End of Life Care: Communication Challenges in Intensive Care Unit

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Abstract: ***Communication is a crucial point in end of life (EOL), and it is important to recognize and handle the difficulties of EOL communication. The objective of this review was to summarize current research and recommendations for Intensive Care Unit (ICU) EOL communication and to explore end of life communication challenges encountered within the ICU and to identify the strategies in overcoming these challenges. A comprehensive literature search was conducted to retrieve all relevant articles published. Databases like ProQuest, PubMed, Medline and Science Direct were systematically searched to identify the research and papers related specifically to challenges encountered in ICU during end of life care and the strategies to overcome those challenges by nurses. The articles that are published in English with end of life communication as a major theme, reporting studies with critically ill patient in the ICU settings and papers published after 2010 were included. The articles published in languages other than English with end of life communication as a secondary theme, reporting studies of general patients in acute, hospice or home setting and the papers published prior to 2010 were excluded. From 47 papers read in full, 17 were eligible in inclusion. Major end of life communication challenges in the ICU occurs due to lack of advance directives, disagreement of families over treatment options, absence of team and family meetings and lack of communication skills of critical care team. Effective end of life communication involves adequate training, good communication between the ICU team and the family and interdisciplinary collaboration. The findings of this review suggests that there is strong need to strengthen the end-of -life communication in ICUs in order to provide quality care which eventually leads to quicker palliative care transfers for patients who do not survive, as well as satisfaction of the family and critical team.***

Keywords: End of Life Communication; Critical Care; Communication Barriers; Health Communication; Interdisciplinary Communication

1. Introduction

The overall process of end of life (EOL) communication is often emotionally challenging and complex in Intensive Care Unit(ICU) [1]. ICU is defined as a setting where death is common, end-of-life decisions are often made and end-of-life care is provided [2]. Critical care is very complex with health care team members working from various disciplines, all working under pressure towards the same objective: taking care of the families while healing critically ill patients. Uncertainty about disease condition is constant in relation to the results, affects decision making, increased stress to patient, families, and clinicians. Communication is challenging in the intensive care unit due to various fundamental aspects of critical care such as complexity, acuity, uncertainty, and ethical challenges[3].

End-of - life communication and decision-making process in ICUs is complicated by the fact that ICU admissions are often unexpected, and many family members and patients lack defined reciprocal relationship with ICU clinicians [4]. Many patients in the ICU require withdrawal of active treatment and commencement of end of life care. High stake ICU decision often involve life or death and due to which the situations may be further complicated by a dynamic in which many deaths in the ICU occur after a choice to withdraw life sustaining treatment [5]. Since only few ICU patients at risk of death can express their life-sustaining needs or desires or make decisions about end-of - life care, palliative therapies frequently include physicians and family members [4].The burden of decision-making is usually placed on families because patients admitted in ICU are unable to participate in this level of decision-making [3]. The ICU team including the doctors and nurses find difficult to deal with end of life discussions because they are not comfortable with death, and also uncomfortable with withholding or withdrawing the treatment and most importantly they lack communication skills[4]. Given all these elements it can be clearly understood, how challenging ICU communication can be [6].

The aim of this review is to give an overview of challenges and strategies that have been addressed in recent research about end of life communication.

2. Methodology

The review aimed at combining review papers and both quantitative and qualitative research papers. A comprehensive literature search was conducted to retrieve all relevant articles published in the English language. Databases were systematically searched to identify the research and papers related specifically to challenges encountered in ICU during end of life care and the strategies to overcome those challenges by nurses. The following healthcare and social sciences databases were searched: ProQuest, PubMed, Medline and Science Direct.

Strict Inclusion and exclusion criteria were adopted. From 47 papers read in full, 17 were eligible in inclusion. The inclusion criteria were the articles published in English with end of life communication as a major theme, reporting studies of critically ill patient in the ICU setting and the papers published after 2010. The exclusion criteria were the

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articles published in languages other than English with end of life communication as a secondary theme, reporting studies of general patients in acute, hospice or home setting and the papers published prior to 2010.

Key words and synonyms end of life communication, challenges, strategies, ICU were formulated and entered in relevant search engines such as ProQuest, PubMed, Medline and Science Direct.

3. Development

The two bodies of relevant literature that emerged during this review include: (i) the end of life communication challenges in the ICU (ii) the strategies to overcome each challenge. The review highlights communication challenges in the end of life care in ICU and their strategies adopted to overcome those challenges.

3.1 End of Life Communication Challenges in the ICU

End-of-life decisions “include decisions about withholding or withdrawing potentially life-prolonging treatment and about alleviation of pain or other symptoms with a possible life-shortening effect”[7]. End of life communication process is often emotionally challenging and difficult in ICU [1]. Moreover, EOL communication and decision-making in ICUs is complicated by the fact that ICU admissions are usually unpredictable for patients and family members, and many family members and patients have no prior established relationship with ICU team including doctors and nurses. While good communication between physicians, patients and family members is recognized as the most significant end-of - life care factor in ICUs, it is the least accomplished. Empirical evidences suggest that integration with end-of - life choices in ICUs is often complicated and flawed as well as this ineffective communication leaves clinicians and family members overwhelmed and disappointed whereas the needs of patients are also ignored [4]. Major end of life communication challenges identified in this review are critically ill patients lack of capacity, disagreement of family over treatment options, inconsistent information, lack of communication skills and training of ICU team.

Patients are admitted to ICU when they are critically ill, and the physical environment of the ICU has been identified as a factor affecting nurse–patient communication. Nurse patient communication has always been a challenging issue in ICU as patients admitted to ICU are restricted by intubation, sedation and critical illness preventing verbal and non-verbal exchange [8]. In addition to this, 90 % of patients admitted to ICUs do not have advance directive while only few ICU patients are able to engage in end-of - life decision-making [4]. Communication difficulties may lead to unanswered questions about patients’ desires regarding their end of life care[9]. In a recent Canadian study,physicians, residents and nurses mentioned that one of the top barriers was patients lack of capacity in relation to goals of care discussions [10].

End of Life decisions place great demand and responsibility on families and ICU staff and are often made without the patient’s input, due to their life-threatening condition. This may place significant emotional burden on the family, as well as health team members involved in order to make a critical decision on the patient’s behalf, at a time of extreme stress [1]. A study by Grant, (2015) mentioned that decisions around treatment, especially at the EOL, are a major source of communication challenges between the team and the family in the ICU. The author also found that the principal EOL conflicts occur when families insist on treatment that the team considers inappropriate or when families disagree with the treatment the team recommends. Decisions of life and death escalate moral and ethical issues whereas the health care team members and families may not come to a common understanding. Due to varying religion, race, culture, and geography of families can arise to serious discussions with the critical care team. In the same study, author also found that the main perceived EOL conflicts involved lack of psychological support, absence of team meetings, and problems with the decision-making process. The author underlines that distress and anxiety for families in intensive care may occur because of poor communication or inconsistent information. The critical care team’s use of medical jargon or lack of communication training are also factors affecting communication. Levin, Moreno, Silvester, and Kissane, (2010) adds to this subject that shared decision making can be more challenging within the ICU setting where families do not have a preexisting relationship with critical care team members.

Doctors are said to have a key or leading role, which includes arranging correspondence with families, communicating prognosis and finding consensus on resuscitation decisions [12]. Levin et al., (2010) points that difficulty in communication could arise due to the physician’s unconscious reaction to EOL communication. The physician could be totally unaware of these subtle emotional undertones, whereas they might be quite apparent to others. Moreover, it is also mentioned that the doctors do not value the opinions of the nurses in decisions about end of life unless they are considered skilled and experienced in caring for end of life ICU patients. The extent of participation of nurses in end-of - life communication was also based on the particular physician who leads the conversation [12]. According to Grant,(2015) nurse-physician/team conflict about EOL issues and goals of care are among the leading causes of ICU nurse moral distress which subsequently affects team cohesion and morale. Evidence are suggestive that many doctors and nurses have difficulty initiating the end of life discussions which might result due to lack communication skills which is a crucial factor in achieving successful end-of - life outcomes [4].

3.2 Strategies to improve end of life communication

The aim of communication and decision-making in the EOL is to have a common understanding of the values and preferences of an individual, leading to a care plan compatible with those beliefs and preferences. Improvements in end of life communication and decision-making have been described as a high concern from the patient and family point of view [13]. The major strategies to improve EOL communication identified in this review are surrogate and shared decision making, team engagement in the process of decision making, education and training for ICU team, interdisciplinary family meetings.

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In ICU, the patient's goals should be the emphasis of all care, and when the patient is incapable to direct that care, the appropriate surrogate should deliver the goals in the patient's place [3]. When decisions about continuing treatment are made, patients should be involved in the decision-making process which is not usually possible in the ICU since patients are critically ill and for this reason such decisions are usually made collaboratively by physicians, nurses and the patient's family (Briggs, 2017Akroute & Bondas, 2016). The ethical principle to be followed in ICU is making decisions in the patient's best interests, which is best determined by considering the patient's condition, prognosis, the benefits/burdens of treatment options and the patient's previous views. It is also essential to make decisions based on knowing what the patient might have wanted is preferable to decide based on the perceived best interests of that person. The author argues that, the most common way this is done is through substituted judgment which is used when a patient is debilitated and has not left written EOL advance directives to guide treatment and the surrogate decision-maker is supposed to make medical decisions as if they were in the patient's place[11].

Critical care involves teamwork so, the team should communicate properly. Many factors improve communication within the critical care team. Preferably, ICU clinicians should practice in such environment that helps to promotes respect, professionalism, and civility [3]. Experienced doctors working in the critical care settings must include nurses in the process of decision-making to avoid extending the patient's lives past the point of futility. These types of engagements in the process of decision-making helps to increase the nurses' value and significantly decrease conflicts and communication problems, streamlining the decision making process at the end of life [1].

Levin et al., (2010), mentions that all the critical care members must have education and training about cultural competence to be sensitive to various perspectives with their co-workers, patients, and families. Additional area of training must include communication education particularly about difficult conversations because many critical care members may not have ever received such training. Basic palliative care concepts education should be provided to critical care staffs such as symptom and pain management, cultural and spiritual assessment, family conferences and EOL care. Good and effective therapeutic communication skills are very important clinical competencies. Every health care member should be adequately trained on how to effectively and profoundly communicate with their colleagues, the patients, and families or care givers [16].

Communication with family begins as soon as the critically ill patient is admitted to the ICU for which the nurse or physician should arrange the family meetings in order to introduce the team, review the patient's goals, stated advance directives and update about the ICU plan. Whenever the patient's medical status changes or key decisions need to be made, formal interdisciplinary family meeting should be organized by ICU team members, to review patient's medical status andprognosis and to discuss appropriate treatment options given the patients goals/wishes [3].

Another strategy is to determine the balance between clinical realism and family hopefulness is to propose a time-limited, empirical trial of treatment, with a decision that, if there is no improvement in clinical parameters, treatment goals shall be reviewed with an opinion to withdrawing futile life-extending treatments. Shared decision-making also updates ICU EOL communication and has resulted with a higher family satisfaction with communication [11]. For effective end of life communication with family, ICU team members should use nontechnical terms and language that families can understand (Wong, Liamputtong, Koch, & Rawson, 2015).

4. Conclusion

EOL communication among clinicians, families and ICU patients is complicated and inconsistent, leaving physicians and family members frustrated and depressed, as well as this patient's wishes are ignored. This article has highlighted the various challenges identified in the ICU and the strategies to overcome those challenges. Existing evidence indicates that the main challenges encountered with respect to end of life communication ICU is due to lack of advance directives, disagreement of families over treatment, absence of team and family conferences and poor communication skills and training of critical care team. The recent articles in end of life communication underlines that providing appropriate and high-quality critical care needs training and focus within the interdisciplinary team on ethical decision-making, communication and teamwork, constructive interaction with patients and families, and recognition and resolution of conflict within the team and with patients and families. Furthermore, evidences also indicate that enhancing end-of -life communication in ICUs will augment the quality of care by contributing to faster transition to palliative care for patients who eventually do not recover, and through family and critical care team satisfaction.

References

[1] L. Flannery, L. M. Ramjan, and K. Peters, "End-of-life decisions in the Intensive Care Unit (ICU) - Exploring the experiences of ICU nurses and doctors - A critical literature review," *Aust. Crit. Care*, vol. 29, no. 2, pp. 97–103, 2016, doi: 10.1016/j.aucc.2015.07.004.

[2] E. V Ball, "USING SELF-EFFICACY AND TRANSFORMATIVE LEARNING THEORIES TO EXAMINE INTERPROFESSIONAL COLLABORATIVE PRACTICE AT END OF LIFE IN THE ICU BETWEEN NURSES AND PHYSICIANS by A dissertation submitted to the Faculty of the Graduate School of the University at Buf," 2016

[3] M. Grant, "Resolving communication challenges in the intensive care unit," *AACN Adv. Crit. Care*, vol. 26, no. 2, pp. 123–130, 2015, doi: 10.1097/NCI.0000000000000076.

[4] D. K. Boyle and P. A. Miller, "Communication and End-of-Life Care in the Intensive Care Unit," vol. 28, no. 4, pp. 302–316, 2005.

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[5] A. M. N. Adams, T. Mannix, and A. Harrington, "Nurses' communication with families in the intensive care unit – a literature review," *Nurs. Crit. Care*, vol. 22, no. 2, pp. 70–80, 2017, doi: 10.1111/nicc.12141.

[6] J. R. Curtis and J. L. Vincent, "Ethics and end-of-life care for adults in the intensive care unit," *Lancet*, vol. 376, no. 9749, pp. 1347–1353, 2010, doi: 10.1016/S0140-6736(10)60143-2.

[7] R. Löfmark *et al.*, "Physicians' experiences with end-of-life decision-making: Survey in 6 European countries and Australia," *BMC Med.*, vol. 6, pp. 1–8, 2008, doi: 10.1186/1741-7015-6-4.

[8] K. Dithole, S. Sibanda, M. M. Moleki, and G. Thupayagale-Tshweneagae, "Exploring Communication Challenges Between Nurses and Mechanically Ventilated Patients in the Intensive Care Unit: A Structured Review," *Worldviews Evidence-Based Nurs.*, vol. 13, no. 3, pp. 197–206, 2016, doi: 10.1111/wvn.12146.

[9] E. Ivany and L. Aitken, "Challenges and facilitators in providing effective end of life care in intensive care units," *Nurs. Stand.*, vol. 34, no. 6, pp. 44–50, 2019, doi: 10.7748/ns.2019.e11248.

[10] J. J. You *et al.*, "Barriers to goals of care discussions with seriously ill hospitalized patients and their families: A multicenter survey of clinicians," *JAMA Intern. Med.*, vol. 175, no. 4, pp. 549–556, 2015, doi: 10.1001/jamainternmed.2014.7732.

[11] T. T. Levin, B. Moreno, W. Silvester, and D. W. Kissane, "End-of-life communication in the intensive care unit," *Gen. Hosp. Psychiatry*, vol. 32, no. 4, pp. 433–442, 2010, doi: 10.1016/j.genhosppsych.2010.04.007.

[12] L. A. Brooks, M. J. Bloomer, and E. Manias, "Culturally sensitive communication at the end-of-life in the intensive care unit: A systematic review," *Aust. Crit. Care*, vol. 32, no. 6, pp. 516–523, 2019, doi: 10.1016/j.aucc.2018.07.003.

[13] T. Sinuff *et al.*, "Improving End-of-Life Communication and Decision Making : The Development of a Conceptual Framework and Quality Indicators," *J. Pain Symptom Manage.*, vol. 49, no. 6, pp. 1070–1080, 2015, doi: 10.1016/j.jpainsymman.2014.12.007.

[14] D. Briggs, "Improving communication with families in the intensive care unit," *Nurs. Stand.*, vol. 32, no. 2, pp. 41–48, 2017, doi: 10.7748/ns.2017.e10812.

[15] A. R. Akroute and T. Bondas, "Critical care nurses and relatives of elderly patients in intensive care unit - Ambivalent interaction," *Intensive Crit. Care Nurs.*, vol. 34, pp. 67–80, 2016, doi: 10.1016/j.iccn.2015.08.002.

[16] F. O. Oyebola, "Communication Issues in End-of-Life Care - An African Setting Experience," *J. Healthc. Commun.*, vol. 03, no. 02, pp. 1–5, 2018, doi: 10.4172/2472-1654.100130.

[17] P. Wong, P. Liamputtong, S. Koch, and H. Rawson, "Families' experiences of their interactions with staff in an Australian intensive care unit (ICU): A qualitative study," *Intensive Crit. Care Nurs.*, vol. 31, no. 1, pp. 51–63, 2015, doi: 10.1016/j.iccn.2014.06.005.

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