

Improving Healthcare Provider Communication

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Introduction

Five million patients are admitted annually to critical care settings with mortality as high as forty percent (Society of Critical Care Medicine, n.d.). Critically ill patients are often unable to make their own health care decisions leaving the family members to be surrogate decision makers, often involving end of life (EOL) choices (Davidson et al., 2012). The reasons for this phenomena include that critically ill patients have altered levels of consciousness, are receiving sedating medications and may have impaired cognition secondary to the underlying disease process (Lautrette et al., 2006). EOL decision-making for a critical care patient is a complex process. The management of the care requires an extraordinary amount of time and effort by the health care team (Alvarez & Kirby, 2006). The critical care environment is a stressful place for healthcare providers and family members alike (Alvarez & Kirby, 2006). Family members observe their loved ones unable to communicate, connected to complex technology and lapsing in and out of wakefulness (Alvarez & Kirby, 2006). For all of these reasons, decision-making is complex. Family members are generally the responsible parties tasked with making these decisions (Lautrette et al., 2006). It becomes the healthcare provider's responsibility to communicate effectively to the family members so decisions can be made based on knowledge, facts and patient beliefs (Gay et al, 2009). Unfortunately, healthcare providers are not prepared for these discussions and family members are at their highest level of stress and vulnerability during these difficult times.

Family members of critically ill patients have been dissatisfied with healthcare provider communication regarding treatment options and end of life decisions for decades (Gay, Pronovost, Bassett, & Nelson, 2009). Family members report anxiety, stress and depressive symptoms long after the hospital course related to failed communication (Davidson, Jones, &

Bienvena, 2012; Gay et al, 2009). Despite this known data, much information about feelings or family perceptions of communication of difficult or sensitive content related to is not documented. It is difficult for researchers to obtain sensitive information from families after a patient has died. Lautrette et al. (2006), however, reviewed eight studies related to family satisfaction of patients who died in an intensive care unit (ICU). Family members reported an increase in stress and anxiety associated with poor communication, especially involving EOL decision-making. Effective communication may affect the timeliness of decision-making in the dying patient as well as decreasing length of stay (Ha & Longnecker, 2010). Communication regarding EOL decisions, within the health care team and especially among intensivists needs to be improved. Poor communication ultimately affects outcomes, and results in anxiety, stress and depression experienced by the surviving family (Lilly, Sonna, Haley, & Massaro, 2003).

Communication can be perceived as effective when the patient/family needs and expectations have been identified (Ha & Longnecker, 2010). Abbott, Sago, Breen, Abernethy, & Tulskey (2001) noted over one-third of surveyed families reported dissatisfaction with communication regarding EOL decisions. Even when the provider felt communication was adequate, patients and their families felt differently (Ha & Longnecker, 2010). Effective provider-patient-family communication is central in building a relationship (Ha & Longnecker, 2010). A crucial step in improving outcomes involves improving EOL communication (Lautrette et al., 2006).

Data suggest healthcare providers lack communication skills, a fundamental element to improve outcomes at end of life. There is evidence in the literature, supporting the need to improve outcomes for families, with recommendations for a venue to communicate bad news in the critical care environment (Lautrette, Cioldi, Ksibi, & Azoulay, 2006). A structured, consistent setting is recommended to insure that families receive appropriate information and

choices in which to make the best decisions for their loved ones. Evidence based guidelines have been developed to provide a consistent structure for conducting the family meeting in a critical care setting (Hudson, Quinn, O'Hanlon, & Aranda, 2008). There is an emerging evidence suggesting strategies to improve the family meeting process. One such strategy is providing the formal family meeting in a structured format. It is also essential for providers to examine and understand their own discomfort with discussing death. And lastly, effective communication is a skill that requires training and practice in the same manner as any technical skill in the healthcare setting (Boyle, Miller, & Forbes-Thompson, 2005).

Purpose of Project

Current methods of involving families in decision making for critically ill adult patients are not effective. Health care providers are not confident in their ability to communicate and the environment in which this communication takes place has been shown to be inconsistent. There is a need to implement a standard process to improve family communication, especially communication about EOL. Guidelines for family communication are available in the literature. These guidelines include a documentation tool, to be completed by the provider in charge of coordinating the family meeting. Combining communication guidelines and a documentation tool offers the healthcare provider access to a structured format for discussing EOL decisions with the patient/family and insures that family members will hear the same information on a consistent basis. The purpose of this project is to implement a formal process for conducting family meetings in the ICU, which will include an educational program for healthcare providers working in a large metropolitan university hospital setting. The healthcare provider for this project shall include any of the following, physician, advanced practice nurse, critical care nurse, social worker, spiritual consultant or palliative care consultant who work in a critical care setting.

Potential Significance of Project and Anticipated Outcomes

Improving communication through the use of a standardized documentation tool and a consistent method of sharing information can assist in improving quality of care, specifically family satisfaction regarding EOL communication. Providing high quality healthcare involves all aspects of care, including EOL. The Institute of Medicine (IOM) supports the need for improvement in communication by providing a structured format (Gay et al., 2009). There are several benefits in utilizing a structured format. The structured format serves as a reminder for the healthcare providers to discuss specific items in the meeting, helps the meeting to stay in focus, can also serve as documentation tool which is helpful for those not involved with the meeting and provides the overall framework for the discussion (Nelson, Walker, Luhrs, Cortez, & Pronovost, 2009).

The use of a structured format for sharing bad news and EOL decisions will potentially improve the healthcare provider's level of confidence as well as insure that family members are provided current, accurate information in order to make thoughtful decisions for the continued care of their family members. Health care professionals in the critical care setting are responsible for having fundamental palliative care knowledge and skills. Primary palliative care includes supporting the decision making process across various disease trajectories. Critical care providers have a professional obligation to use such knowledge and skills in the provision of care for all patients and families in that setting (National Hospice And Palliative Care Organization, 2008).

At EOL, it has been estimated up to 50% of critical care days have been utilized providing supportive care for patients who will not survive (Lilly et al, 2003). This consumes limited resources and unfortunately limits potential care for others. (Lilly et al, 2003). It is not the purpose of this project to limit care for patients, but to increase awareness of the use of life-

sustaining processes while decisions regarding futility and quality of life are being made and to increase the use of palliative care resources. A secondary outcome involves the appropriate use of healthcare resources for both patients and families. While critical care resources are being over-utilized in these scenarios, the use of palliative care is often under-utilized (Nelson et al., 2010).

By the year 2020, it is estimated the number of critical care patients requiring prolonged mechanical ventilation will reach >600,000 annually, which is double from the year 2000 (Daly et al., 2010). Complexity of illness along with advanced medical options for care can increase the potential for prolonging life in many otherwise hopeless situations. Through providing information and open, honest communication, families and patients can participate in making care decisions that are best suited for quality of life and patient/family satisfaction.

Ultimately, through effective communication skills, EOL decisions could occur in a timely fashion reducing pain and suffering, decreasing length of stay, improving family satisfaction and managing critical care resources (Ha & Longnecker, 2010). Family members need and expect effective communication (Gutierrez, 2012). Health care providers are not historically trained to deliver some of this sensitive information. Quality care demands the use of evidence-based knowledge and translation of this knowledge into practice.

Critical care is focused toward saving lives, however, death is common in this setting (Lautrette et al., 2006). One of the most essential responsibilities of the critical care provider is the ability to communicate with patients/families (Gay et al., 2009). Evidence-based communication guidelines may be the key for improving outcomes at end of life care in the critical care setting.

Theoretical Framework

According to Bandura (2006), the definition of self-efficacy is the individual's belief in one's ability to be successful in obtaining goals. One's sense of self-efficacy can play a major role in how one approaches goals, tasks and challenges (Bandura, 2006). Individuals express behavior, thinking and feelings based upon the belief of potential success of obtaining set goals (Bandura, 2006). Healthcare providers have reported lack of confidence in providing effective communication, especially involving EOL situations (Treece, 2007). If the individual has weak self-efficacy, the task at hand may be unachievable.

Characteristics of someone with weak self-efficacy include avoidance of task and belief that the difficult task is beyond their capabilities (Bandura, 2006). The literature supports avoidance as one of the barriers of communication (Gay et al., 2009). Avoidance is a way to limit interaction with the family members of a dying patient, which may lead to ineffective communication.

Characteristics of someone with strong self-efficacy include deep interest in the activity, a sense of commitment, and an ability to recover quickly from setbacks or disappointments (Bandura, 2006). The goal of using this theory relates to changing one's behavior and the ability to make that change resides in the individual's level of confidence and willingness to adopt (Curtis et al., 2012). Providing the clinician with the tools to succeed will ultimately improve self-efficacy. Efficacy influences goals and shapes outcomes. Those with a higher self-efficacy expect positive outcomes compared to those with low self-efficacy. People with strong efficacy learn how to adapt around obstacles and can exercise control over the situation (Bandura, 2004).

Literature Review

The literature was reviewed in order to document the problem of family communication in end of life situations, identify gaps in the sharing of information and the family member effects

of bereavement, which include stress, anxiety and depression following the death of a loved one. Figure 1 and Figure 2 demonstrate the literature search and grading of evidence.

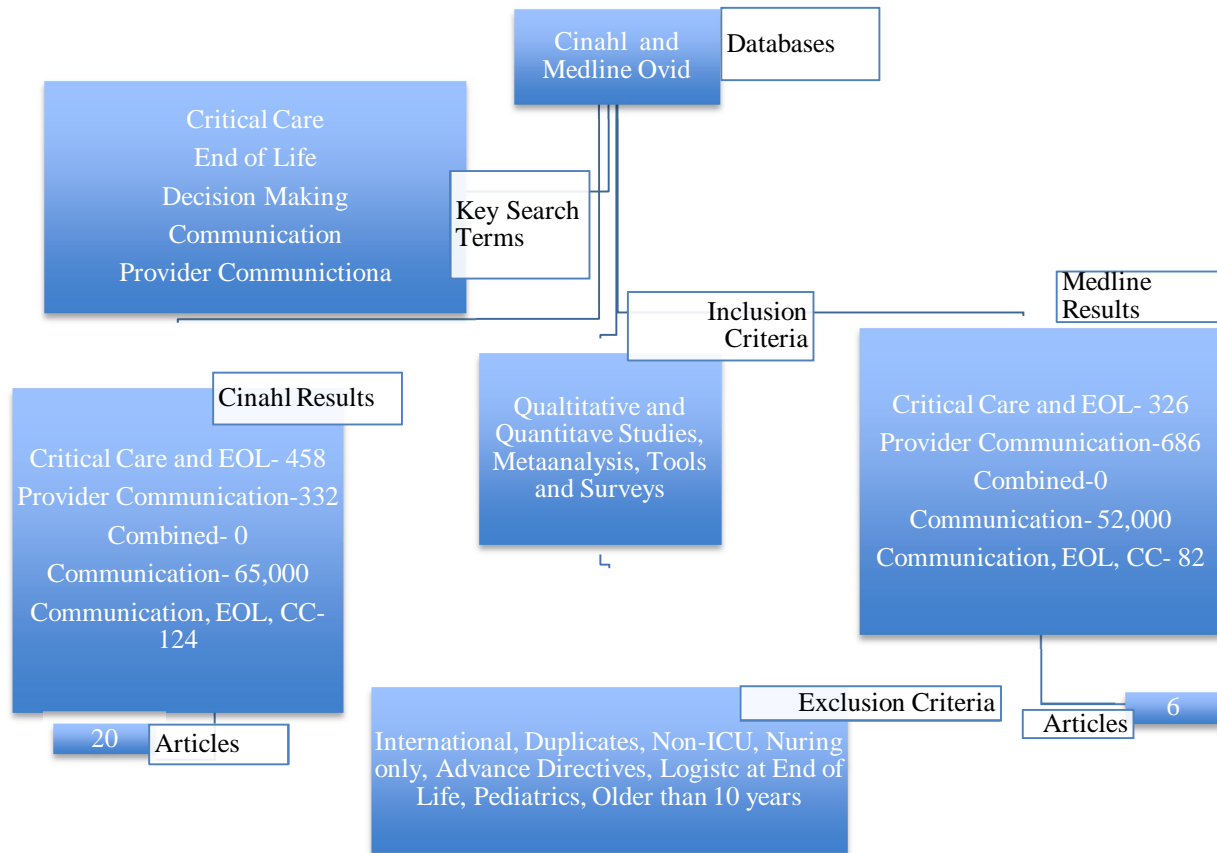


Figure 1: Literature Search

<u>Grade of Recommendation</u>	<u>Level of Evidence</u>	<u>Interventions</u>
A	1a	Systematic review of randomized control trials
	1b	Individual randomized control trial
B	2a	Systematic review of cohort studies
	2b	Individual review of cohort study
	3a	Systematic review of case-control studies
	3b	Individual review of case-control study
C	4	Case Series
D	5	Expert Opinion

Figure 2: Evidence grading using Johns Hopkins Nursing Evidence-Based Practice Rating Scale (Newhouse, Dearholt, Poe, Pugh, & White, 2005)

Six studies were chosen to be included in the review. Each study has a focus on communication in critical care and EOL decision-making. The literature review demonstrates how implementing a structured form of communication could improve family outcomes. The studies address patient and family satisfaction with communication, and also effects of bereavement, including stress, depression and anxiety after discharge.

Family – Health care provider Communication in End of Life

The literature review includes two randomized control trials, two qualitative studies, one systemic review and one quasi-experimental study. The level of evidence was graded using the Johns Hopkins Nursing Evidence-Based Practice Rating Scale (Newhouse, Dearholt, Poe, Pugh,

& White, 2005). The levels range from I-IVB. The highest level of evidence is a study conducted by Curtis et al. (2012), which includes 350 patients and examines family and clinician outcomes. The objective of this randomized control study was to generate evidence by implementing a communication facilitator to increase family and clinician self-efficacy expectations in regards to communication in the ICU (Curtis et al., 2012). Three validated tools were used to collect data in regards to psychological stress among family members. The facilitator is a trained nurse or social worker that will meet with the family during and outside of the structured family meetings. The purpose of the facilitator is to help the family process the information and provide additional emotional support. The facilitators received additional training involving three content areas; clinician-family communication skills, use of attachment theory and mediator skills to resolve conflict between clinicians and family members. Preliminary data collected at three and six months after the ICU course reports improved communication leading to improved quality of care of the dying patient, which ultimately can decrease psychological distress which includes family anxiety, stress and depression that develops after the ICU admission (Curtis et al., 2012).

Lautrette et al. (2007) conducted a randomized control study to evaluate the use of a communication guideline known as the VALUE method along with a brochure on bereavement with the intended goal to measure effects of bereavement. Family members demonstrated a decrease in bereavement symptoms, such as anxiety and depression, at the 90-day follow up (Lautrette et al., 2007). The validated tools utilized to document symptoms included the Impact of Event Scale and the Hospital Anxiety and Depression Scale.

A quasi-experimental study utilizing a control and study group, conducted by Daly et al. (2010), measured outcomes before and after implementation of a structured communication format vs. usual care. Daly et al. (2010) reviewed the effects of implementing early and

consistent communication to discuss patient preferences, values and goals, overall ICU length of stay and limitations of treatment options. This study does not report any significant difference among the control and intervention groups.

A qualitative study conducted by Gutierrez (2012), explored the expectations of family needs for prognostic communication at the end of life in an ICU setting. Families need respect, sensitivity and compassion when discussing poor prognosis information (Gutierrez, 2012). Furthermore, healthcare providers need to present information in a holistic format encompassing both dignity and empathy (Gutierrez, 2012). Results of this study, which were validated by a content expert, suggest that when families receive news regarding poor prognosis the information needs to be communicated with respect, sensitivity and compassion. Providers need to present information in a holistic format encompassing dignity and empathy. Providing information in this content allows the families to receive the needed information while being given emotional support.

Communication Tools

There are many different approaches to finding solutions in meeting the needs of families of critically ill and dying patients in the ICU. A review of literature conducted by Lautrette et al. (2006) demonstrated interventions aimed at improving EOL care, including proactive communication and the use of palliative care and ethics consults. Suggestions made after the review include information on how to conduct a structured family meeting.

A qualitative study performed by Hudson, Quinn, O'Hanlon, and Aranda (2008) resulted in the development of clinical practice guidelines for conducting family meetings. These guidelines were created after review of the literature and the use of focus groups with expert opinion in the specialty of Palliative Care. The guidelines developed offer a framework on how

to prepare, conduct and follow up family meetings (Hudson et al., 2008). Evidence of usability of the guidelines was not provided in the article.

Healthcare Provider Level of Comfort

EOL quality of care continues to gain momentum and is now become part of the national health care agenda (Coulourides, Wilber, & Enduidanos, 2013). Despite this national attention, though, there continues to be evidence in the literature suggesting lack of comfort among providers (Visser, Luc, & Houttekier, 2014).

The Robert Wood Johnson Foundation (RWJF) Critical Care End-of-Life Peer Workgroup identified seven specific domains of ICU palliative care quality, including adequate communication. One of the barriers of effective communication identified for healthcare providers included level of comfort, however, the RWJF review of literature suggests healthcare providers fail to even recognize level of comfort as a potential barrier (Visser, Luc, & Houttekier, 2014).

In a study by Coulourides et al 2013, physicians' comfort level with holding EOL conversations was directly related with referral to EOL care services, such as palliative care and hospice. Healthcare provider level of comfort with having EOL discussions is a modifiable factor and, therefore, an opportunity for change. The study also found that younger physicians were more likely to refer patients to EOL care services; likely a reflection of changes in medical education over the past years. Training in EOL is now mandated as part of the curriculum in medical schools (Coulourides, Wilber, & Enduidanos, 2013). With continued emphasis on improved outcomes and EOL care, the healthcare provider will only benefit from acquiring an increase in level of comfort.

Synthesis of Review

Evidence supports the need for effective communication between patients, families, and

their providers when making EOL decisions in critical care. Family members have been dissatisfied with healthcare provider communication, which ultimately results in poor psychological outcomes after the ICU admission (Davidson et al., 2012). Many barriers affecting the communication process have been identified in the literature, including healthcare provider lack of training, lack of experience and lack of confidence (Ha & Longnecker, 2010). The IOM identifies the need for improved communication and the literature supports the use of a structured format for coordinating and providing information for families in critical scenarios and end of life care (Gay et al., 2009). Therefore, does a standard method of offering the family meeting with detailed documentation provide the best venue for incorporating bad news or end of life information in the critical care setting?

Methods

Description

A quality improvement project was conducted in a high acuity medical intensive care unit of a large tertiary care facility from September 2014-November 2014 for a total of eight weeks. A convenience sample of twenty-one critical care staff participated in the project. The nurse champion of the project, via email, recruited the volunteer participants. Volunteers from the professions of medicine, nursing, social work, palliative care and spiritual care were invited to participate. Although the project received an exempt status from the IRB, the volunteers indicated their willingness to participate by signing an agreement. Criteria for eligibility included being over the age of eighteen, working directly with the select unit and willingness to complete surveys and attend the educational session. There was one primary lead for the project and two volunteer champions. The project included completion of surveys before and after an education session regarding the use of a standard protocol for conducting the meeting in regards to end of life decision-making. The objective of the project was to improve the quality of

communication in EOL discussions by offering a standard format for arranging family meetings and a documentation tool to provide information to all staff caring for the patient and family members.

The pretest-posttest was developed to assess the healthcare providers education, comfort level and experiences of family meetings. The pretest-posttest was validated by two experts in the field of palliative care. The pretest-post test questions have been developed using evidence-based literature and the responses used a likert scale (Appendix A). The education session immediately followed the pre-survey. The provision of an educational program insured that all trained staff would be able to implement the standardized meeting format for family meetings. The structured family meeting protocol was developed by the Center for Advanced Palliative Care (CAPC) and is available to use without permission. The educational format consisted of presentation of the problem, significance, projected outcomes of project and introduction of the communication guidelines (Appendix B). The education format was developed using evidence-based literature and attained validation by field experts in palliative care specialty. The educational program included a video demonstrating a family meeting using the structured format.

A leading expert in the field of palliative care, Dr. Diane Meier, created this video. Dr. Meier is the director of the Lilian and Benjamin Hertzberg Palliative Care Institute at the Mount Sinai Medical Center in New York City, professor of geriatrics and internal medicine and the Cather Gaisman Professor of Medical Ethics at the Mount Sinai School of Medicine. She has published more than 100 articles, four books and twenty-nine book chapters. Under Meier's leadership, since 2004 CAPC doubled the number of palliative care programs in the U.S. Dr. Meier has served as the director of CAPC at Mount Sinai Medical Center. She has publicly

spoken on numerous television shows, provided lectures nationally, developed grants and also served on a U.S. Senate Committee.

The video has been made publicly available through the CAPC website. Volunteers were educated about how to use the evidence-based communication guidelines. These guidelines have been made publicly available through the CAPC website (Appendix C) (Center Of Advanced Palliative Care, n.d.).

An evaluation of the implementation of structured family meeting communication was completed through chart audits following the educational sessions. The expectation was that the use of a standard documentation form reflecting the structured family meeting resulted in better communication through prompts learned by the staff family meeting facilitator (Appendix D). All of these steps took place in the eight-week interval.

Results

Demographics of sample

The volunteers consisted of healthcare providers who work directly in the medical intensive care unit for the project. The volunteers consisted of twelve Registered Nurses, four Acute Care Nurse Practitioners, one Social Worker, two Palliative Care team members, one member from the Spiritual Care team and one Case Manager. Years of experience in this unit ranged from 1-10 years with average being between 1-6 years. Level of education ranged from Bachelor's Degree to Post-Masters with 95% having Bachelor's or Master's degree. When asked if they had received adequate training to discuss EOL issues with families/patients, only 33% demonstrated positive response. And lastly, when asked about level of comfort in participating in an EOL meeting 38% responded as not comfortable.

Precautions were taken to protect the rights of the volunteers, which began with IRB approval for the project. Volunteers in this project were asked to participate by a project champion, not the lead. The IRB did not require consent for the project, but the volunteers were asked to sign in during the education session to indicate they were indeed volunteering for the project. The list of volunteers and signatures were kept in a locked drawer in the coordinators private office.

The surveys were in paper form. To assist with de-identification, each volunteer was given a number to be used for all surveys. The same number was utilized for both pre and post surveys to allow comparison of data. A locked drop off box was provided to insure protection of surveys and kept in a secure location on the unit.

Data has only been shared in a combined form, not as an individual basis. Data will not be shared individually with the stakeholders. There was no link between participation in this project and expectations of their jobs and volunteers were assured privacy of their responses.

Data Collection and Results

The pretest-posttest surveys were made available on paper format and used a likert scale for responses. The likert scale ranged from strongly agree to strongly disagree, coded as 1 – 5 points. The pretest allowed collection of demographics of the participants, identified previous education/training regarding EOL communication, personal comfort level in conducting a family meeting and any previous experience in participating in family meetings (see Appendix A). Descriptive data was used to describe the volunteer participants. Ordinal data from the pre and post-test surveys was entered into an Excel Program and analyzed using Fisher exact test. The specific metrics in the analysis included perception of adequate level of training and level of comfort of the healthcare provider. This statistical analysis formula calculates an exact

probability value for the relationship between two variables, as found in a two by five cross table. The Fisher exact test calculates the difference between the data observed and the data expected, considering the given marginal and the assumptions of the model of independence.

The following tables display data in regards to the variable level of comfort to hold a family meeting. Of the twenty-one volunteers there was an improvement in level of comfort at a rate of 52%. A p-value of 0.165 was calculated using the Fisher exact test.

Table 1: What is your level of comfort in family meeting to discuss EOL decisions?

	Very comfortable	Comfortable	Neutral	Uncomfortable	Very Uncomfortable
Pre education	3	10	3	4	1
Post education	6	10	5	0	0

Table 2: The results of an exact contingency table test performed regarding level of comfort

Data: contingency table						
	A	B	C	D	E	Total
1	3	10	3	4	1	21
2	6	11	4	0	0	21
Total	9	21	7	4	1	42
Expected: contingency table						

	A	B	C		E
1	4.40	10.3	3.91	1.95	0.488
2	4.60	10.7	4.09	2.05	0.512

Note: The given table has probability $1.6E-03$. Pre scores (1) and Post scores (2)

The sum of the probabilities of the above tables, $p = 0.165$

The following tables display data in regards to perception of level of adequate training to hold a family meeting. A total of 19/21 volunteers post survey indicated an improvement rating, indicating a 90% improvement rate. A p value of 0.015 was calculated using the Fisher exact test.

Table 3: Do you feel you have had adequate training to discuss EOL issues with patients/families?

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
Pre education	2	5	6	6	2
Post education	5	11	5	0	0

Table 4: The results of an exact contingency table test performed regarding adequate training.

Data: contingency table						
	A	B	C	D	E	Total
1	2	5	6	6	2	21
2	5	11	5	0	0	21
	7	16	11	6	2	42
Expected: contingency table						
	A	B	C	D	E	
1	3.50	8.00	5.50	3.00	1.00	
2	3.50	8.00	5.50	3.00	1.00	

Note: The given table has probability 7.9E-05. Pre scores (1) and post scores (2)

The sum of the probabilities of the above tables, $p = 0.015$

And lastly, after the education session and viewing of the communication guidelines via video format, the participants were asked if there was a change in level of confidence. The table below displays the results.

Table 5: Do you feel your level of confidence in participating in a family meeting has improved after receiving this education?

Strongly agree	Agree	Neutral	Disagree	Strongly Disagree
N=6	N=9	N=3	N=0	N=0

Note: Three volunteers did not answer the question

Chart Review

The communication guidelines implemented in the project have been developed by experts in palliative care and made publicly available through the Center of Advanced Palliative Care (CAPC) website. A leading expert in the field of palliative care, Dr. Meier, created the video demonstrating use of these guidelines which were utilized in this project and also made publicly available through CAPC (Appendix A).

To assess for consistent use of the structured format during family meetings, a chart review was performed pre and post education session. The following table represents the data collected. These data points were derived from the evidence-based communication guidelines. All thirteen data points show an increase in response, which suggests compliance with use of the guidelines. See Appendix E for complete data sets.

Table 6: Chart Review

Data Point	Pre-project Chart Review N=12 Answer=Yes	Post-project Chart Review N=23 Answer=Yes	Percentage of Difference
1.Prior to the meeting, were goals of meeting discussed with team members	58%	81%	23% increase
2.Prior to the meeting, were benefits of treatment options discussed among the team members	58%	70%	28% increase
3.Were the appropriate consulting teams available for the meeting	25%	76%	51% increase
4.During the meeting, were chairs arranged so everyone could face each other yet at a comfortable distance apart	42%	90.4%	48.4% increase
5.Was the patient present	17%	19%	Patients are usually not present due to illness
6.During the meeting, were introductions of medical team and family performed	58%	90.4%	32.4% increase
7.Did the team leader allow the family to discuss current knowledge of patient's health	50%	81%	31% increase
8.Did anyone from the medical team explain the overall picture	75%	81%	6% increase

and prognosis			
9. Were questions answered using non-medical terms	58%	85.7%	23.7% increase
10. Were patient goals for plan of care identified	75%	85.7%	12.7% increase
11. Were goals translated into an action plan	75%	85.7%	12.7% increase
12. Did the team confirm continued availability to the patient and family regardless of plan of care	53%	95.2%	42.2% increase
13. Was there team debriefing post meeting	33%	66.6%	33.6% increase

Limitations and Future Recommendations

There are a variety of avenues available to improve quality regarding EOL communication in different venues. Ideally, it would be important to capture satisfaction data from family/patients. Due to the limited timeframe for this project and the sensitive nature of this type of request, this was not feasible. A comparison of length of stay, which in this case would represent shorter time to death or discharge to hospice of the patient, could also have been part of the outcome data, but again, not as easy, nor feasible to obtain and evaluate. Despite representatives from multiple disciplines volunteering for the project, physician participation was lacking, which was surmised to be due to physician scheduling and short duration of project.

The project overall received positive feedback from the volunteers, nursing staff in general, the stakeholders and several attending physicians rotating in the unit at the time of the project.

Millions of patients who will die in the hospital are admitted to a critical care unit annually. Family members are often faced with the burden of making end of life decisions, which is a complex process and requires a well-trained healthcare provider to deliver this challenging information in a clear, concise, confident and compassionate manner. Healthcare providers have been described by family members as being just the opposite, leaving the family distressed, anxious and dissatisfied. The literature supports the need for improved communication in this content area. Implementing a set of communication guidelines and a structured format for conducting a family meeting based on evidence may be the key for increased communication and improved outcomes.

The project provided an educational program to apply the contents of a formal, structured family meeting for the healthcare provider to conduct an evidence-based meeting with goals to improve provider confidence and family satisfaction with the communication process. As indicated by data analysis, there was a significant improvement in level of confidence of the healthcare provider after receiving the education and guidelines. Improvement in consistency of EOL communication during the family meetings as indicated by the chart reviews. In the near future, the education and communication guidelines will be implemented as standard of care in the study unit. This process of implementation has yet to be developed. For house-wide implementation, an abstract has been submitted intra-facility, and upon approval, poster presentation will be given during the annual research/education-nursing summit.

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Appendix AEnd of Life Decision Making and The Family MeetingPre-test

This is a voluntary survey to identify End of Life (EOL) communication knowledge in the ICU setting. Your responses will only be used in this project. Your participation indicates your consent to participate in this project.

Please answer the following to the best of your ability. Circle only one answer for each question.

1. What is your current role/position?
A. RN B. NP C. Resident D. Fellow E. Attending F. Other
2. How many years in your current position?
A. Less than 1 year B. 1-3 years C. 3-5 years D. 5-8years E. Greater than 8 years
3. Do you feel you have had adequate training to discuss End of Life issues with families/patients?
A. Strongly agree B. Agree C. Neutral D. Disagree E. Strongly disagree
4. Approximately how many family meetings have you been involved with in the past 3 months in regards to end of life issues/decisions?
A. None B. 1-3 C. 3-5 D. 5-10 E. Greater than 10
5. When do you start thinking about EOL discussions for your patients?
A. On admission B. With significant change in patient status C. When someone else initiates
6. What is your level of comfort to participate in a family meeting discussing EOL issues?
A. Very comfortable B. Comfortable C. Neutral
D. Uncomfortable E. Very uncomfortable
7. Are you aware there are communication tools available for EOL discussions?
A. Yes B. No C. Not Sure
8. Have you ever used a communication tool to guide your discussions?
A. Yes B. No C. Not Sure
9. Which of the following do you feel may represent family members perspective involving communication during EOL discussions?
A. Very satisfied B. Satisfied C. Neutral D. Dissatisfied E. Very Dissatisfied
10. Which of the following could become potential communication barriers during an EOL discussion meeting? Select all that apply
A. Healthcare provider lack of experience with EOL meetings
B. Healthcare provider level of confidence involving EOL discussions
C. Lack of understanding of disease process by family members
D. Lack of clear goals and plan of care discussion
E. Lack of empathy for family

End of Life Decision Making and The Family MeetingPost-Test

Following the education session regarding communication at EOL kindly answer the following questions.

Please answer the following to the best of your ability. Circle only one answer for each question.

1. Did the education session provide knowledge regarding how to conduct a family meeting?

A. Strongly agree B. Agree C. Neutral D. Disagree E. Strongly disagree

2. Which of the following do you feel may represent family members perspective involving communication during EOL discussions?

A. Very satisfied B. Satisfied C. Neutral D. Dissatisfied E. Very Dissatisfied

3. Do you feel using a communication guideline could have a positive impact on the family meeting, i.e. improve outcomes?

A. Strongly agree B. Agree C. Neutral D. Disagree E. Strongly disagree

4. Which of the following could become potential communication barriers during an EOL discussion meeting? Select all that apply

- A. Healthcare provider lack of experience with EOL meetings
- B. Healthcare provider level of confidence involving EOL discussions
- C. Lack of understanding of disease process by family members
- D. Lack of clear goals and plan of care discussion
- E. Lack of empathy for family

5. Do you feel your personal level of confidence in participating in a family meeting has been improved?

A. Strongly agree B. Agree C. Neutral D. Disagree E. Strongly disagree

6. What is your level of comfort to participate in a family meeting discussing EOL issues?

- A. Very comfortable B. Comfortable C. Neutral
- D. Uncomfortable E. Very uncomfortable

Outline for Education

Pre-test followed by: presented in a power point format and participants will have access to review again if desired

I. Introduction of Problem

II. Significance and Background of Problem

III. Satisfaction Survey Scores from Unit

A. Scores from unit-based surveys over past six-twelve months

B. Scores from hospital-based surveys over past six-twelve months

IV. Review of Literature

A. Family dissatisfaction

B. Healthcare provider barriers

C. Interventions available

V. Communication Guidelines

VI. Video of Structured Family Meeting: <https://www.youtube.com/watch?v=7kQ3PUyhmPQ>

VII. Projected Outcomes

A. Improved level of comfort among healthcare providers

VIII. Questions

A. How to complete post-test

B. Plans for attending formal family meeting and introducing guidelines to team prior to meeting

C. How to complete communication checklist for documentation

Appendix C:**THE GOAL SETTING CONFERENCE****Before the meeting the medical team and healthcare providers will**

- Review chart-know all medical issues: history, prognosis, treatment options
- Coordinate medical opinions among consultant physicians
- Decide what tests/treatments are medically appropriate (i.e., likely to benefit the patient)
- Review Advance Care Planning documents
- Review/obtain family psychosocial information
- Decide who you want to be present from the medical team
- Clarify your goals for the meeting-what decisions are you hoping to achieve?

10 STEP GUIDE

(Sample statements included in italics)

1. Establish Proper Setting

- Private, comfortable; Everyone seated, Turn off/forward pager

2. Introductions

- Allow everyone to state name and relationship to patient
- Build relationship: ask non-medical question about patient

“Can you tell me something about your father? What kind of person is he?”

3. Assess Patient/Family Understanding

- Encourage all present to respond
- Ask for a description of changes in function over course of illness/hospitalization

“What have the doctors told you about your wife’s condition at this point?” “What is your assessment of the current medical situation?”

4. Medical Review/Summary

- Summarize “big picture” in few sentences- use “dying” if appropriate; avoid organ-by-organ medical review
- Avoid jargon
- Answer questions

“I’m afraid I have some bad news. I wish things were different. Based on what you have

told me, and what I see, I believe your mother is dying”

5. Silence/Reactions

- Respond to emotional reactions (have tissues available)
- Prepare for common reactions: acceptance, conflict/denial, grief/despair; respond empathically

“This must be very hard” “I can only imagine how scary/difficult/overwhelming this must be” “You appear angry, can you tell me what is upsetting you?”

6. Discuss Prognosis

- Assess how much patient and family want to know
- Provide prognostic data using a range
- Respond to emotion

“Some people like to know every detail about their illness, others prefer a more general outline. What kind of person are you?” “Although I can’t give you an exact time, given your illness and condition, I believe you have (hours to days) (weeks to months).

This is an average, some live longer and some live shorter”

7. Assess Patient/Family Goals

Possible goals:

- prolong life
- improve function
- return home
- see a family milestone
- relief of suffering
- staying in control

“What do you wish to accomplish?” “Are there any important goals or tasks left undone?” “What is most important to you at this time?” “Knowing that time is short, what goals do you have?” “How do you picture your death?” “Where do you want to be when you die?”

8. Present Broad Care Options

- Stress priority of comfort, no matter the goal
- Make a recommendation based on knowledge/experience

“Given what you have told me, about your mother and her goals, I would recommend . . .” “These decisions are very hard; if (patients name) were sitting with us today, what do you think he/she would say?”

“How will the decision affect you and other family members?”

9. Translate Goals into Care Plan

- Review current and planned interventions-make recommendations to continue or stop based on goals
- Discuss DNR, Hospice/Home Care, Artificial Nutrition/Hydration, future hospitalizations
- Summarize all decisions made CONFIRM YOUR CONTINUED AVAILABILITY REGARDLESS OF DECISIONS

“You have told me your goals are ____ With this in mind, I do not recommend the use of artificial or heroic means to prolong your dying process. If you agree with this, I will write an order in the chart that when you die, no attempt to resuscitate you will be made, is this acceptable (ok)?”

“All dying patients lose their interest in eating in the days to weeks leading up to death; this is the body’s signal that death is coming.” “I am recommending that the (tube feedings, IVF) be discontinued (or not started) as these will not improve her living and may only prolong her dying.”

10. Document and Discuss

- Write a note: who was present, what decisions were made, follow-up plan
- Discuss with team members (consultants, nurse, etc.)
- Check your emotions

Team debriefing = Opportunity for Teaching and Reflection

Ask team members:

“How do you think the meeting went?” “What went well?” What could have gone more smoothly? “What will you do differently in the future?”

MANAGING CONFLICT

- Listen and make empathic statements
- Determine source of conflict: guilt, grief, culture, family, dysfunction, trust in med team, etc.
- Clarify misconceptions
- Explore values behind decisions
- Set time-limited goals with specific benchmarks (e.g. improved cognition, oxygenation, mobility)

(Guidelines publicly available at capc.org and permission granted by author)

Appendix DChecklist/Template for EHR-Communication Guidelines

Data Point	Response Yes/No	Text Option
Prior to the meeting, were goals of meeting discussed with team members	Respond yes or no	
Prior to the meeting, were benefits of treatment options discussed among the team members	Respond yes or no	
Were the appropriate consulting teams available for the meeting	Respond yes or no	
During the meeting, were chairs arranged so everyone could face each other yet at a comfortable distance apart	Respond yes or no	
Was the patient present	Respond yes or no	If no, comment here
During the meeting, were introductions of medical team and family performed	Respond yes or no	
Did the team leader allow the family to discuss current knowledge of patient's health	Respond yes or no	
Did anyone from the medical team explain the overall picture and prognosis	Respond yes or no	If unclear, add comment here
Were questions answered using non-medical terms	Respond yes or no	
Were patient goals for plan of care identified	Respond yes or no	If no, comment here
Were goals translated into an action plan	Respond yes or no	
Did the team confirm continued availability to the patient and family regardless of plan of care	Respond yes or no	
Was there team debriefing post meeting	Respond yes or no	

Appendix EChart Review Data Pre-Intervention

N=12 charts reviewed

Data Point	Answer Yes Number/Percentage	Answer No Number/Percentage	Unknown or Comment Number/Percentage
1. Prior to the meeting, were goals of meeting discussed with team members	7-58%	5-42%	
2. Prior to the meeting, were benefits of treatment options discussed among the team members	7-58%	5-42%	
3. Were the appropriate consulting teams available for the meeting	3-25%	9-75%	
4. During the meeting, were chairs arranged so everyone could face each other yet at a comfortable distance apart	5-42%	7-58%	
5. Was the patient present	2-17%	10-83%	
6. During the meeting, were introductions of medical team and family performed	7-58%	5-42%	
7. Did the team leader allow the family to discuss current knowledge of patient's health	6-50%	6-50%	
8. Did anyone from the medical team explain the overall picture and prognosis	9-75%	3-25%	
9. Were questions answered using non-medical terms	7-58%	5-42%	
10. Were patient goals for plan of care identified	9-75%	3-25%	
11. Were goals translated into an action plan	9-75%	3-25%	

12. Did the team confirm continued availability to the patient and family regardless of plan of care	7-58%	5-42%	
13. Was there team debriefing post meeting	4-33%	8-66%	

Chart Review Data Post-Intervention

N=23 charts

Data Point	Answer Yes Number/Percentage	Answer No Number/Percentage	Unknown or Comment Number/Percentage
1. Prior to the meeting, were goals of meeting discussed with team members	17-81%	2-9.5%	2-9.5%
2. Prior to the meeting, were benefits of treatment options discussed among the team members	16-76.2%	3-14.3%	2-9.5%
3. Were the appropriate consulting teams available for the meeting	16-76.2%	4-19%	1-4.7%
4. During the meeting, were chairs arranged so everyone could face each other yet at a comfortable distance apart	19-90.4%	1-4.7%	1-4.7%
5. Was the patient present	4-19%	17-81%	0
6. During the meeting, were introductions of medical team and family performed	19-90.4%	1-4.7%	1-4.7%
7. Did the team leader allow the family to discuss current knowledge of patient's health	17-80.9%	1-4.7%	3-14.3%
8. Did anyone from the medical team explain the overall picture and prognosis	19-90.4%	0%	2-9.5%

9. Were questions answered using non-medical terms	18-85.7%	1-4.7%	2-9.5%
10. Were patient goals for plan of care identified	18-85.7%	1-4.7%	2-9.5%
11. Were goals translated into an action plan	18-85.7%	2-9.5%	1-4.7%
12. Did the team confirm continued availability to the patient and family regardless of plan of care	20-95.2%	0%	1-4.7%
13. Was there team debriefing post meeting	14-66.6%	6-28.5%	1-4.7%

Author, year	Study objective	Design	Sample (N)	Outcomes studied	Results	*Level and Quality Rating
Hudson et al. (2008)	The study sought to develop multidisciplinary clinical practice guidelines for conducting family meetings with a focus of palliative care. Guidelines based on evidence and consensus based expert opinion.	Qualitative study with Literature Review. The design also included the development of conceptual framework and refinement of guidelines based on expert opinion.	Focus groups from three teaching hospitals participated in the study.	A review of literature was conducted followed by development of guidelines based on the review and expert opinion.	The study provided an opportunity to enhance the quality of care provided to patient and families. The clinical guidelines offered a framework for preparing, conducting and evaluating the family meeting process.	IV B
Daly et al. (2010)	To examine patient outcomes before and after implementation of an intensive communication system to test effect of regular family meetings vs. structure family meetings. The communication intervention focused on patient preferences,	Pre and post test design, quasi-experimental. November 2005-April 2006 collected data based on regular family meetings. May 2006-February 2008 the family meetings were conducted using the intensive communication system. The data was compared	There were 135 patients in the control group and 346 patients in the intervention group.	Multivariate analysis to evaluate length of stay as primary outcome and aggressiveness of care as secondary outcome.	There was no significant difference among the groups. The complexity of end of life decision-making among the critically ill likely will require more than one type of communication intervention. Future research should focus on family decision-making preferences.	II B

	values and goals as well as the technique of communication validated in previous work.	between the two groups.				
Lautrette, Ciroldi, Ksibi, and Azoulay (2006)	A review of literature to focus on interventions designed to improve communication with family members of patients dying in the ICU.	Review of literature	N/A	The review listed potential outcomes to be measured. These include family satisfaction with communication, effectiveness of information provided, conflicts, quality of life of the dying patient and family and economic burdens.	The review demonstrated there are interventions aimed at improving end of life care including, proactive communication, involving ethics and use of palliative care consults. Family meetings to discuss EOL decisions need to include time to allow families to ask questions, voice concerns and express emotions. After review of EOL conferences, the following focuses have been suggested, how to prepare for a meeting, how to conduct a meeting and how to end and following a meeting.	IV B

<p>Curtis et al. (2012)</p>	<p>Does use of a communication facilitator increase family and clinician self-efficacy expectations about communication in the ICU.</p>	<p>Randomized Control Trial</p>	<p>350 patients</p>	<p>Psychological distress among family members was measured at three and six months post ICU stay. Study measures included the use of Patient Health Questionnaire, Post-Traumatic Stress Disorder Checklist Civilian Version and Generalized Anxiety Disorder.</p>	<p>This article was written during the study. Preliminary results from the satisfaction surveys were described as the following, improvement of communication among family members and ICU staff could lead to improvements in quality of care of the dying patient. These improvements could lead to decrease in family anxiety, stress and depression post the ICU stay.</p>	<p>I B</p>
<p>Gutierrez, (2012)</p>	<p>To explore the expectations of family members needs for prognostic communication at end of life in the ICU.</p>	<p>Qualitative Study</p>	<p>20 family members</p>	<p>Iterative content analysis with two broad categories. These include family needs during communication and families experience during communication. The data was further validated by an expert in</p>	<p>For families to receive news regarding poor prognosis the information needs to be communicated with respect, sensitivity and compassion. Providers need to present information in a holistic format encompassing dignity</p>	<p>III B</p>

				the filed of qualitative analysis.	and empathy. By providing information in this content allows the families to receive the needed information while being given emotional support.	
Lautrette et al. (2007)	An intervention to improve communication between clinicians and families of the dying patient in the ICU and lessen the effects of bereavement.	Randomized Control Trial Use of VALUE guidelines for communication vs. standard communication for family conferences. Distribution of bereavement brochure to those families in the VALUE group.	126 patients in 22 intensive care units	Telephone interviews conducted 90 days post death. Primary outcome used to assess post-traumatic stress disorder was the Impact of Event Scale. The secondary outcome assessed was anxiety and depression and the method used was Hospital Anxiety and Depression Scale.	By implementing a communication tool and providing a bereavement brochure, family members experienced a decrease in bereavement symptoms at the 90-day mark.	I B

Appendix F: Review of Literature Summary and Level of the Evidence (*Rating system for the Johns Hopkins Nursing Evidence-Based Practice Rating Scale)

