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Research paper

A comparison of the opinions of intensive care unit staff and family members of the treatment intensity received by patients admitted to an intensive care unit: A multicentre survey

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ABSTRACT

Background: Achieving shared decision-making in the intensive care unit (ICU) is challenging because of limited patient capacity, leading to a reliance on surrogate decision-makers. Prior research shows that ICU staff members often perceive that patients receive inappropriate or futile treatments while some surrogate decision-makers of patients admitted to the ICU report inadequate communication with physicians. Therefore, understanding the perceptions of both ICU staff and surrogate decision-makers around wishes for ICU treatments is an essential component to improve these situations.

Objectives: The objectives of this study were to compare perceptions of ICU staff with surrogate decision-makers about the intensity and appropriateness of treatments received by patients and analyse the causes of any incongruence.

Methods: A multicentred, single-day survey of staff and surrogate decision-makers of ICU inpatients was conducted across four Australian ICUs in 2014. Patients were linked to a larger prospective observational study, allowing comparison of patient outcomes.

Results: Twelve of 32 patients were identified as having a mismatch between staff and surrogate decision-maker perceptions. For these 12 patients, all 12 surrogate decision-makers believed that the treatment intensity the patient was receiving was of the appropriate intensity and duration. Mismatched patients were more likely to be emergency admissions to ICU compared with nonmismatched patients (0.0% vs 42.1%, $p = 0.012$) and have longer ICU admissions (7.5 vs 3, $p = 0.022$). There were no significant differences in perceived communication ($p = 0.61$).

Conclusions: Family members did not share the same perceptions of treatment with ICU staff. This may result from difficulty in prognostication; challenges in conveying poor prognoses to surrogate decision-makers; and the accuracy of surrogate decision-makers.

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1. Introduction

Patients admitted to an intensive care unit (ICU) often lack capacity to participate in decision-making. Current guidelines suggest that staff and families undertake a shared decision-making approach in deciding on the treatments received.[1] Despite this, surveys show that ICU staff often perceive that patients receive inappropriate or futile treatments,[2–4] while some surrogate decision-makers of patients admitted to the ICU report inadequate communication with physicians.[5–8] One approach to this is to think about an imbalance or mismatch between the amount or intensity of treatment provided and the patient's expected prognosis and wishes.

Understanding whether ICU staff members have similar perceptions to family members is important to help understand whether the mismatch between ICU staff and family members may contribute to their emotional distress and burnout.[9–11] Providing further understanding about the reasons for this mismatch would be beneficial for patients as clinicians would have a clearer idea of what they would want; their next of kin would experience less turmoil when acting as a surrogate decision-maker, and the provision of unwanted or nonbeneficial treatments may be reduced.[12]

The aim of this multicentre survey was to assess whether the perceptions of the patient's surrogate decision-makers matched those of the ICU staff when asked about the intensity of the treatments being received by the patients.

2. Methods

2.1. Design

A multicentred survey of both ICU staff and, concurrently, surrogate decision-makers of ICU patients was conducted on a single day in 2014 at each site in four hospitals in Australia. Each patient was assigned a unique identifier, allowing the results of the staff survey to be linked to the surrogate decision-makers' survey. This survey was nested within a larger study focused on the mismatch in the treatment intensity between the expected patient prognosis and their wishes, which had provided data to the Australian and New Zealand Intensive Care Society's Clinical Trials Group–approved "Point Prevalence Program".[13] This point prevalence study was an annual, single-day, prospective, multicentre observational prevalence study.

2.2. Settings and participants

Doctors, nurses, and allied health staff were eligible to participate in the survey if they were caring for a patient receiving treatment in the ICU on the day of the study. Four metropolitan teaching hospital ICUs from three Australian states self-selected to be involved in the study, three adult mixed medical and surgical ICUs, and one mixed adult/paediatric ICU. Surrogate decision-makers were eligible to participate in the survey if they were a surrogate decision-maker of a patient admitted to the ICU on the nominated study day. Ethical approval was obtained from all sites.

2.3. Measures

This survey used three instruments: (1) questions within the point prevalence case report form related to the structural characteristics of each ICU (e.g. staffing numbers, size, availability of palliative care services) and characteristics of prevalent patients (diagnosis, illness severity, and treatments received by the patients; (2) a survey completed by ICU staff members on their perceptions of the intensity of treatment received by patients in the ICU for whom they were caring, as well as questions about the ICU, work environment, and personal characteristics including religious beliefs; and (3) a questionnaire completed by the surrogate decision-makers of the prevalent patients regarding their perceptions of treatments received and communication with ICU staff.

The staff questionnaire was customised on SurveyMonkey™ software (Platinum version). Research staff distributed the login details to staff working on the day of the survey, with participation in the survey being voluntary. Mismatched patients were identified based on comparing the responses by ICU staff on the staff survey. Completion of the survey was used as evidence of consent to study participation.

The surrogate decision-maker questions were developed after consultation with members of the Sir Charles Gairdner Hospital Community Advisory Council. Members provided written feedback on the survey, and it was then trialled on a small number of patient family members to test comprehension. The survey instrument was adapted from the questionnaire used in the European Appropricus study, after being trialled on ICU staff in several centres.[14] The survey was completed using a paper version, and the data were subsequently manually entered in the database.

2.4. Statistical analysis

Counts (N) and percentages (%) are provided for all categorical variables, while means and standard deviations are provided for normally distributed continuous variables, and medians and interquartile ranges are provided for non-normally distributed variables. Fisher's exact tests were performed to compare categorical family perceptions and patient outcomes between patients who were and were not labelled as receiving mismatched treatment. Two-sample t-tests were used to compare patient's age, APACHE II score, (log-transformed) days to survey from ICU admission, and (log-transformed) ICU length of stay between patients who were and were not labelled as receiving mismatched treatment. Significance was set at 5% level, and data were analysed using the R environment for statistical computing.[15]

3. Results

3.1. Surrogate decision-maker's demographics

Response rates of surrogate decision-makers across the four hospitals were 32 of 67 patients present in the ICU on the study day. Among the respondents, five (16%) were parents, eight (25%) were spouses, eight (25%) were adult children, and 11 (34%) selected "other" (for the respondents for the mismatched patients there were five spouses, two patients, two adult children, and three parents). The characteristics of the ICU staff were that 68% were nurses (84/123); 20%, doctors (24/123); and 12%, allied health staff members (15/123).

3.2. Surrogate decision-maker's perceptions on treatment and communication

Table 1 displays the family perceptions of the treatment intensity. All felt that the treatment their family member was receiving was of the right intensity (32/32, 100%). Most felt this was for an appropriate duration (30/32, 93.8%), with the remaining two family members identifying the treatment duration as too long (2/30, 6/67%). ICU staff and surrogate decision-makers were asked to identify patients whom they believed were receiving treatments that were mismatched to their expected prognosis or wishes, for example either "too much or too little". Of the 32 patients, ICU staff identified 12 with a mismatch between the treatment they were

Table 1
Family perceptions of treatment.

Family respondents	Overall (n = 32)	No mismatch (n = 20)	Mismatch (n = 12)	P-Value
Had a meeting with the doctors	27/30 (90%)	18/19 (94.7%)	9/11 (81.8%)	0.54
Have received adequate information about their loved one	26/30 (86.7%)	17/19 (89.5%)	9/11 (81.8%)	0.61
Knew their relative's wishes before coming to ICU	18/31 (58.1%)	11/20 (55.0%)	7/11 (63.6%)	0.72
Believe that the treatment intensity received by their relative matches what they would want	31/31 (100%)	19/19 (100%)	12/12 (100%)	Not Performed
Believe that the duration of treatment received by their relative matches with what they would want?	30/32 (93.8%)	18/20 (90.0%)	12/12 (100%)	0.52

ICU, intensive care unit.

receiving and their expected prognosis and wishes. All 12 family members believed the patient was receiving appropriate intensity of treatment. For these 12 patients, seven of 12 family members knew the patient's wishes before ICU admission (Table 1). No significant differences were observed in family perceptions between patients who were and who were not identified as receiving mismatched treatment.

3.3. Clinician perceptions

Table 2 indicates the perceptions of 18 ICU staff members regarding the 12 mismatched patients. Of the 12 mismatched patients, six were identified by two or more staff members, the other six by only one staff member. Most staff members identified a mismatch relating to inconsistent care with the expected quality of life (12/16, 75%); with 14 of the 18 staff members (77.8%) assessing the prognosis as unlikely to survive or left with severe disability.

3.4. Patient outcomes

Table 3 shows the patient outcomes of the entire cohort and whether the patient was classified as receiving mismatched treatment. Mismatched patients were less likely to survive their ICU admission (73 versus 100% $p = 0.045$). All mismatched patients were nonelective admissions to ICU, with significantly longer ICU admissions compared with the nonmismatched group ($p = 0.022$). Surveys for mismatched patients were conducted significantly longer into their ICU admission compared with nonmismatched patients ($p = 0.028$). No mismatched patients were an elective admission to ICU, whereas 42.1% of nonmismatched patients were elective admissions to ICU ($p = 0.012$). All nonmismatched patients were discharged from ICU alive, compared with only 72.7% of mismatched patients ($p = 0.045$).

4. Discussion

ICU staff and surrogate decision-makers did not share the same perceptions of mismatched treatment. Among the mismatched patients, all 12 (100%) family respondents believed that the intensity of care was appropriate. This mismatch occurred despite adequate communication between ICU staff and family members, with 81.8% of mismatched surrogates having a meeting with the ICU doctors, and perceiving they received adequate communication. This raises several interesting questions regarding how accurate ICU medical staff members are at predicting prognoses; challenges with communicating poor prognoses to surrogate decision-makers; and ultimately, the accuracy of surrogate decision-makers in predicting patient's wishes.

Mismatched patients were less likely to survive their ICU admission and to day 28. As these patients had been identified as having a likely poor outcome, the fact that they were less likely to survive is not surprising. This is reflected in all 12 of the mismatched patients being emergency admissions to ICU with longer ICU admissions, which may result in clinical decision-making being more challenging. Furthermore, having identified a patient as having a poorer prognosis, doctors may more readily withdraw life-supporting treatments, with prior studies identifying that doctor's perceptions of patient preferences and predictions of prognosis being the strongest determinants in withdrawing ventilation.[16] However, the proportion surviving out to day 28 remains relatively high, outlining the fact that predictions are difficult and not always correct.

A previous survey of older patients and their family members with life-limiting illnesses in Canada showed that patients wanted to have trust and confidence in their treating doctors, to have information communicated to them in an honest manner and not to be kept alive when there was little hope for a meaningful

Table 2
ICU staff member's opinions on the mismatched patients.

Staff member's perception of prognosis	
Uncertain	3/18 (16.7%)
Likely to improve	1/18 (5.6%)
Unlikely to survive	8/18 (44.4%)
Likely to be left severely disabled	6/18 (33.3%)
Reasons for treatment imbalance	
The intensity of treatment the patient receiving is too much	12/18 (66.7%)
The intensity of treatment was appropriate at admission but is no longer appropriate	10/14 (71.4%)
Amount of care inconsistent with expected survival	12/16 (75.0%)
Amount of care inconsistent with the expected quality of life	14/18 (77.8%)
Patient wishes are unknown	8/16 (61.5%)
Family has been unable to reach a consensus regarding the direction of care	2/13 (15.4%)
Caregivers have been unable to reach a consensus regarding the direction of care	4/13 (30.8%)
Patient is dying, and a more dignified death could be provided elsewhere	7/14 (50.0%)
Patient is too well for ICU	1/18 (5.6%)

ICU, intensive care unit.

Table 3
Outcomes for mismatched patients versus overall cohort.

Outcomes	Overall (n = 32)	No mismatch (n = 20)	Mismatch (n = 12)	P-Value
Mean age in years (SD)	64.9 (18)	65.4 (16)	64.2 (22)	0.87
Female (%)	12/31 (38.7%)	7/19 (36.8%)	5/12 (41.7%)	1.00
Elective admission to ICU (%)	8/31 (25.8%)	8/19 (42.1%)	0/12 (0.0%)	0.012
Mean APACHE II (SD)	19.6 (7.1)	18.8 (7.8)	20.9 (5.9)	0.44
Median number of days to survey from ICU admission (IQR)	3 (3)	1 (2)	4 (12)	0.028[a]
Median number of days in ICU (IQR)	4 (8)	3 (6)	7.5 (23.5)	0.022[a]
Discharged from ICU alive (%)	26/29 (89.7%)	18/18 (100%)	8/11 (72.7%)	0.045
Alive at day 28 (%)[b]	21/26 (80.8%)	15/18 (83.3%)	6/8 (75.0%)	0.63

SD, standard deviation; IQR, interquartile range; ICU, intensive care unit.
[a] Analysis performed on log-transformed outcomes.
[b] Denominator represents the 26 patients alive at ICU discharge.

recovery.[17] Our findings showed that family meetings were commonplace. However, they raise the possibility that honest communication about potential poor outcomes were either not communicated or heard by the family members.

This “optimism bias” is another factor in this incongruence between perceptions of care between medical staff and surrogate decision-makers. This bias is a result of the difficulty conveying poor prognoses to surrogate decision-makers. In one study of 169 surrogate decision-makers in ICU, videos of a simulated family conference were played after which the family members were evaluated for their understanding of the doctor's prognostic estimate.[18] Surrogates were twice as likely to predict survival compared with the doctor, with neither numeric nor qualitative statements influencing surrogate understanding. Another study by Zier et al. assessed 80 surrogate decision-makers in ICU who were given 16 hypothetical prognostic statements and asked to record their interpretation of survival.[19] Zier et al. further illustrated “optimism bias” with surrogates interpreting statements such as “5% chance of survival” in a range from 5 to 40% and “definitely not survive” from 0 to 50%. Our study highlights the problem of optimism bias in impacting family perceptions, with 12 staff members identifying mismatched patients as receiving care inconsistent with expected survival and 14 identifying the amount of care inconsistent with the expected quality of life.

In keeping with other literature, 40% of respondents did not know their family member's wishes before ICU admission.[20,21] Interestingly, this did not seem to impact family perceptions of care, with all respondents perceived appropriate intensity of care, and 93.8% perceived appropriate length of care. This may reflect trust and hope in the treating medical staff, but it also draws attention to other research examining surrogate decision-makers' knowledge of patient preferences. A study by Seckler et al. looked at doctor and surrogate decision-makers' responses compared with competent patients with chronic illness regarding cardiac resuscitation, with poor correlation between patient wishes and family members.[21] Shalowitz et al. conducted a literature review on the accuracy of surrogate decision-makers for end-of-life decisions. Using pooled studies, a total 151 hypothetical scenarios were presented to 2595 surrogate–patient pairs, and collectively 19,526 paired patient–surrogate responses were analysed. Overall, surrogates predicted patients' treatment preferences with 68% accuracy, and interestingly, neither patient designation of a surrogate decision-maker nor prior discussion of treatment preferences improved surrogates' predictive accuracy.[22]

Mismatched patients had spent longer time in the ICU before the survey being conducted compared with the nonmismatched cohort. It is possible that in this interim period that the opinions of both surrogate decision-makers and medical staff had diverged. Expectations of patients and surrogate decision-makers must be contextualised within the psychological stress caused by critical illness. A systematic review of psychological outcomes of family members of ICU patients identified the onset of depressive symptoms among family members particularly among patients ventilated for more than 48 h.[23] The fluctuating mental state of surrogate decision-makers may impact their interpretation of physician prognoses and patient wishes. As identified in other contexts, this may be accompanied by a ‘resetting’ of what is deemed an acceptable outcome for the patient by surrogate decision-makers and contribute to the incongruence in perceptions.[24]

4.1. Limitations

This study was confined to four ICUs with small sample size, limiting statistical analysis and potentially the generalisability of the results. By not having responses for every patient's surrogate decision-maker, we were not able to test the agreement between staff and decision-makers for all patients. Furthermore, the use of voluntary participants and voluntary ICUs introduces preselection bias and may confound the highly positive perceptions of care. In addition, we did not group together the members of the treating ICU team, to determine whether the perceptions voiced were all shared. Nonetheless, this is the first study to attempt to correlate the perceptions of family members and ICU staff on actual patients.

5. Conclusion

In assessing the perceptions about the treatments received by ICU patients, ICU staff and surrogate decision-makers did not share the same perceptions. Family members often do not know patients' wishes regarding medical treatments in the intensive care setting, and family perspectives can differ from our perspectives as treating medical staff. These differences may be related to medical staff interpretation of poor prognosis, the difficulty of surrogate decision-makers to accurately predict patient preferences, and communication challenges in conveying poor prognoses.

For medical staff in the ICU, it is important to understand that most surrogate decision-makers will not know patient preferences. This highlights the importance of communication; however, there are several barriers between communicating a poor prognosis and comprehension by surrogate decision-makers. This goes beyond simply asking surrogates regarding the adequacy of communication but more critically assessing understanding. Furthermore, it is possible that perceptions of surrogate decision-makers change during a prolonged ICU admission. For medical staff, cognisance of changes in perceptions is necessary, and organising repeat family meetings may help address the incongruence of perceptions.

More research involving these perceptions of care of both families and medical staff, linking to longitudinal patient outcomes, would be useful to evaluate for any changes in perceptions and

potential areas of improvement in our efforts to deliver effective, patient-, and family-centred care.

Ethical approval

Ethical approval was obtained from all sites.

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