) A communication strategy and brochure for relatives of patients dying in the ICU. The New England Journal of Medicine 356: 469-480.

7. Scheunemann LP, McDevitt M, Carson SS, Hanson LC (2011) Randomized, controlled trials of interventions to improve communication in intensive care: a systematic review. Chest 139: 543-554.

8. Braun V, Clarke V (2006) Using thematic analysis in psychology. Qualitative Research in Psychology 3: 77-101.

9. Smith JA, Flowers P, Larkin M (2009) Interpretative phenomenological analysis: Theory, method and research. London, UK: Sage.

10. Azoulay E, Pochard F, Chevret S, Jourdain M, Bornstain C, et al. (2002) Impact of a family information leaflet on effectiveness of information provided to family members of intensive care unit patients: a multicenter, prospective, randomized, controlled trial. American Journal of Respiratory Critical Care Medicine 165: 438-442.

11. Lautrette A, Darmon M, B. Megarbane, Joly LM, Chevret S, et al. (2007) A communication strategy and brochure for relatives of patients dying in the ICU. New England Journal of Medicine 356: 469-478.

12. McLeod-Sordjan R (2014) Death preparedness: a concept analysis. J Adv Nurs 70: 1008-1019.

13. Hebert RS, Prigerson HG, Schulz R, Arnold RM (2006) Preparing caregivers for the death of a loved one: a theoretical framework and suggestions for future research. J Palliat Med 9: 1164-1171.

14. Azoulay E, Chaize M, Kentish-Barnes N (2014) Involvement of ICU families in decisions: fine-tuning the partnership. Ann Intensive Care 4: 37.

15. Lind R, Lorem GF, Nortvedt P, Hevrøy O (2011) Family members' experiences of "wait and see" as a communication strategy in end-of-life decisions. Intensive Care Med 37: 1143-1150.

16. Plakas S, Taket A, Cant B, Fouka G, Vardaki Z (2014) The meaning and importance of vigilant attendance for the relatives of intensive care unit patients. Nurs Crit Care 19: 243-254.

17. Plakas S, Taket A, Cant B, Fouka G, Vardaki Z (2014) The meaning and importance of vigilant attendance for the relatives of intensive care unit patients. Nursing in Critical Care 19: 243-254.

18. Karlsson C, Tisell A, Engström A, Andershed B (2011) Family members' satisfaction with critical care: a pilot study. Nurs Crit Care 16: 11-18.

19. Loke AY, Quiping L, Leung SM (2013) Preparing family members for the death of their loved one with cancer. Journal of Hospice and Palliative Nursing 15: E1-E11.