

Developing an intervention around referral and admissions to intensive care: a mixed-methods study

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Declared competing interests of authors: Gavin Perkins reports grants from the National Institute for Health Research (NIHR) during the conduct of the study and non-financial support from Intensive Care Foundation (Camberwell, VIC, Australia) outside the submitted work. Karen Rees reports grants from NIHR during the conduct of the study. Helen Parsons reports grants from NIHR during the conduct of the study. Zoe Fritz has received grant funding from the Wellcome Trust (London, UK) outside this study and is on the executive committee of the Resuscitation Council (UK) (London, UK); expenses are covered for meetings. Zoe Fritz is also chairperson of the Strategic Steering Group for ReSPECT (Recommended Summary Plan for Emergency Care and Treatment); expenses are covered for meetings. Sarah Symons is a member of the Bath Clinical Ethics Advisory Group and has received payment from the University of Warwick for time taken to comment on the study documents as patient and public involvement co-investigator. Anne Slowther is a member of the Board of Trustees of the UK Clinical Ethics Network (Newcastle upon Tyne, UK) and the Institute of Medical Ethics (St Helens, UK). She has received funding in grants from NIHR as a co-investigator outside this study.

Published November 2019

DOI: 10.3310/hsdr07390

Scientific summary

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Health Services and Delivery Research 2019; Vol. 7: No. 39

DOI: 10.3310/hsdr07390

NIHR Journals Library www.journalslibrary.nihr.ac.uk

Scientific summary

Background

Intensive care can provide life-saving treatments for some patients. However, these treatments can be invasive and distressing, and, for those patients who do not survive to leave hospital or who survive with a quality of life they do not value, they will have caused harm rather than provided benefit. Optimum treatment for these patients may be better provided outside an intensive care unit and may include a focus on palliative or comfort care. Deciding whether or not a patient might benefit from intensive care is a difficult clinical and ethical challenge. Outcomes of treatment can be uncertain, patients are often too sick to engage in discussion, and there is little professional guidance or training available.

Objectives

This project sought to answer the research question ‘What is required for an ethically-justified patient-centred decision-making process surrounding admission to intensive care?’ To do this, we identified key objectives, which were broadly categorised as:

- describe current practice and experience of decision-making
- develop and test a decision-support intervention for decision-makers with support materials for patients and families
- develop and test a tool for evaluating the ethical quality of these decisions.

We addressed these objectives through a series of linked investigations.

Ethics approval for the project was obtained from the Coventry and Warwickshire Research Ethics Committee (15/WM/0025).

Investigation 1: systematic reviews of existing literature

Two systematic reviews were undertaken: one regarding the factors that influence whether or not a patient is admitted to the intensive care unit (PROSPERO CRD42015019711) and one regarding the experiences of patients, their families and clinical staff involved in the referral and decision-making process (PROSPERO CRD42015019714).

Methods

Electronic databases were searched using search terms related to intensive care, admissions and professional decision-making. References from key papers were also screened. Quantitative data were combined when possible. Qualitative data were analysed thematically.

Results

Eighty-eight studies were included in the factors review and 12 studies were included in the experiences review. Overall the quality of studies was moderate or poor.

Factors review

There was marked heterogeneity of data, but the key influences on decision-making were age, gender, type of illness, presence of chronic illness, functional status, presence of a do not attempt cardiopulmonary

resuscitation order, referring specialty, seniority of referrer and intensive care unit bed availability. There was no clear association with severity of acute illness.

Experiences review

Experiences were characterised by the relationships between clinicians, communication between stakeholders and working within resource constraints. An overarching theme was the experience of all stakeholders of a lack of agency. There was very little literature on patient or family experience of the decision-making process.

Investigation 2: focused ethnographic study

To better understand current practice and experience, we carried out a focused ethnographic study.

Methods

The study took place in six NHS acute hospitals sampled for size of intensive care unit, geographical location and population served. A researcher shadowed the intensive care doctors during a 3-week period, observing them in the process of receiving referrals and assessing patients for potential admission to the intensive care unit. Those involved in the decision-making process were interviewed about their experience. Interviewees included the intensive care unit doctor, the referring doctor, critical care outreach staff and, where possible, the patient and/or their family. Analysis questions were formulated to inform the development of the choice experiment and decision-support intervention.

Results

In total, 55 decisions were observed regarding 46 patients (27 female; mean age 61 years; age range 19–94 years). Forty-three intensive care unit doctors and 30 referring doctors were interviewed, and 28 senior doctors who refer to the intensive care unit but were not involved in the observed cases were also interviewed. Ten family members were interviewed soon after a decision to admit or not to the intensive care unit, and four family members were interviewed approximately 3 months after the decision. Three patients were interviewed at 3 months.

Analysis to inform the choice experiment focused on identifying the factors that influenced decision-making. The factors identified included the prognosis of the patient; the ability to deliver treatment safely on a ward; the patient's age; the severity of the acute illness; the overall subjective 'look', or 'gestalt' assessment, of the patient; and the patient's functional status pre admission (commonly expressed in terms of exercise tolerance). Some doctors acknowledged that the availability of intensive care unit beds influenced whether or not a patient was admitted. The clinicians seldom sought the patients' views, or the views of the family, although they valued this information when it was available.

Analysis to inform the decision-support intervention explored the contextual and relational aspects of the process, and the values, both implicit and explicit, that informed the decision-making process. It identified poor communication between colleagues, shared misunderstandings of the reason for referral and of what the intensive care unit could achieve, and external pressures as contributing to unsatisfactory decision-making processes. However, there were many examples of good decision-making processes, which included holistic assessment of the patient and respectful communication with and support for colleagues. Explicit balancing of the benefits and burdens of intensive care unit treatment for the patient was seldom observed. Features of an ideal decision-making process identified by clinicians included senior involvement, collegiate decision-making and the presence of decision-makers at the bedside.

Investigation 3: choice experiment

A choice experiment (described below) was used to examine the influence of different patient-related factors on intensive care unit consultants' and critical care outreach nurses' decisions regarding admitting a patient to the intensive care unit.

Methods

The choice experiment was a questionnaire survey in which participants were asked to consider a series of paired patient profiles and indicate whether or not they would admit each patient, and prioritise one for intensive care unit admission. Eight factors, with different descriptors for each, were identified from the systematic reviews and ethnographic study: age, severity of acute illness National Early Warning Score, family preference for admission, functional status, level of ward staffing, subjective assessment by registrar, and type and severity of comorbidity. These factors were combined in hypothetical patient profiles. Intensive care unit consultants and critical care outreach nurses were recruited through regional clinical research networks and e-mails from national professional organisations.

Results

A total of 303 intensive care unit consultants and 187 critical care outreach nurses completed the choice experiment. Response quality was high.

All eight patient features had a significant effect on both consultants' and critical care outreach nurses' decisions. Patient age had the largest influence on consultants' decisions (relative influence 23.9%). This was followed by family views (relative influence 19.9%). The registrar's assessment of the patient (gestalt) was more influential than the National Early Warning Score. Among critical care outreach nurses, patient age was again the most influential feature (relative influence 21.6%), followed by severity of main comorbidity (relative influence 17.1%) and National Early Warning Score (relative influence 17.4%).

Preferences heterogeneity

We used a latent class logit model to investigate preference heterogeneity among participants. This model makes it possible to identify groups which differ in the priority given to each factor. There was considerable heterogeneity in consultants' and critical care outreach nurses' preferences, with four distinct preference patterns identified for consultants and five preference patterns identified for critical care outreach nurses.

Comparison of consultants' and critical care outreach nurses' preferences

Nurses and consultants appear to hold similar preferences regarding patients' admission. However, consultants give significantly more weight to families' views than nurses, whereas nurses give significantly more weight to the National Early Warning Score and less to the gestalt assessment.

Investigation 4: feasibility testing of a decision-support intervention

Development

An intervention was developed to support consistent, transparent, ethically justifiable, patient-centred decision-making.

Methods

Development of the decision-support intervention was informed by the systematic reviews, ethnographic study and choice experiment. An initial draft was developed with input from our patient and public involvement co-investigators and advisory group. This was presented at a conference where invited participants included representatives from patient advocate groups and professional organisations, clinicians, lawyers and a General Medical Council representative. Focus groups were held to explore the views of the different elements of the decision-support intervention. The notes of the focus groups were analysed for key themes and the decision-support intervention was revised informed by the data.

An implementation-planning meeting used an adapted form of the normalisation process theory toolkit to identify, and mitigate, potential difficulties in the implementation of the decision-support intervention.

The final decision-support intervention included:

- A structured framework describing best practice for decision-making that guided the decision-making process, including the collection of relevant evidence, effective reasoning and implementation. A decision-support form based on the framework was provided for clinicians to guide and document their decision-making process.
- Guidance for referral for intensive care support, with a structured referral form.
- Patient and family information leaflets to support discussion between clinicians and the patient or their family.
- Educational resources to support the implementation of the decision-support intervention.

Implementation feasibility study

Methods

Three intensive care units were purposively sampled according to the size of the unit. Two implementation champions were identified at each site. The decision-support intervention was implemented over an 8-week run-in period, which was followed by a 6-week data collection period (during which data were collected from the medical records of patients referred to the intensive care unit). Interviews were conducted with clinicians involved in the process to evaluate both the acceptability of the intervention and the process of implementation.

Results

Interviews were held with all six implementation champions, 19 referring doctors, 20 intensive care unit doctors and three critical care outreach nurses. A total of 227 eligible referrals were logged across the three sites. Data were extracted from 181 patient records.

Analysis of implementation

Eight weeks was considered too short a period for implementation, especially in larger trusts. Facilitators of implementation included implementing across the whole trust, having senior clinicians act as champions in their clinical area, having institutional support for the decision-support intervention, and having established mechanisms for logging referrals to the intensive care unit. Difficulties included the perception of additional workload if information was duplicated in the patient's notes, and misunderstanding of when forms and leaflets should be used.

Analysis of intervention fidelity

Overall, 28.2% of referrals included a referral and/or decision form. Forty-five completed referral forms and 36 completed decision forms were identified, with both forms used in 30 cases. The referral forms were used more often ($n = 45$, 25%) than the decision forms ($n = 36$, 20%). The referral forms (70.4 vs. 60.4 years; $p < 0.001$) and decision forms (71.6 vs. 60.7 years; $p < 0.001$) were used more often with older patients.

Analysis of acceptability

Doctors who used the forms generally found them easy to use. Some doctors used the framework even when the form was not available. Difficulties were encountered in articulating the benefits and burdens of treatment. Some doctors felt that the intervention simply reflected their usual practice and that a requirement to use the framework was a question about their clinical judgement. The patient and family information leaflets were not given out by clinical staff at any of the sites.

Impact on decision-making

Doctors reported that the forms helped them to set out their rationale for a decision and to communicate their reasoning to colleagues. Several referring doctors noted that the forms had prompted them to specifically consider the views of the patient. Both referring and intensive care unit doctors thought that the forms improved transparency and accountability.

Investigation 5: development of an instrument to evaluate ethical decision-making

Systematic review

To identify any existing instruments, we conducted a systematic review (PROSPERO CRD42016039054). Electronic databases and the bibliographies of key papers were searched; 3594 unique records were identified, of which 79 underwent full-text screening and 15 relevant papers were included in the review. All but one of the studies described the use of a tool to assess educational interventions. One study described an instrument developed to evaluate clinical ethics case consultation. No instruments to evaluate interventions to improve ethical decision-making by doctors in clinical practice were identified.

Development and testing of an evaluation tool

Methods

A tool was developed to evaluate ethical decision-making in clinical practice that would be applied to the clinical record of a decision. The evaluation tool was based on the ethical framework of Accountability for Reasonableness because of its focus on process, transparency and review in the light of new evidence/information. We used an iterative analysis of anonymised patient records to develop a draft tool that was piloted with clinical members of the research team. The tool allowed scoring of defined domains of decision-making.

The final version was tested with anonymised records from the three implementation feasibility sites. Pairs of reviewers used the tool to score a sample of 40 anonymised patient records from each site. Analysis of the results was used to measure intersite and interuser variability.

Results

It was not always possible to identify the decision from the clinical record. Reviewers did not always agree on whether or not a record of a decision was present and, if it was, whether or not there was sufficient documentation to enable assessment. Only 234 actual scores were recorded out of a possible 429 (54.5%). For the recognised and assessed decision events (those with unambiguous documentation), significant variability existed between sites and between reviewers.

Summary

These results indicate that this tool is not yet sufficiently reliable to be used as a summative evaluation of decision-making in clinical practice; however, it may be useful formatively in quality improvement or education initiatives.

Discussion

This interdisciplinary mixed-methods project provides a unique insight into how decisions around whether or not to refer or admit a patient to intensive care are made and how this decision-making process might be improved. The empirical investigations into current practice identify a complex decision-making process influenced by a range of patient-related, contextual and organisational factors. Good communication and relationships of respect and trust between clinical teams are essential requirements for a good decision-making process. Decision-makers have difficulty in articulating and balancing the burdens and benefits of the intensive care unit, and values, both implicit and explicit, influence the decision. There is a perceived need for support, especially for junior doctors, and an acknowledgment that decision-making should be more transparent and ethically justifiable.

We developed a decision-support intervention grounded in empirical evidence and supported by an ethical framework. The intervention was generally well received in the implementation study, although difficulties in implementation were encountered and lessons were learned for future implementation initiatives.

Despite the short implementation period, there was an overall form use rate of 28% across all sites. Some sites indicated a willingness to implement a version of the intervention as a longer-term project within their trust.

A striking finding of the study was the lack of involvement of patients and families in the decision-making process. Clinicians appear to value information about the patient's wishes when this is provided but do not often seek it. In the implementation feasibility study, the specially designed information leaflets were not given to patients or families. Further research is required to understand and overcome the barriers to patient and family involvement in this crucial decision-making process.

Study registration

The systematic reviews of this study are registered as PROSPERO CRD42016039054, CRD42015019711 and CRD42015019714.

Funding

Funding for this study was provided by the Health Services and Delivery Research programme of the National Institute for Health Research. The University of Aberdeen and the Chief Scientist Office of the Scottish Government Health and Social Care Directorates fund the Health Economics Research Unit.

Health Services and Delivery Research

ISSN 2050-4349 (Print)

ISSN 2050-4357 (Online)

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This report

The research reported in this issue of the journal was funded by the HS&DR programme or one of its preceding programmes as project number 13/10/14. The contractual start date was in February 2015. The final report began editorial review in May 2018 and was accepted for publication in January 2019. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The HS&DR editors and production house have tried to ensure the accuracy of the authors' report and would like to thank the reviewers for their constructive comments on the final report document. However, they do not accept liability for damages or losses arising from material published in this report.

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