END OF LIFE CARE IN INTENSIVE CARE SETTINGS: A CASE STUDY APPROACH TO EXPLORE DECISION MAKING AND PROCESSES

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EXECUTIVE SUMMARY

AIMS AND OBJECTIVES

1. The aim of this study was to gain an in-depth understanding of end of life care and decision making in an Intensive Care setting, in order to inform service improvements and future research.
2. The objectives were to identify factors influencing end of life decision-making and treatment withdrawal in Intensive Care Units; including understanding the treatments that are withdrawn, and the specific processes used to facilitate end of life care. Understanding the experience of staff and relatives, their involvement in these processes, and the impact that this has, was a further area for exploration. A further objective of this study was to gain greater understanding of how local and national policy guidance impacts on end of life decision making in an Intensive Care setting.

STUDY DESIGN AND METHODS

3. A three phase qualitative case study approach was used to explore the deaths of eighteen intensive care patients for whom a decision to withdraw treatment was made. Two large Intensive Care Units (one general, one specialist) located in the South of England were involved in the study.
4. Weekly retrospective case note review ensured appropriate recruitment to the study against a sampling template. Patients were included in the study if there was documented evidence of end of life decision making in the patient's notes. Patients were excluded if there was evidence of confounding (family, staff, legal) issues that would compromise the case. Nominated clinicians (Medical Consultant and senior nursing staff) led this screening to ensure data protection and confidentiality was maintained.
5. Three health care staff (nurses and doctors) who were identified in the patient notes as having been involved in end of life care decision making, were contacted and invited to be interviewed about their experiences of decision making and care.
6. The next of kin of each participant in the study were was contacted six weeks after the patient's death and invited to be interviewed about their experiences of decision making and care.
7. Data analysis adopted an approach that facilitated the development of themes as data was collected. Utilisation of a developed framework, informed by end of life care policy, literature, and research questions underpinned data synthesis.
8. Analytical frameworks from each interview were compared across and within each case. Each case was compared to others to highlight common experiences, themes and deviant cases.

RESULTS

9. Interviews with 33 health care staff and relatives of 18 non-survivors in Intensive Care, demonstrated that patients who do not survive critical illness follow a trajectory of EoLC from admission through a period of critical interventions with concomitant decision making, and then transition from intervention to palliation resulting in a controlled death. This conceptual framework is broadly consistent with existing palliative care models.

10. There was evidence of local adaptation of Liverpool Care Pathway documentation; but this pathway was not routinely adopted in end of life care in this research. However, the fundamental principles of EoLC policy and palliative care were evidenced within the data. This included: advanced planning, initial and ongoing assessment, and care after death. There was also explicit attention paid to managing: symptom control, comfort measures, anticipatory prescribing, and discontinuation of measures, cognisant of specific needs of the patient in an Intensive Care setting.

11. The initial stage of admission to Intensive Care, together with the later stage of managing a controlled death has clearer processes and management plans. During the admission phase, focus was on full and intensive interventions, and giving time for the patient (to indicate recovery or not) and for the family (to adjust to critical events). In managing a controlled death, focus and interventions were on ending the suffering for all; letting nature takes its course; saying goodbye; and returning the person to the family. In contrast, transitioning form intervention to palliation (including making a diagnosis of dying, managing end of life consensus, and facilitating grieving by families) was a more complex and ambiguous process.

12. Progression to an EoLC trajectory from admission to the transition stage could take hours/days/weeks; however, managing a controlled death usually spanned a matter of minutes/hours. Timing was a significant influence of what EoLC processes were implemented and how said processes were managed within the Intensive Care Units involved in this research. This factor may explain variations in implementing national policy EoLC tools.

13. Exploring experiences of health care staff and bereaved relatives demonstrated a demarcation of roles around the provision of EoLC. Key challenges for medical staff as decision makers arose when initiating intra-professional discussions about the appropriateness of ingoing patient treatment, and in managing the intellectual and emotional burden when making the decision to withdraw treatment. Nursing staff in Intensive Care held a strong caring perspective in relation to EoLC and, whilst this underpinned the aims of patient/family management, this ethos proved problematic when managing the transition from cure to palliation. The experience of relatives was influenced by the ability of health carers to meet the most fundamental human care and communication needs. Relatives' perception of EoLC management in all the 18 Intensive Care cases was overwhelmingly positive.

14. Findings from this work have identified factors influencing end of life decision-making and treatment withdrawal in Intensive Care Units, and specific processes used to facilitate end of life care. Furthermore, explicating experiences of staff and relatives and their involvement in these processes, together with greater understanding of policy impacts at local level, has enabled this study to meet its objectives.

IMPLICATIONS FOR HEALTHCARE

14. Key findings from this study indicate that practice and service initiatives must focus on meeting the information needs of family members, and developing educational frameworks that prepared staff for supporting families during EoLC.
15. Findings indicate the need for further education and training aimed at facilitating intra and interprofessional discussions when seeking EoLC consensus, and to help staff communicate effectively and compassionately with families at this time.
16. Current policy work requires contextualising and further evaluation to determine whether it meets patient and family need in this specific area.
17. EoLC in Critical Care is a developing area of research where use of multiple methods, drawn from different professions, and with the development of complex interventions, can help understanding of practice in this area.