# INTENSIVE CARE NURSE PERCEPTIONS OF FAMILY-CENTRED END OF LIFE CARE AND QUALITY OF DYING

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# DECLARATION

I hereby declare that this submission is my own work and to the best of my knowledge it contains no materials previously published or written by another person, or substantial proportions of material which have been accepted for the award of any other degree or diploma at Macquarie University or any other educational institution, except where due acknowledgement is made in this thesis. Any contribution made to the research by others, with whom I have worked with at Macquarie University or elsewhere, is explicitly acknowledged in the thesis.

I also declare that the intellectual content of this thesis is the product of my own work, except to the extent that the assistance from others in the project's design and conception or in style, presentation and linguistic expression is acknowledged.

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# ABSTRACT

Many Australians will die expectedly within a hospital setting. The intensive care unit (ICU) is a particularly challenging environment to provide excellent end of life care. The aim of this study was to investigate intensive care nurse perceptions of the quality of dying and death of patients who died receiving end of life care and their perspectives as to whether this care met the needs of the patient's families. An ethically-approved descriptive study was conducted, involving 35 nurses reporting via online survey on the most recent patient that they cared for in the ICU, and who subsequently died receiving end of life care. Overall, statistical analysis of quantitative survey items revealed that quality of dying and death was perceived by nurses as good, whereas satisfaction with meeting family needs ranged from fair to good. Following an inductive analysis of the open-ended survey items, six key categories of meeting family needs emerged: quality of care, emotional support, communicating and providing information, spending time with loved one, physical and environmental comfort, and spiritual care. The quantitative and qualitative results of the current study also identified several areas where nurses perceive quality of dying and death and meeting family needs intersect: symptom control, presence of family, dignity, and spiritual care. The development and testing of tools that measure the quality of end of life care in an Australian ICU setting is an important priority for future research.

# ACKNOWLEDGEMENTS

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| | |
|---|---|
| ADBFMI | After-Death Bereaved Family Member Interview |
| ACCCN | Australian College of Critical Care Nurses |
| CCFNI | Critical Care Family Needs Inventory |
| CES | Care Evaluation Scale |
| CPR | Cardio-pulmonary Resuscitation |
| FATE | Family Assessment of Treatment at End of Life survey |
| FS-ICU | Family Satisfaction in the Intensive Care Unit questionnaire |
| GDI | Good Death Inventory |
| ICU | Intensive Care Unit |
| MFN | Meeting Family Needs questionnaire |
| NMI | Needs Met Inventory |
| QODD | Quality of Dying and Death questionnaire |
| SD | Standard Deviation |
| US | United States |

# CHAPTER 1. INTRODUCTION

## 1.1. Importance of the research project

For many Australians, death expectedly occurs within a hospital setting.(1) Between one in three and one in five acute hospital inpatients will have palliation as the goal of care.(1) However, acute hospitals have a limited capacity to provide appropriate care for such patients.(1) This is largely due to organisational and system issues where clinicians feel compelled to discharge patients to other settings if no curative or life-prolonging therapy is available.(1) The intensive care unit (ICU) is a designated hospital ward that provides specialised care to patients with actual or potential life threatening conditions, from which recovery is possible.(2) The goals of ICU care are to restore health and to relieve suffering.(3) Despite this, mortality rates of between 15-35% have been reported in international literature.(4) Mortality rates are expected to increase in Australia due to an ageing population and increasing rates of comorbid conditions.(5) The ICU is a particularly challenging environment to provide excellent end of life care, as the focus of the ICU is on sustaining life and restoring vital organ function, and predicting who will survive is difficult.(6) In 2014, the Australian and New Zealand Intensive Care Society (ANZICS) published a statement on care and decision-making at the end of life for the critically ill(7), which included the following 10 principles:

> 1. The goals of intensive care relate to minimising suffering and achieving a quality of survival that is acceptable to the patient or to compassionately support the dying process if this is not possible.

> 2. All patients should receive concurrent attention to therapeutic medical interventions and controlling distressing symptoms.

> 3. When a decision has been made to withheld or withdraw life-sustaining treatments, an end of life care plan should be enacted, in consultation with the patient and/or family and the ICU nurse. There should be a focus on dignity and comfort, and meeting physical, psychosocial, and spiritual needs.

> 4. There is no ethical or legal obligation to provide treatments that are more burdensome than beneficial to the patient.

5. Patients capable of making decisions about their own care are entitled to refuse or withdraw consent for any treatment at any time.

6. Decisions about treatment options should be the result of consensus between the patient (if capable), a substitute decision maker or family (if the patient is not capable), the ICU team, and other medical teams involved.

7. In cases when there is disagreement that cannot be resolved, additional medical opinion(s), nonmedical professional opinions, clinical ethics consultation, or legal processes may be considered.

8. All decisions regarding withholding or withdrawing life-sustaining treatments should be properly documented.

9. The above principles apply equally whether withholding or withdrawing of life-sustaining treatments is being considered.

10. Guidelines in congruence with the above principles should be developed by each ICU and hospital. Evaluation of care at the end of life as a quality measure forms an essential part of this.

More than half of Australians hospitalised with advanced disease may not be given adequate opportunity to discuss end of life care preferences.(8) Many receive end of life care that is of limited value or is more harmful than beneficial.(8) For example, an audit of 100 inpatient records of people who had died in Australia found that nearly half continued to have medical investigations close to the time of death, even though there was no clear documentation as to how these actions would influence their management.(1) Continuing life sustaining treatments without clinical improvement can cause patient suffering, deprive patients of palliative care and can reduce the time for patients and their families to prepare for dying.(9)

### 1.2. Defining end of life

End of life care refers to the care of patients whose disease is not responsive to curative treatment.(10) In the ICU, end of life care refers to the transition from curative treatment to comfort care.(10) It is initiated when the decision to withhold or withdraw life-sustaining treatment is made.(11) The World Health Organization defines palliative care as "an approach that improves the quality of life of patients and their families facing the problem

associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."(12) As palliative care is generally provided by specialists and end of life care is provided by any clinician, the term end of life care will be used for this study.

In order to conduct a study on end of life care, it is important to first define what time period constitutes the end of life.(13) According to George (2002), the single most challenging and poorly managed issue in end of life research is the mismatch between operational and conceptual definitions of dying.(14)

Previous studies have operationally defined the end of life period in a variety of ways, including by: setting of care (e.g. hospice, palliative care, ICU), disease category, clinical criteria, and prognostication (i.e. clinician prognosis of dying).(13, 14) In a systematic search of end of life studies, George (14) found that dying was not clearly defined by the investigators in most of the 400 identified studies, making it difficult to evaluate the study sample and generalisability. Study investigators frequently use clinician prognosis to define dying; however, it has been shown to be largely inaccurate.(14-17)

A variety of theoretical frameworks of death and dying have been advanced. Copp (18) identified six categories of these frameworks: stage theories of dying, context of awareness theories, dying trajectory theories, living-dying interval/phase theory of dying, task-based theories of dying and readiness-to-die theory. Theories are ways of looking at the world conceptually, and are contrasted with empirical studies. These theories are not necessarily underpinned by rigorous empirical testing and in any case are rarely used by investigators in end of life studies.(14) Lacking theoretical foundations in research means studies are often not well framed or the assumptions underpinning them are not well explicated.(14) It also prevents the development and testing of new hypotheses, and predictably therefore most end of life research does not incorporate hypotheses.(14)

Clearly defining the end of life period is imperative in order to guide study design and instrument selection, as well as making generalisability and comparison with other studies clearer.(13) End of life care can be measured prospectively and retrospectively.(13) Defining the end of life period retrospectively is much easier than prospectively; however, both approaches have inherent biases.

### 1.3.Measuring end of life care prospectively

A major advantage of a prospective study design is the ability to collect data on end of life care directly from the patient, as the subjective aspects of their care and symptom burden can only be assessed by them.(15) However, these types of studies are inherently biased as they will only include a less impaired population of dying patients, who are able and willing to participate.(19) As patients get closer to death, their symptom burden and care needs generally increase, making them too ill to participate in surveys.(15) This is particularly relevant to studies that define their dying population according to setting. Patients admitted to hospice and palliative care are generally more advanced in their disease course.(15) A study from the United Kingdom using the palliative care outcome scale in eight palliative care centres had only one in three enrolled participants completing the scale even though it was brief and not especially burdensome.(20) Participants who completed the scale had higher levels of mobility compared to the general study population.(20)

If patients are too ill to be surveyed, researchers have used family members and/or the healthcare professionals caring for them as proxies. This involves having the proxy respondent answer survey or interview questions on the patient's behalf. Use of family members as proxy respondents is prevalent in end of life care research (14, 19, 21), as family members often act as surrogate decision makers in end of life decisions.(6, 22, 23) Congruence between patient and proxy responses is important, as inaccurate responses may compromise the validity of the research and lead to flawed conclusions.(19) Evidence shows mixed results regarding the precision of proxy responses when compared with patients' self-report.(15) Families tend to report lower quality of life and higher symptom burden than patient informants.(15) Physicians tend to report lower symptom burden and distress.(15) Interestingly, nurse reports of symptom burden and distress are more consistent with the patient than family members' reports.(14, 15) Agreement between patient and proxies is greatest for service quality and observable symptoms, and poorest for subjective experiences, such as pain and anxiety.(19) George (14) recommends that when using proxy respondents, information collected should be restricted to observable behaviours (e.g. requests for pain medication) as some information, such as quality of life ratings, cannot be accurately obtained.

Determining which patients are dying and therefore appropriate for study inclusion, particularly outside the domain of cancer, is a major challenge for investigators undertaking

prospective studies. Prognostication is most often used in late stage cancer, where there is often a predictable outcome; however, it becomes much less reliable when looking at other diseases.(17) This is because chronic illnesses are often characterised by multiple acute episodes and some form of recovery. Predicting which acute episode will be the last is difficult for clinicians.(17, 24) Prospective studies are therefore limited to diseases that have an identifiable terminal stage.(19)

According to Steinhauser (13), classifying patients as dying or not dying is problematic, as it reinforces a dichotomous approach to care. As serious illness progresses, patients and families describe undergoing a series of transitions rather than a movement from one state (not dying) to another (dying). It is not known whether the majority of patients experience a single transition or a more gradual course of change. The dichotomous approach is usually assumed by researchers, but more empirical evidence is needed to understand how patients transition from having life threatening illness to dying.(13)

## 1.4. Measuring end of life care retrospectively

A retrospective study design addresses many of the challenges faced by conducting a prospective study. It avoids the need to determine which patients are terminally ill, avoids burdening dying participants and avoids non-response bias due to being unable to collect information about the sickest patients.(16) Additionally, a retrospective study is more cost- and time-effective. Medical records do not need to be reviewed in order to identify patients most likely to be terminally ill.(16) Hence, a retrospective design has been chosen for this thesis.

Surveying clinicians or family members about the care the deceased patient received overcomes the issue of prognostication. Therefore, the investigators can clearly define the date of death and the care received in the final few weeks of life.(17) Family members can provide information on whether their relative's medical needs were met by their healthcare team at the end of life.(17) An issue in surveying family members retrospectively is the extent to which grief, recall bias and reinterpretation affects their perceptions of the quality of end of life care.(15, 17, 25) Family members may recall their relative's death as being overly negative due to anger over their loss. Alternatively, they may recall a painful death as being less painful in order to make peace with it and move on.(17) Family members'

responses during bereavement have been shown to differ from responses given whilst the patient was dying.(19) Additionally, responses given regarding symptoms and care received have differed between interviews at three and nine months after the patient's death.(19) Further research is needed to identify the optimal time to survey family members after a relative's death.(25) To avoid burdening grieving family members and biased responses due to grief, nurses were selected as the study participants for this research. Nurses focus on care for the family and the family's end of life experience when it comes to providing end of life care in the ICU.(26) Previous studies have also shown nurses to be more critical raters of end of life care than family members and physicians.(27-29) This may be due to nurses spending more time with patients and their families than physicians do (29), and being more familiar with what a 'good death' looks like than family members.(30)

## 1.5. Patient- and family-centred care

The Institute for Patient- and Family-Centred Care, a United States (US)-based body responsible for advancing the understanding and practice of patient-centred and family-centred care in all settings where individuals and families receive health care, defines patient-centred and family-centred care as "an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families" (IPFCC, 2010, para 1).(31) Patient- and family-centred care involves clinicians sharing timely and complete information on the patient's condition; sensitivity to nonmedical and spiritual needs of the patient; and respect for the patient's care needs and preferences.(32) Patient- and family-centred care would appear important in end of life care in the ICU with one qualitative study of 15 patients and 33 family members across nine focus groups defining it as timely, clear and compassionate communication by physicians, decision making focusing on patient preferences, maintaining comfort and dignity in patient care, and open access to the patient and clinician; and bereavement support in family care.(33)

As ICU patients are usually unable to contribute to their own decision making, families generally serve as surrogate decision makers.(6, 22, 23) The transition from curative treatment to end of life care is often difficult for families, making family-centred care important in the ICU.(34) Family-centred care is widely practiced in the neonatal ICU setting in Australia, though there is variation in its application in the adult ICU setting.(22) There were approximately 160,000 admissions to Australian and New Zealand ICUs in 2012–2013,

with a mortality rate of six percent. This means there were over 9,500 patients and families who received some form of end of life care in this period.(35) Currently, there are few Australian studies assessing family-centred end of life care in the ICU.(22) Existing studies focus on the bereavement support provided to families, rather than the quality of end of life care.(35-37) The need for further research on family-centred end of life care in the ICU, particularly given the importance of improving patient- and family-centred care in this area, forms the basis of this thesis.

## 1.6. Aim and research questions

The aim of this thesis is to investigate intensive care nurse perceptions of the quality of dying and death of patients who died receiving end of life care and their perceptions of whether this care met the needs of the patient's families. To achieve this aim, two research questions were devised arising from the literature reviewed above:

**Research Question 1 (RQ1):** What are nurse perceptions of quality of dying and death and whether family needs are met?

**Research Question 2 (RQ2):** Is there an association between nurse perception of quality of dying and death and meeting family needs?

## CHAPTER 2. LITERATURE REVIEW

## 2.1. Overview of Chapter 2

Chapter 2 presents a literature review conducted to identify the most appropriate tool(s) to answer the research questions for this thesis. There are five sections: measurement tools; search strategy; inclusion and exclusion criteria; findings; summary and limitations.

### 2.1.1. Chapter highlights

- MEDLINE, Embase and Scopus were searched for peer-reviewed, English language studies published from the year 2000 onwards.
- In total 30 papers investigating 12 tools were included in this review.
- The most used and validated tools are the Family Satisfaction with Care in the Intensive Care Unit questionnaire (FS-ICU) and the Quality of Dying and Death questionnaire (QODD), however, neither tool may be sufficient to measure end of life care quality on its own.

- The 14-item ICU nurse version of the QODD and the nurse version of the Meeting Family Needs questionnaire (MFN) will be used together for this study.

## 2.2. Measurement tools

While many tools are available to measure end of life care and its outcomes (38, 39), there is little consensus on which tools and criteria are best used to assess it.(40) There is, however, considerable agreement on the key domains that include physical comfort and emotional support, shared decision-making, communication, support to family members, and access to care.(16) Reliable and valid tools that allow comparisons across care settings, populations and conditions are required to develop a solid evidence base for improving end of life care.(38) Tools exist to measure quality of care, quality of life for dying persons and quality of dying and death.(16) Teno (2004) recommends tools with the following characteristics (41):

1. patient-focused, family-centred, clinically meaningful and manageable in their application;
2. reliable, valid and responsive;
3. user-friendly and relevant to quality evaluation and improvement;
4. incorporate patient and family perspectives; and can
5. examine both processes and outcomes of care.

A literature review was conducted to identify and investigate tools that have been used to measure the quality of end of life care in an adult ICU setting. This review was used to identify the most the most appropriate tool(s) to answer the research questions for this thesis.

## 2.3. Search strategy

An informal review of the literature and discussions with a health services academic were undertaken to identify relevant search terms. MEDLINE, Embase and Scopus were searched using the terms "tool*" OR "questionnaire*" OR "instrument*" AND "end of life care" OR "dying" AND "quality" OR "patient cent*" OR "family cent*" AND "intensive care" OR "critical care". The search strategies are presented in Table 2.1.

**Table 2.1: Search strategies used to identify tools to measure end of life care**

| Database | MEDLINE | |
|---|---|---|
| **Strategy** | **Search** | **Results** |
| #1 | ((tool* or questionnaire* or instrument*) and (end of life care or dying) and (quality or patient cent* or family cent*) and (intensive care or critical care or ICU)).ab. | 59 |
| #2 | limit #1 to (English language and yr="2000 -Current") | 54 |
| **Database** | **Embase** | |
| **Strategy** | **Search** | **Results** |
| #1 | ((tool* or questionnaire* or instrument*) and (end of life care or dying) and (quality or patient cent* or family cent*) and (intensive care or critical care or ICU)).ab. | 129 |
| #2 | limit #1 to (English language and yr="2000 -Current") | 120 |
| **Database** | **Scopus** | |
| **Strategy** | **Search** | **Results** |
| #1 | (TITLE-ABS (end of life care) OR TITLE-ABS (dying) ) AND (TITLE-ABS (quality) OR TITLE-ABS (patient cent*) OR TITLE-ABS (family cent*)) AND (TITLE-ABS (intensive care) OR TITLE-ABS (critical care) OR TITLE-ABS (ICU)) AND (TITLE-ABS (tool*) OR TITLE-ABS (questionnaire*) OR TITLE-ABS (instrument*)) | 273 |
| #2 | limit #1 to (LANGUAGE , "English") and PUBYEAR > 1999 AND PUBYEAR < 2017 | 228 |
| #3 | Exclude reviews, conferences, book chapters | 190 |

## 2.4. Inclusion and exclusion criteria

The following inclusion criteria were used: peer-reviewed, primary empirical research articles, English language, published from January 2000 to May 2016, the tool measured the quality of end of life care received by patients and/or their families retrospectively, the tool was used in an adult ICU setting. The following exclusion criteria were used: tool was developed for use in a paediatric ICU, the tool measured the overall quality of end of life care at an ICU level, the tool reports on quality but does not measure it, the tool measures quality with chart based data or through quality indicators only, the tool measured attitudes towards or perspectives on care in general, and article was not peer-reviewed, primary empirical research. Reference lists from systematic review articles were used to identify further relevant articles.

Abstracts were screened against the criteria and either accepted for further review or rejected. Full papers were then screened against the criteria and either accepted for inclusion or rejected. Data from the accepted papers, including study objective, study population, tool description and measurement properties was then extracted.

## 2.5. Findings

The literature search initially identified 364 citations. After duplicates were removed, 253 abstracts were examined. After applying the inclusion and exclusion criteria, 33 articles were identified for further review. Of these articles, 22 were deemed suitable for inclusion, plus an additional eight papers identified from a systematic review. Eleven articles were excluded due to not being primary empirical research and / or not meeting the measurement criteria. In total 30 articles were included in this review (Figure 2.1).
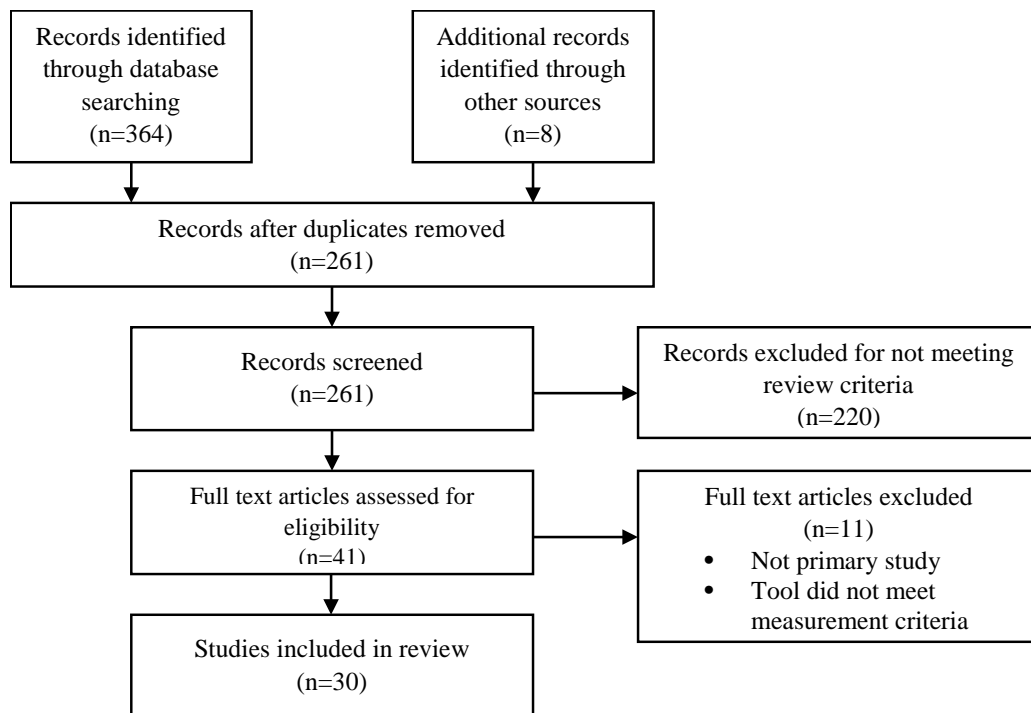


**Figure 2.1: Flowchart of review process**

Twelve tools were identified from the 30 studies included in this review (Table 2.2). These studies are summarised in Appendix A. Only six studies and two tools were used to gather the perspectives of nurses (Table 2.3). Of the 30 studies included in this review, 21 (70%) were conducted in the US (11, 28, 30, 42-59), five (16.67%) were conducted in Canada (60-64), and one each was conducted in Australia (0.03%) (65), Japan (0.03%) (66), The

Netherlands (0.03%) (67), and The Philippines (0.03%).(68) The most frequently used tools were the Family Satisfaction with Care in the Intensive Care Unit (FS-ICU), which was used in 15 (50%) studies (44-46, 48-53, 56, 58, 59, 62, 67, 68), and the Quality of Dying and Death questionnaire (QODD), used in 11 (37%) studies.(28, 30, 44, 45, 47, 52, 54-56, 67, 69) The FS-ICU and QODD were used together in five (17%) studies.(44, 45, 52, 56, 67). The only other tool used in more than one study was the Meeting Family Needs questionnaire (MFN), used in two studies.(53, 70) Tools used in single studies include: the After-Death Bereaved Family Member Interview (ADBFMI) (61); the Care Evaluation Scale (66); Evaluation of Experiences of Withdrawal Tool (11); the Family Assessment of Treatment at End of Life (FATE) (71); the Good Death Inventory (66); and the Quality of End-of-Life Care–10 (QEOLC-10).(60) Tools were developed by Cheung et al. (2010) (65) and Kjerulf et al. (2005) (63) for use in single studies; however, validity and reliability data for these tools were not reported and therefore, they will not be discussed further.

**Table 2.2: Tools identified from included studies**

| Tool | Description | No of studies |
|---|---|---|
| ADBFMI | Measures seven domains of end-of-life care within hospitals, hospices, and residential care facilities, including: physical and emotional support, inform and promote shared decision-making, encourage advance care planning, focus on individual, attend to the emotional and spiritual needs of the family, provide coordination of care, support for the self-efficacy of the family. | 1 |
| CANHELP Bereavement Questionnaire | Measures eight domains of care including patient pain and symptom management, timely and clear communication, information to prepare the family for approaching death, compassionate care, comfort, dignity, and respect, patient-centred decision making, care of the family, family support, and caregiver satisfaction with hospital facilities and staff. | 1 |
| Care Evaluation Scale | Evaluates the structure and process of end-of-life care by rating the necessity of improvement. | 1 |

| Tool | Description | No of studies |
|---|---|---|
| Developed by Cheung et al. | Measures quality of care<br>Family version domains: Patient- and family-centred decision making, Communication, Continuity with care, Emotional and practical support, Symptom management and comfort care, Spiritual support, Patient care.<br><br>Staff version domains: Satisfaction with symptom management, Satisfaction with communication and support, Satisfaction with goals of care, Grading of difficulty in managing family in day-to-day issues, Grading of difficulty in managing family in end-of-life issues, Overall satisfaction with patient management. | 1 |
| Developed by Kjerulf et al. | Questions cover such issues as perceptions regarding the decision to stop life supports, access to the patient, access to physicians and nurses and information regarding the patient's status, support provided by the hospital, and organ donation attitudes. | 1 |
| Evaluation of Experiences of Withdrawal Tool | Assesses the next of kin's level of coping, the level of preparation for the withdrawal of life support, and the effect of the preparation on the experience of withdrawal of life support. | 1 |
| FATE | Measures six domains: the patient's well-being and dignity, adequacy of information and communication, emotional and spiritual support, care around the time of death, access to services before the patient's death, and access to benefits and services after the patient's death. Also includes questions on symptom management, overtreatment, undertreatment, and preferences for site of death. | 1 |
| FS-ICU | The first section assesses family satisfaction with care and the second section assesses family satisfaction with decision making. Measures the following domains in family satisfaction with care: care of family, care of patient, professional care, ICU environment and overall satisfaction. Measures the following domains in family satisfaction with decision making: information need, deliberation and overall satisfaction. | 15 |
| GDI | Evaluates the outcome for end of life care. | 1 |
| MFN | Nurse version: asks nurses to rate their satisfaction with how well they met the family's physical needs, how well they met the family's emotional needs and how well the health care team met the family's needs.<br><br>Social worker version: asks social workers to rate their satisfaction with how well they met the family's physical needs, how well they met the family's emotional needs, | 2 |

| Tool | Description | No of studies |
|---|---|---|
| | how well they communicated with the family, and how well the health care team met the family's overall needs. | |
| QODD | Measures symptoms, experiences, and perceptions about the quality of the dying process in the last week of life. Multiple versions: family (interview and self-administered), clinician and ICU nurse. | 11 |
| QEOLC-10 | Measures five domains of physician skills: communication skills, symptom skills, affective skills, patient-centred values, patient-centred systems. | 1 |

**Table 2.3: Studies using nurse respondents**

| Tool | Author | Country | Study Objective | Population | Measure properties |
|------|--------|---------|-----------------|------------|--------------------|
| **MFN** | Downey et al(70) | US | To evaluate 3 new short questionnaires measuring nurses' perspectives on family-centred end-of-life care in the intensive care unit and to show the usefulness of the questionnaires. | 141 critical care nurses evaluating care given to families of 218 patients. | Goodness-of-fit index: 0.99. Cronbach alpha: 0.79. |
| **QODD** | Curtis et al (2008)(44) | US | To evaluate the effectiveness of a multi-faceted quality improvement intervention to improve palliative care in the ICU. | 275 family members and 523 nurses of 590 patients. | Authors report previously shown to be reliable and validate. |
| | Curtis et al (2011)(45) | US | To evaluate the effectiveness of a quality-improvement intervention to improve ICU end-of-life care. | 822 family members of 1,924 patients and 636 nurses of 1,269 patients. | Authors report previously shown to be reliable and validate. |
| | Hodde et al(30) | US | To determine the feasibility of using nurse ratings of quality of dying and death to assess quality of end-of-life care in the intensive care unit and to determine factors associated with nurse assessment of the quality of dying and death for patients dying in the intensive care unit. | 178 nurses patients of 246 patients. | Cronbach's alpha: 0.96. However, this was based on only 16 cases with data for all 14 items. |
| | Levy et al(28) | US | To describe and compare the ratings of the quality of death between family members, nurses, resident physicians, and attending physicians in the care of medical ICU patients who spent at least 48 h in the ICU. | 38 patient deaths rated by: family member, attending physician, resident physician and nurse. | Authors report previously validated. |

| Tool | Author | Country | Study Objective | Population | Measure properties |
|------|--------|---------|-----------------|------------|--------------------|
|  | O'Mahony et al(55) | US | To provide a culturally competent model of care for critically ill patients at the end of life; to integrate the PCS into daily operations of the ICU; and to increase access to hospice services for patients at the end of life in the ICU. | Nine nurses and ten family members of patients who died in an ICU. | Not reported. |

*FS-ICU*

The FS-ICU was originally developed by Heyland and Tranmer (2001) to measure family members' satisfaction with the care provided to their seriously ill family member during their ICU stay.(62) Questionnaire items were generated from existing conceptual frameworks of patient satisfaction and quality end of life care, existing research on the needs of critically ill patient's families and family satisfaction with medical decision making, and from pilot testing. The questionnaire is divided into two sections. The first section assesses family satisfaction with care and the second section assesses family satisfaction with decision making. The FS-ICU measures the following domains in family satisfaction with care: care of family, care of patient, professional care, ICU environment and overall satisfaction. It measures the following domains of family satisfaction with decision making: information need, deliberation and overall satisfaction. Heyland and Tranmer (2001) assessed the reliability of the FS-ICU in next of kin of surviving patients on discharge and seven to ten days later. They found the Cronbach's alpha coefficient for: care of family was 0.95, care of patient was 0.97, professional care was 0.91, ICU environment was 0.74, information needs was 0.93, and deliberation was 0.87. Validity was assessed by measuring the correlation between satisfaction with overall care and satisfaction with decision making. A moderate correlation was found between satisfaction with overall care and satisfaction with decision making, with a correlation coefficient of 0.636.(62) The original FS-ICU contained 34 items, but it was later revised and shortened to 24 items.(72) The revised FS-ICU's Cronbach's alpha coefficient for family satisfaction with care was 0.92 and for family satisfaction with decision making was 0.88. These two subscales showed good correlation with each other (Spearman $\rho = 0.73$, p <0.001).(49)

The FS-ICU was administered as a postal survey in 11 studies.(44-46, 48, 50, 52, 53, 56, 58, 59, 62) It was administered as a telephone survey in three studies (49, 67, 68), and in-person by researchers in one study.(51) Of the 15 studies identified in this review, ten were descriptive studies (46, 48, 50, 52, 56, 58, 59, 62, 67, 68) and five were intervention studies.(44, 45, 49, 51, 53)

*Quality of Dying and Death questionnaire (QODD)*

The QODD was developed to assess a patient's end of life experiences from either family or clinician perspective. It measures symptoms, experiences, and perceptions about the quality of the dying process in the last week of life. Domains measured in the QODD are: symptoms and personal care, preparation for death, family concerns, treatment preferences, whole-person concerns and moment of death.(54) The 31 item family version of the QODD demonstrated good construct validity, with significant associations with measures of symptom burden, patient-clinician communication about treatment preferences, and several quality of care measures; and good internal consistency, with a Cronbach's alpha of 0.86. The 21 item family version exhibited low interrater reliability, with an intraclass correlation coefficient of 0.44.(44) The 14 item ICU nurse version indicated high internal consistency at 0.96, however, this was only based on a small sample.(30) There is also a single item QODD-1, which assesses the overall quality of dying and death for patients who died in the ICU.(56)

The QODD was completed by family members in ten of the 11 studies.(28, 44, 45, 47, 52, 54-56, 67, 69) It was completed by nurses in six studies (28, 30, 44, 45, 55, 67) and physicians in two studies.(28, 67) It was administered as a postal survey in five studies (44, 45, 47, 52, 56), self-administered in three studies (28, 30, 67), administered in person interview in three studies (54, 55, 69) and as a telephone interview in two studies.(28, 67) Of the 11 studies identified in this review, eight were descriptive (28, 30, 47, 52, 54, 56, 67, 69) and three were interventional.(44, 45, 55)

*Meeting Family Needs (MFN) questionnaire*

The MFN for nurses was used in one of the two MFN studies identified in this review.(70) It was developed to assess the extent to which ICU nurses perceived they and other members of the healthcare team met the needs of patient's families. It consists of three items asking nurses to rate their satisfaction with how well they met the family's physical needs, how well

they met the family's emotional needs and how well the health care team met the family's needs. A 0-10 scale is used, with a score of 0 representing 'not satisfied at all' and a score of 10 representing 'very satisfied'. Principal component analysis of the MFN produced a single domain with a goodness-of-fit index of 0.99, suggesting strong construct validity. The Cronbach's alpha was found to be .79 signifying acceptable internal consistency.(70)

The MFN for social workers was used in the other MFN study identified in this review.(53) It consists of four items to measure how well the social worker met the family's physical needs, how well they met the family's emotional needs, how well they communicated with the family, and how well the health care team met the family's overall needs. The Cronbach's alpha was found to be 0.93 in the included study, indicating excellent internal consistency.

The MFN was administered as a self-administered survey in both studies. The MFN for nurses was used in a descriptive study and the MFN for social workers was used in an interventional study.

*After-Death Bereaved Family Member Interview (ADBFMI)*
The ADBFMI measures seven domains of end of life care across a variety of settings. These domains are: physical and emotional support; inform and promote shared decision-making; encourage advance care planning; focus on individual; attend to the emotional and spiritual needs of the family; provide coordination of care; and, support for the self-efficacy of the family. Gallagher (61) reports reliability varies from 0.58 to 0.87 and validity ranges from 0.36–0.69. The ADBFMI was used in a single descriptive study in this review and was administered to family members by telephone interview.(61)

*CANHELP Bereavement Questionnaire*
The CANHELP Bereavement Questionnaire is a 40-item tool addressing eight domains of care including: patient pain and symptom management; timely and clear communication; information to prepare the family for approaching death; compassionate care, comfort dignity, and respect; patient-centred decision making; care of the family; family support; and caregiver satisfaction with hospital facilities and staff. Psychometric properties were not tested in the single study included in this review, though the authors reported it was previously validated.(64) The CANHELP Bereavement Questionnaire was administered to family members via postal survey in this descriptive study.

*Care Evaluation Scale (CES)*

The CES assesses the structure and process of end of life care by rating the necessity of improvement for each item on a 6-point Likert-type scale. Items include: "the physicians sufficiently explained the expected outcome to the patient", "the physicians sufficiently explained the expected outcome to the family", "the physicians dealt promptly with discomforting symptoms of the patients", "the nurses had adequate knowledge and skills", "there was good cooperation among staff members", and "consideration was given to the health of the family". Psychometric properties of the CES were not reported in the single descriptive study included in this review.(66) The CES was administered to family members via postal survey.

*Evaluation of Experiences of Withdrawal Tool*

The Evaluation of Experiences of Withdrawal Tool assesses the family member's level of coping, the level of preparation for the withdrawal of life support, and the effect of the preparation on the experience of withdrawal of life support. It was administered to family members by telephone interview in the single interventional study included in this review.(11) Psychometric properties of the tool were not reported by the authors.

*Family Assessment of Treatment at End of Life (FATE)*

The FATE measures quality of care at the end of life. It contains 32 items. Six domains encompass 25 items: the patient's well-being and dignity; adequacy of information and communication; emotional and spiritual support; care around the time of death; access to services before the patient's death; and access to benefits and services after the patient's death. The remaining seven items include four questions on symptom management and one each regarding overtreatment, undertreatment, and preferences for site of death Psychometric properties of the FATE were not tested in the single descriptive study included in this review, however good homogeneity (Cronbach's a = .91) and acceptable ceiling effect were previously reported.(71) The FATE was administered to family members by telephone interview in this study.

*Good Death Inventory (GDI)*

The GDI assesses the outcome for end of life care using a 7-point Likert-type scale. The GDI measures: physical and psychological comfort; dying in a favourite place' maintaining hope and pleasure; good relationship with medical staff; not being a burden to others; good relationship with family; independence; environmental comfort; being respected as an

individual; and life completion. Psychometric properties of the GDI were not reported in the single descriptive study included in this review.(66) The GDI was administered to family members via postal survey.

*Quality of End-of-Life Care–10 (QEOLC-10)*

The QEOLC-10 measures five domains of physician skills: communication skills, symptom skills, affective skills, patient-centred values, patient-centred systems.(73) Psychometric properties of the QEOLC-10 were not reported in the single intervention study included in this review, though the authors report the measure as being previously validated.(60) It was administered to family members via in person self-administered survey in this study.

## 2.6. Summary of tools

This literature review identified 12 tools that have been used to measure the quality of end of life care retrospectively in the ICU. Of these 12 tools, nine were used in single studies and one was used in two studies. By far the most used and validated tools in this area are the FS-ICU and the QODD. The FS-ICU and the family version of the QODD both possess the characteristics recommended by Teno (2004).(41) The FS-ICU and the QODD were used together in five studies, suggesting neither tool may be sufficient to measure end of life care quality on its own. In a study using the single item QODD with the FS-ICU, higher QODD scores were significantly associated with: 1) perceived nursing skill and competence, 2) support for family as decision-makers, 3) family control over the patient's care, and 4) ICU atmosphere. FS-ICU items that received low scores and were significantly associated with a higher QODD score were: 1) support of family as decision-maker, 2) family control over patient's care, and 3) ICU atmosphere.(56) Neither of these tools were used in an Australian setting.

The single study conducted in an Australia setting by Cheung et al. (2010) used a tool developed by the authors. The psychometric properties of this tool were not tested. Further studies assessing the quality of end of life care in the ICU in the Australian setting are necessary. This review found that there is a lack of thoroughly tested tools available for this purpose. The development of new tools, or the testing of pre-existing tools, is essential.

The findings in this review are supported by other end of life care literature. Mularski (38) conducted a systematic review of measures of end of life care and its outcomes across

various settings. The authors found that most measures had not been rigorously developed and tested. Of the 99 measures reviewed, 80 (81%) were used only once and only eight measures were used in more than two studies. Hales (39) conducted a systematic review of quality of dying and death instruments. The authors found, of the eighteen measures that met their selection criteria, only six (33.3%) were published with a description of the development process. Less than half of the instruments were based on a clear definition of quality of dying and death. The QODD questionnaire was found to be the most valid and extensively studied instrument.

There are limitations to this review. Firstly, only tools that have previously been used to measure end of life care in an ICU setting were included. There may be other tools available that can be used or adapted for use in the ICU. Secondly, the use of the terms 'end of life care' and 'quality' may have limited the scope of the review. These are broad terms, and may not have captured other relevant tools available to measure specific aspects of care. Thirdly, the search strategy did not include the CINAHL database, which provides indexing for nursing and allied health journals. Whilst this may have revealed additional studies of the tools identified in this review, it is doubtful it would have identified an additional rigorously tested tool.

## 2.7. Summary and limitations

Although a multitude of instruments to measure end of life care quality exist, very few have been subjected to thorough development and testing. To conduct meaningful research on end of life care quality, investigators need to select an instrument that is reliable and valid, is patient-focused and family-centred, and can be easily completed by respondents. None of the tools identified in this review can answer the research questions of this thesis on their own. The ICU nurse version of the QODD identified in the literature review does not specifically assess family-centred care, so the MFN was selected to be used concurrently.

# CHAPTER 3. METHOD

## 3.1. Overview of Chapter 3

Having established the tools to be used, Chapter 3 provides an overview of the methods used in the study. There are six sections: study design; study questionnaires; setting and participants; data collection and analysis; ethical considerations; and summary and limitations.

### 3.1.1. Chapter highlights

- A descriptive approach was used for this study.
- An online cross-sectional survey was created using Qualtrics.
- The QODD and MFN were used with the addition of two open-ended questions: "For me, meeting family needs means" and "Any other comments?"
- The open-ended questions were chosen to define how the nurses in this study perceive meeting family needs and compare it with existing literature from the perspective of both nurses and families; and to allow nurses the opportunity for further commentary on quality of dying and death and/or family-centred care.
- Australian College of Critical Care Nurses (ACCCN) members were emailed a study invitation.
- A study advertisement containing a link to the questionnaire was also posted on the Nurse Uncut blog, Facebook and Twitter accounts.
- Nurses reported on the most recent patient that they cared for in the ICU who subsequently died receiving end of life care.
- Summary statistics were reported for all valid QODD and MFN item responses.
- Spearman correlation coefficients were used to test associations between QODD and MFN items.
- Qualitative data was inductively analysed using a general inductive approach.

## 3.2. Study Design

A descriptive approach was used to address the research questions of this study. A descriptive study reports the existing distribution of variables without testing a hypothesis.(74)As no hypothesis or intervention is being tested, this approach is most appropriate for the current study. An online cross-sectional survey, which involved nurses

reporting on the most recent patient that they cared for in the ICU who subsequently died receiving end of life care, was undertaken.

### 3.3. Study questionnaires

To answer the research questions, the QODD and MFN questionnaires were used. Both questionnaires have demonstrated validity and reliability.(30, 39, 44, 47, 70, 75) Permission to use both questionnaires with a slight modification of the QODD Likert scale anchors ('terrible' and 'almost perfect' changed to 'worst possible' and 'best possible') was granted by the developers at the Palliative & End-of-Life Care Research Program, University of Washington.(76)

Two open-ended questions were added to the online questionnaire: 1) "For me, meeting family needs means" and 2) "Any other comments?" The first question was chosen to define how the nurses in this study perceive meeting family needs and to compare it with existing literature from the perspective of both nurses and families. The second question was chosen to allow nurses the opportunity for further commentary on quality of dying and death and/or family-centred care.

### 3.4. Setting and participants

An Australian ICU may range from four to over 50 beds, depending on its designated level, function, size and the region that it serves.(77) Each ICU must have a medical director who takes overall responsibility for its operation.(77) The ACCCN guidelines require a minimum nurse/patient ration of 1:1 for ventilated and other critically ill patients, and 1:2 nursing staff for high dependency patients.(78) Australian intensive care nurses who recently cared for a patient who died that met the inclusion criteria were invited to take part in the study. Nurses spend more time with patients than physicians do, and are more familiar with what a 'good death' looks like than family members, who have limited experience and are emotionally entangled in the events as they unfold. Nurses are also the clinicians most likely to know and satisfy family needs.(79, 80) Nurses were eligible to participate if they worked in intensive care and recently cared for a patient 18 years or older who died receiving end of life care after a minimum ICU stay of 48 hours. The inclusion criteria were chosen to ensure a switch from curative treatment to end of life care was made, and to maximise nurse observations of the end of life experience for patients and their families.(28) Due to the online nature of the

survey and the sensitivity of the subject area, demographic information on participants and their patients was not collected in order to ensure complete anonymity.(29) In 2014/15, there were 133,217 Australian adult ICU admissions. The median patient age was 65 years. Fifty-seven percent of patients were male. The median length of stay was 1.8 days. The ANZROD (The Australian and New Zealand Risk Of Death) median severity of illness score was 45. The ANZROD mean predicted risk of death was 8.11%. ICU mortality was 5.20%.(81)

## 3.5. Data collection and analysis

An online survey was created using Qualtrics.(82) No power calculation to determine minimal sample size was performed as no hypothesis was being tested. Participants were asked to anonymously respond to questions regarding the most recent patient that they cared for in the ICU who subsequently died receiving end of life care (Appendix B). Members of the ACCCN who had opted to be contacted for research purposes (n = 926) were emailed a study invitation containing a link to the questionnaire in October 2016 (Appendix C). The ACCCN is the peak professional nursing association representing over 2,300 critical care nurses throughout Australia. The College's members work across the critical care clinical spectrum, principally in the area of intensive care.(83) The survey remained available online for two weeks after the email invitations were sent. A study advertisement containing a link to the questionnaire was also posted on the Nurse Uncut blog (http://www.nurseuncut.com.au/), Facebook and Twitter accounts (Appendix D). Nurse Uncut is run by NSW Nurses and Midwives' Association. It is a community site for Australian nurses to share experiences, advice, news and opinions. The blog has approximately 18,000 nurse visits per month, the Facebook account has over 7,500 likes and the Twitter account has over 2,700 followers.

### 3.5.1 Statistical analysis

Statistical analysis was performed using SAS 9.4.(84) Summary statistics (mean, standard deviation (SD), median and range) were reported for all valid QODD and MFN item responses. Valid responses were defined as a score of 0 to 10, removing "Does not apply" and "Don't know" answers. A total QODD score for each participant was calculated by summing all valid responses and dividing by the number of valid responses to get the mean score.  The mean score was then scaled as a score 0-100.(30) Data distribution was assessed using histograms and was found to be abnormally distributed. The parametric Pearson's

correlation coefficient assumes both variables are normally distributed, while the non-parametric Spearman's correlation coefficient is appropriate for use when one or both of the variables used are skewed.(85) Due to the skewed data distribution, Spearman correlation coefficient was chosen to test the three MFN items with the total QODD score and all of the individual QODD items. A *p*-value of ≤0.01 was considered significant. A correlation coefficient of: .00 to .30 was considered negligible; .30 to .50 was considered low; .50 to .70 was considered moderate; .70 to .90 was considered high; and .90 to 1.00 was considered very high.(85)

### *3.5.2. Inductive content analysis*

Qualitative data from the open-ended questions were analysed using an inductive content analysis approach. Content analysis is a method used to concisely describe and quantify phenomena in to categories.(86) It relies less on interpretation than thematic analysis.(87)Inductive content analysis was chosen over deductive content analysis as knowledge in this area limited, and no theory is being tested. (86) Data was inductively analysed using The Framework Method, a highly systematic method of organising and categorising data.(88) This method  involves the charting of data in to a framework matrix.(88) Inductive content analysis occurred in three stages: 1) preparation: transferring of written responses in to one document and multiple readings of written responses to gain familiarity; 2) organisation: inductive coding, involving the copying of words and phrases in the document into emerging categories, and revision and refinement of categories; And 3) reporting: reporting the analysis process and results.

## 3.6. Ethical considerations

Ethics approval for this project was granted by Macquarie University Human Research Ethics Committee (5201600541). Participation in the survey was voluntary and consent was given before the commencement of the survey.

## 3.7. Summary and limitations

This study used a descriptive approach to address the research questions. An online survey was conducted in October 2016. The survey comprised of the QODD, MFN and two open-ended questions. Summary statistics were reported for all valid QODD and MFN item

responses. A total QODD score was also calculated. Spearman correlation coefficients were used to test associations between QODD and MFN items due to the data distribution. Qualitative data from the two open-ended questions were inductively analysed using the Framework Method. The results of both analyses are presented in Chapter 4.

## CHAPTER 4. RESULTS

### 4.1. Chapter overview

Chapter 4 presents the results of the statistical and inductive analyses. The statistical analysis comprises summary statistics and Spearman correlation coefficients.

#### *4.1.1 Highlights*

- Thirty-five participants were included in this study.
- Overall, quality of dying and death was good, with a mean total QODD score of 74.64 (SD: 18.64).
- Satisfaction with meeting families' physical needs was good, with a mean of 7.55; satisfaction with meeting families' emotional needs was good, with a mean of 7.30; satisfaction with the health care team meeting families' needs was fair, with a mean of 6.85.
- All three MFN items were found to be significantly associated with total QODD score.
- Breathing comfortably; rating of having (or not having) someone present at death; and rating of receiving the right amount of sedation were significantly associated with all three MFN items.
- Inductive analysis identified six categories of family needs: 1) Quality of care; 2) Emotional support; 3) Communicating and providing information; 4) Spending time with the patient; 5) Physical and environmental comfort; and 6) Spiritual care.

### 4.2. Participants

Thirty-five participants were included in this study. All participants completed the QODD and 33 participants completed the MFN. As surveys were completed anonymously, no other participant information was available.

### 4.3. Quality of dying and death

Summary statistics for each QODD rating item and the total QODD score are presented in Table 4.1. For each rating item, a mean of >0.00 to ≤4.00 was considered poor; a mean of >4.00 to ≤7.00 was considered fair; and a mean of >7.00 and <10.00 was considered good.

For total QODD score, a mean of >0.00 to ≤40.00 was considered poor; a mean of >40.00 to ≤70.00 was considered fair; and a mean of >70.00 and <100.00 was considered good.

**Table 4.1: QODD rating items and total QODD score results**

| QODD rating item | N | Mean | Standard deviation | Median | Range |
|---|---|---|---|---|---|
| Having control of his/her pain | 29 | 7.28 | 2.48 | 8.00 | 2.00-10.00 |
| Having control over what was going on around him/her | 26 | 4.50 | 2.25 | 5.00 | 0.00-8.00 |
| Breathing comfortably | 34 | 7.29 | 2.77 | 8.00 | 0.00-10.00 |
| Keeping his/her dignity and self-respect | 34 | 7.50 | 3.16 | 9.00 | 0.00-10.00 |
| Spending time with his/her spouse or partner | 31 | 8.29 | 2.37 | 9.00 | 0.00-10.00 |
| Spending time with his/her children | 29 | 7.76 | 2.90 | 9.00 | 0.00-10.00 |
| Spending time with other family and friends | 31 | 7.48 | 3.16 | 9.00 | 0.00-10.00 |
| Being touched or hugged by loved ones | 33 | 8.18 | 2.31 | 9.00 | 0.00-10.00 |
| Having one or more visits from a religious or spiritual advisor | 20 | 6.70 | 3.40 | 8.00 | 0.00-10.00 |
| Having a spiritual service or ceremony before his/her death | 15 | 6.60 | 3.81 | 8.00 | 0.0-10.00 |
| Rating of having (or not having) someone present at death | 34 | 7.74 | 2.35 | 9.00 | 1.00-10.00 |
| Rating of state at moment of death | 33 | 8.58 | 1.48 | 9.00 | 3.00-10.00 |
| Rating of experience of mechanical ventilation | 31 | 7.58 | 2.13 | 8.00 | 2.00-10.00 |

| QODD rating item | N | Mean | Standard deviation | Median | Range |
|---|---|---|---|---|---|
| Rating of receiving the right amount of sedation during his/her stay in the ICU | 34 | 7.35 | 2.78 | 8.00 | 1.00-10.00 |
| **Total QODD Score** | 35 | 74.64 | 18.64 | 80.00 | 13.85-100.00 |

Overall, eleven items were rated as good: "having control of his/her pain"; "breathing comfortably"; "keeping his/her dignity and self-respect"; "spending time with his/her spouse or partner"; "spending time with his/her children"; "spending time with other family and friends"; "being touched or hugged by loved ones"; having (or not having) someone present at death; state at moment of death; experience of mechanical ventilation; and, receiving the right amount of sedation. Total QODD scores were calculated for all 35 participants. Overall, the total QODD score was good, with a mean of 74.64.

Three items were rated as fair overall: "having control over what was going on around him/her"; "having one or more visits from a religious or spiritual advisor"; and, "having a spiritual service or ceremony before his/her death". No item received an overall poor rating. Almost all patients (94.24%) had someone present at the moment of death (Table 4.2). Most patients (85.71%) were in a coma or unconscious at the moment of death.(Table 4.3). Similarly, 88.57% received mechanical ventilation (Table 4.4). Almost three quarters of participants thought their patient received the right amount of sedation.(Table 4.5).

**Table 4.2: Was anyone present at the moment of your patient's death?**

| | N | % |
|---|---|---|
| Yes | 33 | 94.29 |
| No | 1 | 2.86 |

**Table 4.3: State at moment of death**

| | N | % |
|---|---|---|
| Awake | 1 | 2.86 |
| Asleep | 2 | 5.71 |
| In a coma or unconscious | 30 | 85.71 |

**Table 4.4: Did your patient receive mechanical ventilation during his/her stay in the ICU?**

|     | N  | %     |
| --- | -- | ----- |
| Yes | 31 | 88.57 |
| No  | 3  | 8.57  |

**Table 4.5: Do you think that your patient received the right amount of sedation during his/her stay in the ICU?**

|     | N  | %     |
| --- | -- | ----- |
| Yes | 25 | 71.43 |
| No  | 9  | 25.71 |

## 4.4. Meeting family needs

Summary statistics for each MFN item are presented in Table 4.6. For each rating item, a mean of >0.00 to ≤4.00 was considered poor; a mean of >4.00 to ≤7.00 was considered fair; and a mean of >7.00 and <10.00 was considered good.

**Table 4.6: Satisfaction with meeting family needs**

| MFN item | N | Mean | Standard deviation | Median | Range |
| --- | --- | --- | --- | --- | --- |
| Satisfaction with meeting family's physical needs | 33 | 7.55 | 2.03 | 8.00 | 3.00-10.00 |
| Satisfaction with meeting family's emotional needs | 33 | 7.30 | 1.96 | 8.00 | 3.00-10.00 |
| Satisfaction with the health care team meeting family's needs | 33 | 6.85 | 2.80 | 8.00 | 0.00-10.00 |

Overall, satisfaction with meeting family's physical needs was good, with a mean of 7.55 (SD: 2.03). Overall, satisfaction with meeting family's emotional needs was good, with a mean of 7.30 (SD: 1.96). Overall, satisfaction with the health care team meeting family's needs was fair, with a mean of 6.85 (SD: 2.80)

## 4.5. Association between quality of dying and death and meeting family's needs

### 4.5.1. MFN item association with total QODD score

All three MFN items were found to be significantly associated with total QODD score. Satisfaction with meeting family's physical needs and satisfaction with meeting family's emotional needs were both found to have moderate positive associations with total QODD score. Satisfaction with the health care team meeting family's needs was found to have a high positive association with total QODD score (Table 4.7).

**Table 4.7: Spearman correlation coefficients between total QODD score and satisfaction with meeting family's needs**

| MFN items | Total QODD score (n = 33) |
|---|---|
| Satisfaction with meeting family's physical needs | 0.56 ($p<0.001$) |
| Satisfaction with meeting family's emotional needs | 0.66 ($p<0.0001$) |
| Satisfaction with the health care team meeting family's needs | 0.74 ($p<0.0001$) |

### 4.5.2. QODD items associated with three MFN items

Three of the 14 QODD items were found to be significantly associated with all three MFN items. "Breathing comfortably" was found to have moderate positive associations with satisfaction with meeting the family's physical and emotional needs and a high positive association with satisfaction with the health care team meeting the family's needs. Rating of having (or not having) someone present at death was found to have moderate positive associations with all three MFN items. Rating of receiving the right amount of sedation was found to have moderate positive associations with satisfaction with meeting the family's physical and emotional needs and a high positive association with satisfaction with the health care team meeting the family's needs (Table 4.8).

### 4.5.3. QODD items associated with two MFN items

Three of the 14 QODD items were found to be significantly associated with two of the three MFN items. "Having control of his/her pain" was found to have a low positive association with satisfaction with meeting the family's physical needs and a moderate positive

association with satisfaction with the health care team meeting the family's needs. "Keeping his/her dignity and self-respect" was found to have moderate positive associations with satisfaction with meeting the family's emotional needs and satisfaction with the health care team meeting the family's needs. "Being touched or hugged by loved ones" was found to have moderate positive associations with satisfaction with meeting the family's physical needs and satisfaction with the health care team meeting the family's needs.

### 4.5.4. QODD items associated with one MFN item

Five of the 14 QODD items were found to be significantly associated with one of the three MFN items. "Having control over what was going on around him/her" was found to have a moderate positive association with satisfaction with meeting the family's physical needs. "Spending time with other family and friends" was found to have a moderate positive association with satisfaction with meeting the family's emotional needs. "Having one or more visits from a religious or spiritual advisor" and "having a spiritual service or ceremony before his/her death" were found to have moderate positive associations with satisfaction with the health care team meeting the family's needs. Rating of experience of mechanical ventilation was found to have a low positive association with satisfaction with the health care team meeting the family's needs.

**Table 4.8: Spearman correlation coefficients between satisfaction with meeting family's needs and QODD items**

| QODD items | Satisfaction with meeting family's physical needs | Satisfaction with meeting family's emotional needs | Satisfaction with the health care team meeting family's needs |
|---|---|---|---|
| Having control of his/her pain (n = 27) | 0.49[b] | 0.40 | 0.60[b] |
| Having control over what was going on around him/her (n = 24) | 0.53[b] | 0.30 | 0.49 |
| Breathing comfortably (n = 32) | 0.65[a] | 0.58[a] | 0.80[a] |
| Keeping his/her dignity and self-respect (n = 32) | 0.38 | 0.54[b] | 0.63[a] |
| Spending time with his/her spouse or partner (n = 29) | 0.21 | 0.45 | 0.29 |

| QODD items | Satisfaction with meeting family's physical needs | Satisfaction with meeting family's emotional needs | Satisfaction with the health care team meeting family's needs |
|---|---|---|---|
| Spending time with his/her children (n = 27) | 0.53 | 0.32 | 0.23 |
| Spending time with other family and friends (n = 29) | 0.04 | 0.57[b] | 0.34 |
| Being touched or hugged by loved ones (n = 31) | 0.52[b] | 0.36 | 0.61[a] |
| Having one or more visits from a religious or spiritual advisor (n = 18) | 0.49 | 0.47 | 0.67[b] |
| Having a spiritual service or ceremony before his/her death (n = 14) | 0.59 | 0.54 | 0.68[b] |
| Rating of having (or not having) someone present at death (n = 33) | 0.54[b] | 0.50[b] | 0.66[a] |
| Rating of state at moment of death (n = 32) | 0.16 | 0.13 | 0.27 |
| Rating of experience of mechanical ventilation (n = 30) | 0.3 | 0.35 | 0.47[b] |
| Rating of receiving the right amount of sedation (n = 33) | 0.59[a] | 0.59[a] | 0.72[a] |

[a] Significant at $p<0.001$
[b] Significant at $p<0.01$

## 4.6. Understanding nurse perceptions of meeting family needs

Twenty-seven participants provided valid responses to the open-ended question "For me, meeting family needs means" and ten participants provided valid responses to the open-ended question "Any other comments?". Data from the question "For me, meeting family needs means" was inductively analysed. Responses, which ranged from a single sentence to approximately 100 words, were copied in to a Microsoft Word document and read multiple times. Words or phrases were copied in to an Excel spreadsheet to form emerging categories. These categories were continually refined and reduced to form a framework that included six main categories. The framework was reviewed by another researcher and then further refined. Data from the question "Any other comments?", which mostly contained patient and personal stories, was also added to the framework. Six categories were identified: 1)

Quality of care, 2) Emotional support, 3) Communicating and providing information, 4) Spending time with loved one, 5) Physical and environmental comfort, and 6) Spiritual care (Table 4.9). Select quotes provided by the nurses are used to emphasise the themes. These categories add support to the quantitative results of the study. They also provide a deeper understanding of how nurses view their roles in providing family centred end of life care in the ICU.

**Table 4.9: Summary of main categories from the survey text responses**

| Category | Description |
|---|---|
| Quality of care | Giving the best care possible, maintaining dignity of the patient, involving family in decision making and care of the patient, honouring patient and family's wishes, and providing after death information. |
| Emotional support | Providing emotional support, and listening to the family and responding to their needs. |
| Communicating and providing information | Keeping the family informed on the patient's condition, and being open and honest. |
| Spending time with the patient | Allowing the family as much access to the patient as possible. |
| Physical and environmental comfort | Making the family feel comfortable through provision of space, privacy, food and drink, and amenities. |
| Spiritual care | Organising access to spiritual support if needed. |

*4.6.1. Quality of care*

Fourteen participants included quality of care aspects in their definition of meeting family needs and six shared patient and personal stories. Participant 12 described their personal view of meeting family needs as: *"Holistic care. Family are as important if not more important in a way than the patient as the patient dies and their suffering ceases but the family are left to live with consequences."*

The comfort and/or dignity of the patient was mentioned by six participants. Participant 35 explained: *"Making sure [the family] know that I am treating the patient with utmost dignity (and that the patient's comfort is my top priority) and ensuring they witness me dealing with the patient as an INDIVIDUAL ... I do not expect to be able to remove the distress but I do expect to be able to reduce it by ensuring the patient's comfort... I see palliative care as one of the most important aspects of practice - the last days on earth for the patient should be as dignified and comfortable as possible."*

Allowing families to be involved in decision making and providing care, such as through applying moisturising cream, was noted by five participants. Participant 29 commented: *"I enjoy engaging families in patient care where both parties consent as I find this to be helpful later if the patient dies. Family members feel they at least had the chance to do something toward the end; to be involved."*

Honouring the patient's wishes was mentioned by four participants. Participant 7 responded that meeting family needs meant: *"Helping [the family] to feel that their loved one's needs and individual wishes were being acknowledged and that their last days were part of a dignified and compassionate process."*

Three participants gave responses on medical staff not meeting the needs of patients and their families. Participant 20 commented: *"Doctors in ICU are not always good at meeting the needs of the patient and family when it comes to palliative care. Lack of continuity between consultants also hinders good delivery of care."* Participant 7 and Participant 9 shared their patient's stories:

*"Her mouth was so dry she could think of nothing else. She could not keep her O2 mask off long enough to eat. She said she wanted to be allowed to die. Her daughter supported her in her wishes. The medical staff simply would not give up. They spoke over both the patient and her daughter "Oh come on ... That's a bit negative. We haven't given up on you yet". I had read about an independent patient advocate with particular expertise in ICU advocacy and found her details for the daughter. Within a day she had consulted with the patient/daughter and convened a bedside meeting with them and the medical and nursing staff. I was there. Very quickly a decision to cease all treatment and commence palliative measures was agreed. The patient died peacefully 2 days later... I felt both discouraged and elated. I felt the incessant treatment (she said torture) of this woman was unnecessary. Her wishes were*

*not just unmet, they were dismissed. Ultimately both [the patient] and her daughter expressed gratitude with the staff's willingness to work with the advocate. The daughter especially as she was exhausted from the whole endless quest on her mother's behalf."* (Participant 7)

*"In this particular case, the patient had [a pre-existing condition, which] continued to be an issue in the end for her, but the Dr would not allow escalation of medication for that. It was openly discussed by the health care team that the patient was dying, however in discussion with the family over the phone, the Dr continuously stopped short of explaining she was dying, the closest [they] got to explaining this to the family was to state that she was very unwell and unstable, and that she may not survive the night... The Dr would not allow us to withdraw therapies that were bothersome to the patient... [or] change our focus from active treatment to comfort measures. It was distressing for the patient and it was distressing for the nurses."* (Participant 19)

### 4.6.2. Emotional support

More than half of the participants who described their views on meeting family needs referred to providing emotional support to the family in their response. Providing emotional support included treating the family with kindness and respect, listening to the family and being responsive to them. The importance of providing emotional support to the family was emphasised by Participant 34: *"Emotional support is the main need."* Participant 13 shared the positive experience they had providing emotional support to the family of the patient they provided end of life care to: *"While the family had not talked about their father dying and his wishes, they were able to come together and support each other through this difficult time. Seeing how each individual copes in their own way, and encouraging them to accept and support the grieving process in each other was a privilege. Not all families are able to do this, so it was lovely to observe the caring in this family."*

### 4.6.3. Communicating and providing information

Twelve participants referred to communicating and providing information in their response. Family members need to be informed and educated: *"All members of the team need to include family in all discussions taking place"* (Participant 34). The communication of information must be open, honest and timely: *"[Being] honest and direct in all*

*communication with family is a priority for me. Keeping family updated daily is a requirement, even if it's "No Change""* (Participant 14).

### 4.6.4. Spending time with the patient

Nine participants mentioned allowing family's time with the patient in their response. Responses included families having easy access to the patient and no restrictions on this time *"Allowing the family as much time as needed to be with the patient before and after death"* (Participant 25). Staff should also be respectful of the family's time with the patient: *"Time with the patient that isn't interrupted by nurses and doctors unless absolutely necessary"* (Participant 24)

### 4.6.5. Physical and environmental comfort

Nine participants mentioned providing physical and environmental comfort for the family in their response. Physical and environmental comfort needs are met through the provision of space, privacy, food and drink, and amenities: *"[I provide] physical comfort in the way of chairs and refreshments ... removing as much equipment as possible [and] turning monitor to private"* (Participant 25)

Two participants provided additional comments on noise and privacy in their ICU:
*"…our environment is noisy, lacks privacy and often there is other stressful events occurring with other patients and families pick up on theses stressors. Although we are happy to have lots of family in during the dying phase due to environment they can still feel like they are in the way. We often don't have enough chairs for a large family. Family mostly have to share a waiting room when sometimes they would appreciate privacy."* (Participant 12)

*"Unfortunately, unless the patient is in an isolation bay (glass sliding door closed room.) It's very difficult with the noise from other patients, families or the unit as a whole. A curtain drawn over the front of the room doesn't allow loved ones to have enough privacy. As a unit there has been a "please be quiet sign" made up to signal to staff there is privacy and low noise required."* (Participant 4)

*4.6.6. Spiritual care*

Seven participants included spiritual/religious needs as a component of meeting family needs. Specifically ascertaining if the family has any spiritual needs and organising support with a spiritual caregiver*: "Ensuring the spiritual care person touches base to provide some support to the family in the way they need"* (Participant 13).

## 4.7. Summary and limitations

Thirty-five participants were included in this study. Overall, ICU nurses perceived the quality of dying and death to be good based on total QODD score. Individual QODD item means were rated fair to good. The highest rated item was the rating of state at moment of death and the lowest rated item was "having control over what was going on around him/her." A lack of control over surroundings was supported by the qualitative data, with nurses describing physician's decisions not always meeting the needs of patients and the challenges of the ICU environment.

Satisfaction with meeting families' physical needs was high. Inductive analysis identified that physical and environmental comfort as a category of family need. This need was met through the provision of space, privacy, food and drink, and amenities.

Overall, both satisfaction with meeting families' emotional needs was moderate and satisfaction with the health care team meeting families' needs was moderate. Inductive analysis revealed five relevant categories of family needs: quality of care; emotional support; communicating and providing information; spending time with the patient; physical and environmental comfort; spiritual care. Quality of care needs can be met through maintaining the dignity of the patient, and involving family in decision making and care. Emotional support can be provided by making the family feel supported and listened to. Communicating and providing information needs requires strategies such as openness and honesty and keeping the family informed. Spending time with the patient needs can be met through facilitating as much access to the patient as possible. Spiritual care needs can be met through organising access to spiritual support if needed.

All three MFN items were positively associated with total QODD score. Breathing comfortably, having someone present at death and receiving the right amount of sedation were positively associated with all three MFN items. "Having control of his/her pain";

"keeping his/her dignity and self-respect"; and "being touched or hugged by loved ones" were significantly associated with two of three MFN items. "Having control over what was going on around him/her"; "spending time with other family and friends"; "having one or more visits from a religious or spiritual advisor"; "having a spiritual service or ceremony before his/her death"; and rating of experience of mechanical ventilation were significantly associated with one of three MFN items.

# CHAPTER 5. DISCUSSION AND CONCLUSION

## 5.1. Overview of Chapter 5

Chapter 5 discusses the results of the current study to address the research overall aim: to investigate intensive care nurse perceptions of the quality of dying and death of patients who died receiving end of life care and their perceptions of whether this care met the needs of the patient's families. This is followed by discussion of the original research contribution, study limitations, future research directions and an overall conclusion.

## 5.2. RQ1: What are nurse perceptions of quality of dying and death and whether family needs are met?

### 5.2.1. Quality of dying and death

Overall, the quality of dying and death was good, with a mean total QODD score of 74.64 (SD: 18.64). Nurse ratings of the quality of individual QODD items ranged from fair to good. The highest rated item was the rating of state at the moment of death, with a mean of 8.58 (SD: 1.48). Thirty of the 33 patients (85.71%) who were rated on this item were in a coma or unconscious. The next two highest rating were: "spending time with his/her spouse or partner" and "being touched or hugged by loved ones"; both with mean scores >8.00. The lowest rated item was "having control over what was going on around him/her", with a mean of 4.50 (SD: 2.25). This was followed by "having one or more visits from a religious or spiritual advisor" and "having a spiritual service or ceremony before his/her death". The three lowest rated items also had the lowest number of valid responses.

Low participant response rates to questions can indicate the item may not be appropriate for evaluation by participants. In the current study, eleven of the 14 rating items had a valid response rate of >80%. In a larger US study of 178 patients conducted by Hodde (30), only three items had a valid response rate of >80% (ie. "keeping his/her dignity and self-respect", "being touched or hugged by loved ones", and "rating of receiving the right amount of sedation during his/her stay in the ICU").(30) In the current study, only one item had a valid response rate of <50%: "having a spiritual service or ceremony before his/her death". This is also similar to the work of Hodde (30) where this item and "having control of what is going on around him/her" had a valid response rate of <50%. The inability of more than half of the participants in both studies to rate having a spiritual service or ceremony before his/her

death may indicate this item is unsuitable for use in nurse assessed quality of dying and death.

The data collection method of the current research differs from studies utilising the QODD and MFN identified in the literature review that commonly were conducted via paper-based questionnaire. Previous studies have all been hospital-based and the questionnaires were distributed to clinicians within 24 to 48 hours of patient death. No studies utilising the QODD and/or and involving Australian ICU clinicians were identified. This makes it difficult to make assumptions about the results of this research in an Australian context. Comparisons with international studies can give some insight. Levy et al. (2005) conducted a cross-sectional survey of family members and ICU clinicians using the 21-item ICU version of the QODD with 38 nurses included as participants.(28) The study was set in two US ICUs and nurses were asked to complete the QODD within 48 hours of patient death. Table 5.1 presents a comparison of mean item scores between the current study and Levy et al. (2005). As different versions of the QODD were used, only means for items used in both studies are reported. Seven of the 10 items varied by <1.00 between studies. The greatest variation was having control over what was going on around him/her, which had a difference of 1.36 between the studies.

**Table 5.1: Comparison of mean scores for QODD item with Levy et al. (2005)**

| QODD rating item | Testa (2016) | Levy (2005) |
|---|---|---|
| Having control of his/her pain | 7.28 | 6.84 |
| Having control over what was going on around him/her | 4.50 | 5.86 |
| Breathing comfortably | 7.29 | 6.70 |
| Keeping his/her dignity and self-respect | 7.50 | 6.35 |
| Spending time with his/her spouse or partner | 8.29 | 6.96 |
| Spending time with his/her children | 7.76 | 7.55 |
| Being touched or hugged by loved ones | 8.18 | 7.53 |
| Having one or more visits from a religious or spiritual advisor | 6.70 | 7.54 |
| Having a spiritual service or ceremony before his/her death | 6.60 | 6.98 |
| Rating of having (or not having) someone present at death | 7.74 | 7.93 |
| **Total QODD Score** | 74.64 | 66.90 |

The study conducted by Levy (28) had 38 nurse participants, making it a good comparative study in terms of size. Comparison between the current research and that of Levy (28) revealed similar findings. The difference between the mean of seven of the ten QODD items that were reported in both studies was <1.00. The greatest mean difference was 1.36. The mean total QODD score of Levy (28) was 66.9 (SD: 16.3), 7.74 lower than the score of the current study. The difference in overall means is likely to be due to the utilisation of a different version of the QODD. Eleven of the 21 items used to calculate the total score in Levy (28) were not used in the current study. The similarity in sample size and mean scores between Levy (28) and the current study could suggest there are no substantial differences between study populations. If this is the case, the current study results appear comparable to that of other hospital-based studies.

Comparisons of the current research findings with similar research were limited, as other studies tended not to report means for individual questions, only the overall QODD scores. The Levy (28) study was the only identified study to report the mean of individual items. Other studies reported mean total QODD scores only. The overall mean score on the QODD was dissimilar to QODD means scores from two large US studies of death and dying in the ICU involving nurse respondents. In a before and after study evaluating an ICU quality improvement intervention, the pre-intervention mean total QODD score was 63.1 (SD: 18.1).(44) This study was set in a single US hospital and 523 nurses completed the 21-item QODD. In a cluster-randomised trial evaluating an ICU quality improvement intervention, the baseline mean total QODD score was 61.8 (SD: 23.9) in the intervention group, and 59.9 (SD: 21.9) in the control group.(45) This trial involved 12 US hospitals and 636 nurses completed the 21-item QODD. The overall mean score on the QODD was similar to QODD means scores from two other US studies of death and dying in the ICU involving nurse respondents. In a prospective cohort study determining the feasibility of using nurse ratings of quality of dying and death and factors associated with nurse assessment of the quality of dying and death for patients dying in the ICU, the mean total QODD score was 73.1 (SD: 21.4).(30) This study was set in a single US hospital and 178 nurses completed the 14-item QODD. In a before and after evaluation of a standardised order form for the withdrawal of life support in the ICU, the pre-intervention mean total QODD score was 78.3 (SD: 16.7).(89) This study was set in a single US trauma centre and 143 nurses completed the 14-item QODD. The two larger studies (44, 45) utilising the 21-item QODD had lower total scores, similar to Levy (28). The two smaller studies (30, 89) utilising the 14-item QODD

had higher total scores that were comparable to the current study. Based on the available evidence, the data collected in the current study is comparable to data collected internationally in a hospital setting. Further research in an Australian setting with a larger number of participants is needed to confirm this.

Nurse and patient data were not collected in this study, and in any case with the modest sample size, it is not possible to conclude whether nurse and patient characteristics affected the ratings of this study. Previously, Hodde (30) identified three patient factors that positively influenced nurse rated QODD scores: 1) not having cardio-pulmonary resuscitation (CPR) performed in the last 8 hours of life; 2) having someone present at the moment of death; and 3) being admitted with an acute diagnosis. It is unknown whether these or any other nurse or patient factors influenced the QODD ratings and total score of the current study. Downey (70) found no significant association between MFN scores and nurse and patient characteristics.

### 5.2.2. Meeting family needs

Overall, nurses were most satisfied with meeting families' physical needs. In regards to physical needs, participants described making families feel comfortable through provision of space, privacy, food and drink, and amenities. Facilitating access to the patient so family members may be physically near them was also described. Prior studies have found intensive care nurses endeavour to create a dignified bedside for the dying patient's family by adapting the environment and attempting to ensure privacy.(11, 90, 91) Family needs have been assessed in other studies using the Critical Care Family Needs Inventory (CCFNI).(79, 80, 92, 93) The CCFNI investigates the importance of family needs and is divided in to five dimensions: assurance, information, proximity, comfort and support. A descriptive-analytical study utilised the CCFNI to determine the top five family needs identified by nurses and families. The study population were comprised of a randomly selected sample of 80 nurses and 80 family members of ICU patients. There were similarities and differences in the top five needs identified by both populations. The proximity needs of families were underestimated by nurses.(92) Proximity is understood as the state of being physically near to the patient.(80) Kosco (93) compared family and ICU nurse perceptions of family needs being met. A sample of 45 family members and 45 nurses of ICU patients was included in the study. A significant difference was found between nurse and family member perceptions on one item of the Needs Met Inventory (NMI): to visit at any time. In the present study,

only one-third of the participants describing their views on meeting family needs had a spending time with the patient category in their response. It is possible the participants of this study also underestimated families' need to be near their loved one and this affected their perception of meeting family's physical needs. Without data from the patient's family, it is unknown whether this occurred.

Satisfaction with meeting families' emotional needs was reported as slightly lower than physical needs in the current study, but nevertheless "good" overall. More than half of the participants who described their views on meeting family needs referred to providing emotional support to the family, with Participant 34 stating it to be "the main need". Similarly, a previous qualitative study of Australian ICU nurses' end of life care beliefs and practices found a substantial amount of each interview was spent on participants discussing providing emotional support for their patient's families.(26) Likewise, a cross-sectional survey of 159 Australian intensive care nurses and an integrative review both found that nurses provide emotional support to families and prepare them for treatment withdrawal through communicating with them and keeping them informed.(91, 94) Almost half of the participants in the current study who described their views on meeting family needs referred to communicating and providing information to the family. The importance of communicating and providing information to families has been observed in previous studies. Downey (70) found that nurse ratings of the quality of their communication with families had significant positive associations with satisfaction with meeting family needs. A literature review aimed at understanding the family needs of ICU patients found that information and assurance needs were the highest priority for families.(80) Two reviews exploring factors influencing family satisfaction with end of life care in the ICU found good clinician communication positively influenced family satisfaction.(34, 95) Meeting the communication needs of families can, however, be difficult in the ICU due to the lack of prior relationship between clinicians and families.(96) Visser (9) conducted a systematic review to describe physician-related barriers to communication and patient- and family-centred decision making in end of life ICU patients. They found strong evidence for physicians' lack of communication training and skills. Scheunemann (97) conducted a cross-sectional study in five ICUs and found there was no discussion of the patient's preferences or values in 30% of family conferences. Hinkle (34) found specific communication strategies can be used to increase family satisfaction with end of life care in the ICU: expressing empathy, non-abandonment, reassurance and providing written information.

Satisfaction with the health care team meeting the needs of families' was the lowest rated in the current study. One participant commented that ICU physicians do not always meet patient and family needs when it comes to end of life care. Participants 7 and 19 shared stories of the health care team not meeting the needs of their patients and their patients' families. Participants 4 and 12 provided comments on the noise and lack of privacy in the ICU. Previous studies have explored barriers to health care teams meeting the needs of patients and families whilst providing end of life care. Brooks (5) conducted a qualitative focus group study exploring the perspectives of Australian ICU physicians and nurses on providing end of life care. Conflict between ICU clinicians and external medical teams was identified as a common barrier. Conflict was largely due to opposing views on goals of the patient's care. The timing of end of life decision making was a source of frustration for participants, as it was for the two nurses that shared their stories in this study. A literature review exploring issues in end of life care which impact on ICU nurses was performed by Fridh (98). They found issues reported by nurses around end of life care have remained the same for over 30 years: problems with collaboration between medical teams and communication about the transition from treatment to end of life care. Delays in end of life care and providing treatment nurses view as futile may explain why participants rated satisfaction with the health care meeting families' needs lower than satisfaction with themselves meeting families' needs.

Without the involvement of family members of the patient in the current study, the extent to which their needs were met is unknown. Previously, Kosco (93) found significant differences between nurses and family members for two of the 45 CCFNI items; to have a specific person to call at the hospital when unable to visit, and to have someone be concerned with the relative's health; and one of the 45 NMI item: to visit at any time. This suggests nurse perceptions of meeting family needs are largely in agreement with family members perceptions.

Just as there is evidence that nurses are more critical raters than families on quality of dying and death, there is some evidence they may also be more critical raters of meeting family needs. A study of 30 ICU nurses and 20 families compared their perceptions that family needs were met. Family members report that their needs were met to a greater extent than nurses on all 22 items of the NMI.(99) This was conducted in a single hospital and had a small sample size, but when combined with the other evidence of ICU nurses as critical raters (27-29), it can be argued that the participants in the current study were more likely to

underestimate meeting family needs than overestimate it. Further research comparing nurse and family perceptions of meeting family needs is warranted.

## 5.3. RQ2: Is there an association between nurse perceptions of quality of dying and death and meeting family needs?

### 5.3.1. Symptom control

The four QODD items associated with symptom control were all found to have positive associations with at least two MFN items. Breathing comfortably and the rating of receiving the right amount of sedation were significantly associated with all three MFN items. Having control of his/her pain was associated with satisfaction with meeting the family's physical needs and satisfaction with the health care team meeting the family's needs. The rating of experience of mechanical ventilation was found to have a low positive association with satisfaction with health care team meeting family's needs. Thirty-one (88.57%) participants had patients that received mechanical ventilation. This experience was rated as good overall. Prior studies support the association of symptom control and meeting family needs. Coombs (91) found the process of withdrawal of life support was managed by nurses per the needs of the patient and their family. It was important to families that their loved ones were not distressed and were comfortable and meeting this need substantially influenced family satisfaction with end of life care. Two reviews exploring factors influencing family satisfaction with end of life care in the ICU found good symptom control positively influenced family satisfaction.(34, 95) A cross-sectional US national survey of seriously ill patients, recently bereaved family, physicians, nurses and other care providers aimed to determine factors considered important at the end of life. Pain and symptom management was rated as being important across all surveyed groups.(100) Pain and symptom control is therefore prioritised by dying patients, families, and clinicians. As commented by one of the participants in the current study, the patient's suffering ceases at death, but the family lives with the consequences of the dying process. Providing greater symptom control can ease the burden experienced by both patient and family, leading to better outcomes for both.

### 5.3.2. Presence of family

The rating of having someone present at the moment of death had moderate positive associations with all three MFN items. Similarly, two qualitative studies noted agreement

amongst the intensive care nurse participants that patients should not die alone without family present.(90, 101) Evidence from prior studies suggests having family present at the moment of death leads to better outcomes for both the patient and their family. Hinkle (34) found family presence at time of death was associated with increased family satisfaction. Hodde (30) found that having someone present at death was associated with a higher quality of dying and death. A study exploring the circumstances under which patients died in ten Swedish ICUs found the patients who died without a family member present received less sedation and analgesia.(102) The authors concluded that patients without family present at the time of death were at risk of having their physical needs underestimated.

Being touched or hugged by loved ones was found to have moderate positive associations with two MFN items: satisfaction with meeting family's physical needs and satisfaction with health care team meeting family's needs. Likewise, nurse participants of prior studies have described encouraging family members to touch the patient.(26, 90, 94) Hov (103) described nurses using touch to reduce stress experienced by the patient and to confirm the patient's sense of being alive.(103) A qualitative study explored the emotional support needs of dying patients and using focus groups involving terminally ill participants identified that comfort being provided through touch as an important component of emotional support.

Spending time with other family and friends was found to have a moderate positive association with satisfaction with meeting family's emotional needs. Family presence at the end of life is encouraged as it gives the opportunity for family members to spend important time together and say final goodbyes.(104) Spending time with his/her spouse or partner and spending time with his/her children was not found to have any significant associations with any of the MFN items. Further research is needed to explore why spending time with other family and friends is significantly associated with meeting family's emotional needs, but spending time with spouse/partner and children is not.

### 5.3.3. Dignity

Keeping dignity and self-respect was found to have moderate positive associations with two MFN items: satisfaction with meeting family's emotional needs and satisfaction with health care team meeting family's needs. Having control over what was going on around him/her was found to have a moderate positive association with satisfaction with meeting family's physical needs. The loss of autonomy for a dying patient in the ICU can lead to a loss of

dignity.(103) A systematic review of literature involving dignity and patient-centred care for people with palliative needs in the hospital setting found many threats to patients dying with dignity within acute care. These threats include symptom control and existential distress; approaches and models in care provision (especially communication, attitudes and behaviours of healthcare providers, as perceived by patients and families); and healthcare settings and design.(105) A qualitative interview study involving nine experienced intensive care nurses explored their descriptions of providing care to dying patients. Providing dignified end of life care and giving family members a lasting memory of a calm and dignified death despite previous suffering and the ICU environment was a dominant theme.(90)

### *5.3.6. Spiritual care*

Having one or more visits from a religious or spiritual advisor and having a spiritual service or ceremony before his/her death were both found to have moderate positive associations with satisfaction with health care team meeting family's needs. Spiritual care was identified as a category of meeting family needs by participants. Comparably, two reviews exploring factors influencing family satisfaction with end of life care in the ICU found spiritual care positively influenced family satisfaction.(34, 95)

### *5.3.8. Comparing nurses' end of life perceptions internationally*

Comparisons have been made with the perceptions of the intensive care nurse participants in the current study and those of international studies. Legal and cultural environments vary between countries, and may affect perceptions of end of life care and quality of dying. Differences in clinician's end of life care actions and attitudes have been demonstrated in comparative international studies.(106, 107) A qualitative, multi-centre study exploring and comparing intensive care nurses' perceptions of a good death and quality of end of life care between countries with different legal and cultural contexts was conducted in England and Israel. Nurses' perceptions of factors that facilitate and prevent a good death and good quality end of life care were similar in both countries, despite clear differences in legal and cultural systems.(108) Whilst end of life practices and attitudes may vary between countries, this provides evidence of the comparability of intensive care nurse perceptions of what constitutes good quality end of life care.

## 5.4. Original research contribution

As best as can be ascertained, this study is the first to explore associations between nurses' perceived quality of dying and death and meeting family needs in an adult intensive care environment. No identified study in an Australian or international setting has measured these two constructs together in this environment. A study utilising a modified QODD and the MFN was recently conducted in a paediatric intensive care environment. Paediatric intensive care is studied separately from adult intensive care as there are important differences between the two, especially in terms of family involvement and experiences.(75)

This study has provided insight into how intensive care nurses perceive family-centred care. Several categories of meeting family needs emerged in this study: quality of care, emotional support, communicating and providing information, spending time with loved one, physical and environmental comfort, and spiritual care. This study has also identified several areas where nurses perceive patient care and family care intersect: symptom control, presence of family, dignity and spiritual care. Tools that measure, and interventions to improve, the quality of patient- and family- centred end of life care should target these constructs.

## 5.5. Limitations

There are several limitations to this study. Firstly, the small sample size, low response rate and lack of demographic information on nurses and their patients make it difficult to draw firm conclusions on the generalisability of the study results. The small sample size and low response rate may in part be due to excluding patients who died within 48 hours of ICU admission. As no information was collected about patient ICU stay and there are no other studies assessing QODD and MFN together in an adult intensive care setting, 48 hours was chosen to ensure nurses had greater contact with family and were more aware of their needs. Due to the sampling method and inclusion criteria, the true response rate is unknown. Of the 926 ACCCN members emailed a study invitation, it is unknown how many of the emails were undeliverable and how many of those who received an invitation were eligible to participate in the study. Likewise, it is unknown how many eligible participants saw the Nurse Uncut advertisement and chose not to participate. As noted by Downey (70), whilst there are multiple studies that demonstrate significant differences in the characteristics of responders versus non-responders (109-111), there are also studies that have found that when the data from responders were compared to the data from a combination of responders and

non-responders, the effects of non-response on study results were insignificant.(110, 112, 113) These studies had a larger number of participants and higher response rates than the current study, therefore it cannot be assumed the effect of non-responders in the current study would be insignificant.

The lack of patient data means it was not possible to look at factors which have been shown to influence QODD score, for example, route of admission to ICU.(114) Other factors, such as patient age, chronic disease, and Glasgow Coma Scale scores have not been found to be associated with the 14-item QODD.(30) It is difficult to draw conclusions about the overall quality of dying and death in Australian ICU's or how representative this sample is without patient information. Nurses and patient characteristics were not found to have significant associations with MFN scores.(70)

Secondly, it is unknown how much time elapsed between the patient's death and nurse completion of the online survey. In previous studies conducted in hospital settings, the QODD has been distributed to nurses for completion within 24 hours of the patient's death.(28, 67) In one study the QODD was distributed within 72 hours of death with follow-up requests made to non-responders up to 5 weeks later.(45) The MFN has been previously distributed to nurses for completion within 48 hours of the patient's death with follow-up requests made to non-responders up to 4 weeks later.(70) There may be concerns about the accuracy of data when there has been a lapse of time between patient death and survey completion. However, as this survey was completed voluntarily and without reward and is based on nurse perceptions, it is probable the respondents provided valid information relating to their experiences.(70) Additionally, a study determining the reliability of nurse recall in measuring adverse patient outcomes in inpatient psychiatry found the period of recall (two vs. four weeks) did not significantly affect the reliability of nurse recall.(115) This suggests nurses are reliable reporters of adverse patient outcomes.

Thirdly, this study only looks at nurse perceptions of quality of dying and death and meeting family needs. Gerritsen (67) compared family, nurse and physician QODD ratings and found family members tended to rate pain control lower than nurses and physicians. It is not known how the patient's family members or physicians (or the patient's themselves) would have rated the quality of end of life care. There is evidence of agreement between nurse perceptions and family perceptions of family needs being met, and of nurses being more critical of family needs being met than family.

Finally, while there has been some validation of the QODD and MFN, neither of these tools has been validated in an Australian setting. A lack of validated tools to assess the quality of end of life care in Australian ICUs is problematic, especially given that there is an increased focus at all levels of government to improve the safety and quality of end of life care in Australia.(116) The QODD was developed in the US and has mostly been used in an American population. A European study using the QODD found that it needed modification to be suitable for use in a European ICU population.(67) Prior to further use in Australia, the QODD and MFN should be subjected to expert review to establish face validity of their items and determine whether modification is necessary. The current study modified the scale anchors of the QODD to assist in the conversion of the tool to an Australian context. A study with a larger number of participants would allow these tools to undergo psychometric testing in an Australian setting.

## 5.6. Future research

Further study in the area is warranted to confirm and build upon the findings of this study, and to help gain a greater understanding of patient- and family-centred end of life care in the ICU in an Australian context. Future research should be conducted in hospital settings, where patients with a shorter ICU stay time can be included and patient and clinician information can be collected. This will allow for the inclusion of a larger number of participants. Family member assessments of the quality of dying and death of their loved one and of their needs being met should also be sought to compare with clinician assessments and to provide a more in depth picture of family-centred care. Family-centred care cannot fully be assessed without including families as participants.

The tools used in this study do not measure communication or shared decision making. Both are essential components of family-centred care and have been shown to influence family satisfaction with end of life care.(34, 95) The nurse completed tools identified in the literature review did not measure these two constructs. New tools to more comprehensively measure patient- and family-centred end of life care should be developed and validated. If pre-existing tools are to be used, they should be adapted and validated for the Australian setting.

## 5.7. Conclusion

Caring for the family is an integral part of providing end of life care for intensive care nurses. This study has provided insight into how intensive care nurses perceive family-centred care and a direction for future research. In the main, quality of dying and death of patients in an ICU setting was perceived as good. Overall satisfaction with meeting family needs ranged from fair to good. Quality of dying and death for the patient and family needs being met were shown to have significant positive associations with each other. A larger hospital-based study measuring the perspectives of clinicians and family members is necessary to confirm these findings and to provide a greater picture of end of life care in the ICU in an Australian setting.

Several categories of meeting family needs emerged in this study: quality of care, emotional support, communicating and providing information, spending time with loved one, physical and environmental comfort, and spiritual care. This study also identified several areas where nurses perceive quality of dying and death and meeting family needs intersect: symptom control, presence of family, dignity and spiritual care. Future research investigating the quality of patient- and family- centred end of life care should measure these constructs.

Measuring the quality of end of life care in the ICU is hindered by a lack of available tools. Communication and shared decision making, essential components of patient- and family-centred care, were not measured by either of the nurse completed tools used in the current study. Future research should involve the development and testing of tools for an Australian setting or consideration of the modification of pre-existing tools.

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# APPENDICES

## Appendix A: Summary of studies included in literature review

| Tool | Author | Country | Study Objective | Population | Respondent | Method | Measure description / domains | Measure properties |
|------|--------|---------|-----------------|------------|------------|--------|-------------------------------|--------------------|
| **ADBFMI** | Gallagher et al(61) | Canada | To assess perceived level of satisfaction with end-of-life care, focusing on the last 48 hours of life. | 90 bereaved family members of patients who died within an organisation in British Columbia | Family members | Telephone Interview | Measures seven domains of end of life care within hospitals, hospices, and residential care facilities, including: physical and emotional support; inform and promote shared decision-making; encourage advance care planning; focus on individual; attend to the emotional and spiritual needs of the family; provide coordination of care; support for the self-efficacy of the family | Authors report reliability varies from 0.58 to 0.87 and the validity ranges from 0.36–0.69 |
| **CANHELP Bereavement Questionnaire** | Sadler et al(64) | Canada | Assess family members' satisfaction with EOL care; identify associations between level of satisfaction and patient factors; and identify high-priority targets for quality improvement in the care of dying patients and their family members. | 352 family member contacts of patients who died in a large academic tertiary care hospital | Family members | Postal survey | 40 item tool addressing eight domains of care including patient pain and symptom management; timely and clear communication; information to prepare the family for approaching death; compassionate care, comfort, dignity, and respect; patient-centred decision making; care of the family; family support; and caregiver satisfaction with hospital facilities and staff | Authors report previously validated |
| **CES** | Kinoshita et al(66) | Japan | To investigate the evaluation of end-of-life care from bereaved family of cancer | 4011 bereaved family of cancer patients who had died in ICUs in Japan | Family members | Postal survey | Evaluates the structure and process of end-of-life care by rating the necessity of improvement for each item on a 6-point Likert-type scale | Not reported |

| Tool | Author | Country | Study Objective | Population | Respondent | Method | Measure description / domains | Measure properties |
|---|---|---|---|---|---|---|---|---|
| | | | patients who had died in ICUs in Japan | | | | | |
| **Developed by authors** | Cheung et al(65) | Australia | To determine whether palliative care teams can improve patient, family and staff satisfaction for patients receiving end-of-life care in the intensive care unit and reduce surrogate markers of health care costs | Patients admitted with a terminal or preterminal condition, for whom the treating intensivist considered that escalating or continuing treatment was unlikely to achieve significant improvement in the patient's clinical condition. | Family members Staff | Self-administered | Measures quality of care Family version domains: Patient- and family-centred decision making, Communication, Continuity with care, Emotional and practical support, Symptom management and comfort care, Spiritual support, Patient care Staff version domains: Satisfaction with symptom management, Satisfaction with communication and support, Satisfaction with goals of care, Grading of difficulty in managing family in day-to-day issues, Grading of difficulty in managing family in end-of-life issues, Overall satisfaction with patient management | Not reported |
| **Developed by authors** | Kjerulf et al(63) | Canada | To determine levels of satisfaction with care, visitation, support, comfort and pain measures in three critical care areas where the stated goals were to provide not only quality care to patients, but also support to families | 300 next of kin who had a loved one die in the critical care areas of an urban tertiary care centre within the prior three years | Family members | Postal survey | Survey questions covered such issues as perceptions regarding the decision to stop life supports, access to the patient, access to physicians and nurses and information regarding the patient's status, support provided by the hospital, and organ donation attitudes | Reliability and validity data are not available |
| **Evaluation of Experiences of** | Kirchhoff et al(11) | US | To assess the feasibility of testing four tailored messages to prepare families of patients | 22 participants who were next of kin to patients in a critical | Family members | Telephone interview | Consists of 25 questions to assess the next of kin's level of coping, the level of preparation for the withdrawal of | Not reported |

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| Tool | Author | Country | Study Objective | Population | Respondent | Method | Measure description / domains | Measure properties |
|---|---|---|---|---|---|---|---|---|
| **Withdrawal Tool** | | | having a planned withdrawal of life support, to assess barriers to conducting such a study, and to obtain preliminary data on measurable effects that could be used to compare such preparation with usual care | care unit at the University of Wisconsin Hospital who were having life support withdrawn | | | life support, and the effect of the preparation on the experience of withdrawal of life support | |
| **FATE** | Finlay et al(71) | US | To evaluating the quality of end-of-life care for veterans dying with cancer | Surrogates for 262 cancer patients five VA Medical Centers | Family members | Telephone interview | Contains 32 items. Six domains encompass 25 items: the patient's well-being and dignity, adequacy of information and communication, emotional and spiritual support, care around the time of death, access to services before the patient's death, and access to benefits and services after the patient's death. The remaining seven items include four questions on symptom management and one each regarding overtreatment, undertreatment, and preferences for site of death. | To evaluating the quality of end-of-life care for veterans dying with cancer |
| **FS-ICU** | Curtis et al (2008)(44) | US | To evaluate the effectiveness of a multi-faceted quality improvement intervention to improve palliative care in the ICU | 590 patients who died in the ICU or within 24 hours of transfer | Family members | Postal survey | The first section assesses family satisfaction with care and the second section assesses family satisfaction with decision making. Measures the following domains in family satisfaction with care: care of family, care of patient, professional care, ICU environment and overall satisfaction. | Authors report previously shown to be reliable and validate |

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| Tool | Author | Country | Study Objective | Population | Respondent | Method | Measure description / domains | Measure properties |
|---|---|---|---|---|---|---|---|---|
| | | | | | | | Measures the following domains in family satisfaction with decision making: information need, deliberation and overall satisfaction | |
| | Curtis et al (2011)(45) | US | To evaluate the effectiveness of a quality-improvement intervention to improve ICU end-of-life care | Patients dying in the ICU or within 30 hours of ICU discharge in 12 hospitals | As above | As above | As above | As above |
| | Dalisay-Gallardo et al(68) | Phillipines | To determine the level of satisfaction of family members with the quality of EOL care in the medical ICU | 43 adult family members of loved ones who stayed in the ICU of a tertiary hospital | As above | Telephone survey or a written questionnaire | As above | Authors report partial validation of this filipino version of the questionnaire. Cronbach's alpha for the translated questionnaire and its subscales and domains are all higher than the 0.7 criterion for modest reliability, except for the ICU environment domain, which has a Cronbach alpha of 0.57 |
| | Gerstel et al(46) | US | To examine the duration of life-support withdrawal and its association with overall family satisfaction with care in the ICU | Family members of 584 patients who died in an ICU at 1 of 14 hospitals after withdrawal of life support | As above | Postal survey | As above | As above |
| | Gerritsen et al(67) | The Netherlands | To elucidate how family members and ICU caregivers experience the dying process of their patient | 100 consecutive patients that died in three ICUs | As above | Telephone interview | As above | As above |
| | Gries et al(48) | US | To determine patient and family characteristics and | A cohort of ICU patients dying in 10 | As above | As above | As above | Authors report previously shown to be reliable and validate |

| Tool | Author | Country | Study Objective | Population | Respondent | Method | Measure description / domains | Measure properties |
|------|--------|---------|-----------------|------------|------------|--------|-------------------------------|--------------------|
| | | | chart the documentation of processes of care that are associated with increased family satisfaction with end-of-life decision making for ICU patients | medical centres in the Seattle-Tacoma area | | | | |
| | Heyland et al(62) | Canada | To develop and test the feasibility of administering a questionnaire to measure family members' level of satisfaction with care provided to them and their critically ill relative. | 33 family members of no surviving ICU patients | As above | As above | As above | Authors found the questionnaire has some measure of reliability and validity and is feasible to administer to next of kin of critically ill patients |
| | Jacobowski et al(49) | US | To test the hypothesis that family attendance at structured interdisciplinary family rounds would enhance communication and facilitate end-of-life planning | 227 patients in a 26-bed medical ICU | As above | Telephone survey | As above | Authors report Cronbach's alpha coefficients for the two subscales (care and decision making) were 0.92 and 0.88, respectively, and the 2 subscales showed good correlation with each other (Spearman $\rho = 0.73$, $P < .001$), supporting their combination into a single scale with a Cronbach $\alpha$ coefficient of 0.94. Also report validity was demonstrated by a significant correlation with results of the previously established Family-QODD |
| | Johnson et al(50) | US | To evaluate the activities spiritual care providers' conduct to support patients | 275 family members of patients who died in the ICU or within | As above | Postal survey | As above | Authors report previously validated |

| Tool | Author | Country | Study Objective | Population | Respondent | Method | Measure description / domains | Measure properties |
|------|--------|---------|-----------------|------------|------------|--------|-------------------------------|--------------------|
| | | | and families, and whether those activities are associated with family satisfaction with ICU care | 30 hours of transfer from the ICU. | | | | |
| | Kaufer et al(51) | US | To examine family satisfaction with end-of-life care in a medical ICU before and after a palliative care intervention was implemented there | Family members of patients who died in the ICU in 2005 and 2006 | As above | Interview | As above | Authors report previously shown to be reliable and validate |
| | Lewis-Newby et al(52) | US | To assess measurement characteristics of two family-assessed questionnaires across three patient age groups. | One family member for four hundred and ninety-six patients who died in an ICU at a single hospital | As above | Postal survey | As above | As above |
| | McCormick et al(53) | US | To examine the social worker component of an intervention to improve interdisciplinary palliative care in the ICU | 275 families of patients who died in the ICU or within 30 hours of transfer from ICU | As above | As above | As above | As above |
| | Osborn et al(56) | US | To investigate the relationship between family satisfaction with ICU care and overall ratings of the quality of dying as a means of identifying targets for improving end-of-life experiences for patients and families. | 1,290 family members of patients who died in the ICU or within 30 h of transfer out of the ICU | As above | As above | As above | As above |

| Tool | Author | Country | Study Objective | Population | Respondent | Method | Measure description / domains | Measure properties |
|------|--------|---------|-----------------|------------|------------|--------|-------------------------------|--------------------|
| | Wall et al (2007a)(59) | US | To confirm these whether families of patients dying in the ICU reported higher satisfaction with their ICU experience than the families of survivors and identify specific aspects of care that were rated more highly by the family members of patients dying in the ICU compared to family members of ICU survivors | 539 family members with a patient in the ICU | As above | As above | As above | As above |
| | Wall et al (2007b)(58) | US | To determine whether ICU family members who rate an item about their spiritual care are different from family members who skip the item or rate the item as "not applicable" and to identify potential determinants of higher family satisfaction with spiritual care in the ICU | 356 family members of patients dying during an ICU stay or within 24 h of ICU discharge | As above | As above | As above | As above |
| GDI | Kinoshita et al(66) | Japan | To investigate the evaluation of end-of-life care from bereaved family of cancer patients who had died in ICUs in Japan | 4011 bereaved family of cancer patients who had died in ICUs in Japan | Family members | Postal survey | Evaluates the outcome for end of life care using a 7-point Likert-type scale | Not reported |
| MFN | Downey et al(70) | US | To evaluate 3 new short questionnaires measuring nurses' perspectives on | 141 critical care nurses evaluating care | Nurses | Self-administered survey | Asks nurses to rate their satisfaction with how well they met the family's physical needs, how well they met the | Principal component analysis of the MFN produced a single domain with a goodness-of-fit index of 0.99, |

| Tool | Author | Country | Study Objective | Population | Respondent | Method | Measure description / domains | Measure properties |
|---|---|---|---|---|---|---|---|---|
| | | | family-centered end-of-life care in the intensive care unit and to show the usefulness of the questionnaires | given to families of 218 patients | | | family's emotional needs and how well the health care team met the family's needs | suggesting construct validity. The Cronbach alpha was found to be .79 suggesting acceptable internal consistency |
| | McCormick et al(53) | US | To examine the social worker component of an intervention to improve interdisciplinary palliative care in the ICU | 35 social workers involved in care of 353 patients who died in the ICU or within 30 hours of transfer from ICU | Social workers | Self-administered survey | Asks social workers to rate their satisfaction with how well they met the family's physical needs, how well they met the family's emotional needs, how well they communicated with the family, and how well the health care team met the family's overall needs | Cronbach's alpha was 0.93 indicating excellent internal consistency |
| QODD | Curtis et al (2008)(44) | US | To evaluate the effectiveness of a multi-faceted quality improvement intervention to improve palliative care in the ICU | 590 patients who died in the ICU or within 24 hours of transfer | Family members Nurses | Postal survey | Measures symptoms, experiences, and perceptions about the quality of the dying process in the last week of life | Authors report the 31-item ICU version has been shown to have moderate to good interrater reliability among family members, with an intraclass correlation coefficient of 0.44. The ICU nurse–assessed QODD has been shown to have construct validity with significantly higher scores among patients who did not receive cardiopulmonary resuscitation in the last 8 hours of life and for patients who had someone present at the time of their death |
| | Curtis et al (2011)(45) | US | To evaluate the effectiveness of a quality-improvement intervention to improve ICU end-of-life care | Patients dying in the ICU or within 30 hours of ICU | As above | As above | As above | Authors report previously shown to be reliable and validate |

| Tool | Author | Country | Study Objective | Population | Respondent | Method | Measure description / domains | Measure properties |
|---|---|---|---|---|---|---|---|---|
| | | | | discharge in 12 hospitals | | | | |
| | Gerritsen et al(67) | The Netherlands | To elucidate how family members and ICU caregivers experience the dying process of their patient | 100 consecutive patients that died in three ICUs | "Family member | Gerritsen et al | The Netherlands | To elucidate how family members and ICU caregivers experience the dying process of their patient |
| | Glavan et al(47) | US | To identify chart-based markers that could be used as measures for improving the quality of end-of-life care | 356 patients who died in the ICU or within 24 hrs of transfer from an ICU | Family members | As above | As above | Authors report ICU version of the QODD had statistically significant, moderate inter-rater reliability when used in a population of ICU patients in which the survey was completed by two to four family members, and demonstrated good construct validity in the ICU setting |
| | Hodde et al(30) | US | To determine the feasibility of using nurse ratings of quality of dying and death to assess quality of end-of-life care in the intensive care unit and to determine factors associated with nurse assessment of the quality of dying and death for patients dying in the intensive care unit. | 178 patients who died in an intensive care unit during a 10-month period at one hospital | Nurses | Self-administered survey | Authors used a 14-item version that contained only those items appropriate for nurse assessment in the ICU setting. These items were selected by two focus groups of ICU nurses | Cronbach's alpha was used to assess the internal consistency of the 14-item QODD for the total score and was found to be highly internally consistent at 0.96. However, this was based on only 16 cases with data for all 14 items |
| | Levy et al(28) | US | To describe and compare the ratings of the quality of death between family members, nurses, resident physicians, and attending physicians in the care of medical ICU | 68 patients dying in the two medical ICUs | Nurses Physicians Families | Self-administered (nurses and physicians) Telephone | Measures symptoms, experiences, and perceptions about the quality of the dying process in the last week of life | Authors report previously validated |

| Tool | Author | Country | Study Objective | Population | Respondent | Method | Measure description / domains | Measure properties |
|------|--------|---------|-----------------|------------|------------|--------|------------------------------|--------------------|
| | | | patients who spent at least 48 h in the ICU | | | interview (families) | | |
| | Lewis-Newby et al(52) | US | To assess measurement characteristics of two family-assessed questionnaires across three patient age groups. | One family member for four hundred and ninety-six patients who died in an ICU at a single hospital | Family members | Postal survey | As above | Not reported |
| | Mularski et al (2004)(69) | US | To measure the agreement among family members who rate a loved one's dying experience | 94 family members of 38 patients who died in an intensive care unit | As above | Interview | As above | Authors found moderate agreement among family members on total QODD score as measured by an intraclass correlation coefficient (ICC) of 0.44. Variability on individual items ranged from an ICC of 0.15 to 1.0. Families demonstrated more agreement on frequencies of events (ICC 0.54) than on determinations of quality (ICC 0.32). Due to variability, authors suggest multiple raters may more accurately reflect the quality of dying and death |
| | Mularski et al (2005)(54) | US | To explore the quality of the dying experience and associations to higher quality ratings for people who died in an ICU | 94 family members of 38 deceased ICU patients | As above | Interview | As above | Authors report ICU QODD instrument to have statistically significant, although moderate interrater reliability for patients dying in the ICU when completed by two to four family members |
| | O'Mahony et al(55) | US | To provide a culturally competent model of care for critically ill patients at the end of life; to integrate the PCS | Nine nurses and ten family members of patients who died in an ICU | Nurses Family members | Interview | As above | Not reported |

| Tool | Author | Country | Study Objective | Population | Respondent | Method | Measure description / domains | Measure properties |
|---|---|---|---|---|---|---|---|---|
| | | | into daily operations of the ICU; and to increase access to hospice services for patients at the end of life in the ICU | | | | | |
| | Osborn et al(56) | US | To investigate the relationship between family satisfaction with ICU care and overall ratings of the quality of dying as a means of identifying targets for improving end-of-life experiences for patients and families. | 1,290 family members of patients who died in the ICU or within 30 h of transfer out of the ICU | Family members | Postal survey | Single-Item Quality of Dying (QOD-1) questionnaire containing the following summary item: "Overall, how would you rate the quality of your loved one's dying?" | Authors report previously validated |
| QEOLC-10 | Cook et al(60) | Canada | To bring peace to the final days of a patient's life and to ease the grieving process | Dying patients and their families in a 21-bed medical–surgical intensive care unit after they decided to withdraw advanced life support in anticipation of death or after discussion with the physician, who determined that the probability of dying in the ICU was greater than 95%. | Family members | Self-administered survey | Measures five domains of physician skills: communication skills, symptom skills, affective skills, patient-centred values, patient-centred systems | Authors report previously validated |

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**Appendix B: Online survey**

INTENSIVE CARE NURSE PERCEPTIONS OF FAMILY-CENTRED END OF LIFE CARE AND QUALITY OF DYING

You are invited to participate in a study of intensive care nurse perceptions of family-centred end of life care and quality of dying. The purpose of the study is to investigate intensive care nurse perceptions of the quality of dying of patients who died receiving palliative care and their perceptions of whether this care met the needs of the patient's families.

The study is being conducted by Professor Jeffrey Braithwaite and Mr Luke Testa at the Australian Institute of Health Innovation, Macquarie University. If you have any queries regarding the questionnaire, Professor Braithwaite can be contacted by email: jeffrey.braithwaite@mq.edu.au or phone: 02 9850 2401, and Mr Testa can be contacted by email: luke.testa@mq.edu.au or phone: 02 9850 2448. This project is being conducted to meet the requirements of Master of Research under the supervision of Professor Jeffrey Braithwaite of the Australian Institute of Health Innovation, Macquarie University.

If you work in intensive care and recently cared for a patient 18 years or older who died receiving palliative care after a minimum ICU stay of 48 hours, you can take part in this project. If you decide to participate, you will be asked to complete a questionnaire asking about this patient. Completing the questionnaire will take approximately 10-15 minutes. You may feel that some of the questions we ask are stressful or upsetting. If you do not wish to answer a question, you may skip it and go to the next question, or you may stop immediately. If you are feeling distressed as a result of participation in this study, please contact your organisation's Employee Assistance Program provider for counselling or contact beyondblue on 1300 22 4636.

Any information or personal details gathered in the course of the study are confidential, except as required by law. No individual will be identified in any publication of the results. Please note that no identifiable patient information should be included in your open text responses. Data is only to be viewed by Professor Jeffrey Braithwaite, Mr Luke Testa and Associate Professor Rebecca Mitchell at the Australian Institute of Health Innovation, Macquarie University and Professor Ken Hillman at South Western Sydney Clinical School, UNSW. A summary of the results of the data will be made available to NSW Nurses and Midwives' Association. Participation in this study is entirely voluntary: you are not obliged to participate and if you decide to participate, you are free to withdraw at any time without having to give a reason and without consequence. Macquarie University HREC approval number: 5201600541

❍ I have read and understand the information above and any questions I have asked have been answered to my satisfaction. I agree to participate in this research, knowing that I can withdraw from further participation in the research at any time without consequence. (Please click to agree)

EXPERIENCES AT THE END OF LIFE
Consider the most recent patient that you cared for in the ICU who subsequently died receiving palliative care. The following questions are about experiences that your patient may have had during the time he/she was in the ICU. Please rate each experience

from your perspective, selecting a number from 0 to 10. On the rating scale below, 0 = "worst possible experience" and 10 = "best possible experience". If your patient did not have a particular experience, or if you do not know enough to rate it, please select one of the boxes on the right.

| | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Does not apply | Don't know |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Having control of his/her pain | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ |
| Having control over what was going on around him/her | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ |
| Breathing comfortably | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ |
| Keeping his/her dignity and self-respect | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ |
| Spending time with his/her spouse or partner | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ |
| Spending time with his/her children | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ |
| Spending time with other family and friends | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ |
| Being touched or hugged by loved ones | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ |
| Having one or more visits from a religious or spiritual advisor | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ |
| Having a spiritual service or ceremony before his/her death | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ | ❍ |

EXPERIENCES AT THE MOMENT OF DEATH
The next questions are about your patient's moment of death.

Was anyone, including family, friends or staff, present at the moment of your patient'sdeath? (Select one)
- ○ Yes
- ○ No
- ○ Don't know

How would you rate this aspect of your patient's death? (Select one number)

|  | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Don't know |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
|  | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |

In the moment before your patient's death, was s/he: (Select one)
- ○ Awake
- ○ Asleep
- ○ In a coma or unconscious
- ○ Don't know

How would you rate this aspect of your patient's death? (Select one number)

|  | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Don't know |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
|  | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |

MEDICAL CARE AT THE END OF LIFE
The following questions are about aspects of medical care that your patient received in the ICU.

Did your patient receive mechanical ventilation during his/her stay in the ICU? (Select one)
- ○ Yes
- ○ No

How would you rate this aspect of your patient's death? (Select one number)

|  | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Don't know |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
|  | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |

Do you think that your patient received the right amount of sedation during his/herstay in the ICU? (Select one)
- ○ Yes
- ○ No

How would you rate this aspect of your patient's dying experience? (Select one number)

| | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Don't know |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |

MEETING FAMILY NEEDS

Consider the family of patient that you cared for. On the scales below, "0" = "not satisfied at all" / "not close at all" and "10" = "very satisfied" / "very close". Please select one number for each question.

How satisfied were you with how well you met the family's physical needs while their loved one was in the ICU? (Select one number)

| | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |

How satisfied were you with how well you met the family's emotional needs while their loved one was in the ICU? (Select one number)

| | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |

How satisfied were you with how well the health care team met the family's needs while their loved one was in the ICU? (Select one number)

| | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |

For me, meeting family needs means:

Any other comments?

**Appendix C: Study invitation email**

**Subject: Intensive care nurse perceptions of family-centred end of life care and quality of dying**

You are invited to take part in this research project, which is called 'Intensive care nurse perceptions of family-centred end of life care and quality of dying'. You have been invited because the research team is investigating intensive care nurse perceptions of the quality of dying of patients who died receiving palliative care and their perceptions of whether this care met the needs of the patient's families. This study will produce an assessment of family-centred end of life care in an Australian ICU setting, an area where there is currently limited data.

If you work in intensive care and recently cared for a patient 18 years or older who died receiving palliative care after a minimum ICU stay of 48 hours, you can take part in this project. If you decide to take part, you will be asked to complete a questionnaire asking about this patient. Completing the questionnaire will take approximately 10-15 minutes.
Participation in the questionnaire is entirely voluntary. You are not obliged to participate and if you decide to participate, you are free to withdraw at any time without having to give a reason and without consequence. Your decision whether or not to participate will not prejudice your future relations with the Australian Institute of Health Innovation, Macquarie University, or your employer.

The study is being conducted by Professor Jeffrey Braithwaite and Mr Luke Testa at the Australian Institute of Health Innovation and Macquarie University. If you have any queries regarding the questionnaire, Professor Braithwaite can be contacted by email: jeffrey.braithwaite@mq.edu.au or phone: 02 9850 2401, and Mr Testa can be contacted by email: luke.testa@mq.edu.au or phone: 02 9850 2448.

Any information or personal details gathered in the course of the study are confidential, except as required by law. No individual will be identified in any publication of the results.

You can complete the questionnaire here.

**Appendix D: Study advertisement**



**Intensive care nurse perceptions of family-centred end of life care and quality of dying**

Intensive care nurses are invited to take part in this research project investigating intensive care nurse perceptions of the quality of dying of patients who died receiving palliative care and their perceptions of whether this care met the needs of the patient's families. This study will produce an assessment of family-centred end of life care in an Australian ICU setting, an area where there is currently limited data.

If you work in intensive care and recently cared for a patient 18 years or older who died receiving palliative care after a minimum ICU stay of 48 hours, you can take part in this project. If you decide to take part, you will be asked to complete a questionnaire asking about this patient. Completing the questionnaire will take approximately 10-15 minutes.

The study is being conducted by Professor Jeffrey Braithwaite and Mr Luke Testa at the Australian Institute of Health Innovation and Macquarie University. If you have any queries regarding the questionnaire, Professor Braithwaite can be contacted by email: jeffrey.braithwaite@mq.edu.au or phone: 02 9850 2401, and Mr Testa can be contacted by email: luke.testa@mq.edu.au or phone: 02 9850 2448.

You can complete the questionnaire here.