

# Factors Influencing Medical Decision-Making For Seriously Ill Patients In The Acute Care Hospital

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## Abstract

**Aim:** To acquire a fuller understanding of the influences on decision-making in an acute care hospital for seriously ill patients.

## Background:

From the moment of a diagnosis of serious, potentially life-limiting illness, patients and their families are faced with multiple, complex and significant decisions that will influence the entire illness trajectory, including their end-of-life care (EOLC). Compounding personal factors is the complexity of dying today with acute ward areas in tertiary hospitals use of technological interventions to prolong life, at all costs being the norm. If hospice care is initiated, in these areas, it is often at too late a stage to relieve distressing symptoms and to offer the person the best possible path of care for a dignified death.

## Design and methods:

A retrospective cohort research design was used for this study.

**Results:** Thirty nine (39) medical records that met the inclusion criteria were audited. While medical records are limited in terms of the quality of the information contained in them in terms of social, behavioural and other qualitative information, the audit obtained detailed clinical information on patient characteristics, clinical care, and family and clinician involvement in the care of these patients. Communication between health professionals and patient and or family were limited. Poor documentation in the medical record did not support shared decision-making with decisions to amend the care pathway to palliative not undertaken in most instances despite no improvement in response to care or deterioration in the patient's condition.

**Conclusion:** Communication between health care professions, patients and their family's needs to be addressed. The management of patients who are seriously ill in acute ward areas should be altered to reflect the patient's condition. Nurses, using a person-centred approach, have a role in advocating for the patient and the family in times of stress. Discussions concerning end-of-

life of seriously ill patients need to be open, transparent and communicated as these discussions are critical to ensuring the patient's wishes are realised.

**Keywords:** decision-making, acute care, end-of-life-care, communication

## Introduction

From the moment of a diagnosis of serious, potentially life-limiting illness, patients and their families are faced with multiple, complex and significant decisions that will influence the entire illness trajectory, including their end-of-life care (EOLC). Historically, the decisionmaking relationship between patients and clinicians has been characterized by considerable power and knowledge inequalities and dominated by paternalism. With the rise of patientcentred care philosophy however, the patient-physician relationship slowly has become more egalitarian [1] [2]

Compounding personal factors is the complexity of dying today. The Dartmouth Institute (2013) attest that EOLC has become medicalised and death now often occurs in Intensive Care Units (ICU) and acute ward areas of tertiary hospitals with the use of technological interventions to prolong life, at all costs, the norm [3]. If hospice care is initiated, in these areas, it is often at too late a stage to relieve distressing symptoms and to offer the person the best possible path of care for a dignified death. Family and next-of-kin are often uninformed of the route of care having little formal communication with the health professionals' in-charge of the person requiring care. Despite the contention by Whitehouse (2013, p.8) that "when treating a patient who has reached the end of life, clear communication and collective decision-making are as important as any clinical intervention"

[4].

Patient and family involvement in medical decision-making; that is, shared decision making (SDM), has become something of a gold standard for high quality medical and nursing care. This is particularly so in the specialities of oncology and palliative care where shared decision making is advocated as essential for respecting patient autonomy and for avoiding harm in the form of receiving unwanted or futile aggressive medical care [5]. In addition, open and frequent discussions between health professionals and family carers of people diagnosed with life threatening illness has recently been shown to be an effective way of providing psychosocial support [6]. Shared decision making is consistent with most public health care priorities, including improving health literacy, patient-provider communication, and empowering individuals to be more involved in their own healthcare [7] [1]. Indeed, shared decision making is advocated as the gold standard of care as a shift from a medical model to one based on respecting patient autonomy [8].

With this said, it is still not clear to what extent patient/family preferences, hospital culture and/or health professional's practice patterns influence decisions and decision-making related to care at the end-of-life [8] Patterns of overly aggressive care near the end of life, like, admission to ICU and life-sustaining technology use, surgery may be a marker for situations where providers are avoiding difficult discussions to prepare patients to accept terminal care. Similarly, aggressive care at the end of life may reflect a lack of available palliative and hospice resources [9]. Alternatively, the same data could equally be interpreted as the result of patient centred care discussions and informed decision-making yet with more aggressive care at the end of life reflecting environmental, cultural and health care professional influences that support a decision to provide aggressive care up to death. Bakitas, Kryworucho, & Matlock et al., (2011) claim that patient and family involvement in shared medical decision making is still a relatively new phenomenon and there has been little research regarding its effectiveness across potential outcomes [10]. Medical decisionmaking about treatment for complex, chronically ill inpatients is a sensitive, multifaceted but important phenomenon and yet, it is not well understood. Acute care for these patients is particularly complex because comorbidity is so common, vulnerability to infection is high, and hospitalisation and sudden death in the context of a long-term chronic condition are frequent[11]).

The aim of this project was to obtain a better understanding of the process of, and influences on decision-making for patients in an acute care setting with , life-threatening illnesses who died in one tertiary hospital in Western Australia. This paper focuses on the pathway of patients from admission (generally emergency department) to time of death, considering health professional involvement in EOLC decision-making, related to recategorising patients as palliative despite clinical evidence that their deterioration was lasting and their potential for death imminent.

## Research question

What factors influence medical decision-making for seriously ill patients in the acute care hospital?"

## Ethical considerations

This research was approved by the University and Hospital Human Research Ethics Committees (HREC 2010-125).

## Method

A retrospective cohort research design was used for this study. A consecutive decedent patient sample was selected from a retrospective medical record audit of all eligible deaths (18 years of age or older, in the hospital at least 24 hours, not receiving community-based palliative care prior to admission, and who may be referred to palliative care after admission to hospital) in a tertiary hospital over a three-month period (April 1 and June 30, 2014).

**Sample:** An eligible decedent sample will be selected for a retrospective audit of the last hospitalization from a list of all deaths at a tertiary hospital occurring between April 1 and June 30, 2014. Eligible patients included those 18 years of age or older, had a hospital stay of greater than 24 hours, was not receiving community-based palliative care prior to admission; and, who may have been referred to hospital palliative care services after admission to hospital. Exclusion criteria covered those patients being served by the community palliative care services or, those admitted to hospital for palliative care services on admission.

## Data Collection

Medical record audit covering the care provided during the decedent's last hospitalisation was conducted for a consecutive sample (N=50) of all inpatients, 18 years of age or older, are in the hospital for at least 24 hours, who may have been referred for palliative care after 24 hours in the hospital, and who died between in the research period with a primary cause of death of cancer, cardiovascular disease, cerebrovascular disease, diabetes, renal failure, or respiratory failure and focusing on sectors of the hospital where deaths would be expected. The medical record audit covering the care provided during the decedent's last hospitalisation was conducted within one week of death.

An audit tool, developed for a project evaluating the implementation of a terminal care clinical guideline in the acute care setting, was modified to collect this data. Analysis of treatments (including chemotherapy, radiology, nuclear medicine, ICU care, ED care, dialysis, coronary care monitoring, inotrope infusion, HDU, non-invasive ventilation [CPAP, BIPAP] and mechanical ventilation, etc.), procedures (e.g., surgery), laboratory investigations, medications, and medical notes were conducted.

Eligible patients were identified through the hospital Information Management and Systems Department TOPAS data system by cause of death. Hospital personnel responsible for the TOPAS system worked with the researchers in identifying patients who died in the hospital on a weekly basis.

A select amount of personal, identifying information was used to enable research personnel to determine study eligibility. A master list was developed of all inpatients who died in the hospital during the research period. The master list of patients was reviewed to eliminate any patients who did not meet the criteria. The remaining eligible patient names and medical record numbers were then retrieved from the hospital's medical records department for auditing on a weekly basis, in conformance with the medical record department policies and procedures.

The master list was kept on a password protected laptop, stored at the University, and was accessible only to research staff. Only de-identified medical and treatment information from the patient's medical record was collected for analysis during the medical record audit. Once the medical record was pulled and patient eligibility verified, a Research Project Identification Number was assigned to the medical record on the data collection laptops and no patient identifiable information was collected beyond necessary demographic information

**Analysis**

Data was analysed using PASW (formerly SPSS) version 17 or later. Specifically, descriptive statistics such as means, standard deviations and frequencies were calculated for each variable. The 95% confidence interval for the means and proportions will be presented. )

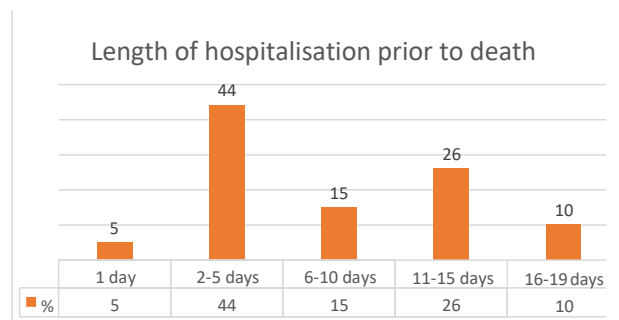
**Results**

A total of 39 randomly selected medical records of patients who died in the hospital in the three-month period, who meet the inclusion criteria, were audited as part of the data collection activities. The sample included 19 (49%) males and 20 females (51%) with 7 (18%) aged 24-65; 19 (49%) aged 66-85; and, 13 (34%) being older than 86 years.

At the time of admission, in the emergency department patients were categorised to acute health care treatment (n=36, 82%), 2 (5%) patients were admitted for specific medical treatments and one patient for surgery (3%). Most patients were an unplanned admission through the ED (82%, n=32). Six patients entered the hospital under a planned admission (15%) and one patient transferred from another facility (n=3%).

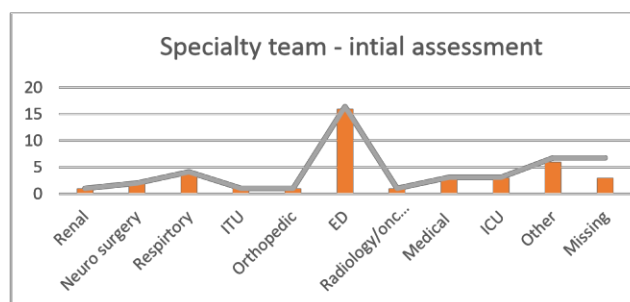
Table 1 presents data on length of stay. The number of days from the date of admission to the date of the patient's death were calculated. Length of stay ranged from 1 day (n=2, 5%) to 19 days (n=1, 3%).Seventeen patients (44%) were in the hospital for 2 - 5 days, six patients were hospitalised for 6 - 10 days (15%), ten patients were hospitalised for 11 - 15 days, and four patients were hospitalised between 16 - 19 days. Average length of stay was 10 days; the median 10 days, and the mode was 2 days. It should be noted that approximately half (n=19) of these patients were only in the hospital 1 to 5 days prior to death.

Table1: Length of hospitalisation prior to death



Multidisciplinary teams have been advocated for management of complex patients. Patients were managed by a variety of specialists and generalists on admission to the emergency department.

Table 2



Forty one percent of patients were initially assessed in the ED, reflecting the unplanned/emergency admission status of the sample. Five percent of patients were assessed by the neuro-surgical team and 10% by the respiratory team.

Table 3 presents data on the treatment intent or the care of plan after initial assessment by the health care team. Fifty-one per cent 51% (n=20) of admitted patients had curative care plans established, while six (15%) had routine care, two patients did not have a treatment intent coded in their record, and eleven patients (28%) had a care plan focusing on symptom management.

Table 3 Treatment intent following initial assessment

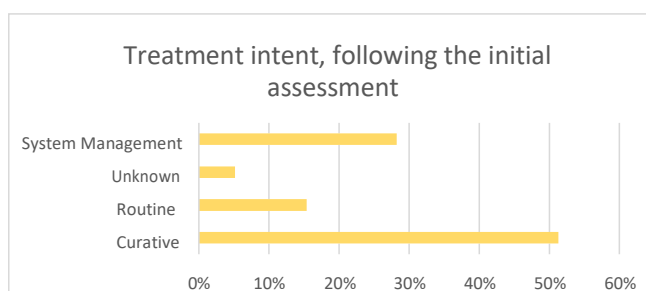


Table 4 presents data on whether the treatment intent, as stated in the medical record following assessment, was followed. 90% (n=35) of patients' subsequent hospital care conformed to the treatment identified in the initial assessment.

Table 4

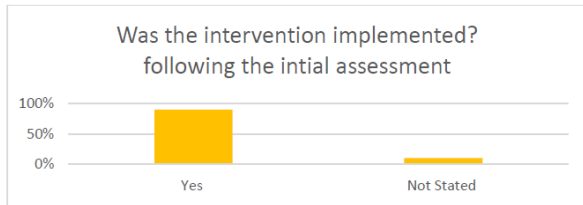


Table 6 Number of changes in bed type

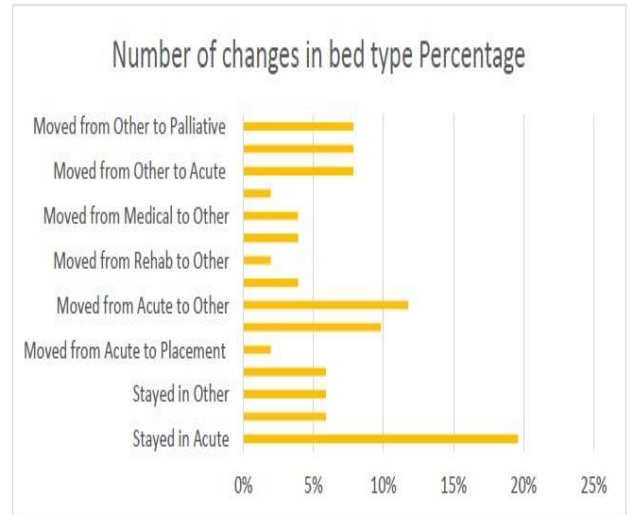
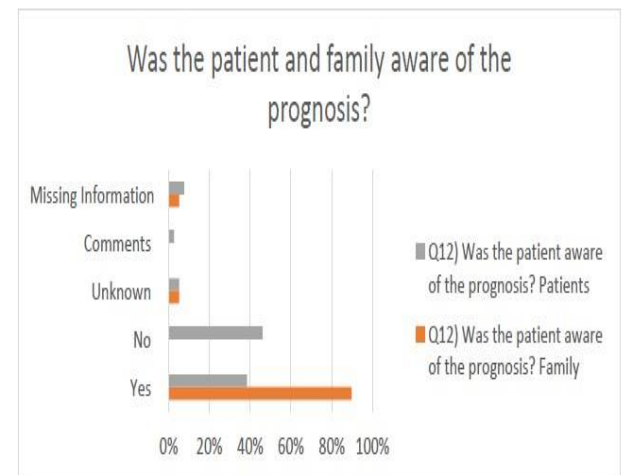
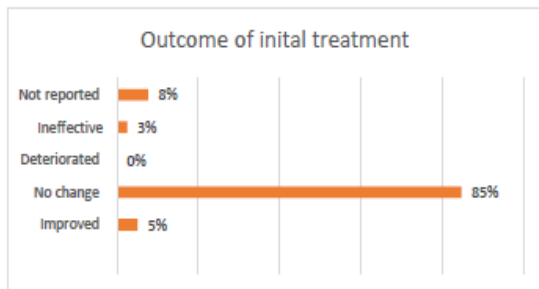


Table 5 Outcome of initial treatment indicates that there was no change to the patient's condition following treatment (85%) and in one case (3%) there was a deterioration in condition.

Table 5 Outcome of initial treatment

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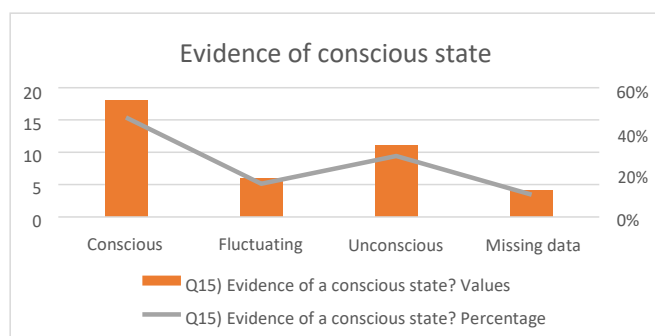
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Changes in bed type are often reflective of treatment intent as well as the fluctuations of the patient's medical status and treatment decisions. Table 6 presents data on the number of changes in bed type for each of the sample. Some patients changed bed type more than once thus the total is greater than 39. For example, some patients experienced between 2 and 6 changes. Just under one third of patients (n=10) remained in an acute bed throughout their hospitalisation (20%), three patients remained in a medical while 12% of patients changed bed type to other. That is, home or radiology or oncology across the rest of the sample. Notably, 18% of the 39 patients who went on to die on this hospitalisation were transitioned to palliative care. But 8% of patients were moved from palliative care and went on to die.

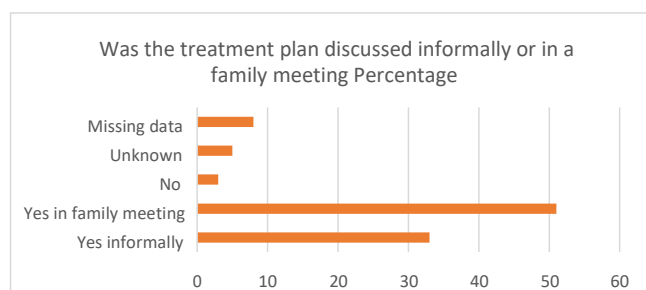
Table 7 shows that 90% of family members were aware of the patient's prognosis while only 38% of patients had this knowledge. 46% were not aware of their prognosis.

Table 8 Level of conscious state



The patient's cognitive status (conscious/unconscious) by treatment intent it was noted at the initial assessment (Table 8). Of 26 patients with curative treatment intent, nine (35%) were conscious; four (15%) were fluctuating in/out of consciousness, nine were unconscious at the initial assessment (35%), and status was unrecorded for four patients (15%). Thirteen patients were admitted for symptom management. Of these, nine (69%) were conscious, two were fluctuating, and two were unconscious.

Table 9 Was the treatment plan discussed informally or in a family meeting?



**Communication.** Communication is one of the main components of quality medical care and is of major importance to patients and families (Table 9). Data collectors were asked to record any notes regarding discussions -formal or informal, including documentation of a family meeting. Just over half of all patient's families (n=20, 51%) had what was documented as a 'family meeting' while approximately one-third of families (n=13, 33%) had informal conversations with treating clinicians. One patient's family had neither formal nor informal treatment discussions and five patients had no written documentation of any communication. The notes were reviewed for content but the data concerning the content of the communication was lacking in detail and clarity. Nevertheless, because all these patients went on to die in the acute setting, it appears that most families (n=33) may have had some form of treatment discussion.

## Discussion

The importance of quality end-of-life decision making and care has been noted over recent years. EOLC has a significant impact on the process of dying and dying patients' comfort in the last days of life and the impact of not following the person's wishes cannot be ethically justified. It is true that some patients and families do not want to have the 'death and dying' discussion and wish to remain passive in decision making, and it remains that having the discussion with those that do is still very challenging for health professionals. It is also remains shocking that EOLC does not follow patient's wishes and those health professionals are unwilling to even involve themselves in discussions concerning medical decision-making and death and dying within an openly attested research context.

Patients with cancer want to participate in decision-making and be involved in discussions concerning their treatment options and chance of survival. This is especially true for people with advanced disease who need to layout their intentions for family and friends. Some patients may elect for aggressive therapy care aimed at prolonging life, whilst others opt for supportive therapy accepting that their life expectancy is limited and wish for a less days in hospital, with more at home and their pain minimized as much as possible [12]. Recent research has attested that the most important consideration in end-of-life decision making is the comfort of the patient with regard to symptom and pain alleviation, with the least important considerations being the comfort of health professionals and caregivers and the futile delaying of an inevitable death [2]. Further, pre-death interventions concerning grief and bereavement counselling can benefit family and care-givers before and after the death of their loved one [12]).

Currently discussion is occurring within medical circles of the need to move beyond a 'death denying culture' with the call for more open communication by people and health professionals concerning, death, dying and EOLC [13]. Indeed, at The Royal Australian College of Physicians 2016 Congress, 28 recommendations for EOLC were made inclusive of improving communication skills by doctors.

The *Marie Curie Cancer Care Centre* published a report in 2014 titled "Difficult conversations with dying people and their families" which concluded that the wishes of terminally ill people and their carers' and/or NOK were often missing in discussions concerning EOLC. Further the report attested that most people wished for a 'good death' meaning if possible they could die at home. This allowed them the emotional support that the home environment can offer the person, and although not the most important issue, dying at home can offer considerable healthcare cost savings to the economy [14].

Medical professionals around the world have called for more evidence-based guidance of how to communicate EOLC and

treatment and/or non-treatment options. Strategies for the conversation and communication of the futility of treatment and what to say to relatives is continually raised as an issue for health professionals [2] [15]. Acknowledged is the fact that some people do not wish to discuss death and prefer to believe that they will not die, others plead to be told the truth whilst they are conscious and not cognitively impaired, so as to 'get their affairs in order' and to plan for death. Advance Care Planning (ACP) provides the conduit to assist in EOLC. Family members with ACP are more likely to receive the EOLC they wish for and family members involved experience less stress, anxiety and depression [16].

Dying is understood as the end of life - it is inevitable. The majority of general public has considered their own death and thought about their ideas and preferences regarding EOLC and decision-making. Many have actively discussed these ideas with relatives; however, many have indicated a need for more information about EOLC and ACP and wished this to be initiated by the treating Doctor [17]. People often have these thoughts when they are most unwell and vulnerable and in hospital and these discussions should occur with treating health professionals and family or NOK. However, ACP is rarely discussed with physicians in clinical practice [18]). It is important to reflect upon the fact that as recently as 2008, 54% of complaints to the Healthcare Commission of the UK were related to EOLC, with 39% related in some way to communication issues [4]). Bernacki & Block (2014) suggested systematising conversations with patients about serious illness care goals, which allows identification and recording of issues surrounding terminal care within medical records and offers a guide to treating physicians for those discussions [19].

Communication about EOLC goals is an intervention that should be systematically integrated into clinical care. It is with disbelief then that the health professionals that *could* and possibly *should* have been involved in this study to discuss medical decision-making and EOLC did not take the opportunity to do so.

### Limitations

We acknowledge that due to the lack of ANY feedback from the health professionals the researchers have made an interpretive link to their lack of involvement in the research and caused a pronounced shift in our expectations as researchers and with our focus of this paper.

### Conclusion

It is important for contemporary health professionals to engage in transparent communication with their patients for a more person - centred care, throughout a health life and towards a dignified death. This study has revealed the remaining

reluctance of health professionals to engage openly in the discussion of death, dying, EOLC and medical decision making, yet it behoves us as researchers to continue to seek more insight into end-of-life decision-making practices which can contribute to international understanding and better quality care for our patients.

### Funding

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