Review Article

Intensive Care Unit death and factors influencing family satisfaction of Intensive Care Unit care

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Abstract

Introduction: Family satisfaction of Intensive Care Unit (FS-ICU) care is believed to be associated with ICU survival and ICU outcomes. A review of literature was done to determine factors influencing FS-ICU care in ICU deaths. **Results:** Factors that positively influenced FS-ICU care were (a) communication: Honesty, accuracy, active listening, emphatic statements, consistency, and clarity; (b) family support: Respect, compassion, courtesy, considering family needs and wishes, and emotional and spiritual support; (c) family meetings: Meaningful explanation and frequency of meetings; (d) decision-making: Shared decision-making; (e) end of life care support: Support during foregoing life-sustaining interventions and staggered withdrawal of life support; (f) ICU environment: Flexibility of visiting hours and safe hospital environment; and (g) other factors: Control of pain and physical symptoms, palliative care consultation, and family-centered care. Factors that negatively influenced FS-ICU care were (a) communication: Incomplete information and unable to interpret information provided; (b) family support: Lack of emotional and spiritual support; (c) family meetings: Conflicts and short family meetings; (d) end of life care support: Resuscitation at end of life, mechanical ventilation on day of death, ICU death of an elderly, prolonged use of life-sustaining treatment, and unfamiliar technology; and (e) ICU environment: Restrictive visitation policies and families denied access to see the dying loved ones. **Conclusion:** Families of the patients admitted to ICU value respect, compassion, empathy, communication, involvement in decision-making, pain and symptom relief, avoiding futile medical interventions, and dignified end of life care.

Keywords: Death, family satisfaction of care, Intensive Care Unit

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Introduction

It is a common belief that families of patients admitted to Intensive Care Unit (ICU) have better satisfaction of ICU care if the patient survives, or desired clinical outcomes are achieved and will have a negative perception of ICU care if the patient dies or desired clinical outcomes are not achieved. In this paper, we would like to review the literature to answer the following research question – In an ICU death, what are the factors that influence family satisfaction of ICU (FS-ICU) care?

Methods

Research question was defined using Population Intervention Comparator Outcomes (PICO) model, where population group is patients admitted to intensive care and intervention is intensive care treatment. Comparison between ICU survivors and nonsurvivors made in few studies and the outcome measured is family satisfaction.

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The search was carried out using electronic databases such as Medline, CINAHL, PsycINFO, PubMed, Scopus, and Web of Science.

The Boolean operators used for literature search were death(s) or dying and ICU or critical care unit and family satisfaction of care or caregiver satisfaction of care.

Advanced search of Medline, CINAHL, and PsycINFO presented 24 research papers; after initial screen of title and abstract, only 8 papers were considered relevant to literature search research question. Advanced search of Scopus presented 153 papers; after initial screen of title and abstract, only 12 papers were considered relevant to literature search research question. Advanced search of PubMed and Web of Science presented 62 papers; after removal of duplicates from previous searches, only 5 papers were considered relevant to literature search research question. Of 25 papers, those papers appearing in the systematic review and those papers not answering the research question were excluded. The next set of advanced search done using Boolean operators (ICU or critical care unit and family satisfaction of care or caregiver satisfaction of care) using above-mentioned search engines presented 971 papers; after screening of title and abstract, only 54 papers were found appropriate. Among these 54 papers, only those papers related family satisfaction of care related to ICU death/end of life were included. Duplicates from previous searches and papers included in the systematic review were excluded. Twenty-three papers were finally chosen to be included in the literature review.

To answer the research question, systematic review, surveys, observational studies, and qualitative studies were included. Only those papers related to FS-ICU care were included, and other research relating to family satisfaction was excluded. Only research published in English language in the last 10 years (2005 and later) were included. All unpublished literature and gray literature were excluded.

Each research paper was analyzed and outcomes were presented along with reviewer's own discussion of results. Two systematic reviews included in the literature review were critically appraised using study tool sourced from critical appraisal skills program tool kit.

Results

A systematic review by Hinkle and his associates[1] reviewed "factors associated with family satisfaction on end of life care in the ICU." Twenty-three relevant articles were chosen from 1072 searches and analysis was carried out using Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist. Seven of the articles included evaluated ICU interventions, of which three were randomized controlled trials. Sixteen articles were descriptive studies of varying sample sizes (range - 29–1290) where the families of the deceased were interviewed using a validated family satisfaction questionnaire. Results of the descriptive studies showed courtesy, compassion, respect, good communication, empathic statements, active listening, respecting patient wishes, family involvement in decision-making, shared decision making, support family receive during discussions and decision-making to forego life-sustaining interventions, staggered withdrawal of life support, management of pain, assurance of nonabandonment, and family-centered care positively influenced family satisfaction and poorly controlled symptoms, poor communication skills, incomplete information, short family meetings, conflict during family meetings, increased length of ICU stay, and resuscitation at end of life negatively influenced family satisfaction. Results of intervention studies showed that in only one of the four studies, palliative care intervention positively influenced FS-ICU care. Rest of the studies showed no significant change in satisfaction. Providing written information on what to expect during cessation of life-sustaining interventions and critical care nurse intervention were the other factors that positively influenced family satisfaction. On critically appraising this systematic review, it is evident that the author had adopted a clearly focused research question and relevant studies were included. Studies were assessed for quality and results were displayed as descriptive and interventional studies. The results of this study may encourage researchers to do more intervention-based studies but this systematic review in itself lacks robustness, as most of the studies included in the review are descriptive in nature. A study by Wall *et al*.[2] included in this systematic review stands out as a prominent study as it demonstrated higher family satisfaction among ICU nonsurvivors when compared to ICU survivors. This was attributed to greater involvement of families of ICU nonsurvivors in decision-making and enhanced compassion and communication offered to families of ICU nonsurvivors.

A retrospective family survey[3] was carried out at "Veteran Affairs health care system" to determine family satisfaction of end of life care using "Family Assessment of Treatment of End of Life (FATE)" questionnaire. Two hundred sixty-two families of deceased elderly veterans, who died of advanced cancer, were telephonically interviewed 6 weeks after death. The patients who died

in the ICU and those who were mechanically ventilated on the day of death had poor FATE scores and patients who received palliative care consultation and had discussion of "do not resuscitate" orders scored better on FATE scores. A similar study[4] evaluating perspectives of 535 families on admission of the very elderly (>80 years) to the ICU in Canada showed that comfort, symptom control, less suffering were the positive factors and poor communication, no involvement in decision-making, and prolonged use of life-sustaining treatment were the negative factors. These studies reiterate that subjecting elderly advanced cancer patients to futile life-sustaining measures leads to more patient and family distress.

A prospective Dutch study[5] involving 100 consecutive patients in three Dutch ICUs assessed quality of death using quality of dying and death questionnaire. Most of the families rated quality of deaths in ICUs well and physician communication and inclusion of the family in decision-making were the two main factors that influenced FS-ICU care. In a Philippines study,[6] forty families of ICU nonsurvivors were surveyed 4–6 weeks after death using Filipino version of FS-ICU questionnaire, and majority of the respondents were happy with the end of life care provided in the medical ICU. A prospective observational study[7] done in Australia interviewed 25 families of the deceased who had withdrawal of life-sustaining treatment before death. Most of the families were satisfied with the ICU care provided except for issues related to communication and lack of spiritual support. The Dutch study was a prospective study that demonstrated how good decision-making process and good communication improved ICU outcomes. The studies conducted at Philippines and Australia were both retrospective, cross-sectional studies involving a very small group of patient population in Asian and Australian continents. These results may not completely represent the cross-section of the population studied, and hence, results of these studies cannot be extrapolated to a larger population.

A German multi-ICU prospective cohort study[8] which was a mixed quantitative-qualitative study involving 215 families showed "consistency, clarity, and completeness of information," respect, compassion, and emotional support as positive factors and poor ICU infrastructure as a negative factor. A Swiss multicenter ICU study[9] involving 996 families showed information providing and involvement in decision-making improved family satisfaction as positive factors and poor communication, poor coordination of care and lack of emotional support as negative factors. The German and Swiss ICU studies with larger sample size are a mixture of families of ICU survivors and nonsurvivors. Subgroup analysis of ICU survivors and nonsurvivors would have facilitated better understanding of the contributory factors between the groups.

A study conducted in an ICU in Morocco[10] evaluating FS-ICU care showed that information provided by the senior clinicians and information provided about diagnosis and prognosis positively influenced satisfaction of ICU care. A Swiss study[11] involving 197 families showed patient and family communication, sharing medical information and treating the patient as an individual were the positive factors. A prospective Portuguese study[12] that enrolled 164 families in a tertiary cancer care ICU showed that insufficient information given by the doctors, accessibility of ICU doctors, and conflict regarding prognosis adversely influenced FS-ICU care. A retrospective survey[13] of 457 families in Netherlands showed that family meetings and participation in family meetings improved ICU survival. A large prospective observational study[14] of involving 610 families on End of Life Care in German ICUs in patients with severe sepsis showed that decision-making, communication and coordination of care positively influenced satisfaction of ICU care. A retrospective study[15] of 27 families who required mechanical ventilation felt respect and meaningful explanation about life support enhanced family experience. An Australian study[16] involving 108 families showed meeting with social worker and regular medical meetings decreased family dissatisfaction. A prospective, questionnaire-based study conducted in India by Venkataraman *et al*.[17] showed that family communication, involvement of family counselors, and family meetings positively influenced FS-ICU care and restrictive family visitation policy negatively influenced FS-ICU care.

A 3-year FS-ICU care[18] studied at Critical Care Family Assistance Program (CCFAP) carried out at pilot sites showed family communication, quality of ICU care, flexibility of visiting hours, safe hospital environment, and alleviation of family stress/anxiety were the important determinants that improved satisfaction of ICU care. This was an intervention-based study where improvement in family satisfaction was studied pre- and post-CCFAP.

A qualitative nursing study[19] was conducted recruiting 17 close relatives of 15 families. It was an interview-based study and interviews were analyzed using a phenomenological method. The results of the study showed "unfamiliar technology, distressing

information, and waiting characterized by uncertainty, not being invited to enter into a caring relationship, not being allowed access to the dying loved one, and not being assisted in interpreting information" as factors that negatively influenced FS-ICU care. Another qualitative study[20] conducted about families lived experience of ICU care – a phenomenological study involving indepth interviews of 6 family members showed that honest information about patient's progress, caring reassurance, family support, and family being able to make sense of the situation positively influenced family experience of ICU care. A qualitative study conducted at Melbourne by Wong *et al*.[21] showed that information providing, interpersonal skills, family communication, and support positively influenced FS-ICU care.

According to a pediatric intensive care study by Meert *et al*.,[22] family visitation, rounds centered around family, family presence during invasive procedures and resuscitation, and family meetings improved family satisfaction of care. A systematic review by Latour *et al*.,[23] which critically appraised 12 original studies, demonstrated family-centered care as the single most important factor that influenced FS-ICU care.

Discussion

Factors influencing FS-ICU care specifically in an ICU death setting were analyzed from 23 studies included in the literature review and broad themes were derived.

Communication with families and caregivers as a factor influencing FS-ICU care was seen in 15 out of the 23 studies included in the literature review. Honest and accurate communication of diagnosis and prognosis, active listening, emphatic statements, consistency and clarity of information, information provided by senior clinicians, and involvement of family counselors positively influenced FS-ICU care. Poor communication skills, incomplete information, unable to interpret information provided, and making families wait to provide distressing information negatively influenced FS-ICU care.

Family support as a factor influencing FS-ICU care was seen in 9 out of the 23 studies included in the literature review. Respect, compassion, courtesy, treating patient as an individual, consideration of family needs, respecting family wishes, emotional and spiritual support, alleviation of family stress and anxiety, caring reassurance, family able to make sense of the situation, and good interpersonal skills positively influenced FS-ICU care. Lack of emotional and spiritual support and family not being invited to be part of the caring patient-family-physician relationship negatively influenced FS-ICU care.

Role of family meetings in decision-making as a factor influencing FS-ICU care was seen in 5 out of the 23 studies included in the literature review. Consideration of family needs, meaningful explanation, and frequency of meetings involving social worker and counselor positively influenced FS-ICU care. Conflicts during family meetings and short family meetings negatively influenced FS-ICU care.

Family involvement in decision-making as a factor influencing FS-ICU care was seen in 5 out of the 23 studies included in the literature review. Involving families in decision-making and shared decision-making and involving families in decisions pertaining to limitation of life support positively influenced FS-ICU care.

End of life care support as a factor influencing FS-ICU care was seen in 4 out of the 23 studies included in the literature review. Support family receive during discussions and decision-making to forego life-sustaining interventions, staggered withdrawal of life support, assurance of nonabandonment, discussion of "do not resuscitate" orders, providing written information on what to expect during cessation of life-sustaining intervention, meaningful explanation about life support, and family presence during invasive procedures and resuscitation positively influenced FS-ICU care. Resuscitation at end of life, mechanical ventilation on the day of death, ICU death of an elderly, prolonged use of life-sustaining treatment, and unfamiliar technology negatively influenced FS-ICU care.

ICU stay and ICU infrastructure as a factor influencing FS-ICU care were seen in 6 out of the 23 studies included in the literature review. Flexibility of visiting hours and safe hospital environment positively influenced FS-ICU care. Poor ICU infrastructure, poor coordination of ICU care, restrictive visitation policies, poor access to ICU doctors, and families denied access to see the dying loved one negatively influenced FS-ICU care.

The other factors that positively influenced family satisfaction of care were control of pain and physical symptoms (4 out of 23 studies), family-centered care (3 out of 23 studies), and palliative care consultation (2 out of 23 studies).

In pediatric ICUs, family-centered care, relaxed family visitation, rounds centered around family,

family presence during invasive procedures and resuscitation, and family meetings positively influenced FS-ICU care.

Conclusion

Family satisfaction is one of the most important ICU outcomes in both patients with acute illness and life-limiting illness. Review of literature shows that families of the patients admitted to ICU value respect, compassion, empathy, communication, involvement in decision-making, pain and symptom relief, avoiding futile medical interventions, and dignified end of life care. These are as important as ICU survival or prolongation of life. It is not uncommon to get lost in the micro-milieu of disease management and forget the basic attributes of holistic person-centered care. The family and caregiver burden in ICU setting is very high, and it is important for all the health care providers to be aware of this and provides augmented support to families and caregivers of ICU patients. None of the studies analyzed in the systematic review or the descriptive studies included

Table 1: Description of individual studies included in the literature review

Author	Type of study	Description	Positive factors	Negative factors
Hinkle *et al*. 2015	Systematic review	Total of 23 studies 7 intervention-based studies (3 RCTs and 4 non-RCTs) 16 descriptive studies	Courtesy, compassion, respect, good communication, empathic statements, active listening, respecting patient wishes, Family involvement in decision-making, shared decision-making, support family receive during discussions and decision-making to forego life-sustaining interventions, staggered withdrawal of life support, management of pain, assurance of nonabandonment family-centered care palliative care intervention, providing written information on what to expect during cessation of life-sustaining interventions and	Poorly controlled symptoms, poor communication skills, incomplete information, short family meetings, conflict during family meetings, increased length of ICU stay resuscitation at end of life
Wall *et al*. 2007	Survey of 539 families in Seattle, the USA	Retrospective survey of families of ICU survivors versus nonsurvivors	Inclusion in decision-making, good communication, emotional support, respect, compassion, consideration of family needs	
Finlay *et al*. 2008	Survey of 262 families in Veteran Affairs Hospital, the USA	Retrospective survey of the families of elderly deceased cancer patients admitted to ICU	Palliative care consultation, discussion of 'do not resuscitate' orders	ICU death, mechanical ventilation on day of death
Heyland *et al*. 2015	Canadian prospective study involving 535 families	Family survey regarding admitting very elderly patients to ICU	Comfort, symptom control, and less suffering	Poor communication, no involvement in decision-making, and prolonged use of life-sustaining treatment
Gerritsen *et al*. 2013	Survey of 100 families in the Netherlands	Retrospective survey of families admitted to ICU	Pain control, good physician communication, Inclusion of the family in decision-making	
Dalisay-Gallardo *et al*. 2012	Survey of 40 families in the Philippines	Retrospective survey of families admitted to ICU	Care given to patients and family, professional care, communication by the healthcare team	
Rajamani *et al*. 2015	Survey of 25 families in Australia	Retrospective survey of families admitted to ICU		Poor communication skills communication Lack of spiritual support symptom management
Schwarzkopf *et al*. 2013	Survey of 215 families in Germany	Retrospective survey of families of ICU survivors and nonsurvivors	Consistency, clarity and completeness of information, respect, compassion, and emotional support	Poor ICU infrastructure
Stricker *et al*. 2009	Multicenter study, 996 families in Switzerland	Retrospective survey of families of ICU survivors and nonsurvivors	Information providing, involvement in decision-making	Poor communication, poor coordination of care, and lack of emotional support
Damghi *et al*. 2008	Study conducted at Morocco, 194 families	Family satisfaction of ICU care evaluated using Society of Critical Care Medicine's Family Needs Assessment questionnaire	Information provided by the senior clinicians, information provided about diagnosis and prognosis	
Dullenkopf *et al*. 2009	Swiss study that interviewed, 197 families	Survey of families admitted to ICU	Family communication, sharing medical information, and treating the patient as an individual	
Fumis *et al*. 2008	Prospective, Portuguese study involving 164 families	Survey of families admitted to ICU		Insufficient information given by the doctors, accessibility of ICU doctors, and conflict regarding prognosis

Contd...

Table 1: Contd...

Author	Type of study	Description	Positive factors	Negative factors
Kodali *et al*. 2014	Retrospective survey of 457 families in the Netherlands	Survey of families admitted to ICU	Family meetings and participation in family meeting	
Hartog *et al*. 2015	Prospective, observational study-610 patients	Survey of families admitted to ICU with severe sepsis	Decision-making, communication, and coordination of care	
Sinuff *et al*. 2009	Retrospective study-27 families	Survey of families admitted to ICU needing mechanical ventilation	Respect and meaningful explanation about life support	
Sundararajan *et al*. 2012	Retrospective survey of 108 families in Australia	Survey of families admitted to ICU	Meeting with social worker and regular medical meetings	
Venkataraman *et al*. 2015	Prospective study involving 200 consecutive families in India	Questionnaire-based survey	Family communication, involvement of family counselors, and family meetings	Restrictive ICU visitation policy
Dowling *et al*. 2005	Study conducted by Chest foundation-American College of Chest Physicians	Intervention-based study pre- and post- Critical Care Family Assistance Program	Family communication, quality of ICU care, flexibility of visiting hours, safe hospital environment, and alleviation of family stress/ anxiety	
Fridh *et al*. 2009	Qualitative study-17 close relatives of 15 deceased patients	Qualitative, interview-based study and analyzed using phenomenology method		Unfamiliar technology, distressing information, waiting characterized by uncertainty, not being invited to enter into a caring relationship, not being allowed access to the dying loved one, and not being assisted in interpreting information
McKiernan *et al*. 2010	Qualitative study-6 families	Qualitative, interview-based study and analyzed using phenomenology method	Honest information about patient's progress, caring reassurance, family support, and family being able to make sense of the situation	
Wong *et al*. 2015	Qualitative study-11 families	Qualitative, interview-based study using grounded approach	Information providing, interpersonal skills, family communication, and support	
Meert *et al*. 2013	Family-centered care in PICU at Children's Hospital Minnesota, the USA	Survey of parents	Family visitation, rounds centered around family, family presence during invasive procedures and resuscitation, and family meetings	
Latour *et al*. 2005	Systematic review	12 original studies on family satisfaction in PICU critically appraised	Family-centered care	

PICU: Pediatric Intensive Care Unit; ICU: Intensive Care Unit; RCTs: Randomized controlled trials

in the literature search showed ICU survival as a factor that influenced family satisfaction [Table 1].

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Conflicts of interest

There are no conflicts of interest.

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