Australian Journal of Advanced Nursing 39(1) • 2020.391.214

RESEARCH ARTICLES

Intensive care nurses' perceptions on barriers impeding the provision of end of life care in the intensive care setting: a quantitative analysis

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ABSTRACT

Background: Intensive care nurses look after the most critically ill patient population with the highest mortality rate on a daily basis. Whilst research to date has highlighted and provided some insights into the current provision of end of life care, further research is much needed to improve the efficacy of nurses existing practice.

Objective: To investigate the specific barriers and contextual characteristics that nurses experience within the Intensive Care Unit environment.

Study Methods: The National Questionnaire of Critical Care Nurses Regarding End of Life Care was used to collect quantitative and qualitative data to answer the research questions. This study was conducted in a major intensive care unit located in a tertiary public hospital in metropolitan Western Australia.

Results: The respondent rate was 67.31%. Obstacles with the highest perceived intensity score (PIS) reported by participants involved issues around the communication and practice of end of life care including family interaction. The ranges of mean scores for supportive behaviours were much higher than the ranges for obstacles. These supportive behaviours included allowing family members to have adequate time alone with the patient after death, and families being taught how to engage with the dying patient.

Conclusion: The findings reflect that the most intense and frequently occurring obstacles are consistent with past research. A perceived negative end of life care experience by the nurse was found to negatively impact the nurse's psychological and physiological health. The research demonstrates the need for a stronger multidisciplinary patient centred approach. It is envisaged that the findings will support the review and development of appropriate guidelines to support nurses caring for intensive care patients in the initial and progressive phases of end of life care.

What is already known about this topic?

- ICU patients have the highest incidence of mortality in the acute care setting with one in four patients dying in an ICU, accounting for 15% of all hospital deaths annually.
- This patient population presents nurses with a set of unique, yet significant challenges related to increased rate of mortality.

https://doi.org/10.37464/2020.391.214

- There is a significant amount of existing literature that has explored moral distress amongst nurses, particularly in relation to end of life care.

What this paper adds:

- This research suggests that there continues to be obstacles that impede critical care nurse's ability to facilitate EOLC in the ICU setting.
- The participants of this study highlighted the need for stronger emphasis being placed on decision making processes, communication, and standardised practice.
- The most supportive behaviours reported were associated with practice that could be initiated by the nurse such as, allowing family members adequate time with their loved one pre and post death, and teaching family members how to act and engage with their loved ones during this time.

Keywords: Barriers; obstacles; intensive care nurse; end of life care; supportive behaviours; intensive care unit; The National Questionnaire of Critical Care Nurses Regarding End of Life Care

1. BACKGROUND

The cohort of patients admitted to Australian intensive care units (ICU) are a critically ill and vulnerable patient population in the acute care setting. Due to the advancement in medicine and technology, ICUs have the capacity to treat patients who would have previously not been expected to survive.[1] The ICU setting is unique, in most cases the patients have been admitted in emergency circumstances with a life-threatening condition, where the primary goal is to save the patient's life,[2] and where there is often a smaller time frame for the physicians to deliberate on the patient's trajectory. This adds to the difficulty of the End of Life Care (EOLC) decision making process. The Australian Institute of Health and Welfare (AIHW) reported that between 2014 to 2015, 63% (n=39,543) of patients admitted into a public hospital had received acute care prior to their death in hospital.[4] Of those, patients aged 65 years and over accounted for nearly two thirds (63% n=6,148) of deaths in hospital that involved a stay in an ICU.[4] ICU patients have the highest incidence of mortality in the acute care setting with one in four patients dying in an ICU, which accounts for 15% of all acute care deaths annually.[4,5] This aligns with the 2014 Australian and New Zealand Intensive Care Society (ANZICS) report, that found of all intensive care admissions, approximately 10% (n=12,000) die annually in ICU.[6] The AIHW reported the number of deaths occurring in the hospital settings increased by almost 8% (n=5,409) comparatively, between the years of 2005 and 2014.[4]

EOLC in the ICU setting has significant considerations. These include the medical decision to limit treatments that are or could be provided that may not be beneficial to the patient's quality of life, and may directly contribute to worsening patient outcomes.[7] The decision to limit medical intervention, would result in the patient dying from their underlying disease process, however, the withdrawing or withholding of treatment may not be the direct cause of the patient's death.[8] According to Latour et al.,[2] EOLC in the ICU is defined as the care and support services provided to the patient and his/her family after the decision has been made to withdraw or withhold treatments. For the purpose of this research, the researcher used the definition of EOLC by Latour et al.[2]

Research indicates that ICU nurses have a higher exposure rate to dying patients than nurses practicing in other specialty areas of the hospital.[4,5,9,10] EOLC is therefore an inherited part of intensive care nursing practice. However, 60% of nurses at any one-time associate death and EOLC practice with a perceived sense of failure and abandonment.[11,12] While physicians are burdened with the responsibility of making the decision, nurses regularly implement it and must live with the decisions made by somebody else. The nurses' position in the hierarchy of the healthcare system can render them unable to influence EOLC decision making, despite their explicit knowledge and involvement with patients and families.[13,14,15] Furthermore, nurses can often feel their voice is disregarded and this is reported to be a key source of moral distress with 25% of ICU nurses feeling psychologically burnt out at any one time.[12,14] One study found nurses had internal turmoil and expressed feelings of compassion fatigue and burnout, believing they did not provide their patient with a good death.[16] EOLC is emerging as a significant speciality in the ICU setting, which should have the same level of knowledge and competence as other specialities yet remains one of the most poorly understood specialties in ICU at present.[17]

This study investigated the specific barriers and contextual characteristics that nurses experience within the ICU environment concerning a patient's EOLC. A descriptive survey research design was considered appropriate to understand the nurse's perceptions of the specific care of their patients following the decision to withdraw or withhold treatment.

2. STUDY METHOD

This study explores the experiences of ICU nurses caring for patients following the decision to withdraw or withhold treatment. The study was conducted in a level three tertiary ICU setting which has 23 funded beds and provides comprehensive critical care to cardiothoracic, neurology, surgical, and general medical patients. The convenience sample was employed permanent ICU registered nurses (n=175) who had cared for patients in the acute end of life phase. Nurses with less than one year of experience in the ICU, on leave, or who had not been exposed to caring for at least one patient in the end of life phase in ICU were excluded from the study.

The National Questionnaire of Critical Care Nurses Regarding End of Life Care developed and created by Kirchoff and Beckstrand,[9] was deemed the most appropriate tool to meet the intentions of this study. This tool has a Cronbach α score of 0.89 which indicates a highly reliable tool.[9] This validated tool has been used in several international studies.[9,18,19] The National Questionnaire of Critical Care Nurses Regarding End of Life Care was used with permission granted from the authors with one additional obstacle question added to the existing validated tool.[9] The additional question on standardised practice was considered to be relevant, and related to the Western Australian (WA), State-Wide Framework for the Provision of Comprehensive, Coordinated Care at End of Life which had been developed along with the WA End of Life and Palliative Care Strategy 2018-2028.[20] The questionnaire provided the researcher with a statistical trend on the attitudes and beliefs of the nursing population in the ICU about EOLC. The questions used a Likert scale where participants rated the intensity of the listed obstacles from 0= not an obstacle to 5= extremely large obstacle, the intensity of the listed supportive behaviours from 0= not a help to 5= an extremely large help. The frequency of occurrence for both the obstacles and supportive behaviours where 0= never occurs to 5= always occurs. Information on the release dates and the purpose of the questionnaire was provided to ICU nurses through posters in the ICU environment. Verbal and written information was provided to participants prior to the study commencing. This study used the informed consent approach, where returning the anonymous questionnaire was considered consent. The data collection period went for one month in which hard copy questionnaires were placed in individual nurses' mailboxes in the ICU and completed questionnaires collected in a secure box situated in a secure central location in the ICU.

Participant's questionnaires were analysed using IBM SPSS version 25.0. P-values <0.05 were considered statistically significant. The accuracy of data entry was checked by two independent researchers for all the returned questionnaires. The researcher determined which obstacles and supportive behaviours were perceived as both being the most intense and the most frequently occurring. Descriptive summaries of demographic data consisted of frequency distributions (n= %) for categorical data and mean and standard deviations or median, interquartile range and range for continuous data, depending on normality. Grouped comparisons of the outcome data between categorical variables seen in Table 1 was conducted using the Chi-square test. The Chi-square test was used to determine whether there was an association between categorical variables. There were no identified associations between variables. The questionnaire outcome data (size and frequency of obstacles and supportive behaviours) were summarised using frequency distributions per category in the Likert scales. Frequencies, measures of central tendency and dispersion and reliability statics were calculated for all obstacle and supportive behaviour items.

A perceived intensity score (PIS) was then determined by calculating mean average of the intensity and frequency of the obstacle. The Perceived Supportive Behaviour Score (PSBS) was calculated by the mean average of the intensity and frequency of the supportive behaviour. The PIS and the PSBS scores were considered by the researchers to be the most important and sensitive indicator and finding to be examined when looking at this research topic results.

Ethical approval and permission to conduct the study was obtained from the Western Australia Department of Health Research Governance Service (SCGOPHCG RGS0000003227) and the University Human Research Ethics Committee (019053F).

3. RESULTS

Of the 175 potential respondents, n=15 (8.57%) were ineligible due to not being present in the unit to receive their internal mail due to sick leave, maternity leave, long service leave, change of position or annual leave. A further n=4 (2.29%) nurses were excluded from the results as they did not meet the inclusion criteria. The usable response rate was 67% (n=105) from the eligible sample pool of ICU nurses (n=156). The variables, as described in Table 1, show that most participants surveyed were female (89%), of the participants surveyed (78%) held a post graduate qualification, with more than two thirds (68%) of participants having worked as a nurse in an intensive care setting for over 10 years.

On further analysis nearly half of the 105 participants (43%) reported having received no education on EOLC care during their time as ICU nurses. Furthermore, only 19 participants (18%) reported having the opportunity to receive over 10 hours of education on EOLC care in ICU. Over 45% of participants reported having cared for a patient requiring EOLC and subsequently dying on their shift within the last one to six months prior to this survey being conducted. A further 20% of participants having cared for a patient in the last week to one month and 10% having cared for a patient receiving EOLC in the last week or less before the survey was conducted. As over 75% of participants had provided EOLC in the last six months, and over one third of participants (39%) reported having cared for over 20 patients during the EOLC phase in the ICU setting it was hoped that the recency in practice and exposure would render the findings and data to be more meaningful and richer in quality. The completed demographic information is reported in Table 1.

TABLE 1: DEMOGRAPHIC DATA OF PARTICIPANTS

Demographic Information	N (%)
Gender n=105	
Female	93 (88.6)
Male	12 (11.4)
Years of ICU Experience	
<10	33 (31.4)
10-15	38 (36.2)
>15	34 (32.4)
Highest Degree	
Diploma/Bachelor of Nursing	22 (21.0)
Postgraduate Qualifications (Postgraduate Certificate, Diploma or Master)	82 (78.1)
Hours of EOLC education	
Nil	45 (42.9)
<10	39 (37.1)
>10	19 (18.1)
Recency of the provision of EOLC and patient death on shift	
<=1 week	11 (10.5)
1 week to 1 month	21 (20.0)
1 to 6 months	47 (44.8)
6-12 months	12 (11.4)
> 1 year	14 (13.3)

3.1 OBSTACLES

Perceived Intensity Score

To determine which obstacles the participants reported as being the most significant both in intensity and frequency, the PIS score was deemed to be a sensitive indicator when it came to understanding the perceptions of the participants. PIS scores ranged from 0.75 to 12.75 (Table 2). The obstacle item receiving the highest score was having multiple physicians involved with one patient, who differ in opinion about the direction care should go (12.75). The second and third highest PIS scores reported were the lack of standardised practice in how to manage dying patients in ICU (12.08) and families not accepting the poor patient prognosis (11.85).

Of the remaining top 10 high scoring PIS obstacles, issues around interpersonal communication and current practice surrounding EOLC in ICU were recognised by participants. These included: Having family and friends who continually call the nurse for updates rather than designated contact person (11.81), the nurse's inability to communicate with the patient to learn of his/her wishes regarding treatment due to sedation or depressed neurological status (11.21), a poorly designed unit which does not allow for privacy for the dying patient and grieving family (11.20), the family not understanding the term 'lifesaving measures' and its implications (10.66) and, physicians who would not allow the patient die from the disease process (10.40).

The lowest scoring PIS obstacles identified were in relation to ICU visiting hours protocols and the funding and management of ICU patients care for organisational financial benefit. With family visiting hours that are too restrictive (0.75) being the lowest reported PIS obstacle and continuing to provide advance treatments to dying patients because of financial benefits to the hospital (1.17) identified as the second lowest PIS obstacle. The completed break down of each obstacle item surveyed, along with each item ranking for intensity, frequency, and PIS has been reported in Table 2.

3.2 SUPPORTIVE BEHAVIOURS

Perceived Supportive Behaviour Score

To determine which supportive behaviours the participants reported as being the most supportive and the most frequently occurring, the PSBS was deemed to be a sensitive indicator when it came to understanding the perceptions of the participants. PSBS scores ranged from 4.09 to 15.90 (Table 3). The top three items which received the highest PSBS scores were allowing family members to have adequate time to be alone with the patient after he or she has died (15.90), family members having a peaceful dignified bedside scene (14.33) and having family members accept that the patient is dying (14.32).

The subsequent highest scoring behaviours were related to the nurse-family interactions, family members being taught how to act around the dying patient (13.57), family members showing gratitude to nurse for care provided to patient who has died (12.77) and having physicians involved agree about the direction of care (12.53).

The lowest PSBS included letting the social worker/religious leader taking primary care of the grieving family (4.09), talking with the patient about his/her feelings and thoughts about dying (4.66), and nurses scheduled so that the patient receives continuity of care (4.93). The completed break down of each supportive behaviour item surveyed along with each item ranking for intensity, frequency and PSBS has been reported in Table 3.

TABLE 2: OBSTACLES INTENSITY, FREQUENCY AND PIS IN THE PROVISION OF END OF LIFE CARE

Obstacles	Intensity*		Frequency+		PIS‡
	Mean	Rank	Mean	Rank	
Multiple physicians, involved with one patient, who differ in opinion about the direction care should go.	4.21	1	3.03	5	12.75
There is a lack of standardised practice in how to manage dying patient in ICU.	3.70	7	3.26	2	12.08
Families not accepting what the physician is telling them about the patient's poor prognosis.	3.99	2	2.97	7	11.85
Family and friends who continually call the nurse wanting an update on the patient's condition rather than calling the designated family member for information.	3.72	6	3.17	3	11.81
The nurse not knowing the patient's wishes regarding continuing with treatments and tests because of the inability to communicate due to a depressed neurological status or due to pharmacologic sedation.	3.55	11	3.16	4	11.21
Poor design of units which do not allow for privacy of dying patients or grieving family members.	3.73	5	3.00	6	11.20
Family members not understanding what "life-saving measures" really means, i.e., multiple needle sticks causing pain and bruising, ribs may be broken during chest compressions.	3.60	10	2.96	8	10.66
Physicians who won't allow the patient to die from the disease process.	3.85	3	2.70	10	10.40
Not enough time to provide quality end of life care because the nurse is consumed with activities that are trying to save the patient's life.	3.42	14	2.64	11	9.02
The nurse having to deal with angry family members.	3.61	9	2.43	12	8.76
The nurse having to deal with distraught family members while still providing care for the patient.	3.01	20	2.86	9	8.62
Intra-family fighting about whether to continue or stop life support.	3.65	8	2.27	16	8.28
Continuing treatments for a dying patient even though the treatments cause the patient pain or discomfort.	3.51	12	2.26	17	7.96
When the nurses' opinion about the direction patient care should go is not requested, not valued, or not considered.	3.33	15	2.37	14	7.91
Employing life sustaining measures at the families' request even though the patient had signed advanced directives requesting no such treatment.	3.80	4	2.04	19	7.74
Lack of nursing education and training regarding family grieving and quality end of life care.	3.19	17	2.40	13	7.64
Physicians who are overly optimistic to the family about the patient surviving.	3.14	18	2.28	15	7.16
The nurse knowing about the patient's poor prognosis before family is told the prognosis.	1.99	27	3.49	1	6.94
Physicians who are evasive and avoid having conversations with family members.	3.48	13	1.99	20	6.93
Being called away from the patient and family because of the need to help with a new admit or to help another nurse care for his/her patient.	2.66	24	2.15	18	5.71
Continuing intensive care for a patient with a poor prognosis because of the real or imagined threat of future legal action by the patient's family.	3.29	16	1.68	24	5.53
The family, for whatever reason, is not with the patient when he or she is dying.	2.68	23	1.94	22	5.21
The unavailability of an ethics board or committee to review difficult patient cases.	3.07	19	1.67	25	5.12
Dealing with the cultural differences that families employ in grieving for their dying family member	2.57	26	1.97	21	5.07
The patient having pain that is difficult to control or alleviate.	2.96	21	1.60	26	4.73
No available support person for the family such as a social worker or religious leader.	2.63	25	1.79	23	4.72
Pressure to limit family grieving after the patient's death to accommodate a new admission to that room.	2.69	22	1.42	27	3.82
Unit visiting hours that are too liberal.	1.38	29	1.24	28	1.72
Continuing to provide advance treatments to dying patients because of financial benefits to the hospital.	1.97	28	0.59	30	1.17
Unit visiting hours that are too restrictive.	0.99	30	0.76	29	0.75

* Ranging from 0, not an obstacle to 5, extremely large obstacle.

+ Ranging from 0, never occurs, to 5, always occurs.

‡ Perceived Intensity Score (mean for intensity multiplied by mean frequency)

TABLE 3: SUPPORTIVE BEHAVIOURS INTENSITY, FREQUENCY AND PSBS IN THE PROVISION OF END OF LIFE CARE

	Intensity*		Frequency+		PSBS‡
Supportive	**Mean**	**Rank**	**Mean**	**Rank**	
Allowing family members adequate time to be alone with the patient after he or she has died.	4.27	5	3.73	1	15.90
Providing a peaceful, dignified bedside scene for family members once the patient has died.	4.42	3	3.24	3	14.33
Having family members accept that the patient is dying.	4.65	1	3.08	6	14.32
Teaching families how to act around the dying patient such as saying to them, "she can still hear… it is ok to talk to her."	3.91	10	3.47	2	13.57
Having family members thankyou or in some other way show appreciation for your care of the patient who has died.	4.09	8	3.13	5	12.77
Having the physicians involved in the patient's care agree about the direction care should go.	4.56	2	2.75	8	12.53
Having enough time to prepare the family for the expected death of the patient.	4.17	7	2.75	8	11.46
Having one family member to be designated contact person for all other family members regarding patient information.	4.40	4	2.59	11	11.40
Having a fellow nurse tell you that "You did all you could for that patient," or some other words of support.	3.64	12	3.08	6	11.22
Allowing family's unlimited access to the dying patient even if it conflicts with nursing care at times.	3.54	13	3.16	4	11.19
Having a fellow nurse put his or her arm around you, hug you, pat you on the back or give some other kind of brief physical support after the death of your patient.	3.37	16	2.72	10	9.16
Having fellow nurses take care of your other patient(s) while you get away from the unit for a few moments after the death of your patient.	3.44	14	2.51	12	8.63
Having a support person outside of the work setting who will listen to you after the death of your patient.	3.40	15	2.47	13	8.41
Having the physician meet in person with the family after the patient's death to offer support and validate that all possible care was done.	4.04	9	1.87	15	7.57
The nurse drawing on his/her own previous experience with the critical illness or death of a family member.	3.10	18	2.34	14	7.25
A unit designed so that the family has a place to go to grieve in private.	4.24	6	1.61	16	6.81
Having the family physically help care for the dying patient.	3.09	20	1.60	17	4.94
Having a unit schedule that allows for continuity of care for the dying patient by the same nurses.	3.34	17	1.48	18	4.93
Talking with the patient about his or her feelings and thoughts about dying.	3.65	11	1.27	20	4.66
Letting the social worker or religious leader take primary care of the grieving family.	3.09	19	1.32	19	4.09

* Ranging from 0, not a help to 5, extremely large help.

\+ Ranging from 0, never occurs, to 5, always occurs.

‡ Perceived Supportive Behaviour Score (mean for intensity multiplied by mean frequency)

4. DISCUSSION

The purpose of this research was to investigate the specific barriers and contextual characteristics that nurses experience within the ICU environment concerning a patient's EOLC. The research applied a descriptive approach to devise a greater understanding of what is most important from the perspective of the primary care givers, the critical care nurses. Several obstacles and supportive behaviours in the facilitation of EOLC practice that were identified in this research were consistent with past research.[9,19,22-26]

The greatest concerns for the nurses in this single site study, as in the original Beckstrand and Kirchoff study, suggests that nurses find difficulty with obstacles that ultimately hinder the quality of care provided to the dying patient as seen in Table 4.[9] The results from this study suggest that there are still concerns surrounding the standard of care and management of ICU patients post withdrawal or withholding of treatment.

TABLE 4: COMPARISON OF DATA TO THE ORIGINAL RESEARCH

Hynes, Coventry & Russell Identified Highest PIS Obstacles	Beckstrand & Kirchoff (2005)
1. Multiple physicians, involved with one patient, who differ in opinion about the direction care should go.	Listed as the third highest identified PIS Obstacle.
2. There is a lack of standardised practice in how to manage dying patient in ICU.	This obstacle was not in the original questionnaire by Beckstrand and Kirchoff.
3. Families not accepting what the physician is telling them about the patient's poor prognosis.	Listed as the sixth highest identified PIS Obstacle.
4. Family and friends who continually call the nurse wanting an update on the patient's condition rather than calling the designated family member for information.	Listed as the highest identified PIS Obstacle.

The highest-ranking obstacle identified in this study was nurses' perceptions that physicians involved in care often had differing opinions about the direction of care. Bloomer et al.,[16] identified that disparities between individual physicians regarding the goals of care and prognosis (curative verses supportive) was reported as being seen to cause the most conflict amongst physicians and nurses.[27] Furthermore, the authors reported that 40% of family members in retrospect perceived conflict had occurred between physicians and nurses.[16] Nurses reported taking a stoic approach, limiting their communications with the families in fear of voicing their moral conflict with treatment, which increases the risk of both the nurses and family feeling isolated.[16] A key compounding factor that causes delay in EOLC discussions is the significant reporting of communication breakdown between physicians and nurses regarding goals of care and rationale of interventions requested.[12] The fast turnover of critical care staff, both nurses and physicians, subsequently results in an increased number of staff caring for a singular patient. This creates several challenges in care of the dying patient as the potential for discontinuity of care and conflicting goals of care among the healthcare professionals is substantially higher.[28,29] The result is families receiving a multitude of differing and inconsistent information and views about the patients' health status, both in a formal and informal setting from numerous healthcare professionals, producing further confusion and creating obstacles for providing positive EOLC experiences.[9] Therefore, increasing the likelihood of both the nurse and family perceiving a negative EOLC. The achievement of cohesion between physicians and nurses is crucial to ensure the family are presented with a transparent plan of care for the patient.

The second most significant obstacle identified was the lack of standardised practice in how to manage dying patients in ICU. It can be noted that the acute hospital setting is intended to provide short term episodic care, where the default practice is to continue to intensely treat and manage the symptoms.[30] Furthermore, the recognition of dying is frequently inadequate, resulting in missed opportunities to consider appropriate referrals to palliative care.[3] In Australia, all states and territories have different approaches to developing and delivering policies, strategies, and programs about different aspects of EOLC.[31] Various aspects of EOLC are funded by different governing bodies across Australia.[31] This results in fragmentation of services with healthcare professionals finding it challenging to navigate the system. Thus adding another level of complexity as there is no overall sole standard of care and practice in Australia. Internationally, Australia's EOLC system is highly ranked.[32] However, it should be noted that Australia's EOLC has less emphasis on holistic practises compared to Europe, Canada, the United Kingdom and New Zealand.[33,34]

In WA, the Palliative Care Network Advisory Committee oversees a range of activities aimed at developing an integrated model of palliative care across the state. The WA state-wide framework for the provision of a coordinated framework for EOLC was developed to recognise the need for a standardised approach to ensure all clinicians received adequate training and support to deliver EOLC.[30] However, there is no detailed strategy on how to manage patients who have had an unexpected catastrophic event leading to a rapid, life-threatening acute deterioration.[21,30] An informal analysis of current EOLC practices within WA hospitals indicates a lack of formal guidelines on how to manage a patient during the initial and progressive phases of EOLC after withdrawal or withholding of treatment in a tertiary ICU setting despite a number of frameworks being available. EOLC and palliative care is at the forefront of the national health agenda, with government policy driving change through policies and guidelines such as the National Safety and Quality in Health Care Standard 5, Comprehensive Care: At the end of life and the National Palliative Care Strategy 2010: Supporting Australians to Live Well at End of Life.[21,30] Localised ICU standardised care pathways or guidelines as seen in the ward setting or community, would ensure a standardised approach is taken to managing the dying patient. These care pathways could consider the management of pain, dyspnoea, secretions, and agitation. By having a standardised care pathway for EOLC in ICU, nurses potentially will feel more empowered in the EOLC process.[35]

The third most significant obstacle identified was the nurse's perception that the families were not accepting of poor patient prognosis. A possible explanation for this obstacle relates to the highest scoring obstacle which was that physicians often differ in opinion about the direction of patient's care. As patients present acutely with severe life-threatening illnesses, often requiring multiple treatment considerations, indecision and ambiguity are commonly seen in the ICU.[11] The findings of this study suggest that after the decision to withdraw treatment has been made, uncertainty remains. This is further compounded by the short timeframe in which the decision to withdraw treatment is made. The concept of timing related to withdrawal of treatment has been highlighted in many other studies.[11,36,37] Research has uncovered some clear factors that affect a family's readiness to withdraw treatment.[11,36,37] These included the way communication is conducted, the uncertainty around the patient prognosis, and the potential impending loss of their loved one.[11,36,37] Critical care nurses are highly skilled professionals who work in a fast paced environment in which their skills and expertise are of an advanced level, with 82% of participants in this study holding a postgraduate qualification. Subsequently their understanding, knowledge, and decision-making abilities may be considered as greater to that of the patients' family members. Communication with family members experiencing an acute crisis in EOL situations is challenging as they may experience difficulties in processing and understanding the information given.

A significant factor in determining family satisfaction, both in the initial and progressive phases of initiating EOLC is 'good communication', with current literature reporting that providing information on the patients' status is directly linked with greater family satisfaction.[25,28,38,39] The ability to empathise and emotionally interact with family members is the key determinant to building a strong foundation, in which frank communications regarding prognosis can be had allowing for further opportunities to openly discuss EOLC.[27] It is clear that families appreciate honest and complete information being provided rather than vague information, which is associated with a greater incidence of traumatic stress, apprehension and depressive symptoms.[40,41] However, the challenge lies in the ability to ensure the families receive real time updates without compromising the care provided to the patient.[25,28] The literature recommends that families receive education on admission about the importance of creating one primary contact who can relay and communicate information with other family members and friends.[25,28] By doing so, more of the nurses' time can then be spent on caring for the patient.[25,28] Providing families with a clear understanding of the channel of communication may reduce the stress of many requests for information to the nurse providing care, and ultimately reduce misinterpretation and miscommunications occurring between family members. However, having a nominated family representative may be challenging in some situations such as interfamily disharmony.

Providing family members adequate support and preparation for withdrawal of treatment may help to increase the family's readiness and reduce the intensity of this perceived obstacle. In addition, an understanding of the family's health literacy level can allow the nurse to tailor information, ensuring there are no gaps in the family's understanding on the patient's prognosis and potential trajectory. Furthermore, there is a clear need for early, honest, open, and transparent communication with a discussion on all potential eventualities. The outcome of effective communication is timely decisions in the provision of comfort care and a reduction in the time of prolonged futile treatments.[28,40,42-44]

The ranges of supportive behaviours PSBS were higher than the obstacles PIS, as the higher scoring behaviours were typically ones that the nurse could control, and therefore perceived as being very supportive. The supportive behaviours that related to the pre and post EOLC that nurses could offer to the patient were; providing adequate time alone with patient pre/post death, facilitating a peaceful dignified bedside scene, having family members accept that the patient is dying and providing instruction on how to act around the dying patient. These findings aligned with the original studies top supportive behaviour PSBS findings.[9] Nurses perceived the PSBS controlled by clinicians other than nurses as lower primarily because these specific behaviours occurred at a less frequent rate than the supportive behaviours initiated and controlled by nurses.

5. RECOMMENDATIONS

The importance of evidence-based practice guidelines and policies have been highlighted in research to date. The intention of evidence-based guidelines is to assist clinicians in providing high-quality EOLC by having a standardised practice that supports the management of principles related to legal, moralistic, ethical and medical considerations and the implications that arise normally during withdrawal of life-sustaining measures.[14,6,45,46,47] In this study, the participants acknowledged the lack of current guidelines as impacting on their EOLC practice. The findings from this study support the need to have local guidelines and policies around EOLC in the ICU. Further research would consolidate the findings and increase the reliability, validity, and generalisability of the study. Additional research is required to understand if a guideline, once in place, will impact positively on nurses' and family's wellbeing by increasing nurses' professional job satisfaction and their psychological wellbeing. This would also help to determine whether the barriers recognised currently by participants change or improve, for example seeing an increase or decrease in the intensity and/or frequency of occurrence. Additionally, whether the change in practice and policy results in nurses perceiving more positive EOLC experiences.

6. STUDY LIMITATION

The study was a single site survey with a small sample size at only one tertiary adult ICU in Western Australia, the transferability of this study may be limited as participants at other sites may rate the obstacles and supportive behaviours differently. Although this is a single site study from one ICU unit the aim of this research was to gain insight into this area of practice. For a comprehensive understanding to occur, it is recommended that further research on the same topic be conducted in auxiliary ICUs and consider other contexts such as paediatric ICUs and the private sector. A potential perceived bias by the participants could be considered as the main researcher is employed by the organisation in which the research was conducted and although the participants completed the survey anonymously and through self-nomination this could be considered a limitation. The researchers have no sources of funding to declare.

7. CONCLUSION

EOLC is emerging as one of the most significant specialties in the ICU setting. However, EOLC still remains one of the most poorly understood and undereducated specialties in ICU at present. The research to date highlights that ICU nurses have the highest exposure rate to dying patients in the acute care setting. Although EOLC is an inherited part of intensive care nursing practice, this study demonstrates that there continues to be obstacles that impede the nurse's ability to perceive and facilitate a positive EOLC for the patient and their family. The results of this study confirm that nurses continue to struggle with many of the same barriers identified 15 years ago by the original researchers. Furthermore, the study demonstrates the need for a stronger multidisciplinary patient centred approach. It is envisaged that the findings will support the review and development of appropriate guidelines to assist nurses caring for ICU patients in the initial and progressive phases of EOLC.

8. ACKNOWLEDGMENT

The author would like to thank, the institutions ICU Research Nurse Jing Cherry Ning and Research Biostatistician Angela Jacques for their expert advice, support, and guidance during the completion of this research. I would also like to sincerely thank the participants who so generously and graciously gave up their time to participate in this research.

Conflicts of interest: The authors have no conflict of interest to declare.

Funding: This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

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