Nursing perspective of preparedness to deliver end-of-life care: A descriptive study

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Nursing perspective of preparedness to deliver end-of-life care: A descriptive study

Abstract

Background: Death of patients in the intensive care unit (ICU) is often sudden and unexpected. When ICU care transitions from curative to palliative, nursing staff frequently feel ill prepared to effectively care for dying patients and their families [1, 2]. The purpose of this study was to identify ICU nursing staff’s perception of the effectiveness of current end-of-life care (EOLC) education methods and their preparedness to deliver EOLC to dying patients and their families.

Methods: A newly developed online survey was utilized on Qualtrics survey generator and distributed through social media to allow for snowball sampling. Descriptive statistics were used through Excel to examine past employment and educational experience along with nursing staffs level of preparedness and comfort with providing EOLC.

Results: Over eighty percent of nurses received some form of formal education as part of their undergraduate or graduate education, while only one third received formal training from their institution of employment. Most nurses felt that more education was required to better prepare staff to provide care. Barriers to providing high-quality EOLC included lack of time, lack of resources, lack of education, and other, which included “provider push back from surgeons,” “lack of doctor education,” and “families often need more information from the providers.” Supports to providing high-quality EOLC included formal training, leadership resources, palliative care consult team and other, which included “social work,” “chaplain,” “other staff nurses,” and “facilities (eg private waiting room/conference room ).”

Conclusions: Although death is a common occurrence in the ICU, the training and education for staff providing care is not sufficient. Future research examining family member satisfaction after implementation of EOLC and bereavement education would be beneficial to correlate nurses’ perceptions of the care provided with family members perceptions.

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Nancy Wilk

Second Supervisor
Christine Nelson-Tuttle

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Keywords
Intensive Care Unit, End-of-life care, Nursing, Education, Preparedness, Critical Care, Bereavement, Registered Nurse

Subject Categories
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Nursing perspective of preparedness to deliver end-of-life care: A descriptive study

By

Caitlin McCann, RN, BSN

Submitted in partial fulfillment of the requirements for the degree

Master’s in Advanced Practice Nursing

Supervised by Dr. Nancy Wilk & Dr. Christine Nelson-Tuttle

Wegmans School of Nursing

St. John Fisher College

April 2017
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Abstract

Background: Death of patients in the intensive care unit (ICU) is often sudden and unexpected. When ICU care transitions from curative to palliative, nursing staff frequently feel ill prepared to effectively care for dying patients and their families [1, 2]. The purpose of this study was to identify ICU nursing staff’s perception of the effectiveness of current end-of-life care (EOLC) education methods and their preparedness to deliver EOLC to dying patients and their families.

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Keywords: Intensive Care Unit, End-of-life care, Nursing, Education, Preparedness, Critical Care, Bereavement, Registered Nurse.

Background

Mortality rates are often highest within ICUs, and death is frequently inevitable and occurs more frequently than on other units [1, 2]. Therefore, it is critical that nursing staff be sufficiently prepared to care for dying patients and their families. However, minimal attention is focused on educating ICU nurses to be effective in providing such EOLC and bereavement support. In palliative care units, EOLC and bereavement support is an integral part of the care provided [3]. However, nurses working in ICUs may not have access to the same level of support to care for dying patients and their family members [1].

In the United States, ICU mortality rates average 10-29% of all adult admissions to the ICU [4]. Due to death being a frequent occurrence within ICUs, EOLC and bereavement support is a fundamental area that requires expertise by ICU nurses equal to that of all other critical care practice skills and competencies [5]. Critical care nurses are often those responsible for providing EOLC and bereavement support to patients and families because about one fifth of ICU patients die while hospitalized [6]. Bedside nurses often find EOLC and bereavement support most challenging because of their constant presence during the hospitalization of dying patients [7]. Competent EOLC and bereavement support is a common challenge for critical care nurses. When life-preserving treatment transitions to EOLC, critical care teams often view this as a failure of care provided causing reluctance by ICU team members to implement necessary EOLC interventions for both the patients and their families [5, 8].

It is important to acknowledge that EOLC does not cease with the death of a patient.
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Bereavement support is essential to provide to the families of patients who have passed within the ICU. Death within the ICU is often sudden, traumatic, and unexpected, and because of this, it often has adverse effects on the family members [9]. Adverse effects experienced by family members include social distress, worsening physical health, negative role changes, sleep disturbances, and grief-related disorders [3,10,11]. Although current health care practices are shifting to the inclusion of family-centered care, current clinical practice within ICUs is not matching EOLC and bereavement support expectations [12].

Because nurses serve as a constant presence in caring for patients and their families, understanding their perceived confidence and knowledge with providing services such as EOLC and bereavement support is required. Nursing staff are commonly responsible for preparing and presenting the body in a dignified manner, supporting the family, and responding to the family members need for information on what to do next [1]. However, current practice and review of the literature highlights critical care nurses’ apprehensions with providing such care. Nursing as a whole is known as a caring profession. ICU education focuses upon skills to preserve life such as ventilation and perfusion but does not properly prioritize education highlighting how to care for those patients and their families when such care becomes futile. Because of this, education of critical care staff members focusing on EOLC is crucial.

At this time, there is limited research available regarding implementation of EOLC and bereavement support programs within ICUs and its effects on patient’s families after the death of a loved one. Once a patient has passed, the study sample population left to research is the family members. It is difficult to assess how such programs affect the family members’ satisfaction with care and help promote positive grieving. Clinical trials involving family members of deceased patients remain challenging due to family members being a vulnerable research population. Prior
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to initiating research of a vulnerable population, such as family members of deceased ICU patients, it is imperative to assess the nurses' perceptions and abilities to provide adequate care to those patients and families. Therefore, studies evaluating ICU education programs effectiveness is obligatory to better understand what ICU nurses require in order to be able to provide effective, supportive, and knowledgeable care to dying patients and their families.

Methods

This study aimed to identify areas of strengths and areas for improvement based upon nursing staff perception of level of comfort in providing the different aspects of EOLC. Inclusion criteria for participants included currently working as a Registered Nurse, currently working in an adult ICU, access to a computer, being willing to participate in an online survey, and the ability to read and comprehend English. Exclusion criteria for participants included pediatric nursing staff, inability to read and comprehend English, and not currently employed in an ICU. The measures for this survey included administration of an online survey deployed utilizing Qualtrics through social media. The survey was developed utilizing Likert scaling to answer questions to provide quantitative data based upon an extensive literature review and was reviewed by 2 Advanced Practice Nurses with experience on the subject content. The data collection tool was composed of demographic questions and the remaining questions were focused on nursing staff's perception of delivery of EOLC and the training they had received to provide such care. Snowball sampling was utilized to distribute the online survey through social media (Facebook and Twitter). Survey data was collected from June 2016 to January 2017. Furthermore, descriptive statistics were used to analyze this data in Excel.
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Results

The results for demographic questions are displayed in the Table 1 below.

Table 1: Population Descriptive Statistics

<table>
<thead>
<tr>
<th>VARIABLE</th>
<th>Percentage (Total Number)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender:</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>11.6 (5)</td>
</tr>
<tr>
<td>Female</td>
<td>88.4 (33)</td>
</tr>
<tr>
<td>Age Range:</td>
<td></td>
</tr>
<tr>
<td>20-30</td>
<td>76.7 (33)</td>
</tr>
<tr>
<td>31-41</td>
<td>16.3 (7)</td>
</tr>
<tr>
<td>42-52</td>
<td>4.7 (2)</td>
</tr>
<tr>
<td>&gt;52</td>
<td>2.3 (1)</td>
</tr>
<tr>
<td>Years working as RN:</td>
<td></td>
</tr>
<tr>
<td>1-5</td>
<td>76.7 (33)</td>
</tr>
<tr>
<td>6-10</td>
<td>14.0 (6)</td>
</tr>
<tr>
<td>&gt;10</td>
<td>9.3 (4)</td>
</tr>
<tr>
<td>Highest nursing education obtained:</td>
<td></td>
</tr>
<tr>
<td>Diploma</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Associates Degree</td>
<td>11.6 (5)</td>
</tr>
<tr>
<td>Bachelor's Degree</td>
<td>83.7 (36)</td>
</tr>
<tr>
<td>Master's Degree</td>
<td>4.7 (2)</td>
</tr>
<tr>
<td>Doctoral Degree</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Years worked in adult ICU:</td>
<td></td>
</tr>
<tr>
<td>1-5</td>
<td>86.9 (37)</td>
</tr>
<tr>
<td>6-10</td>
<td>7.0 (3)</td>
</tr>
<tr>
<td>&gt;10</td>
<td>7.0 (3)</td>
</tr>
<tr>
<td>Work experience in hospice/palliative Care:</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>11.6 (5)</td>
</tr>
<tr>
<td>No</td>
<td>88.4 (33)</td>
</tr>
</tbody>
</table>

Of the nurses surveyed, approximately 4 out of 5 nurses received formal education as part of their undergraduate or graduate education. However, almost all had never received any formal education or training through the End-of-Life Nursing Education Consortium (ELNEC) and more than half of the nurses surveyed had never received any formal training from their institution of employment. Below are the results of the survey questions in Table 2 and Table 3.

Table 2: Level of Comfort and Preparedness Descriptive Statistics

<table>
<thead>
<tr>
<th>VARIABLE</th>
<th>Percentage (Total Number)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Delivering end-of-life care to dying patients &amp; their families:</td>
<td></td>
</tr>
<tr>
<td>Underprepared</td>
<td>18.6 (8)</td>
</tr>
<tr>
<td>Prepared with mentor</td>
<td>20.9 (9)</td>
</tr>
<tr>
<td>Prepared</td>
<td>48.8 (21)</td>
</tr>
<tr>
<td>No response</td>
<td>11.6 (5)</td>
</tr>
<tr>
<td>Level of knowledge providing care to dying patient &amp; their families:</td>
<td></td>
</tr>
<tr>
<td>Little or none</td>
<td>9.3 (4)</td>
</tr>
<tr>
<td>Moderate knowledge</td>
<td>74.4 (32)</td>
</tr>
<tr>
<td>Expert knowledge</td>
<td>4.7 (2)</td>
</tr>
<tr>
<td>No response</td>
<td>11.6 (5)</td>
</tr>
<tr>
<td>Comfort with caring for those who are actively dying:</td>
<td></td>
</tr>
<tr>
<td>Uncomfortable</td>
<td>2.3 (1)</td>
</tr>
<tr>
<td>Comfortable with a mentor</td>
<td>18.6 (8)</td>
</tr>
<tr>
<td>Comfortable</td>
<td>67.4 (29)</td>
</tr>
<tr>
<td>No response</td>
<td>11.6 (5)</td>
</tr>
<tr>
<td>Comfort administering medications for pain relief:</td>
<td></td>
</tr>
</tbody>
</table>
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<table>
<thead>
<tr>
<th></th>
<th>Percentage (Total Number)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Uncomfortable</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Comfortable with a mentor</td>
<td>4.7 (2)</td>
</tr>
<tr>
<td>Comfortable</td>
<td>83.7 (36)</td>
</tr>
<tr>
<td>No Response</td>
<td>11.6 (5)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Comfort with assessment skills of dying patient after withdraw of treatment:</th>
<th>Percentage (Total Number)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Uncomfortable</td>
<td>11.6 (5)</td>
</tr>
<tr>
<td>Comfortable with a mentor</td>
<td>4.7 (2)</td>
</tr>
<tr>
<td>Comfortable</td>
<td>72.1 (31)</td>
</tr>
<tr>
<td>No response</td>
<td>11.6 (5)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Comfort with discussing palliative/hospice measure with families:</th>
<th>Percentage (Total Number)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Uncomfortable</td>
<td>23.3 (10)</td>
</tr>
<tr>
<td>Comfortable with a mentor</td>
<td>20.9 (9)</td>
</tr>
<tr>
<td>Comfortable</td>
<td>44.2 (19)</td>
</tr>
<tr>
<td>No response</td>
<td>11.6 (5)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Comfort with educating families about the withdraw of treatment procedure and the dying process</th>
<th>Percentage (Total Number)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Uncomfortable</td>
<td>14.0 (6)</td>
</tr>
<tr>
<td>Comfortable with a mentor</td>
<td>23.3 (10)</td>
</tr>
<tr>
<td>Comfortable</td>
<td>51.2 (22)</td>
</tr>
<tr>
<td>No response</td>
<td>11.6 (5)</td>
</tr>
</tbody>
</table>

Table 3: Nursing Perspective Descriptive Statistics

<table>
<thead>
<tr>
<th>VARIABLE</th>
<th>Percentage (Total Number)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identified barriers to providing high quality end-of-life care:</td>
<td></td>
</tr>
<tr>
<td>Lack of time</td>
<td>51.2 (22)</td>
</tr>
<tr>
<td>Lack of resources</td>
<td>41.9 (18)</td>
</tr>
<tr>
<td>Lack of education</td>
<td>51.2 (22)</td>
</tr>
<tr>
<td>Other</td>
<td>7.0 (3)</td>
</tr>
<tr>
<td>No response</td>
<td>16.3 (7)</td>
</tr>
</tbody>
</table>

| Identified supports to providing high quality end-of-life care:          |                           |
| Formal training                                                         | 44.2 (19)                 |
| Leadership resources                                                    | 32.6 (14)                 |
| Palliative care consult team                                            | 83.7 (36)                 |
| Other                                                                    | 4.7 (2)                   |
| No response                                                              | 11.6 (5)                  |

| Identified barriers to providing high quality end-of-life care:          |                           |
| Feel those who receive end-of-life care in palliative/hospice unit experience a better dying process: | Percentage (Total Number) |
| Yes                                                                      | 79.1 (34)                 |
| No                                                                       | 9.3 (4)                   |
| No response                                                              | 11.6 (5)                  |

<table>
<thead>
<tr>
<th>Aware of policy/procedure tool at institution for withdraw of treatment:</th>
<th>Percentage (Total Number)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>34.9 (15)</td>
</tr>
<tr>
<td>No</td>
<td>53.5 (23)</td>
</tr>
<tr>
<td>No response</td>
<td>11.6 (5)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Aware of resources available at institution for families after their loved one has passed:</th>
<th>Percentage (Total Number)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>22.9 (12)</td>
</tr>
<tr>
<td>No</td>
<td>60.5 (26)</td>
</tr>
<tr>
<td>No response</td>
<td>11.6 (5)</td>
</tr>
</tbody>
</table>

| Feel more education is required to better prepare nursing staff:          |                           |
| Yes                                                                      | 83.7 (36)                 |
| No                                                                       | 4.7 (2)                   |
| No response                                                              | 11.6 (5)                  |

Discussion

In this study, most ICU nurses received some form of formal education as part of their undergraduate or graduate education, and two thirds had never received formal education from their institution of employment. The majority of nurses also felt that more education was required to better prepare nursing staff. While more than half of the study participants were unaware of their institutions policy/procedure for the withdrawal of treatment or the available
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resources for families after their loved one had passed. Because of this, more education and training is required to sufficiently prepare nursing staff to care for dying patients and their families. It is also important to note that the majority of nurses felt that patients who received EOLC in palliative/hospice units experienced a better dying process; but the reason for this was not asked in this study. However, in a field where mortality rates are so high, EOLC must be a priority to provide to patients and families at a level equivalent to that obtained in palliative and hospice care units. Through examination of barriers and supports to providing high quality EOLC and bereavement support, gaps in knowledge can be better understood to assist with future development of educational and occupational programs to improve the quality of care.

The majority of study participants felt comfortable caring for those who were actively dying, administering medications for pain relief, assessing the dying patient after the withdrawal of treatment, and educating families about the withdrawal of treatment procedure and the dying process. However, less than half of nurses felt comfortable discussing palliative/hospice measures with families and about a quarter of nurses actually felt uncomfortable. When providing EOLC to dying patients and their families, it is crucial to ensure families remain informed and supported throughout the process. Discussing palliative care and hospice measures before, during, and after the dying process is a key responsibility of the bedside nurse. It is interesting to note that a smaller percentage of nurses were comfortable with their assessment skills of the dying patient, but a greater percentage were comfortable administering medications for pain relief. Proper assessment and identification of pain in the dying patient is crucial to be able to accurately titrate and administer pain medications. For nurses expected to care for a patient population like that of the ICU, education on EOLC must be included in facility education to review proper policies and procedures regarding assessment, medication
administration, and crucial conversations with families. The findings of this study were similar to prior studies on the subject of nursing education on EOLC and bereavement support. Mainly, critical care nurses feel they are ill prepared to deal with dying patients and their families [1, 2, 8, 13]. It is not uncommon for critical care nurses to learn their EOLC and bereavement support skills through on the job learning and experience gained over the course of their nursing career or by watching more experienced nurses [1, 5, 13].

Limitations for this study included the inability to verify participants fully met the requirements and inability to verify that participants only submitted the survey one time. Inclusion and exclusion criteria were included at the start of the survey to maximize participants only meeting requirements to complete one survey. An additional limitation was the data collection tool was a newly developed survey that had not previously been tested for validity. Further research testing should be done to validate data collection tools for further exploration of this topic. For a future study, it would be important to know specific educational content provided to nurses about EOLC within an institution to identify gaps in education.

Conclusion
Nurses who work in the ICU are frequently confronted with providing EOLC to dying patients and support to bereaved family members. Although death is not uncommon in the ICU, nurses still felt that more education was required to provide better EOLC, because they did not feel they were properly prepared to independently and adequately provide high-quality EOLC to their patients and the family members. As a result, dying patients and their families do not consistently receive the support and services they require at a challenging time equivalent to that experienced in palliative and hospice care units. Improvements in EOLC within the ICU can be
beneficial for family members to facilitate a positive grieving process. Future research examining family member satisfaction after implementation of EOLC and bereavement education would be beneficial to correlate nurses’ perceptions of the care provided with family members perceptions.

List of abbreviations

Intensive Care Unit: ICU
End-of-life-care: EOLC

Declarations

Ethics approval and consent to participate
Ethics approval for the study was obtained from the Institutional Review Board at St. John Fisher College in Rochester, New York. Implied consent was utilized with participation of the voluntary online survey.

Consent for publication
Implied consent was utilized with participation of the voluntary online survey.

Availability of data and material
All data will be stored in a locked file cabinet in a locked office or a password protected computer. Original data collection tools with individually identifiable data will be destroyed after 3 years.

Competing interests
The author declares that there are no competing interests.

Funding
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The study obtained no funding.

Authors' contributions

C.B.M. was leader of analysis, drafting and revising the manuscript.

Acknowledgements

The author thanks Dr. Kathleen Donovan and Dr. B. Evan Blaine for statistical advice, Dr. Colleen Donegan and Dr. Nancy Wilk for assistance editing the data collection tool and Dr. Nancy Wilk, Dr. Christine Nelson-Tuttle, and Robert Ruehl for assistance with revising the manuscript.

Authors' information:

C.B.M. is a Registered Nurse, currently working in an Intensive Care Unit. The research was done to meet the requirements of St. John Fisher College to obtain a Master's degree as an Adult-Gero Acute Care Nurse Practitioner.
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End-of-life care in the intensive care unit: the perceived barriers, supports, and changes

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Nursing Perspective of Preparedness to Deliver End-of-Life-Care (EOLC)

Katie McCain
Adult-Gero Acute Care Nurse Practitioner Student

ARTICLES OF SUPPORT:

Article 1
- Providing end-of-life care to patients: Critical care nurses perceived obstacles and support behaviors

Article 2
- A study of the lived experiences of registered nurses who have provided end-of-life care within an intensive care unit

Article 3
- End-of-life care in the intensive care unit: The perceived barriers, supports and changes needed

METHODOLOGY

Sample
- Snowball sampling
- Surveys distributed through social media (Facebook, Twitter)

Project Description
- Online survey through Qualtrics
- Inclusion criteria
- Exclusion criteria
- Setting
- Adult ICU
- Participants
- Registered Nurses

Data collection tool:
- Quantitative data
  - Demographic
  - End-of-life education/training
  - Comfort level with delivery of care
  - Comfort level with inclusion of dying patient

FINDINGS

- Previous Education/Training Reported
  - 4/5 received some form of education as part of Graduate or Undergraduate Program
  - Almost all had never received any formal education or training through EOLC
  - More than 1/3 had never received any formal training from their institution of employment

Purpose
- To identify ICU nursing staff perception of the effectiveness of current end-of-life care (EOLC) education methods and their preparedness to deliver EOLC.
- How do nursing staff perceive the effectiveness of current end-of-life care education/training in adult ICUs?
FINDINGS

Supports to Care
- Formal training
- Leadership resources
- Patient care manual team

Barriers to Care
- Lack of time
- Lack of resources
- Lack of education

REFERENCES

IMPLICATION OF RESULTS

Clinical Needs
- More education at the institutional level
- Increase the number of policies for withdrawal
  process
- Institute changes within ICUs to better educate
  inpatient nurses before ICU, and in the
  after a loved one has died

Future Research Needs
- Family member experience with EDUC.
  Intervention support in the ICU
  - Interventions in quantitative
- Nurses' experience
- Nurses' perspective after implementation of an
  educational initiative

DISSEMINATION PLANS

- Submission to BioMed Central Journal of Critical Care
<table>
<thead>
<tr>
<th>Section</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Purpose</td>
<td>To examine how use of multiple interventions could improve nurses’ experience of end-of-life care in 5 areas: knowledge and ability, work environment, support for staff, support for patients and patients’ families, and work stress related to specific end-of-life situations.</td>
</tr>
</tbody>
</table>
| Number of Subjects | *Phase 1*: 270 nurses were distributed the tool. Of those 91 nurses returned data that was useable (Response rate of 34%)  
*Phase 2*: 271 nurses were distributed the tool. Of those 127 nurses returned data that was useable (Response rate of 47%) |
| Sample Characteristics | *Phase 1*:  
- Gender: Women (73), Men (10), no answer (8)  
- Age: Mean 35.8, Range 24-58  
- Years in ICU: Mean 7.5  
- Educational preparation: Associate (10), Baccalaureate (61), Masters (3), doctoral (0), no answer (17)  
- Specialty Certifications (17)  
*Phase 2*:  
- Gender: Women (71), Men (12), no answer (44)  
- Age: Mean 37.4, Range 23-64  
- Years in ICU: Mean 7.3  
- Educational preparation: Associate (27), Baccalaureate (83), Masters (10), doctoral (5), no answer (12)  
- Specialty Certifications (16) |
| Study design     | Quantitative  
- 4 Adult ICUs (MICU, SICU, Cardiac and trauma-neurosurgical ICUs) |
| Methodology      | - 5-subscale tool consisting of 30 items was developed on the basis of the literature.  
- 5 domains: Knowledge and ability, work environment, support for staff, support for patients and their families, and work stress.  
- Items scored on a 4-point Likert scale  
- Single open-ended question soliciting qualitative data from participants  
- Validity was assessed by 8 experts and pilot tested in the ICUs by 33 nurses and revised accordingly  
- Interventions:  
  - Nurse developed bereavement program for patients’ families  
  - Palliative medicine and comfort care team  
  - Use of preprinted orders for the withdrawal of life-sustaining treatments  
  - Hiring of a mental health clinical nurse specialist  
  - Staff education in end-of-life care |
| Data Analysis Method | - 2 way analysis of variance with nursing units and phase as the between subject factors  
- Pearson $X^2$ analysis for categorical variable  
- t tests for continuous variables |

| Results | |

| Implications | Implementing an ICU-based support program composed of an interdisciplinary team to address bereaved family members would be beneficial to determine the need for psychological and social support. Further studies would be beneficial to determine feasibility of support programs and effectiveness. |

| Strengths | - Able to conduct telephone interviews of sensitive subject during a difficult time for family members suffering a loss  
- Used a pragmatic approach focusing on the early bereavement period  
- Included ICU clinicians’ perspectives, which showed important complimentary data |

| Limitations | - Unable to measure the pre-death prevalence of mood disorders, anxiety disorders, and other psychiatric illnesses among family member.  
- Included “sub-threshold” family member who were bereaved for less than 6 months. Therefore, the results may not be generalizable to true CG or PGD.  
- Low response rates from family member concerns about sampling bias. |

| Section | Description |

| Citation | Holms, N., Milligan, S., & Kydd, A. (2014). A study of the lived experiences of registered nurses who have provided end-of-life care within an intensive care unit. *International Journal Of Palliative Nursing, 20*(11), 549-556. doi:10.12968/ijpn.2014.20.11.549 |

| Purpose | To explore the lived experiences of registered intensive care nurses who have provided end-of-life care to dying patient and their families within an ICU. |

| Number of Subjects | Target population was all registered nurses within 1 ICU. Potential participants were identified and recruited via a hand-delivered participant invitation letter and participant information sheet.  
- 40 participants were identified  
- 20 agreed to take part and 5 were selected based on their availability at the times interviews were being conducted. |

| Sample Characteristics | - Inclusion criteria:  
- Must be Band 5 or Band 6 registered nurses working within the ICU  
- Working full or part time  
- Having cared for a dying patient and supported their relatives within the last 2 years  
- Exclusion criteria:  
- Any nurse who felt uncomfortable or distressed when discussing EOLC was excluded.  
Demographics for the participants was not included in the data collection. |

| Study design | Qualitative  
- 1 Adult General ICU in Scotland  
- Used phenomenological approach was selected which describes the... |
meaning of the lived experiences of several individuals about a concept or phenomenon
- Used purposeful, non-random sampling

<table>
<thead>
<tr>
<th>Methodology</th>
<th>Data was collected using semi-structured, in-depth interviews.</th>
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<tbody>
<tr>
<td></td>
<td>- Interviews were held in a small room within the hospital</td>
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<td>- Topic guide was compiled from the main themes identified within the literature</td>
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<td>- Topic guide allowed participants to talk about their experiences with EOLC while allowing the researcher to direct the interview process.</td>
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<td>- Interviews took between 30-45 minutes</td>
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<td>- Interviews were audiotaped and transcribed verbatim before analysis.</td>
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<thead>
<tr>
<th>Data Analysis Method</th>
<th>Transcripts were analyzed using thematic content analysis</th>
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<tbody>
<tr>
<td></td>
<td>Burnards 14 step framework was used to guide analysis.</td>
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<td></td>
<td>- Benefits of Burnards 14 step framework are that it provides a systematic approach to data analysis which is replicable and reliable</td>
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<td></td>
<td>- Themes and patterns were identified based of data analysis</td>
</tr>
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</table>

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<thead>
<tr>
<th>Results</th>
<th>51 categories were derived from the collated transcripts which resulted in 5 themes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1. <em>Integrated care systems:</em> Provide clearer guidance, less paperwork and a better structure to EOLC. Help to standardize EOLC and alleviate stress surrounding withdrawing care. Provides for more autonomy. It was also noted that the pathway was implemented with little training and education which at times causes distress because participants were unsure of the principles of the guideline.</td>
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<td></td>
<td>2. Communication: Feel communication is vital between the multidisciplinary team. All 5 interviewers felt that at some point communication broke down between doctors, nurses, patients and their families which led to mixed messages and inconsistencies in end-of-life practice.</td>
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<td></td>
<td>3. The ICU environment: ICU environment is not an ideal place for dying due to noise and privacy needs. Beneficial when dying patients and their families have a 1:1 nurse: patient ratio.</td>
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<td></td>
<td>4. Education and training: Very little formal education and training on EOLC was given, especially in the ICU setting. Learned primarily through watching other staff members and through good and bad experiences. “I feel as a nurse in the caring profession we are expected to know how to deal with such diverse ethically challenging situations, with really no education or training.”</td>
</tr>
<tr>
<td></td>
<td>5. Staff distress: Lack of support from other staff and managers, differences in the consultants’ EOLC decisions and a lack of involvement in EOLC decision-making were the most common areas causing distress. “It is hard dealing with so many dying patients. It’s heartbreaking, upsetting and exhausting, sometimes it’s an occupational hazard unfortunately. There have been numerous occasions when I’ve been really upset and to be honest not well supported, you are left just to get on with it.”</td>
</tr>
</tbody>
</table>
Implications

This qualitative study illustrated issues pertaining to EOLC in an ICU which is supported by other literature stating that this issues continue to remain current and problematic. By identifying 5 common themes experienced by the nurses providing EOLC care, ways in which to improve upon these themes can be established and studied accordingly.

Strengths

- Compiled a topic guide using available literature
- Utilized appropriate measures to analyze data collected
- Burnards 14 step framework was appropriately used to maximize validity

Limitations

- Small sample size
- Research was executed by a student researcher operating within a limited time-frame
- Participants were recruited from the researchers workplace
- Generalizability is of concern since the data collection only utilized one ICU

Section | Description
--- | ---
Purpose | To identify a compare the perceptions of critical care physicians and nurses in regards to barriers, supports and the changes most needed to improve EOLC in the ICU.
Number of Subjects | - 382 surveys sent, responses included from 263 nurses and physicians.
Sample Characteristics | - Specific characteristics were not provided.
- Nurses made up 332 of the study participants that received mailed surveys
- Physicians made up 50 of the study participants that received mailed surveys
Study design | Quantitative
Methodology | - Mailed surveys with three open ended questions
  - The biggest barrier towards providing good End-of-Life Care in the ICU is...
  - The strongest support towards providing good End-of-Life care in the ICU is...
  - The one change that I would make to improve current End-of-Life care in the ICU is...
Data Analysis Method | - Chi-square and Fisher exact test for comparisons between the two groups of nurses and physicians
- 2-sided P value of less than 0.05 was considered statistically significant
- JMP software was used for statistical analysis
Results | - 263 responses were collected to at least one of the questions with proper identification of their professional role for a total response rate of 69%
- 8 Categories of Barriers were identified:
  - Physicians (35% Nurses, 29% physicians- p= 0.52)
  - Lack of communication (23% Nurses, 29% physicians- p= 0.45)
  - Family issues (11% Nurses, 23% physicians- p=0.07)
  - Lack of education (9% Nurses, 19% physicians- p=0.06)
- Over-treatment (9% Nurses, 3% physicians - p=0.20)
- Inadequate time (3% Nurses, 10% physicians - p=0.12)
- Pain (4% Nurses, 0% physicians - P=0.61)
- Advanced directives (3% nurses, 10% physicians - p=0.07)

- Strongest Support for good end of life care in the ICU:
  - Nursing staff- 33%
  - Teamwork- 17%
  - Communication- 14%
  - Chaplain- 11%
  - Physicians- 8%
  - Comfort Care- 8%
  - Education- 7%
  - One-on one Nursing Care- 6%

- Changes most needed to provide good end-of-life care in the ICU
  - Better communication- 30%
  - More education- 17%
  - Improved comfort care- 11%
  - Clear goals/advanced directives- 9%
  - Change in Physicians attitudes- 6%
  - Improved environment- 4%
  - More time devoted to the dying patients- 4%
  - More family support- 2%

**Implications**: Providing good end-of-life care is essential within the ICU, however, challenging for providers and nurses to shift focus from curative to palliative. Identifying areas of strength and weakness within the ICU system for providing end-of-life care is critical to improve the support available to patients and their families. By identifying areas needed to improve, future research studies and quality improvement projects can implement the needed changes and focus on areas of strength when initiating new end-of-life programs for ICUs. Future studies would benefit from looking at pts families views of current End-of-life care practices in the ICUs.

**Strengths**
- Relatively high response rate of 69%
- Study was conducted within the United States
- Open-ended nature of the survey allowed for a range of responses
- Used appropriate statistical tests

**Limitations**
- Small sample size
- Conducted at a single institution
- Only looked at the views of physicians and nurses

<table>
<thead>
<tr>
<th>Section</th>
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<tbody>
<tr>
<td>Purpose</td>
<td>To measure critical care nurses' perceptions of the intensity and frequency of occurrence of (1) providing end-of-life care and (2) supportive behaviors that help in providing end-of-life care in the ICU.</td>
</tr>
<tr>
<td>Number of</td>
<td>A geographically dispersed, random sample of 1,500 members of the</td>
</tr>
</tbody>
</table>
**Subjects**

American Association of Critical Care Nurses (AACN) was surveyed from a membership base of 68,000.

- Subjects Requirements: Currently employed staff nurses who had worked at least part-time in a critical care setting, were living in the US, were able to read English, and had cared for at least 1 patient who was at the end of life.
- Of the 1,500 potential respondent, 955 returned surveys.
- 91 were eliminated either because the questionnaire could not be delivered or because the respondent reported they were not eligible based on the requirements.

Therefore usable responses were collected from a total of 864 nurses.

**Sample Characteristics**

- Gender: Male (6.6%) Female (92.4), did not report (1)
- Age: Mean 44.2, SD 8.1, Range 26-72
- Years as RN: Mean 19, SD 8.2, Range 3-50
- Years in ICU: Mean 15.4, SD 7.0, Range 2-40
- Hours worked per week: Mean 36, SD 9.8, Range 0-80
- No. of beds in unit: Mean 15, SD 8.1, Range 1-88
- Dying patients cared for, %:
  - > 30- 68.5
  - 21-30- 9.9
  - 11-20- 8.6
  - <10- 4.0
  - Other- 9.0
- Highest degree, %:
  - Diploma: 14.0
  - Associates: 19.4
  - Bachelors: 51.7
  - Masters: 14.1
  - Doctorate: 0.8
- Ever CCRN, %:
  - Yes: 73.4 /No: 26.6
- Currently CCRN, %:
  - Yes: 68.4/No: 9.6
  - No Answer: 22.0
- Years as CCRN: Mean 9.14, SD 4.8, Range 1-24
- Practice Area, %:
  - ICU/CCU: 60.5
  - CV/shock-trauma-neuro: 20.0
  - Medical/surgical: 11.3
  - Other: 8.2
- Hospital Type, %:
  - Nonprofit: 59.5, Profit: 10.3
  - University medical centers 15.5
  - Other: 10.3

**Study design**

- Quantitative
- Random sampling
Methodology
- Random selection from AACN membership database
- Original questionnaire (National Survey of Critical-Care Nurses Regarding End-of-Life Care) was developed, pretested and administered in 1998.
  - Questionnaire was adapted for this study by adding the component of frequency of occurrence, for both obstacles and supportive behaviors, to determine if the most frequently listed items reported in the original study were still the most frequently listed when nurses were also asked to report how often each item occurred.
- The first mailing was sent to entire sample of 1,500 nurses. A second mailing was sent approximately 5 weeks later to all non-responders (n=936). A third mailing was sent approximately 8 weeks after the second to all non-responders (n=686).

Data Analysis Method
- SPSS
- Two researchers checked the accuracy of the entered data for all returned questionnaires.
- Frequencies, measures of central tendency and dispersion, and reliability of statistics were calculated for all obstacle and supportive behavior items.
- Items were then ranked on basis of their mean scores to determine which were perceived to be the most intense obstacles and supportive behaviors and which items were perceived to occur most often.

Results
- Top 3 Obstacles perceived as most intense:
  1. Having multiple physicians who difference in opinion about the direction of the patients care
  2. Patients family members and friends who continually called a nurse for an update on the patient’s condition rather than calling the designated contact person
  3. Physicians who were evasive and avoided conversations with patients family members

- Top 3 Most frequently occurring Obstacles:
  1. Friends and family continually calling a nurse rather than the designated contact person for updates on the patients condition
  2. Nurses knowing a patient’s poor prognosis before the family knew the prognosis
  3. Patients and family members not understanding what the term life-saving measures really means.

- Top 3 Supportive behaviors perceived as most intense:
  1. Agreement among physicians about the direction a patients care should go
  2. Family members’ acceptance that a patient was dying
  3. Designation of a single family member as the contact person for all the other family members about information on the patient.

- Top 3 Most frequently occurring Supportive Behaviors:
  1. Providing patients family members with unlimited time alone with the patient after death
  2. Dignified bedside scene after a patients death
Teaching patient families how to act around a dying patient

**Implications**
Providing end-of-life care to patients and their families can be stressful and challenging. In order to implement a program designed to enhance this process for the staff providing the care and the families receiving this care it is crucial to better understand nurses’ perspectives of the barriers and supportive behaviors to providing such care. A better understanding of the most intense and frequently occurring obstacles could potentially assist with development and testing of interventions to lower the frequency and intensity of these obstacles and improve or maintain the supportive behaviors.

**Strengths**
- Relatively high response rate of 61.3%
- Moderately large sample size
- Random selection from a large database of AACN members
- Used appropriate analysis measures to assess data collected

**Limitations**
- Response rate slightly lower than the initial study 61.3% from 68.5%

<table>
<thead>
<tr>
<th>Section</th>
<th>Description</th>
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<tbody>
<tr>
<td>Purpose</td>
<td>To determine the desirability and need for an intensive care unit-based bereavement screening and support program for family members of intensive care decedents. As well as, to determine whether ICU clinicians were currently involved in bereavement care and their interest in participating in a follow-up support program.</td>
</tr>
</tbody>
</table>
| Number of Subjects | 215 eligible participants, 32 participated  
- 148 of the participants were unable to be contact due to incomplete contact information (71), no response to contact (64), responded but lost contact (13)  
- 3 met exclusion criteria  
- 32 refused to participate  
94 eligible staff members, 57 staff physicians and nurses completed surveys |
| Sample Characteristics | - At least 18 years old  
- English speaking  
- Family members/emergency contact who were close to the deceased, as defined by either having lived with the deceased or involved in the patient's care and decisions during the hospital stay  
- Nursing & physician staff from 2 Toronto hospitals working in medical-surgical intensive care units |
| Study design       | Quantitative  
- Telephone administered survey of family members  
- Hospital physicians completed an online survey via SurveyMonkey  
- Paper copies of the online surveys were handed out to nursing staff |
| Methodology        | Survey Instruments:  
- Inventory of Complicate Grief- Revised |
- Social Difficulties Inventory
- Questionnaires developed by study investigators to assess the use of existing services and the desire for additional supports during bereavement.

- Staff questionnaires, focusing on current involvement with bereavement support and interest in further training and willingness to participate in a program of bereavement screening and follow-up.

<table>
<thead>
<tr>
<th>Data Analysis Method</th>
<th>Primarily descriptive</th>
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<tbody>
<tr>
<td></td>
<td>Fisher exact test for all categorical comparisons</td>
</tr>
<tr>
<td></td>
<td>Mann-Whitney U test</td>
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<table>
<thead>
<tr>
<th>Results</th>
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<tbody>
<tr>
<td>1 patient met all criteria for CG, 28% met sub threshold criteria for either CG or PGD.</td>
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<tr>
<td>SDI revealed a low burden of social difficulty</td>
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<td>32% reported receiving professional help for mood or anxiety problems.</td>
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<td>26% reported seeing a psychiatrist/psychologist</td>
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<tr>
<td>29% reported seeing a non-psychiatric/non-psychologist professional</td>
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<tr>
<td>15% reported only support from family and friends.</td>
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<tr>
<td>19% reported no support</td>
</tr>
<tr>
<td>58% wanted to receive support and 19% would not have wanted any follow up</td>
</tr>
<tr>
<td>85% of staff reported providing support at time of death</td>
</tr>
<tr>
<td>69% of clinicians reported feeling comfortable reviewing the events around the death</td>
</tr>
<tr>
<td>85% wanted to receive formal training for bereavement support</td>
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</table>

**Conclusion:** A bereavement program is both desired and needed.
- Although there was a low prevalence of CG/PGD, there was however a significant proportion of family members who experienced “sub-threshold” CG/PGD, as well as social distress.
- Family members expressed wanting support whether or not they suffered from symptoms of CG/PGD
- Emotional support and a meeting to review the events prior to death is what family members most want. Clinicians reported that this type of support is what they felt most comfortable participating in.

**Implications**
Implementing an ICU-based support program composed of an interdisciplinary team to address bereaved family members would be beneficial to determine the need for psychological and social support. Further studies would be beneficial to determine feasibility of support programs and effectiveness.

**Strengths**
- Able to conduct telephone interviews of sensitive subject during a difficult time for family members suffering a loss
- Used a pragmatic approach focusing on the early bereavement period
- Included ICU clinicians’ perspectives, which showed important complimentary data

**Limitations**
- Unable to measure the pre-death prevalence of mood disorders, anxiety
disorders, and other psychiatric illnesses among family member.
- Included “sub-threshold” family member who were bereaved for less than 6 months. Therefore, the results may not be generalizable to true CG or PGD.
- Low response rates from family member concerns about sampling bias.

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<tr>
<td>Purpose</td>
<td>To describe the characteristics of bereavement, to find out if there is a need for follow-up bereavement service and to determine if the information and care in the ICU is sufficient for relatives of the deceased ICU patients.</td>
</tr>
<tr>
<td>Number of Subjects</td>
<td>69 eligible participants, 56 participated, final population study of 51 participants. Of the 56 that met inclusion criteria and informed consent, 1 lost contact and 4 declined a second interview resulting in a final population study of 51 participants.</td>
</tr>
<tr>
<td>Sample Characteristics</td>
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<tr>
<td>Inclusion criteria:</td>
<td>- Family members of patients who died in ICU between June ‘08- June ‘09, who were present during the ICU stay preceding death and had sufficient knowledge of the Dutch language.</td>
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</tbody>
</table>
| Population characteristics: | - 15 male, 36 female  
- 13 spouses of deceased  
- 32 children of deceased  
- 1 sibling to deceased  
- 3 daughter-in-laws to deceased  
- 2 sister-in-laws to deceased |
| Study design & Methodology | Quantitative  
- Telephone survey adapted from Cuthbertson et al. (2000) of family members. The questionnaire incorporated multiple choice and yes or no style questions with additional room for respondents to give explanatory comments. |
| Data Analysis Method | - Data entered into Microsoft Access and later exported to the Statistical Package for the Social Science (SPSS 17 for Windows)  
- Chi-square analysis was used to test differences in incidence between groups (p <0.05 was judged to indicate statistical differences)  
- Explanatory comments were used to improve understanding and gain a complete picture of the respondents' situation. |
| Results | Characteristics of bereavement:  
- 7.8% used new sleeping medications  
- 37.2% reported having sleeping problems (of these 17 were female)  
- 39.2% had minimal problems resuming work or other tasks they had to perform |
- 13.7% resumed no activities after their family members had died
- All male respondents (15) resumed their usual activities compared to 80.6% of female respondents.
- 11.8% reported financial problems, saying the impact was high.

**Quality of care & information provided:**
- 76.5% considered themselves totally informed by ICU staff (of these 37.3% were informed by the doctor and 15.5% reported being informed by nurses)
- 11.7% reported a lack of information

**Need for follow-up bereavement service:**
- 35.3% reported a need for follow-up
- 64.7% reported no need for follow-up

**Conclusion:** The most common characteristic of bereavement was sleeping problems. Most respondents were satisfied with delivered care and information provided. Those not satisfied with level of care mostly complained about communication and lack of information provided. A substantial proportion of respondents reported a need for follow-up. Therefore, a follow-up bereavement program has the potential to be beneficial for grieving family members. Furthermore, care provided to patient and family members leading up to the death of the patient can influence bereavement and the effects of unresolved grief.

**Implications**
This study helps to identify common characteristics of bereavement that family members experience. Understanding the common characteristics is critical in terms of developing future bereavement programs to be implemented. Through this study it was identified that family members would find a follow-up beneficial. It was also identified that sleep problems were a common complication following death, implementation of a bereavement program addressing common sleep disturbances would be useful. It is possible that a future bereavement program could help family members adapt after the loss of a family member and help resolve any negative emotional or physical disturbances related to unresolved grief.

**Strengths**
- Family members of almost 75% of patients who died in the study period agreed to participate in the study which probably yielded reliable results in the setting.
- Attempt to reduce recollection issue by sending questionnaire prior to the telephone interview to prepare participants
- Participants were able to leave explanatory comments which gave a better understanding of the respondents situation reducing potential bias
- Hospital staff was unaware that care would be evaluated which ensured results would not be influenced by anticipation for evaluation
- Study questionnaire was translated and adapted for the local setting and then validity of translation was checked by four colleagues not involved in the study to determine any source of misinterpretation and thus was corrected.

**Limitations**
- Single study center in the Netherlands
- Family members were contact 4-16 months after the death, which could
have effected their recollection of that period
- Small sample size

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<tr>
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<tbody>
<tr>
<td><strong>Purpose</strong></td>
<td>To evaluate the effect of a proactive communication strategy that consisted of end of life family conference conducted according to specific guidelines and that concluded with the provision of a brochure on bereavement.</td>
</tr>
</tbody>
</table>
| **Number of Subjects** | - 132 family members were eligible  
- 126 family members were randomly assigned to a study group, of them 108 were interviewed 3 months after the patients' death  
- Inclusion criteria: Belief by the physician in charge that the patient would die within a few days  
- Exclusion criteria: Less than 18 years old, family members who had insufficient knowledge of French for telephone interviews |
| **Sample Characteristics** | - 22 ICUs in France were included in the study  
- Characteristics of the ICUs:  
  - Medical ICU: 10  
  - Surgical ICU: 3  
  - Medical/surgical ICU: 9  
  - From a teaching hospital: 15  
- Characteristics of patient and family members in control group (63):  
  - Patients age: 56-76  
  - Male: 37  
  - Reasons for ICU admission: Acute respiratory failure (28), coma (27), shock (21), acute renal failure (11), cardiac arrest (14).  
  - Treatment needed at end of life: Mechanical ventilation (56), vasopressors (42), dialysis (16), sedation (47).  
  - Family members age: 46-64  
  - Relationship to patient: Spouse (22), child (22), parent (5), other (3)  
- Characteristics of patient and family members in intervention group (63):  
  - Patients age: 56-80  
  - Male: 33  
  - Reasons for ICU admission: Acute respiratory failure (27), coma (25), shock (24), acute renal failure (14), cardiac arrest (16).  
  - Treatment needed at end of life: Mechanical ventilation (58), vasopressors (49), dialysis (14), sedation (49).  
  - Family members age: 47-58  
  - Relationship to patient: Spouse (20), child (30), parent (2), other (4) |
| **Study design** | - Prospective, randomized controlled trial involving 22 ICUs in France  
- Study took place from May 2005 and October 2005  
- Approved by the institutional review board of the French Society of Critical |
Care.
- Quantitative design
- One investigator was responsible for six patients and their family member

Methodology
- Random assignment to control and intervention group
- Control group: Interactions between the family and the ICU staff, including the end-of-life conference, occurred according to usual practice at each center
- Intervention group: The end-of-life family conference was held in accordance with detailed guidelines developed by one of the authors at the University of Washington. Families were also given a brochure on bereavement. The end-of-life conference had 5 objectives; to value and appreciate what the family members said, to acknowledge the family members' emotions, to listen, to understand who the patient was as a person, and to elicit questions from the family members.
- Investigators recorded patient and family characteristics on standardized forms
- Specific forms were used to collect data describing the end-of-life family conference and investigators were asked to clock family conference times
- 1 family member was interviewed over the phone 90 days after the patients’ death (Interviews took place from August 2005 to January 2006)
- Outcome measured using: Impact of Event Scale and Hospital Anxiety and Depression Scale.
- Type 1 error of 0.05 and a power of 0.90, determined 100 families needed to be recruited with 50 in each group.

Data Analysis Method
- Wilcoxon rank-sum test was used to compare continuous variables between the two randomized groups
- Pearson chi-square test or Fisher exact test was used to compare categorical variables between the two randomized groups
- All tests were two sided- and p values of less than 0.05 were considered to indicate statistical significance
- Statistical tests were performed using the SAS software package, version 9.1

Results
- There were fewer non-beneficial interventions (continued life support after decision to withhold or withdraw life-sustaining treatments) in the intervention group
- It was more common for the intervention group to withdrawal of mechanical ventilation and vasopressors
- Among relatives that initially disagreed with the ICU clinicians, those in the intervention group were more likely to agree eventually (6 in the intervention group vs none in the control group)
- In both groups 89% reported a sufficient amount of time was spent providing information, 90% felt the information was clear, 38% reported a desire for additional information that was not provided
  - Those who reported a need for additional information, who received newly prescribed psychotropic drugs, and who expressed feelings of guilt were lower in the intervention group
  - 95% of the intervention group said they were able to express their
emotions to the ICU team, compared to 75% in the control group
- IES scores in the intervention group were lower in the intervention group
(Median score 27 (intervention) vs median score 39 (control))
  - Indicating that 45% of family members in the intervention group were
  at risk for PTSD compared to 69% in the control group
- Family members in the intervention group also had lower HADS scores
(Median score 11 (intervention) vs. median score 17 (control))
  - With 45% reporting clinically significant symptoms of anxiety and
  29% reporting clinically significant symptoms of depression in the
  intervention group, compared with 67% and 56% in the control group.

Implications
Family members of dying patients could benefit from proactive interventions
to improve communication before time of death to assist with decision
making and to decrease PTSD related symptoms and symptoms of anxiety
and depression. This intervention was implemented prior to the death of a
patient and could potentially be used in combination with a follow-up
bereavement support intervention. However, further studies would need to be
done to determine the effectiveness and benefits of combining interventions.
Providing a brochure on bereavement may also be beneficial for family
members at time of death to improve comprehension.

Strengths
- Adequate sample size was determined prior to initiating study
- 22 centers participated in the study enhancing generalizability of the study
- Random assignment was used
- Interviewer and analysts were blinded to group assignments

Limitations
- Performed in France, where patient-physician relationship is considered
  more paternalistic. However, the intervention was rooted in international
  literature making it relevant to other countries
- Only inclusion criteria for the study was that the patient was expected to die
  within a few days, this could potentially have negative effects if the patient
  survives.
- Did not determine how families read the bereavement brochure or how they
  reacted to it
- Did not assess the HADS scores prior to the critical illness or time of death.
  Therefore, it is difficult to determine if the two groups were different at
  baseline
- Blinding family members and ICU clinicians was not feasible

<table>
<thead>
<tr>
<th>Section</th>
<th>Description</th>
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<tbody>
<tr>
<td>Purpose</td>
<td>To examine family caregiver reports about how often bereavement services were used, predictors of their use, and reported reasons for not using the bereavement services.</td>
</tr>
</tbody>
</table>
| Number of Subjects | - 391 caregivers were initially approached by the primary care nurse at the center to participate in the study
  - 100 opted not to participate |
- 28 could not be contacted due to inaccurate contact information
- 6 were determined to be too ill or cognitively impaired
- 51 agreed to be contacted but later refused to participate in the study
- Final sample for baseline interview included 206 caregivers
- Out of 206, 161 completed all 3 interviews conducted by a masters degree level prepared social worker with extensive experience evaluating depression

Sample Characteristics
- 74.5% female/Male 25.5%
- Relationship to patient:
  - Spouse- 30.4%
  - Daughter- 39.1%
  - Son- 12.4%
  - Other relationship- 18.1%
- Level of education: 69.6%-more than high school, 30.4% high school or less
- Major depressive disorder at baseline: 26.1%
- Caregiver reported being told illness could not be cured: 75.2%
- Caregiver reported being told patients prognosis: 45.3%
- Had adequate help with instrumental support: 71.4% (Instrumental activities include: Grocery shopping, housecleaning, cooking & transportation)
- Had adequate help with emotional support: 83.9%

Study design
- Prospective, longitudinal cohort study of hospice patients and their family caregivers
- Enrolled in hospice and palliative care center between October 1999 and September 2001
- Approved by Institutional Review Boards of the Yale School of Medicine and the hospice and palliative care center with which the study was conducted

Methodology
- Participants were interviewed at time of patients enrollment in hospice, and 6 months and 13 months after the patient’s death
- In-person baseline interviews, 36% completed the baseline interview prior to the patients’ death. Those unable to complete the interview prior to the patients’ death were interviewed within the month after death
  - All interviews were conducted with only the primary caregiver and took place at the location where the caregiver indicated that he/she would be most comfortable
- Outcome variable: Use of bereavement services at 6 months and 13 months (Closed-ended list of bereavement interventions that the respondents may have used)
- Predictor variables:
  - MDD at baseline, 6 months, and 13 months
  - Caregivers experiences based upon 7 variables
  - Assessed caregiver-physician communication
  - Assessed social support using a 5 point Likert scale
- Reasons for nonuse:
  - Opened-ended responses were transcribed verbatim by the interviewer
<table>
<thead>
<tr>
<th>Data Analysis Method</th>
<th>Details</th>
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<tbody>
<tr>
<td>Data - Major depressive disorder module of the structured clinical interview for DSM-IV (SCID) Axis I modules - The stressful caregiving adult reactions to experiences of dying (SCARED) - Modified version of Zarit Burden interview scale - Standard frequency analysis to describe the characteristics of the participants - Bivariate analyses to assess potential predictors of use of bereavement services and logistic regression to assess independent contributions of predictor variables - Content analysis was used to summarize reasons for not using services/stopping services (Coding categories was used)</td>
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<tr>
<th>Results</th>
<th>Details</th>
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<tbody>
<tr>
<td>Results - 30.4% used bereavement services at some time during the 13 months - 87.8% who used services used it within the first 6 months post loss - 49% used bereavement services offered through hospice or with a professional counselor - Of those who used services, 44.2% stopped using services by 13 months post-loss - Spouses were more likely to use bereavement services 95% confidence interval - Use of bereavement services was significantly associated with higher scores measures on SCARED scale - Caregivers were more likely to use services if their own activities were restricted, more likely to use if MDD was present at baseline, having discussed the prognosis with the MD, and having assisted the patient with IADLS prior to death. - Reasons for not using services: - They were adjusting well to the loss- 66.7% - Developed informal or other support- 44.6% - Uncomfortable talking to others- 12.5% - No time or too busy- 9.8% - Anticipated service will not be helpful/dissatisfied with service- 7.1% - Too far or does not drive- 6.3% - Unaware of service- 2.7% - Assumed it cost money- 0.9%</td>
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</table>

| Implications | In order to accurately identify the desirability and need for bereavement support of family members, it is valuable to understand reasons for using specific services and reasons family members wish to not use such services. By evaluating why some family members do not chose to use services, future research studies can utilize the information to address barriers to service use. In doing so, service providers can tailor bereavement services to best meet the needs of family members. |

| Strengths | - Reliable tools were used - longitudinal follow-up a year after bereavement - Clinical assessment of MDD and other symptoms of distress - Large sample size - Assessed MDD at baseline |
Limitations
- Took place in a single state, one hospice and palliative center, limits its generalizability
- Experienced loss of follow up, especially in men
- Would have been helpful to have had more information on prior episodes of MDD or related medication use
- Unable to evaluate the impact of bereavement services on MDD or other health outcomes due to it being outside the scope of the study

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<tr>
<td>Purpose</td>
<td>To explore family members' perceived needs for bereavement follow-up by quantifying their perceived needs or bereavement follow-up, and their wishes concerning when and how to meet, and qualitatively describing their wishes concerning the form, content, and perceived meaning of bereavement follow-up.</td>
</tr>
<tr>
<td>Number of Subjects</td>
<td>- During the study period 398 deaths occurred of them 4 had no family, 17 were excluded due to exclusion criteria (unknown addresses, family members declined due to weakness, and family members declining due to dementia)</td>
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<td>- 377 family members were mailed the survey and a reminder, of them 248 responded (66% response rate)</td>
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<tr>
<td>Sample Characteristics</td>
<td>A family member was defined as the person identified by the patient (and notes within the medical record) as being the person primarily involved in the care of the patient.</td>
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<td>- Study population was from 4 palliative care units in two different counties of Sweden</td>
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<td>Characteristics of the family members</td>
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<td>- 147 female, 99 male (2 with no response)</td>
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<td>- Median age 62 years old (Range 27-93)</td>
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<td>- Relationship to the patient (Husband- 132, wife-54, parent-37, child-4, friend-19, other- 2)</td>
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<td>Characteristics of the patient to whom the respondents were family members</td>
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<td>- 122 female, 124 male (2 with no response)</td>
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<td>- Median age 75 years old (Range 26-97)</td>
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<td>- Cancer diagnosis- 214, nonmalignant diagnosis- 22, no response 12</td>
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<td>- Duration of care with palliative services (44- 0-2 weeks, 83- 2-8 weeks, 67-3-6 months, 45- &gt;6 months, 9- no response)</td>
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<tr>
<td>Study design</td>
<td>Cross-sectional study that targeted family members 3-9 months after the patients' death</td>
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<tr>
<td></td>
<td>- Quantitative- Characteristics of the family members responding</td>
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<td>- Qualitative- Qualitatively describe their needs</td>
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<td>- Data was collected from autumn of 2003 and the spring of 2004</td>
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<td>- Approved by the Regional Ethics Committee</td>
</tr>
<tr>
<td>Methodology</td>
<td>Questionnaire composed of both quantitative and qualitative questions using 5-grade Likert scale for the quantitative part and open-ended questions for</td>
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</table>
qualitative questions.
- Content validity was check by clinic staff (nurses and social work) experienced in palliative care and by researchers who were not involved in the development of the questionnaire.
- Family members were identified through clinical databases or routines and were mailed an invitation letter with questionnaire. A reminder was sent 2-4 weeks.
- Pilot study was preformed to show the questionnaire worked well, no further changes were require

| Data Analysis Method | - Open-ended questions were analyzed using manifest qualitative content analysis with no perceived codes.
| | - Coding and development of categories was next performed based on the qualitative portion of the questionnaire by first and second authors. Each response was read by a minimum of two authors and the categories were discussed until an agreement was reached. Analysis was then scrutinized by the last author for overlaps and suitable expressions. |
| Results | - 46% of family members expressed a perceived need for bereavement follow-up
| | - The most favored point of time for such support was 2-6 weeks after death with 34% (20% preferred 0-2 weeks, 15% preferred 6-12 weeks)
| | - 39% preferred a follow up visit at home
| | - 22% preferred a visit to the ward
| | - 21% preferred a telephone call
| | - 50% had personal experience with bereavement follow-up (52% reported it as very good, 33% reported it as good, 5% reported it as acceptable, 2% reported it as bad, 1% reported it as bad)
| | - Six categories emerged in the analysis of the responses to the open-ended questions, the categories concerned the following aspects
| | 1. The person preforming the bereavement follow-up
| | 2. The meaning
| | 3. The content of such support
| | - The person preforming the follow-up should be someone who listens (doctors, nurses, priests, and social workers) and someone who knows the patient and the family members
| | - The meaning of bereavement follow up- To put feelings of guilt into words, to get comfort in times of loneliness, and to be acknowledged as individuals.
| | - The content of such support- Family members expressed a need to talk about the past present and future. In other words, they wanted to discuss before the death occurred, how they were doing in the present, and also about what the future might bring.
| Implications | This study helps to identify bereavement needs of family members regarding the content and form in which bereavement follow-up are preformed, as well as the meaning behind it. Thus far, no studies by randomization have evaluated the efficacy of bereavement programs on peoples’ ways of coping. In the past, research has shown that most bereaved persons overcome grief
without any intervention. Therefore, a study quantitatively evaluating the
effectiveness of bereavement interventions would be beneficial. This study
showed that not all family members identified a need for follow-up. It may be
beneficial to allocate time and resources to identify those that may actually be
at risk for complicated grief using tools, such as the 12-item Family
Relationship Index and the modified four-item Bereavement risk index.
Implementing standard risk assessment procedures into practice may be
beneficial in order to identify those that would most benefit from a
bereavement follow-up.

Strengths
- Open-ended questions provide supplemental data to better understand the
phenomenon and gives greater generalizability than interviews because of the
larger possible number of participants.
- Relatively large sample size
- Used qualitative data to identify the characteristics of the study population
but the main focus was quantitative to better understand family members’
wishes concerning the form, content, and perceived meaning of bereavement.

Limitations
- Risk of recall bias due to the collection date time period being 3-9 months
after the patients’ death, study design should have been prospective to lower
the risk of bias. However, this seemed unethical to bother grieving family
members at times when their sorrow may be at its peak
- More than 2/3 of the participants perceived their care as very good. This
may have consequences in terms of transferability for groups of family
members that had negative experiences
- Family member participants were only those from palliative care which
could have effects in terms of external validity for other patient populations

<table>
<thead>
<tr>
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</table>
|                 | Nursing care of the family before and after a death in the ICU-An exploratory
|                 | doi:10.1016/j.aucc.2012.01.001                                             |
| Purpose         | To describe the way nurses working in ICU care for family members through
|                 | the patient's dying phase and after death; to explore the nurses’ perspectives
|                 | on their preparedness and ability to provide this care for the family; and to
|                 | identify organizational processes and environmental factors that may exist in
|                 | the ICU, that either facilitate or limit this nursing care.                 |
| Number of       | - Two focus groups of up to 6 people in each group                          |
| Subjects        | - Recruited through initial contact with Nurse Unit Managers, followed by the
|                 | dissemination of study information and flyers about the ICUs.               |
| Sample          | - Two ICUs from two hospitals in metropolitan Melbourne, Victoria,           |
| Characteristics | Australia with similar multicultural populations                            |
|                 | - ICU A:                                                                    |
|                 |   - 14 beds, ICU and high dependency                                        |
|                 |   - General medical surgical, including ear, nose, and throat, colorectal    |
|                 |       and orthopedic                                                         |
|                 |   - 1,400 pasts last year                                                   |
|                 |   - 110 deaths last year                                                   |
- Average length of stay 3.5 days
- 115 nursing staff, 70% with a critical care qualification

- ICU B:
  - 21 beds, ICU and high dependency
  - General medical surgical, including cardiothoracic and neurological
  - 2,164 patients last year
  - 137 deaths last year
  - Average length of stay 3 days
  - 222 nursing staff, 60% with critical care qualifications

- Nursing Characteristics:
  - Registered Nurse with more than 12 months experience in ICU
  - Previous experience with caring for patient who died in ICU

| Study design | - Qualitative descriptive approach
  - Exploratory pilot study
  - Focus groups were held in May and June 2011, in a non-clinical space within the health organization |
| Methodology | - Utilization of focus groups to gather data
  - Open-ended questions and guided concepts, the aim of the focus group is to encourage participants to engage in dialogue with the Principle investigator and each other
  - Focus group discussions took between 42 and 50 minutes to complete
  - All participants were encouraged to contribute to the discussion and express their own views.
    - A second investigator observed the group interactions and recorded field notes related to body language and participation
    - Group discussions were recorded and transcribed verbatim |
| Data Analysis Method | - Inductive method: Each investigator independently analyzed the narrative data using inductive content analysis (Codes and theme noted were made on the side of the transcript)
  - Emergent themes and subthemes were determined and shared amongst the investigator team
  - The data underwent further collaborative refinement until consensus was achieved and the final themes were settled on |
| Results | - Four main themes emerged (Time, place, presence, and culture)
  - Time:
    - Spending time with families: To help families understand the diagnosis, guiding families with what to do after death, providing time for families to ask questions
    - Prolonging time to death: Sometimes death comes as a relief to families, provides time for families to resolve conflict and say goodbye, costly for staff and organization to free up beds for other patients
    - After death: Time to view the body, patients go to the nurses for guidance with what to do next,
  - Place:
    - ICU design: Space utilized for quick access and clinical care but
sacrifices individual privacy. Lack of privacy impacts patients ability to have “good death,” especially if life support was being withdrawn.

- Facilities for families: The need to accommodate families who wish to keep vigil but lack the necessary facilities such as waiting rooms and sleeping quarters to keep family members comfortable.

- Presence:
  - Working with families: Families like to be included in treatment options with the provision of information to allow family members to make informed decisions. Nurses often act as a translator for family member to explain information provided by other medical staff.
  - Support after death: Great emphasis on nurses to provide support to family after death. Social work and pastoral care services also play an important role but are not as feasible outside of normal business hours.

- Culture:
  - Nurses who demonstrate the right qualities, along with previous experience were often chosen to care for the dying patients and their families. Qualities include: empathy, caring, and good listener.
  - Identified the need for experience or instruction on how to handle what to do with the families at the time of death. Also, identifying the poor training the nursing staff receives to provide for the family afterwards.

**Implications**

At time of death, caring for bereaved family members can be challenging for clinical staff members, including nurses. In order to implement a bereavement support program, it is important to understand the perspective of those already providing bereavement support. Within this study, nurses explained their role in caring for families at time of death and areas in which support is lacking. By understanding the current nursing staff role in supporting families at time of death, it identifies gaps in care that can be improved upon and implemented in further research of bereavement support programs.

**Strengths**

- Used more than 1 site for research to increase generalizability to more than one ICU
- Small focus groups so that all participants had ample opportunity to contribute
- Inductive method was used to ensure any themes and subthemes were derived from the raw data rather than trying to get the data to fit pre-determined themes.

**Limitations**

- Participants in the study volunteered and the motivation to do so is unknown
- Small number of participants

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<tbody>
<tr>
<td>Purpose</td>
<td>To describe the adoption of a novel and ambitious bereavement service in a large secondary care institution and to consider its impact.</td>
</tr>
</tbody>
</table>
Number of Subjects
- 1,425 deaths within the hospital in 2010 (Patients under 16 years old were excluded)
- 1,390 condolence cards were sent (Letters may have not been sent if the relative was involved in a complaint process or if another specific reason why felt to be inappropriate)
- 1,384 follow-up letters sent
- 311 relatives replied (May relatives expressed thanks but declined a meeting)
- 142 requested a follow-up meeting (Some questions were answered over the phone with Bereavement care follow up service (BCFS) lead)
- 119 meetings were held with relatives

Sample Characteristics
- Characteristics of those who did not have a follow up meeting:
  - Age at death: 80.6
  - Male: 51%
  - ICU stay: 24%
  - Length of hospital days: Median 7.0
  - Length of stay within 1 week: 52%
  - LOS within 24h: 19%
  - Specialty group: Medicine 69%, surgical 20%, other 11%
- Characteristics of those who had a follow up meeting:
  - Age at death: 73.0
  - Male: 45%
  - ICU Stay: 26%
  - Length of hospital days: Median 6.0
  - Length of stay within 1 week: 54%
  - LOS within 24h: 23%
  - Specialty group: Medicine 67%, surgical 22%, others 30%  

Study design
- Qualitative descriptive approach
- Service evaluation
- Evaluation of themes that emerged within the follow up meetings

Methodology
- Family members are given information leaflets and sent a condolence card a few days after death. They then are invited to BCFS led by a chaplain with assistance from the bereavement care team about 4 weeks after death.
- Themes from the BCFS were categorized from the follow up
- Factors that may assist with predicting which relatives seek follow up were evaluated

Data Analysis Method
- Fishers exact tests
- $X^2$ tests
- Mann-Whitney tests
  - All three tests were used to compare the groups who used and did not use the BCFS
- Logistic regression method was preformed to evaluate the effect of several variables
- SPSS version 18 was used for data analysis with 0.05 as significance level

Results
Themes family members addressed in the meeting:
- Sudden clinical deterioration:
- Diagnosis questions
- Final moments before death
- What if?
- End of life decisions
- Communication of death

- No difference in gender, ICU stay length, or day of death between groups who sought the meeting and those who did not
- Those who sought the meeting were significantly younger
- Significant difference between specialty of those requesting follow up, mainly coming from specialty outside of surgical and medicine.

Implications
Although this study was based upon a service evaluation, it highlights what families a bereavement program initiate might best be targeted at and what families would be interested in participating. For example, family members of younger patients that die and patients outside of the medicine specialty. It also categorizes many questions that family members would like to discuss at the follow up meeting. By identifying those that did use the service and what their concerns were after bereavement it illustrates that some family members do wish to participate in a bereavement support service. Further research needs to be done on why families choose not to participate and the effectiveness of such services on the families’ grief process.

Strengths
- Over 800 beds within the hospital and covers all specialties, enhances its generalizability
- Use of reliable tools

Limitations
- Considers the bereavement service at a single center which limits its generalizability
- Did not review many other predictors of requesting bereavement follow up, such as diagnosis and variables of family members that may have influenced requesting the service were not evaluated

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<tbody>
<tr>
<td>Purpose</td>
<td>To explore staff members’ perspectives on providing bereavement follow-up in palliative home care: (a) to quantify the perceived importance of bereavement follow-up, allocation of resources, time spent, and also the staff members’ assessments (in terms of difficult or ease) of providing bereavement follow-up and (b) to qualitatively describe the staff members perception of providing bereavement follow-up.</td>
</tr>
</tbody>
</table>
| Number of Subjects | - 6 palliative care units were used including 3 advanced palliative home care teams (APHC) and 3 primary care services in Sweden  
  - Only members of the profession that were used to carrying out bereavement follow-up at the unit were included  
  - Those identified through an existing database as being involved in |
Bereavement follow-up were mailed an invitation letter and an uncoded questionnaire (n=208).
- 120 responses to the survey were collected

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<tbody>
<tr>
<td>- Gender: Female-115, Male-3, no response-2</td>
</tr>
<tr>
<td>- Profession: Nurse-80, nursing assistant-23, DR-6, physiotherapist-3, OT-3, Social worker-2</td>
</tr>
<tr>
<td>- Work place: Specialized palliative home care- 95, Non-specialized palliative care- 25</td>
</tr>
<tr>
<td>- Median years of experience in palliative care: 8 years</td>
</tr>
<tr>
<td>- Median number of bereavement follow-ups performed over the last year: 2 (Median range 0-60, 12 did not respond)</td>
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<thead>
<tr>
<th>Study design</th>
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<tr>
<td>- Mainly qualitative questionnaire with a minor quantitative portion concerning background of the staff members.</td>
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<tr>
<td>- Likert-scale for quantitative questions</td>
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<tr>
<td>- Data collection between winter 2005 and spring of 2006</td>
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<thead>
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<tbody>
<tr>
<td>- Postal questionnaire was sent out with an invitation to participate. A reminder was sent out 2-4 weeks later.</td>
</tr>
<tr>
<td>- Quantitative portion of questionnaire:</td>
</tr>
<tr>
<td>- Background of the staff: Age, gender, profession, number of years working in palliative care, number of times having preformed bereavement care over the past years</td>
</tr>
<tr>
<td>- Approximate time spent for a bereavement follow-up</td>
</tr>
<tr>
<td>- Their opinion of 2 statement: “Bereavement follow-up is an important part of palliative care” and “My unit allocates enough resources to bereavement follow-up” using a 4 grade Likert scale from disagree and fully agree</td>
</tr>
<tr>
<td>- Assessment of preforming bereavement follow-up using 4-grade Likert scale from most often difficult to most often easy</td>
</tr>
<tr>
<td>- Qualitative portion of questionnaire:</td>
</tr>
<tr>
<td>- Describe in their own words their perception of performing bereavement follow up</td>
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<tr>
<td>- At the end of the questionnaire an area was provided to allow staff to add any information regarding bereavement follow up</td>
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<tbody>
<tr>
<td>- Box plots and X2 tests were used to summarize and evaluate quantitative data</td>
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<tr>
<td>- Manifest qualitative content analysis was used to evaluate open-ended responses with no preconceived codes</td>
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<tr>
<td>- Responses were read through to gain a sense of the whole and to develop themes</td>
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<tr>
<td>- Then, systematically reread, line by line, to identify significant text segments, i.e. “meaning units” to develop matching codes</td>
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<tr>
<td>- Next, statements in each preliminary category were scrutinized and compared to find their central component</td>
</tr>
<tr>
<td>- Final categories were then compared to avoid obvious overlapping, and content descriptions and relations to other categories were developed</td>
</tr>
</tbody>
</table>
- To strengthen validity, peer-debriefings were conducted where the results were presented and discussed in research seminars involving clinically experienced staff members and social workers, as well as senior researchers.

### Results
- 96% of staff members responded partly or fully agree that bereavement follow-up is an important part of palliative care
- 23% had experienced that bereavement follow-up was “most often rather difficult, 52.5% “most often rather difficult,” 12.5% “most often easy”
- Categories concerned two areas (a) perceptions of performing bereavement follow-up (b) aspects influencing the perception of performing bereavement follow-up
  - A rewarding conclusion of the relationship
  - To support family members coping with bereavement
  - To get feedback on the palliative care provided
  - Whose needs are being met
  - The family members coping and acceptance
  - Their own competence, experience, and coping
  - The relationship to the family member
  - Time, peace, and setting priorities in the units
  - Support to the staff members
  - Clarity in format and content

### Implications
Currently, minimal research is available regarding bereavement support for family members after the death of a loved one. There is however, more literature available regarding bereavement support in palliative care. This study explored the staff’s perceptions of providing bereavement care to palliative patients families, which could be used to form future research studies involving staff in ICUs and other specialty area units within hospitals. Although bereavement follow-up is often mandatory and expected with palliative care populations, staff still expressed concerns regarding providing care such as inadequate training and resources. Staff also expressed concern that not all family members desire or need bereavement care. This information may be relevant to other services as barrier to providing sufficient bereavement support to family members.

### Strengths
- Strong tools to analyze
- Use of 6 different units to get a rich variation of staff members perceptions which increases generalizability

### Limitations
- 58% response rate to questionnaire
- Cross-sectional design which could lead to recall bias
- Only concerned palliative care nurses which could limit generalizability to other services