

End of life clinician-family communication in ICU: a retrospective observational study - implications for nursing

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KEY WORDS

End of life, communication, family support

ABSTRACT

Objective

The objective of this study was to identify practice issues that influence end of life communication and care of patients and families in the intensive care unit (ICU).

Design

This study used a retrospective observational approach utilising a medical record review.

Setting

An Australian metropolitan mixed medical/surgical ICU.

Subjects

There are two parts to this study. The first part related to all of the patients who died in the ICU in one calendar year, a total of 97. The second part of this study related to a random selection of 25% of these patients, a total of 24.

Results

This study showed that death in the ICU was often anticipated, and that whilst communication between family and medical personnel was evident in the medical record, the involvement or occurrence of communication between the nurse and the family was not recorded, and that nurses were included in only 25% of formal family meetings.

Conclusion

Whilst this study confirmed that death is often predicted for critically ill patients, and opportunities for communication with the family or next of kin assists to achieve consensus on end of life decisions, the involvement of nurses, as primary care-givers is not well represented in the medical record, thus undermining the importance of the nurses role in direct patient care that extends to the family in the ICU.

INTRODUCTION

George, a 66 year old male was admitted to the ICU following a cardiac arrest at a golf course with a 22 minute delay to return of circulation. He was intubated, ventilated and sedated, and admitted to the ICU following investigation and Intra-Aortic Balloon Pump (IABP) insertion to maintain his cardiac output and, thus keep him alive. Upon arrival in the ICU, his condition was critical.

Following admission to the ICU and development of a management plan, George's care was managed by his allocated nurse for the shift, and included invasive haemodynamic support and monitoring, various pharmacological therapies, management and manipulation of his ventilation status according to pre-determined parameters and arterial blood gas results. A naso-gastric tube was inserted to enable administration of parenteral medications and early feeding. Pressure area care, mouth care and hygiene were also performed. Haemodialysis was commenced to address anuria and hyperkalaemia. Neurological assessment suggested signs of neurological injury, necessitating further medical review and nursing management.

Over the course of the next 24 hours, his condition deteriorated, and George died peacefully.

ICU are places where the sickest patients receive the most technologically sophisticated care (Hamric and Blackhall 2007), where the primary goals are to help patients survive acute threats to their lives while preserving and restoring quality to their lives (Truog et al 2008). Despite these goals, death is common in the ICU, with as many as one in five Americans dying while using ICU services (Angus et al 2004).

Many studies have reported on the quality of practices in end of life care delivered in the ICU (Azoulay et al 2009; Crighton et al 2008; Bloomer et al 2010), and in particular, end of life decision making, involving clinicians and the family (Gries et al 2008). NSW Health also released *Guidelines for end of life care and decision making* (2005) to assist in guiding clinicians in working with patients and families reaching for consensus in end of life

decisions. Reaching consensus in outcomes requires effective communication.

Insufficient and inadequate communication between ICU staff and family members is a common complaint and families rate communication with staff amongst their most important concerns (Carlet et al 2004), with high levels of anxiety and depression amongst family members of patients in the ICU (Pochard et al 2001). Commonly, care of the ICU patient extends to include the family, where the nurse is often their most visible source of support and education, through spending more time at the bedside than any other clinician (Hamric and Blackhall 2007). Family-centred care acknowledges that the patient is embedded within a social structure and web of relationships (Truog et al 2000), and as a result, the patient cannot be cared for in isolation from their family. This caring relationship that develops between nurse and family facilitates communication and enables the nurse to be privy to information about the social structure of the family, dynamics and value systems (Hamric and Blackhall 2007), all of which assists clinicians in determining care.

When the patient's condition is critical, Crighton et al (2008) endorse open communication with family as essential for clinicians to be able to direct the communication, enabling the family to transition from a curative focus, to end of life care. Interestingly, in the case study described by Crighton et al (2008), the family meeting included family members, physician, and palliative care behavioural psychologist, but not a nurse. This is despite the fact that the meeting occurred at the patient's bedside, suggesting that either the nurse's presence at this meeting was not recognised as significant/important and hence not mentioned, or that the nurse was not included in the family meeting.

The apparent lack of nurse involvement or significant presence in such family meetings may lead to conflict among clinicians. Recent studies (Hamric and Blackhall 2007; Ferrand et al 2003) report that conflict may occur between nurses and physicians regarding end of life care, in particular, concerns regarding quality of life and communication. A

family-centred approach (Truog et al 2008), ensures that the patient is considered in the context of their family structure, and ensures that a consensus in care decisions is achieved, minimising conflict (NSW Health 2005).

Whilst there is little argument that the nurse in ICU plays an integral role in caring and managing a critically ill patient and their care, as depicted in George's story, what is not evident from this story and similar ICU stories, is the hidden work undertaken by nurses, which is no less significant or important.

The concept of hidden work is not new, in fact caring exemplifies the hidden, and often unrecognised work of nurses that is core to the nursing role (Norman et al 2008). In the palliative care setting the nursing work associated with after death care in caring for the family as well as the deceased patient is regarded as hidden work (O'Connor et al 2005), often not acknowledged, and yet essential to care. In the case of ICU, nursing care can include so much more than just the management of therapies and associated technology, work that is often not acknowledged or recorded. By its omission, it undermines the importance of this work and its impact on the patient and their families.

The aim of this study was to identify practice issues that influence end of life communication and care of patients and families in the ICU.

METHOD

Following ethical approval from the Human Research and Ethics Committee at the health service, two sets of data were collected:

demographic data was collected on all of the patients who died in one metropolitan mixed medical/surgical ICU over a 12 month period (n=97) including:- length of entire hospital stay, length of stay in ICU, simplified acute physiological score (SAPS II) and acute physiology and chronic health evaluation (APACHE) II and III scores recorded in first 24 hours.

from this cohort, a random selection of 25% (n=24) were utilised for a retrospective medical record audit. Data collected included reason for admission, cause

of death (as documented on the Death Certificate), NFR status, date of NFR status, time from NFR status to death, next of kin as documented on the hospital admission sheet, next of kin as documented on the ICU nursing admission sheet, all medical and nursing entries relating to end of life/poor prognosis/palliative care decision making, number of meetings held with family, who family meetings were initiated by, who was present at the family meetings, presence of family at death, and evidence of palliative care referral or involvement.

FINDINGS

From the sample population of 97, the length of entire hospital admission ranged from 1 to 318 days (average 9.7 days). The length of stay in ICU ranged from <1 day to 49 days (average 4.1 days). The mean SAPS II score was 65, the mean APACHE II score was 28, and the mean APACHE III score was 113.

From the randomly selected 25% of the sample population, which were used for a retrospective medical record audit, the following results were obtained. The length of stay in ICU ranged from <1 day to 62 days (average nine days). The mean SAPS II score was 63, the mean APACHE II score was 27, and the mean APACHE III score was 110.

Of this smaller population, 37.5% (n=9) were admitted for a respiratory diagnosis, 25% (n=6) for a cardiac diagnosis, 20.8% (n=5) for sepsis, 8.3% (n=2) postoperatively and another 8.3% (n=2) were admitted with a neurological diagnosis. At the time of death, 96% (n=23) of patients in this population were documented as NFR, and the NFR status was determined between 5 days and <1 day before death, with the average time between determination of NFR status and death being one day.

Next of kin (NOK) is recorded at admission to the hospital, and again upon admission to ICU. In this cohort, NOK as documented on admission to the hospital, and admission to the ICU was different in 25% (n=6) cases.

The researchers also searched for written entries regarding end of life/poor prognosis or other similar wording that would indicate or suggest

communication with family. Whilst very few entries were made by nursing staff in the medical record regarding communication with family about these issues, multiple entries were made by medical staff, including detail of who the conversation was with.

References to formal 'family meetings' were also recorded. The average number of family meetings was two (minimum one, maximum five). The medical record which reported five family meetings was for a patient whose stay lasted seven days. In this particular case, the patient had been hospitalised for 16 days prior to admission to ICU, his SAPS II, APACHE II and APACHE III score were 58, 24 and 87 respectively, and NFR status was determined within one day of admission to ICU. This case highlights that where death is seen as a likely outcome early in the admission, prompt and consistent communication with family facilitated appropriate care decisions, with both family and clinicians in agreement.

Nurse involvement in family meetings was also investigated. Nurses were involved in 25% (n=6) of family meetings. Although it was difficult to determine who initiated the family meetings, written entries about the initiation of a family meeting were made by a medical officer in 79% (n=19) of the cases, with no entries suggesting that a family meeting was initiated by a nurse.

Family members were present at the time of death in 66% (n=16) of cases, not present in 1% (n=2) of cases, and in the remaining six cases, the presence or lack thereof was not recorded at all. Family presence may be related to the time of death, as 25% (n=6) died between 0700hrs and 1500hrs, 46% (n=11) died between 1500hrs and 2300hrs and the remaining 29% (n=7) died between 2300hrs and 0700hrs. A referral to the palliative care consultant team was made in only one case, at six hours before death. There was no documentation about input from the palliative care team.

DISCUSSION

Given the similarity of the measured predictors of mortality such as SAPS II and APACHE II and III scores between the entire sample population, and the

smaller randomly selected population, this suggests that the smaller randomly selected population are representative of the larger population in terms of acuity and severity of illness. The SAPS and APACHE scores confirmed that patients in both the larger sample of all deaths over a 12 month period, and the smaller population of 25%, were critically ill on admission to the ICU. These data are consistent with a previous study which found that the mean APACHE II and SAPS II scores of patients where life support was withdrawn or withheld was 27 and 59 respectively, and death was seldom unexpected (Bloomer et al 2010).

The high SAPS and APACHE scores are also consistent with the NFR status. This highlights that confirmation of NFR status is appropriate for the acuity and likelihood of death in this cohort. Furthermore, achieving agreement on NFR status requires communication and negotiation between family members and clinicians, until acceptance and unity is reached (Crighton et al 2008).

It is also important to note that despite the critical condition of these patients on admission, NFR status was determined late in the admission, with the medical records showing that NFR status was determined, on average, within one day of death. Despite their critical illness, there may have been factors that delayed the determination of NFR status, that are not apparent to this audit, such as awaiting family or allowing time for the family to comprehend what NFR meant for their loved one (Payne et al 2010), and prepare for death of their loved one.

This study also uncovered that between hospital admission and ICU admission, there had been a change in nominated NOK, from the spouse to another family member in 25% (n=6) cases. Spouses are considered to be the main source of information about the patient and as the best 'proxy decision maker', because individuals are more likely to have shared their wishes and values regarding serious illness with their spouse (Pochard et al 2005). The reasoning behind the change in NOK is not known or determinable. However literature describes the heavy burden that can be carried by the nominated

NOK, who is often asked to contribute to the decision making around care and palliation (Crighton et al 2008). Relatives can experience high levels of anxiety and depression whilst the patient is in ICU (Pochard et al 2001; Azoulay et al 2004), symptoms that can also impact upon family members satisfaction (Gries et al 2008; Carlet et al 2004) and feelings of support in relation to decision making. Whilst some studies support shared decision making between family and clinicians (Cook et al 2006), Azoulay et al (2004) reported that 53% of families in their study did not wish to share in decision making. Given the significant emotional burden it can place on the NOK to participate in decision making, it may be that an alternate family member was deemed more appropriate or capable for this role, in place of the true NOK.

This audit also revealed that on average, there were two formal family meetings for patients in this cohort, often including multiple family members. Multiple meetings assist the family members to comprehend, and learn to accept a poor prognosis, and prepare for the death of their loved one (Morita et al 2004). It is important to note, that despite the nurses' provision of direct patient care and their traditional ICU role of 1:1 nursing, the nurse was only included in 25% of family meetings, even though they may have valuable information, and an alternate perspective derived from their role in delivering patient care, that could be of use in these meetings. NSW Health's *Guidelines for end-of-life care and decision making* (2005) promote that nurses play a significant role in providing clinical and social information about the patient and family, and should be included in a collaborative team, where each team member may bring different but valuable perspectives and information to the process.

Despite the importance of communication in end of life care, what is evident from this study, and George's case study, is that the role of the nurse, in particular in communication with family, is significantly underrepresented in the literature. Primary care for ICU patients is the responsibility of a suitably highly trained critical care registered nurse,

who works independently, prioritising care needs, managing bedside technology, and acting as the primary support and first source of information for the patient and their family, up to and after death (Payne et al 2009). Yet the nurse's role is not demonstrated in the medical record; the legal record of events and a major communication tool (Knowlton 2003). Given that the nurse is present during the patients' suffering, and spends more time at the patient's bedside than any other clinician, their perspective is essential to end of life discussions (Hamric and Blackhall 2007).

Carter reports that the focus on technology has overshadowed caring in the ICU (2008), with minimal recognition of psychological, social and other needs of the patient and their family (Parish et al 2006), thereby creating a situation where essential family-centred communication comes second, and is overlooked in medical record documentation. To overcome this imbalance, several studies have reported positive outcomes for end of life communication in the ICU. These studies support the involvement of nurses in end of life decision making by mandating their involvement in family meetings and multidisciplinary case reviews (Lilly et al 2003; Campbell and Guzman 2003). This creates an opportunity where nursing and medical perspectives can be shared with the perspectives of patients and their families to achieve a consensus (Hamric and Blackhall 2007).

The study revealed that family were present at the time of death in 66% of cases. As the primary carer, the nurse is also responsible for the welfare of the family, and care of the body after death until removal (O'Connor et al 2005), aspects of nursing care which are often not reported, and as a result are part of the hidden work of nursing (Norman et al 2008). The lack of documentation about care and communication with family after death contributes to this under-representation and incomplete recording of care events.

Communication with patients and family is not, however, just an element of nursing care over-ridden by technology. Nurses must also take responsibility for their role in communication, and primary care

providers. What is clear from this study is that if nurses were involved in communication with family, it is not documented, and as a result, becomes part of the hidden work of nursing (Norman et al 2008) that does not receive due recognition. Documentation of this important nursing role is essential if nurses wish to demonstrate their role in family communication and with other health professionals. This is essential if nurses are to abolish inaccurate and outdated stereotypes of nurses and their role in delivering quality nursing care (Armstrong 2005) devoid of any expertise or influence in communication and end of life decision making with patients and their families.

LIMITATIONS

Whilst medical records can assist clinicians to evaluate and learn from the record of care delivered, they are equally inadequate in that there is no way of determining what care was provided and in what form, if it was not recorded in some way in the medical record. Similarly, whilst the sample size was small and randomly selected, the outcomes cannot be assumed to apply to any other sample group.

CONCLUSION

Whilst this study showed that the risk of death in some ICU patients is often clearly predicted using well known prognostic indicators, and associated clinical assessment and expertise, clinicians could benefit from reflecting on end of life decision making and communication processes that are present in the ICU, and most importantly, the role of the nurse in these processes.

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