

# Family's Perceived Needs and Satisfaction with Intensive Care Services: A Questionnaire-based Prospective Observational Study

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## ABSTRACT

**Background:** Holistic intensive care management involves the treatment of critically ill patients in the intensive care unit (ICU) as well as catering to family psychosocial needs helping in bettering satisfaction/perception of care. There is scarce data in the Indian intensive care setting regarding the same, especially in times of increasing end-of-life practices. Our study aimed to determine the factors impacting family perception/satisfaction with intensive care.

**Materials and methods:** A total of 336 family bystanders of patients in ICU with more than 72 hours of stay were surveyed using family satisfaction in the ICU 24 revised (FS-ICU 24R) questionnaire.

**Results:** Multivariable logistic regression analysis showed that the significant factors associated with the satisfaction among bystanders of ICU patients were the treatment of patient's physical symptoms like pain/breathlessness (Adjusted OR 3.73,  $p = 0.003$ ), ICU staff's approach to family's need consideration (Adjusted OR 4.44,  $p < 0.001$ ), concern and care towards patients' family (Adjusted OR 2.67,  $p = 0.023$ ). Participation in patient care, ICU waiting room atmosphere, and emotional support are the other factors independently associated with satisfaction with ICU care. Family satisfaction was not associated with the patient's survival ( $p = 0.331$ , Chi-square test) or the length of ICU ( $p = 0.328$ , Chi-square test) and hospital stay ( $p = 0.865$ , Chi-square test).

**Conclusion:** Treatment of a patient's physical symptoms like pain, approach to family's needs consideration, and concern/care towards the patient's family are independent factors associated with optimal satisfaction among family members of ICU patients, which even takes precedence over the survival outcomes or length of ICU stay.

**Keywords:** Decision-making, Family, Family satisfaction in the ICU 24 revised, Consideration of need, Intensive care, Treatment of physical symptoms, Perception, Satisfaction, Treatment outcome.

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"Camaraderie Rather than the Destination, Brings us Solace"

## HIGHLIGHTS

Factors like care for patients pain or breathlessness, an approach to families needing consideration, concern/care towards patients' families, and participation of families in patient care far outweigh even the final survival outcomes, to ensure satisfaction among family members of patients admitted to the ICU. We, as clinicians, must be aware that it is not factors like a lesser severity of organ dysfunction or a shorter ICU stay but rather emotional support during the challenging period that ensures the patient's relatives' satisfaction with ICU care.

## INTRODUCTION

With newfound advances in medicine and affordable health care, life expectancy in India has improved to 70.4 years by 2020.<sup>1</sup> However, this has also led to an increase in the number of hospital admissions per year due to co-morbid illnesses, including intensive care unit admissions. Immediate kin of patients admitted to ICU face onerous times during this period when they are least prepared for it and the reasons are multifactorial. Expectations from health care providers, decision-making dilemmas, higher ICU costs, and financial repercussions to name a few. Patient's family members are found

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to have experienced anxiety, depression, and posttraumatic stress during and after their loved ones stay in the intensive care unit.<sup>2-4</sup> Comprehensive ICU care should not only address patient's needs but also be family centered.<sup>5</sup> It is the responsibility of the health care provider to understand and meet the needs of the patient's family members. Their understanding of the criticality of a patient's

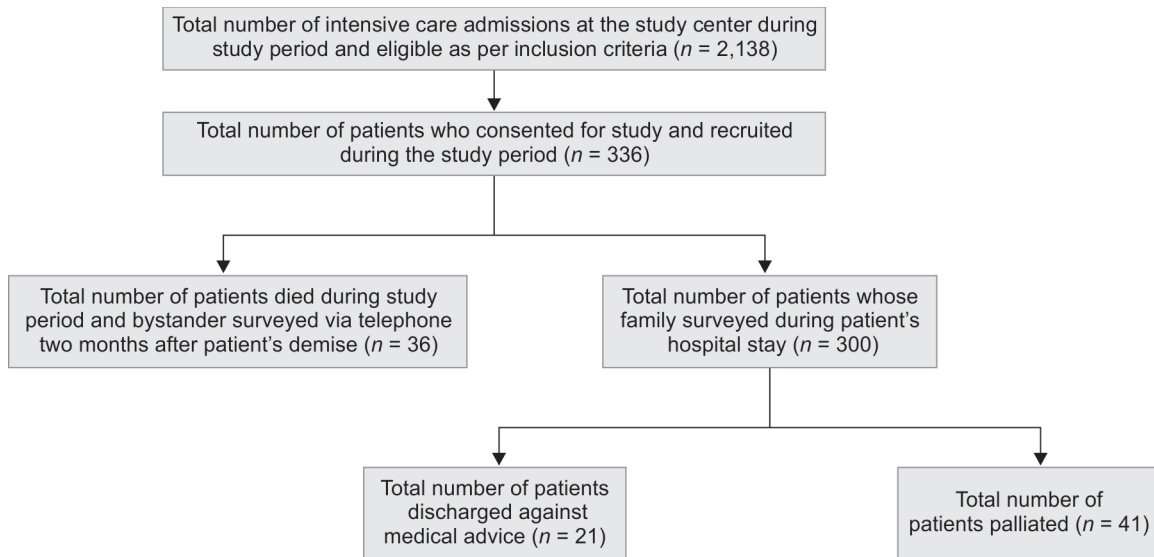


Fig. 1: Figure depicting methodology and patient recruitment for the study

illness and involvement in clinical decision-making will aid in better satisfaction and reasonable expectations about patient outcomes.<sup>6</sup> In fact, family satisfaction has been one of the quality indicators for ICU performance both in Indian and Western scenarios.<sup>7</sup>

Unlike the West, India is a nation with a diverse cultural, spiritual, and socioeconomic fabric with the government's health care expenditure being only 2.1% of the gross domestic product (GDP).<sup>8</sup> There have only been a few studies in the past regarding family perception and satisfaction with the treatment of their loved ones in ICU in the Indian setting.<sup>9,10</sup> For the reasons mentioned above, the needs, expectations, and other factors leading to ICU perception by Indian family differs from that of families in the West.<sup>11</sup>

The primary objective of the study was to determine which of the factors in the family satisfaction in the ICU 24 revised (FS-ICU 24R) questionnaire were independently associated with patients' family satisfaction with ICU care. The secondary objective was to determine if the outcome in terms of mortality and length of ICU and hospital stay were significantly associated with patients' family satisfaction.

## MATERIALS AND METHODS

This prospective single-center questionnaire-based observational study was conducted from May 2022 to June 2023 surveying 336 patient's family members after institutional ethical clearance (IEC 27/2022) and CTRI registration (CTRI/2022/09/045571). The reporting of the manuscript has been done in accordance with statement guidelines for reporting observational studies (STROBE).

### Setting

The study was conducted in a multidisciplinary tertiary care medical college hospital in India. The intensive care unit setting was multidisciplinary with a total of 30 beds admitting patients from both surgical and medical broad/super-specialties. Every treatment decision was made with a multidisciplinary approach with discussions involving required medical/surgical specialties.

The treating team involved the primary unit, intensive care physicians, intensive care nurses, and other allied health specialties such as respiratory therapists, physical rehabilitation specialists, and dietitians. The patient-nurse ratio for the unit was 2:1. Family counseling was planned daily following a structured care plan for

the day and involved a multidisciplinary team with the primary and intensive care team (postgraduates and registrars as well). Counseling sessions were done in a dedicated isolated room in the intensive care unit complex. The counseling room was an isolated dedicated room with good lighting, adequate sitting provisions, and also had round-the-clock closed camera monitoring of the proceedings. Daily counseling sessions were documented in the patient's case record as discussed and countersigned by the patient's bystanders as well. The unit had a dedicated palliative services team aiding in goals of care discussion, end-of-life proceedings, and grief address. Intensive Care Unit team through the survey, had a process of sourcing family experiences through a feedback system for further improvisations.

The patient's family was surveyed using the FS-ICU 24R questionnaire on the day of the patient's discharge from the ICU in order to have a reasonable account of the family's perception of ICU care and their involvement in clinical decision-making.<sup>12</sup> A survey of the patient's family whose dear one had expired in ICU owing to illness/end of life was done with the same questionnaire used telephonically after 2 months of demise.

Family satisfaction in the ICU 24 revised questionnaire has been included in the supplementary appendix.

Family visitations were as per hospital protocol restricted to two hours a day on an hour basis daily morning and evening. Two immediate patient's kin were allowed for each session. Extra visitations were allowed if necessary and were considered helpful in patient care. Families were allowed bedside during end-of-life proceedings and the unit had dedicated end-of-life care isolated rooms for those patients with terminal illnesses for the family's privacy in consideration. Patients with a length of stay in ICU of more than 72 hours were included in the study.

### Inclusion Criteria

Adult patients with age more than 18 years admitted to the intensive care unit for more than 72 hours.

### Exclusion Criteria

The family bystander's age of less than 18 years was exclusion criteria. A total of 336 patients' family bystanders were surveyed using a survey questionnaire spanned over a period of 13 months as described in Figure 1.

**Table 1:** Basic demographics

|  |   |
|--|---|
| Mean age of patients in study population   | 56.54 years ± 16.21 (SD)  |
| Patient's gender   | 208 (61.9%) male, 128 (38.1%) female  |
| Patient's bystander gender   | 215 (64%) male, 121 (36%) female  |
| Relationship of patient's bystander with patient   |   |
| Immediate kin (father, mother, wife, husband, son, daughter)   | Immediate kin – 72.3%   |
| Near relatives (brother, sister, father-in-law, mother-in-law, son-in-law, daughter-in-law, granddaughter, grandson, etc.) | Near relatives – 14%  |
| Others (Far relatives and friends)   | Others – 13.7%  |
| Address  | Village 120 (35.7%)<br>Taluk 79 (23.5%)<br>Town 64 (19%)<br>District 73 (21.7%)   |
| Whether patients' bystanders live with patient?  | Yes 238 (70.8%)<br>No 98 (29.2%)  |
| Bystander literacy status  | Higher primary 10 (3%)<br>Secondary 60 (17.9%)<br>Pre-university 104 (31%)<br>Undergraduation 129 (38.4%)<br>Postgraduation 33 (9.8%) |
| Whether patient's bystander has ICU experience in the past?  | Yes 40 (11.9%)<br>No 296 (88.1%)  |
| Number of decision makers in the family  | One 243 (72.3%)<br>Two 86 (25.6%)<br>Three 7 (2.1%)   |
| Insurance  | Cash 109 (32.4%)<br>Governmental health cover 118 (35.1%)<br>Private Insurance 109 (32.4%)  |
| Outcome  | Survived 234 (69.6%)<br>Expired 102 (30.4%)   |
| Charlson comorbidity index (Median with interquartile range)   | 2 (1.0–4.75)  |
| SOFA score (Median with interquartile range)   | 8 (6–11)  |
| Length of stay in intensive care unit (Median with interquartile range)  | 6 (4–10)  |
| Length of stay in hospital (Median with interquartile range)   | 16 (11–26)  |

### Statistical Data Analysis

The analysis was done by the Statistical Software for the Social Sciences (SPSS) version 29.0 (IBM SPSS Statistics for Windows version 6.0 Armonk, NY: IBM). The basic demographic variables were expressed as frequencies and percentages. For the continuous variables with parametric distribution, mean ± standard deviation (SD) was calculated, whereas, for the non-parametrically distributed continuous variables, median and interquartile range (IQR) were calculated. The independent student *t*-test was used to compare the means between the two groups for parametrically distributed variables, and the Mann–Whitney *U*-test was used to compare the medians between the two groups for variables having non-parametric distribution. The Chi-square test was used to determine the association between categorical variables. The Phi and Cramer *V* values were used to determine the strength of nominal association between the categorical variables in the Chi-square test, with values 0.20–0.40 showing moderate association and 0.40–0.60 showing moderately strong association.

For determining the variables that were the independent predictors of family satisfaction, a multivariable logistic regression was done, for the variables that were found significant after the univariate analysis for predicting family satisfaction. After the

multivariable logistic regression, adjusted Odds ratio, and 95% confidence interval (95% CI) were calculated, and a *p*-value ≤ 0.05 was considered significant. For internal validation, bootstrap multivariable regression analysis with 1,000 samples was done using Bias corrected accelerated (BCa) method.

### RESULTS

The study period saw 2,138 admissions to intensive care units. Of these, family bystanders of 336 patients whose length of ICU stay was more than 72 hours and who had consented to participation were interviewed on a consecutive sampling basis. Responses to all 24 questions of the FS-ICU 24R questionnaire were assessed and mentioned in [Supplementary appendix Table S18](#).

The mean ± SD of age was 56.54 ± 16.21 years and the median (IQR) of the SOFA score was 8 (6–11), the Charlson comorbidity index score was 2 (1–4.75), the length of ICU stay was 6 (4–10) days, and length of hospital stay was 16 (11–26) days ([Table 1](#)). The variables like the number of decision-makers in the family, bystander literacy status, and health insurance available for treatment are expressed as frequencies ([Table 1](#)). There were 234 survivors at the end of ICU stay (69.6%).

**Table 2:** Pain assessment and treatment by ICU staff and amount of satisfaction to care

|  | Amount of satisfaction to care |                |       |
|--|--------------------------------|----------------|-------|
|  | Minimally satisfied            | Very satisfied | Total |
| Pain assessment and treatment by ICU staff |                                |                |       |
| No   |                                |                |       |
| Count                                      | 93                             | 34             | 127   |
| % within amount of satisfaction to care    | 62.9%                          | 18.1%          | 37.8% |
| Yes  |                                |                |       |
| Count                                      | 55                             | 154            | 209   |
| % within amount of satisfaction to care    | 37.2%                          | 81.9%          | 62.2% |
| Total                                      |                                |                |       |
| Count                                      | 148                            | 188            | 336   |
| % within amount of satisfaction to care    | 100%                           | 100%           | 100%  |

Chi-square,  $p$ -value < 0.001, Phi and Cramer's V 0.458

**Table 3:** Consideration for need and amount of satisfaction to care

|   | Amount of satisfaction to care |                |       |
|---|--------------------------------|----------------|-------|
|   | Minimally satisfied            | Very satisfied | Total |
| Consideration for need                  |                                |                |       |
| No                                      |                                |                |       |
| Count                                   | 100                            | 30             | 130   |
| % within amount of satisfaction to care | 67.6%                          | 16%            | 38.7% |
| Yes                                     |                                |                |       |
| Count                                   | 48                             | 158            | 206   |
| % within amount of satisfaction to care | 32.4%                          | 84%            | 61.3% |
| Total                                   |                                |                |       |
| Count                                   | 148                            | 188            | 336   |
| % within amount of satisfaction to care | 100%                           | 100%           | 100%  |

Chi-square,  $p$ -value < 0.001, Phi and Cramer's V 0.526

The variables that were significant for contributing to patients' relative satisfaction with ICU care after the Chi-square test included adequacy of pain assessment of patients ( $p$  < 0.001, Phi and Cramer's V 0.458) and consideration of need ( $p$  < 0.001, Phi and Cramer's V 0.526), and are depicted in Table 2 and 3. Likewise, other factors that were found significant after the Chi-square strength of association for patients' relative satisfaction with ICU care included concern and caring by ICU staff to patients, breathlessness assessment and treatment by ICU staff, agitation assessment and treatment by ICU staff, emotional support, coordination of care, concern and care by ICU staff to the family bystander, skill and competence of ICU nurses, frequency of communication with ICU nurses, skill and competence of ICU doctors, the atmosphere in ICU waiting room, the atmosphere in ICU, family participation in daily rounds, family participation in the care of the patient and the frequency of communication with ICU doctors (all factors having Chi-square,  $p$ -value < 0.001, Supplementary appendix Tables S1–S14). Notably, the literacy of family bystanders and health care expenditure were not found

to be significant for patients' relative satisfaction (Supplementary appendix Tables S15–S17).

Multivariable logistic regression of the variables that were found to be significantly associated with patients' relatives' satisfaction in Chi-square analysis showed that six variables were independently associated with satisfaction outcomes. They were pain assessment and treatment by ICU staff, consideration of need, emotional support, concern and care by ICU staff, atmosphere in the waiting room, and participation in the care of the patient (Table 4). The Hosmer and Lemeshow test  $p$ -value was 0.219 and the Nagelkerke R square value was 0.528, showing that the regression model was a good fit model. Out of the six parameters, consideration of need as well as pain assessment and treatment by ICU staff had the highest adjusted OR (4.448,  $p$ -value < 0.001 and 3.738,  $p$ -value 0.003 respectively) (Table 4). The Bootstrap multivariable logistic regression with 1,000 samples showed that six parameters were validated internally with  $p$ -values  $\leq$  0.05 to predict patients' relatives' satisfaction.

There were a few notable factors that were not found to significantly affect satisfaction levels among patients' relatives. The outcome of patients in terms of survival (Chi-square  $p$ -value = 0.331), the severity of organ dysfunction depicted by the SOFA score ( $p$ -value 0.636, independent student  $t$ -test), Charlson co-morbidity index score ( $p$ -value 0.525, Mann–Whitney  $U$ -test), length of ICU, and hospital stay ( $p$ -value 0.328 and  $p$ -value 0.865 respectively, Mann–Whitney  $U$ -test) were not found to significantly determine satisfaction among patient relatives (Tables 5 and 6). Palliative care was received by only 41 of 336 patients and was not found to be significantly associated with family satisfaction ( $p$  = 0.304, Chi-square test). Likewise, discharge against medical advice (DAMA) was not associated with family satisfaction in the 21 patients who requested DAMA ( $p$  = 0.570, Chi-square test).

## DISCUSSION

Studies in the past, both from India and overseas have looked at family perceptions towards intensive care and also the incidence of anxiety, depression, and posttraumatic stress amongst family members during a patient's ICU stay.<sup>9–11</sup> A family's perception of ICU care can be affected by various components such as patient-related factors, bystander demographics including literacy status, their understanding of the patient's illness/prognosis, and psychological/financial assistance at the time of crisis.<sup>13–15</sup> Family's satisfaction depended not only on perceiving of ICU staff's and doctor's approach to the patient's symptoms in the ICU but also on their conduct towards the family while appraising and counseling them regarding the patient's clinical status.

The present study, with its questionnaire and assimilated data, was able to analyze the above-mentioned components of family perception of care in good detail. The present study had few significant notable findings. We could identify specifically six important factors outlined in the FS-ICU 24R questionnaire that have to be addressed by the intensivists to ensure optimal family satisfaction. This is significant because certain factors like the participation of family in the daily rounds in ICU may not be feasible across all settings. In such scenarios, clinicians can focus on the most important factors which are associated with family satisfaction.

A total of 188 family bystanders responded with good satisfaction to the amount of care, approximately 81.9% of patients had good assessment and treatment of physical symptoms like

**Table 4:** Multivariable regression analysis model of the variables of FS- ICU 24R questionnaire predicting satisfaction of care

| Variable   | Adjusted odd's ratio | 95% CI on Exp (B) |             | p-value          |
|--|----------------------|-------------------|-------------|------------------|
|  |                      | Lower bound       | Upper bound |                  |
| Concern and caring towards patient by ICU staff      | 0.440                | 0.189             | 1.028       | 0.058            |
| Pain assessment and treatment by ICU staff           | 3.738                | 1.572             | 8.887       | <b>0.003</b>     |
| Breathlessness assessment and treatment by ICU staff | 1.076                | 0.511             | 2.266       | 0.847            |
| Agitation assessment and treatment by ICU staff      | 0.845                | 0.374             | 1.910       | 0.685            |
| Consideration of need                                | 4.448                | 2.072             | 9.547       | <b>&lt;0.001</b> |
| Emotional support                                    | 0.308                | 0.126             | 0.754       | <b>0.010</b>     |
| Coordination of care                                 | 1.942                | 0.892             | 4.227       | 0.094            |
| Concern and caring by ICU staff                      | 2.679                | 1.145             | 6.269       | <b>0.023</b>     |
| Skill and competence of ICU nurses                   | 0.728                | 0.319             | 1.664       | 0.452            |
| Frequency of communication by ICU nurses             | 1.790                | 0.890             | 3.597       | 0.102            |
| Skill and competence of ICU doctors                  | 0.844                | 0.388             | 1.836       | 0.669            |
| Atmosphere in ICU waiting room                       | 2.164                | 1.157             | 4.048       | <b>0.016</b>     |
| Atmosphere in ICU                                    | 1.405                | 0.699             | 2.825       | 0.340            |
| Participation in daily rounds                        | 1.993                | 0.951             | 4.178       | 0.068            |
| Participation in care of patient                     | 2.171                | 1.039             | 4.538       | <b>0.039</b>     |
| Frequency of communication by ICU doctors            | 0.981                | 0.419             | 2.297       | 0.964            |
| Constant   | 0.067                |                   |             | <b>&lt;0.001</b> |

Hosmer and Lemeshow test *p*-value 0.219, Nagelkerke R square *p*-value 0.528; Bold values indicate significant *p*-values of independent predictor variables after multivariable regression analysis

**Table 5:** Patient outcome and satisfaction to amount of care

|   | Amount of satisfaction to care |                |       |
|---|--------------------------------|----------------|-------|
|   | Minimally satisfied            | Very satisfied | Total |
| Patient outcome                         |                                |                |       |
| No (Expired)                            |                                |                |       |
| Count                                   | 49                             | 53             | 102   |
| % within amount of satisfaction to care | 33.1%                          | 28.2%          | 30.4% |
| Yes (Survived)                          |                                |                |       |
| Count                                   | 99                             | 135            | 234   |
| % within amount of satisfaction to care | 66.9%                          | 71.8%          | 89.1% |
| Total                                   |                                |                |       |
| Count                                   | 148                            | 188            | 336   |
| % within amount of satisfaction to care | 100%                           | 100%           | 100%  |

Chi-square, *p*-value = 0.331

**Table 6:** Multiple related variables and satisfaction to amount of care

|                                       | Amount of satisfaction of care |                |                 |
|---------------------------------------|--------------------------------|----------------|-----------------|
|                                       | Minimally satisfied            | Very satisfied | <i>p</i> -value |
| SOFA score                            | 8.77 ± 3.43                    | 8.59 ± 3.46    | 0.636           |
| Length of stay in intensive care unit | 6 (4–10)                       | 6 (4–10)       | 0.328           |
| Length of stay in hospital            | 16 (10–26.75)                  | 16 (11–25)     | 0.865           |
| Charlson comorbidity index            | 3 (1–4)                        | 2 (1–5)        | 0.525           |

pain and breathlessness by ICU staff. Element of satisfaction was not only limited to patient-related factors like treatment of pain, breathlessness, and agitation but also to bystander factors like

psychological/emotional assistance by ICU staff and doctors. Almost 84–78% of family bystanders of 188 patients with good satisfaction with care had felt their psychological needs were duly addressed and emotionally supported as well. The study center did not have a dedicated counselor/medical social worker for the purpose. However, this was addressed by frequent communication and intimation of patient's status on the part of ICU staff (78.2%) and doctors (83.5%) resulting in good perception and satisfaction.

Nearly 3/5th of families (59.2%) in the study belonged to rural backgrounds (village/taluka). Approximately 51.9% bystander population had studied till pre-university and 88% of them did not have previous ICU experience. However, unlike studies from the past, it was interesting to note that family satisfaction with the amount of care was neither significantly related to the patient's organ dysfunction severity (*p* = 0.636) nor to their length of stay in the intensive care unit (*p* = 0.328) or hospital (*p* = 0.865).<sup>16,17</sup> Concept of advance directives by patients with regards to goals of care is still in infancy in the Indian health care setting.<sup>18</sup> Hence it mostly becomes the responsibility of family bystanders to make surrogate decisions during times of crisis. Our present study noted an important aspect that the transfer of decision-making responsibility regarding patient care was entrusted by bystanders to treating health care professionals. This highlights the very important fact that family bystanders in the study believed in the value of beneficence (do no harm) which is one of the core medical ethical principles.<sup>19</sup> Family counseling of ICU patients in the study center was multidisciplinary and also had a dedicated team of palliative services for difficult goals of care decision-making and end-of-life care. Previous studies showed the financial implications of ever-increasing ICU costs on families.<sup>14</sup> On the contrary, our study did not have a major correlation between health care expenditure and level of satisfaction. It can be due to the fact that the health care costs of nearly 2/3rd (67.5%) of the study population were borne by insurance (private insurance/government sponsored).

This study, to our knowledge, is the first to assess family perception/satisfaction in an Indian ICU cohort that had robust end-of-life care plans and palliative support for patients. Consideration of advanced directives, foregoing life supports/end-of-life care has gained much dimension over a decade in India with more clarity from the Indian judicial framework and joint guidelines from intensive care/palliative societies.<sup>20-22</sup> The study surveyed and noted vital relevant information from families opting for (A) discharge against medical advice (DAMA), and (B) in hospital end-of-life services in the view of clinical care futility. We found that the incidence of discharge against medical advice ( $p = 0.570$ ) or palliative care (0.304) was not associated with the level of satisfaction in our study. This could be because the number of patients requesting DAMA (6.25%) and palliative care (12.2%) was extremely small for a reliable association. The study rightly points towards the fact that how a specific advanced health care communication with family via multidisciplinary counseling meets end-of-life care needs such as optimizing patient comfort and ensuring dignity near death, grief address for consoling family (maintaining privacy, catering to spiritual needs) affects family satisfaction in a positive manner despite negative outcomes, as echoed in studies from past.<sup>23-25</sup>

Our study had many major strengths to it. This questionnaire-based survey was evaluated on a large sample size and the survey was done on the last day of the patient's intensive care stay thereby rightly eliciting disparity in the family's perception and satisfaction with ICU care. The study also analyzed responses from families of patients who died during ICU stay adding value to the survey. Unlike previous studies, the present survey also studied the importance of palliative services in difficult decision-making regarding goals of care, end of life, discharge against medical advice, and its implications for family perception/satisfaction. Satisfaction scores were analyzed against patients' illness severity scores, ICU survivors and non-survivors, comorbid conditions, length of stay in ICU/hospital, and other influencing factors like financial assistance, and bystander literacy. We also did bootstrap analysis for reliable internal validation of the independent factors that ensure patients' relatives' satisfaction with ICU care. The study had its share of limitations as well. It was a single-center survey and cannot be generalized to all health care systems considering the variability in care provided. The number of patients receiving palliative care was small, so the reliability of the association of palliative care with patients' relatives' satisfaction cannot be validated. The survey also had responses for open-ended questions which we could not analyze.

## CONCLUSION

We found that empathic communication with a family centered approach apart from assiduous management of physical symptoms of critically ill patients in the ICU yields a better family understanding of care and satisfaction. Also noteworthy was the fact that the family's perception of the patient's illness as appraised by the treating intensivist was rather more important to ensure family satisfaction compared to the patient's objectively measured severity organ dysfunction scores.

## Clinical Significance

The study becomes clinically relevant in identifying the unmet needs of families during crisis hours. Specific strategies to address this gap will go a long way in mitigating the incongruous stress of attending to family resulting in mutual doctor bystander consensus and best care to patients in ICU.

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**SUPPLEMENTARY APPENDIX**

**Table S1:** Concern and caring by ICU staff to patient and amount of satisfaction to care

|   | <i>Amount of satisfaction to care</i> |                       |              |
|---|---------------------------------------|-----------------------|--------------|
|   | <i>Minimally satisfied</i>            | <i>Very satisfied</i> | <i>Total</i> |
| Concern and caring by ICU staff to patient and amount of satisfaction to care |                                       |                       |              |
| No  |                                       |                       |              |
| Count   | 82                                    | 40                    | 122          |
| % within amount of satisfaction to care                                       | 55.4%                                 | 21.3%                 | 36.3%        |
| Yes   |                                       |                       |              |
| Count   | 66                                    | 148                   | 214          |
| % within amount of satisfaction to care                                       | 44.6%                                 | 78.7%                 | 63.7%        |
| Total   |                                       |                       |              |
| Count   | 148                                   | 188                   | 336          |
| % within amount of satisfaction to care                                       | 100%                                  | 100%                  | 100%         |

Chi-square, *p*-value, and Phi and Cramer's V 0.352

**Table S2:** Breathlessness assessment and treatment by ICU staff and amount of satisfaction to care

|  | <i>Amount of satisfaction to care</i> |                       |              |
|--|---------------------------------------|-----------------------|--------------|
|  | <i>Minimally satisfied</i>            | <i>Very satisfied</i> | <i>Total</i> |
| Breathlessness assessment and treatment by ICU staff |                                       |                       |              |
| No   |                                       |                       |              |
| Count  | 79                                    | 34                    | 113          |
| % within amount of satisfaction to care              | 53.4%                                 | 18.1%                 | 33.6%        |
| Yes  |                                       |                       |              |
| Count  | 69                                    | 154                   | 223          |
| % within amount of satisfaction to care              | 46.6%                                 | 81.9%                 | 66.4%        |
| Total  |                                       |                       |              |
| Count  | 148                                   | 188                   | 336          |
| % within amount of satisfaction to care              | 100%                                  | 100%                  | 100%         |

Chi-square, *p*-value < 0.001, Phi and Cramer's V 0.371

**Table S3:** Agitation assessment and treatment by ICU staff and amount of satisfaction to care

|   | <i>Amount of satisfaction to care</i> |                       |              |
|---|---------------------------------------|-----------------------|--------------|
|   | <i>Minimally satisfied</i>            | <i>Very satisfied</i> | <i>Total</i> |
| Agitation assessment and treatment by ICU staff |                                       |                       |              |
| No  |                                       |                       |              |
| Count   | 91                                    | 40                    | 131          |
| % within amount of satisfaction to care         | 61.5%                                 | 21.3%                 | 39.0%        |
| Yes   |                                       |                       |              |
| Count   | 57                                    | 148                   | 205          |
| % within amount of satisfaction to care         | 38.5%                                 | 78.7%                 | 61.0%        |
| Total   |                                       |                       |              |
| Count   | 148                                   | 188                   | 336          |
| % within amount of satisfaction to care         | 100%                                  | 100%                  | 100%         |

Chi-square, *p*-value < 0.001, Phi and Cramer's V 0.458

**Table S4:** Emotional support and amount of satisfaction to care

|   | <i>Amount of satisfaction to care</i> |                       |              |
|---|---------------------------------------|-----------------------|--------------|
|   | <i>Minimally satisfied</i>            | <i>Very satisfied</i> | <i>Total</i> |
| Emotional support                       |                                       |                       |              |
| No                                      |                                       |                       |              |
| Count                                   | 89                                    | 46                    | 135          |
| % within amount of satisfaction to care | 60.1%                                 | 24.5%                 | 40.2%        |
| Yes                                     |                                       |                       |              |
| Count                                   | 59                                    | 142                   | 201          |
| % within amount of satisfaction to care | 39.9%                                 | 75.5%                 | 59.8%        |
| Total                                   |                                       |                       |              |
| Count                                   | 148                                   | 188                   | 336          |
| % within amount of satisfaction to care | 100%                                  | 100%                  | 100%         |

Chi-square, *p*-value < 0.001, Phi and Cramer's V 0.361



**Table S5:** Coordination of care and amount of satisfaction to care

|   | Amount of satisfaction to care |                |       |
|---|--------------------------------|----------------|-------|
|   | Minimally satisfied            | Very satisfied | Total |
| Coordination of care                    |                                |                |       |
| No                                      |                                |                |       |
| Count                                   | 87                             | 35             | 122   |
| % within amount of satisfaction to care | 58.8%                          | 18.6%          | 36.3% |
| Yes                                     |                                |                |       |
| Count                                   | 61                             | 153            | 214   |
| % within amount of satisfaction to care | 41.2%                          | 81.4%          | 63.7% |
| Total                                   |                                |                |       |
| Count                                   | 148                            | 188            | 336   |
| % within amount of satisfaction to care | 100%                           | 100%           | 100%  |

Chi-square,  $p$ -value < 0.001, Phi and Cramer's V 0.415

**Table S7:** Skill and competence of ICU nurses and amount of satisfaction to care

|   | Amount of satisfaction to care |                |       |
|---|--------------------------------|----------------|-------|
|   | Minimally satisfied            | Very satisfied | Total |
| Skill and competence of ICU nurses      |                                |                |       |
| No                                      |                                |                |       |
| Count                                   | 78                             | 29             | 107   |
| % within amount of satisfaction to care | 52.7%                          | 15.4%          | 31.8% |
| Yes                                     |                                |                |       |
| Count                                   | 70                             | 159            | 229   |
| % within amount of satisfaction to care | 47.3%                          | 84.6%          | 68.2% |
| Total                                   |                                |                |       |
| Count                                   | 148                            | 188            | 336   |
| % within amount of satisfaction to care | 100%                           | 100%           | 100%  |

Chi-square,  $p$ -value < 0.001, Phi and Cramer's V 0.397

**Table S6:** Concern and care by ICU staff to family bystander and amount of satisfaction to care

|   | Amount of satisfaction to care |                |       |
|---|--------------------------------|----------------|-------|
|   | Minimally satisfied            | Very satisfied | Total |
| Concern and care by ICU staff to family bystander |                                |                |       |
| No  |                                |                |       |
| Count   | 94                             | 32             | 126   |
| % within amount of satisfaction to care           | 63.5%                          | 17.0%          | 37.5% |
| Yes   |                                |                |       |
| Count   | 54                             | 156            | 210   |
| % within amount of satisfaction to care           | 38.5%                          | 83%            | 62.5% |
| Total   |                                |                |       |
| Count   | 148                            | 188            | 336   |
| % within amount of satisfaction to care           | 100%                           | 100%           | 100%  |

Chi-square,  $p$ -value < 0.001, Phi and Cramer's V 0.477

**Table S8:** Frequency of communication with ICU nurses and amount of satisfaction to care

|  | Amount of satisfaction to care |                |       |
|--|--------------------------------|----------------|-------|
|  | Minimally satisfied            | Very satisfied | Total |
| Frequency of communication with ICU nurses |                                |                |       |
| No   |                                |                |       |
| Count                                      | 91                             | 41             | 132   |
| % within amount of satisfaction to care    | 61.5%                          | 21.8%          | 39.3% |
| Yes  |                                |                |       |
| Count                                      | 57                             | 147            | 204   |
| % within amount of satisfaction to care    | 38.5%                          | 78.2%          | 60.7% |
| Total                                      |                                |                |       |
| Count                                      | 148                            | 188            | 336   |
| % within amount of satisfaction to care    | 100%                           | 100%           | 100%  |

Chi-square,  $p$ -value < 0.001, Phi and Cramer's V 0.403

**Table S9:** Skill and competence of ICU doctors and amount of satisfaction to care

|   | Amount of satisfaction to care |                |       |
|---|--------------------------------|----------------|-------|
|   | Minimally satisfied            | Very satisfied | Total |
| Skill and competence of ICU doctors     |                                |                |       |
| No                                      |                                |                |       |
| Count                                   | 80                             | 37             | 117   |
| % within amount of satisfaction to care | 54.1%                          | 19.7%          | 34.8% |
| Yes                                     |                                |                |       |
| Count                                   | 68                             | 151            | 219   |
| % within amount of satisfaction to care | 45.9%                          | 80.3%          | 65.2% |
| Total                                   |                                |                |       |
| Count                                   | 148                            | 188            | 336   |
| % within amount of satisfaction to care | 100%                           | 100%           | 100%  |

Chi-square,  $p$ -value < 0.001, Phi and Cramer's V 0.358

**Table S10:** Atmosphere in ICU waiting room and amount of satisfaction to care

|   | Amount of satisfaction to care |                |       |
|---|--------------------------------|----------------|-------|
|   | Minimally satisfied            | Very satisfied | Total |
| Atmosphere in ICU waiting room          |                                |                |       |
| No                                      |                                |                |       |
| Count                                   | 108                            | 69             | 177   |
| % within amount of satisfaction to care | 73.0%                          | 36.7%          | 52.7% |
| Yes                                     |                                |                |       |
| Count                                   | 40                             | 119            | 159   |
| % within amount of satisfaction to care | 27.0%                          | 63.3%          | 47.3% |
| Total                                   |                                |                |       |
| Count                                   | 148                            | 188            | 336   |
| % within amount of satisfaction to care | 100%                           | 100%           | 100%  |

Chi-square,  $p$ -value < 0.001, Phi and Cramer's V 0.361

**Table S11:** Atmosphere in ICU and amount of satisfaction to care

|   | Amount of satisfaction to care |                |       |
|---|--------------------------------|----------------|-------|
|   | Minimally satisfied            | Very satisfied | Total |
| Atmosphere in ICU                       |                                |                |       |
| No (unpleasant)                         |                                |                |       |
| Count                                   | 91                             | 43             | 134   |
| % within amount of satisfaction to care | 61.5%                          | 22.9%          | 39.9% |
| Yes (pleasant)                          |                                |                |       |
| Count                                   | 57                             | 145            | 202   |
| % within amount of satisfaction to care | 38.5%                          | 77.1%          | 60.1% |
| Total                                   |                                |                |       |
| Count                                   | 148                            | 188            | 336   |
| % within amount of satisfaction to care | 100%                           | 100%           | 100%  |

Chi-square,  $p$ -value < 0.001, Phi and Cramer's V 0.391

**Table S12:** Family participation in daily rounds and amount of satisfaction to care

|   | Amount of satisfaction to care |                |       |
|---|--------------------------------|----------------|-------|
|   | Minimally satisfied            | Very satisfied | Total |
| Family participation in daily rounds    |                                |                |       |
| No                                      |                                |                |       |
| Count                                   | 87                             | 29             | 116   |
| % within amount of satisfaction to care | 58.9%                          | 15.4%          | 34.5% |
| Yes                                     |                                |                |       |
| Count                                   | 61                             | 159            | 220   |
| % within amount of satisfaction to care | 41.2%                          | 84.6%          | 65.5% |
| Total                                   |                                |                |       |
| Count                                   | 148                            | 188            | 336   |
| % within amount of satisfaction to care | 100%                           | 100%           | 100%  |

Chi-square,  $p$ -value < 0.001, Phi and Cramer's V 0.453

**Table S13:** Family participation in care and amount of satisfaction to care

|   | <i>Amount of satisfaction to care</i> |                       |              |
|---|---------------------------------------|-----------------------|--------------|
|   | <i>Minimally satisfied</i>            | <i>Very satisfied</i> | <i>Total</i> |
| Family participation in care            |                                       |                       |              |
| No                                      |                                       |                       |              |
| Count                                   | 98                                    | 37                    | 135          |
| % within amount of satisfaction to care | 66.2%                                 | 19.7%                 | 40.2%        |
| Yes                                     |                                       |                       |              |
| Count                                   | 50                                    | 151                   | 201          |
| % within amount of satisfaction to care | 33.8%                                 | 80.3%                 | 59.8%        |
| Total                                   |                                       |                       |              |
| Count                                   | 148                                   | 188                   | 336          |
| % within amount of satisfaction to care | 100%                                  | 100%                  | 100%         |

Chi-square, *p*-value < 0.001, Phi and Cramer's V 0.471

**Table S15:** Literacy of family bystander and satisfaction to amount of care

|   | <i>Amount of satisfaction to care</i> |                       |              |
|---|---------------------------------------|-----------------------|--------------|
|   | <i>Minimally satisfied</i>            | <i>Very satisfied</i> | <i>Total</i> |
| Literacy of family bystander            | 69                                    | 105                   | 174          |
| No                                      |                                       |                       |              |
| Count                                   |                                       |                       |              |
| % within amount of satisfaction to care | 32.4%                                 | 32.4%                 | 32.4%        |
| Yes                                     |                                       |                       |              |
| Count                                   | 79                                    | 83                    | 162          |
| % within amount of satisfaction to care | 53.4%                                 | 44.1%                 | 48.2%        |
| Total                                   |                                       |                       |              |
| Count                                   | 148                                   | 188                   | 336          |
| % within amount of satisfaction to care | 100%                                  | 100%                  | 100%         |

Chi-square, *p*-value 0.093 (Not significant)

**Table S14:** Frequency of communication with ICU doctors and amount of satisfaction to care

|   | <i>Amount of satisfaction to care</i> |                       |              |
|---|---------------------------------------|-----------------------|--------------|
|   | <i>Minimally satisfied</i>            | <i>Very satisfied</i> | <i>Total</i> |
| Frequency of communication with ICU doctors |                                       |                       |              |
| No  |                                       |                       |              |
| Count                                       | 82                                    | 31                    | 113          |
| % within amount of satisfaction to care     | 55.4%                                 | 16.5%                 | 33.6%        |
| Yes   |                                       |                       |              |
| Count                                       | 66                                    | 157                   | 223          |
| % within amount of satisfaction to care     | 44.6%                                 | 83.5%                 | 66.4%        |
| Total                                       |                                       |                       |              |
| Count                                       | 148                                   | 188                   | 336          |
| % within amount of satisfaction to care     | 100%                                  | 100%                  | 100%         |

Chi-square, *p*-value < 0.001, Phi and Cramer's V 0.429

**Table S16:** Health care expenditure and satisfaction to amount of care

|   | <i>Amount of satisfaction to care</i> |                       |              |
|---|---------------------------------------|-----------------------|--------------|
|   | <i>Minimally satisfied</i>            | <i>Very satisfied</i> | <i>Total</i> |
| Health care expenditure                 |                                       |                       |              |
| No (insured)                            |                                       |                       |              |
| Count                                   | 48                                    | 61                    | 109          |
| % within amount of satisfaction to care | 32.4%                                 | 32.4%                 | 32.4%        |
| Yes (self paying)                       |                                       |                       |              |
| Count                                   | 100                                   | 127                   | 227          |
| % within amount of satisfaction to care | 67.6%                                 | 67.6%                 | 67.6%        |
| Total                                   |                                       |                       |              |
| Count                                   | 148                                   | 188                   | 336          |
| % within amount of satisfaction to care | 100%                                  | 100%                  | 100%         |

Chi-square, *p*-value 0.864 (Not significant)

**Table S17:** Health care expenditure and decision for discharge against medical advice/Palliation

|   | <i>Decision for discharge against medical advice/palliation</i> |       |       |
|---|---|-------|-------|
|   | No  | Yes   | Total |
| Health care expenditure                 |   |       |       |
| No (insured)                            |   |       |       |
| Count                                   | 84  | 25    | 109   |
| % within amount of satisfaction to care | 30.7%   | 40.3% | 32.4% |
| Yes (self paying)                       |   |       |       |
| Count                                   | 190   | 37    | 227   |
| % within amount of satisfaction to care | 69.3%   | 59.7% | 67.6% |
| Total                                   |   |       |       |
| Total                                   | 274   | 62    | 336   |
| % within amount of satisfaction to care | 100%  | 100%  | 100%  |

Chi-square, *p*-value: Not significant

**Table S18:** Responses to FS-ICU 24R questionnaire

| <i>Question</i>   | <i>Numerical rating on a scale from 1 to 5 in percentage (from most dissatisfied to most satisfied)</i> |       |       |       |       |
|---|---|-------|-------|-------|-------|
|   | 1   | 2     | 3     | 4     | 5     |
| Concern and caring by ICU staff   | 5.7%  | 6.3%  | 24.4% | 28%   | 35.7% |
| Assessment and treatment of pain by ICU staff                           | 3.9%  | 8.9%  | 25%   | 29.2% | 33%   |
| Assessment and treatment of breathlessness by ICU staff                 | 4.5%  | 6.5%  | 22.6% | 26.2% | 40.2% |
| Assessment and treatment of agitation by ICU staff                      | 4.5%  | 8.3%  | 26.2% | 28.6% | 32.4% |
| Consideration for your needs  | 6%  | 11%   | 21.7% | 26.2% | 35.1% |
| Emotional support   | 3%  | 7.1%  | 30.1% | 28.9% | 31%   |
| Coordination of care  | 3%  | 6.3%  | 27.1% | 25%   | 38.7% |
| Concern and caring by ICU staff   | 5.1%  | 6.8%  | 25.6% | 25.9% | 36.6% |
| Skill and competence of ICU nurse                                       | 6.5%  | 4.2%  | 21.1% | 27.4% | 40.8% |
| Frequency of communication with ICU nurse                               | 6.3%  | 8.9%  | 24.1% | 26.8% | 33.9% |
| Skill and competence of ICU doctors                                     | 2.7%  | 6%    | 26.2% | 31%   | 34.2% |
| Satisfaction with atmosphere in waiting room                            | 11.9%   | 10.7% | 30.1% | 24.1% | 23.1% |
| Satisfaction with atmosphere in ICU                                     | 4.8%  | 8.6%  | 26.5% | 30.1% | 30.1% |
| Satisfaction with participation in daily rounds                         | 5.1%  | 6%    | 23.5% | 29.5% | 36%   |
| Satisfaction with participation in care of critically ill family member | 3.6%  | 8%    | 28.6% | 28.9% | 31%   |
| Satisfaction with amount or level of care received                      | 4.2%  | 7.7%  | 32.1% | 31%   | 25%   |
| Frequency of communication with ICU doctors                             | 4.5%  | 4.5%  | 24.7% | 34.2% | 32.1% |
| Ease of getting information   | 3.9%  | 8.6%  | 22.6% | 30.7% | 34.2% |
| Understanding of information  | 3%  | 7.1%  | 25.6% | 30.4% | 33.9% |
| Honesty of information  | 2.7%  | 8%    | 25.6% | 30.4% | 33.3% |
| Completeness of information   | 3%  | 7.4%  | 20.8% | 29.2% | 39.6% |