TRANSITIONING TOWARDS END-OF-LIFE CARE IN JORDANIAN CRITICAL CARE UNITS: HEALTH CARE PROFESSIONALS' PERSPECTIVES

Issa Mohammad Ali Almansour

Thesis submitted to the University of Nottingham for the degree of
Doctor of Philosophy

December 2015

Study abstract

This study explored the experiences of Jordanian critical care staff about the transition to, and provision of, end of life care. It examined the difficulties they encountered, and how they sought to care for and communicate with the families of patients who were approaching the end of life. The study took place in two University hospitals in different cities. A mixed methods design in two phases was adopted. The first phase employed the "National Survey of Critical Care Nurses' Perceptions of End-of-Life Care" (adapted with permission) to elicit the views of critical care staff (N=104) about the obstacles and facilitators to providing end of life care for critically ill patients and their families. In the second phase, qualitative interviews were conducted with staff (15 nurses; 10 junior doctors; 5 head nurses).

The key overarching finding from the study is that staff experience moral distress when working with critically ill patients whom they perceive to be dying. There were three main dimensions to the experience of moral distress:

First, nurses experience moral distress when they are aware when the patients are likely to die, know that continuing life sustaining treatment is futile and yet are expected to continue to provide treatment as normal to the patients. Aggressive modalities of treatments are usually pursued for most terminally ill patients, with both nurses and doctors perceiving there to be no planned, clear or distinct transition from curative focused care to end of life care.

Second, with regard to their relationship with patients' families, the staff found themselves to be in a problematic and paradoxical situation. One the one hand, they expected patients' families to take the lead in the care decision making process and perceived that the power in decision-making should lie with patients' relatives; but on the other hand, they also perceived that it is difficult and sometimes impossible to disclose bad news openly to families meaning that families are not fully informed in a way that would enable them to take the lead in the care decision making process.

Third, staff have an appreciation of the principles of end of life decision making as a team activity and as a collaborative venture, but they are not able to put these principles into practice

for many reasons, ranging from difficulties in their relationships with each other to health care system factors.

This study sheds light on two central ethical problems in end of life decision-making in Jordan: the problem of disclosure of terminal prognosis at the end of life and limited involvement of nurses and junior doctors in the process of end of life communication and decision making. The study recommendations focus on developing practice in and disseminating understanding of ethically sound end of life decision-making.

Acknowledgment

First and foremost, I would like to thank my two wonderful supervisors: Professor Jane Seymour and Doctor Aimee Aubeeluck. This thesis would not have been possible without their supervision, guidance and support throughout the long process of the thesis. They were my mentors, my source of optimism, and a great light that I could follow with complete confidence, knowing that they were 'there' for me whenever and as much as I needed them. Additionally, their kind, caring and immeasurable support for family life give me a sense of being among friends and family; their support will never be forgotten. Thank you Jane; thank you Aimee … I learned from you how to 'care' and support others; I am blessed by having you as my supervisors.

I wish to thank all of the doctors, head nurses and critical care nurses who participate in my project and share their experiences, feelings, and needs with me; this thesis would not have been possible without their contribution. I do hope this thesis meet their expectation and helps them to understand things they have encountered at work over a number of years and answers a lot of questions that they always have in their minds.

I would like to thank my examiners Professor Angela Tod and Mr Stuart Nairn for their willingness to examine me and I assure that they enriched my thesis with their constructive comments.

I owe a special thanks to Ahed, my wife who constantly instilled hope for and stayed with me for all those difficult moments of my PhD life. Thanks for everything you have done for me; you made my dream come true. I also thank my kids, Taim and J'wan who missed their baby days of being with their father. Thank you my boys.

I thank all my family members, friends and colleagues, who have been supportive during my study time and thank you very much for your honest prayers of success.

I am grateful for having received a scholarships from the University of Jordan. This scholarships allowed me to dedicate myself to the PhD.

I would like to thank the Jane's family, Jerry, Tom, and Elaine, for their generosity, hospitality, and encouragement.

Table of Contents

List of Tables

List of Figures

Chapter1:   Project Overview

1.1 Background

The emergence of chronic progressive diseases (e.g. cancer, cardiovascular disease, and respiratory disease) has changed the patterns of death from the sudden death that was typically experienced a century ago, to a range of trajectories associated with specific disease types (Thompson, 2006). Three illness trajectories have been described in the literature: 1) steady progression of the disease followed by a clear terminal phase, which is common in cancer patients; 2) gradual decline until death, as in patients with stroke or dementia; 3) an uncertain, relapsing and remitting trajectory, which occurs in patients with organ failure such as cardiovascular and respiratory disease (Murray et al., 2005). In the latter trajectory patients are likely to experience a gradual decline with episodes of acute deterioration and recovery and finally sudden and unexpected death. This type of trajectory is characterised by uncertainty, which has been identified as a primary barrier to the provision of timely end of life care from the health care providers' perspective (Truog et al., 2008).

In the 21st century, with death in hospital common-place and continuing developments in life prolonging technologies, providing care for dying patients is a contemporary challenge facing health care professionals in hospitals (Thompson, 2006). For example in the UK, studies show that almost a quarter of hospital beds are occupied by patients in their last year of life (Jeffrey, 2009). This, along with the findings that almost 60% of people die in the hospital in the same country (Costello, 2006), illustrate the need for knowledgeable and skilled health care professionals who can provide end of life care along with curative and life-saving care.

Critical care units are highly technical areas which are equipped with a wide range of advanced medical technologies for the purpose of delivering critical care that may save the lives of critically ill patients who would otherwise die. Critical care units are staffed with health care professionals who have expertise in providing supportive and life-saving interventions. Patients admitted to critical care units are increasingly of older age and suffering acute exacerbation of chronic illness. Although the primary goal of critical care units is to help patients to survive and restore their quality of life, death is a common phenomenon in this area; studies report that 22% of all deaths in the United States occur on or after admission to critical

care units (Angus et al., 2004). This is comparable with data from a review of a large case mix program in the UK, (Harrison et al., 2004) where overall mortality results of 20.3% are reported within the participating critical care units.

Critically ill patients go through a lot of transitional phases during their disease trajectory, including: transition related to loss, transition between care setting and psychosocial and spiritual transitions (Duggleby and Berry, 2005). Transition to end of life care has been observed to be the most difficult and stressful phase that patients, families and health care providers encounter in the critical care units (Coombs et al., 2011). Yet, providing quality end of life care in critical care units requires a shift in direction of care from focusing in curing and disease remission to provide comfort care and relieving suffering (Badger, 2005).

Early recognition of the end of life transition point in the disease trajectory along with optimal management of the transition to end of life care is imperative in providing a quality end of life care. Planned, swift and smooth transition to end of life care helps in addressing patient and families care preferences, using less aggressive care and providing appropriate palliation. In addition, effective and timely transition to end of life care may reduce the possibility of conflicts between patients' families and their physicians, increases family and health care professionals satisfaction and minimises the emotional and psychological burden upon families during bereavement (Gardiner et al., 2011; Boyle et al., 2005; Badger, 2005).

On the other hand, failure to achieve a timely transition to end of life care and continuing with providing aggressive care in the face of obvious decline in a patient's condition impacts negatively on patients, families and health-care professional themselves (Boyle et al., 2005). Identifying the point at which transition should occur has been identified as the essential problem (Gott et al., 2011). Marsella (2009) pointed out that it is not easy to identify dying patients because of difficulties in disease prognostication in critical illness. As a result, shifting the goals of care towards palliation and comfort is often delayed until the last minutes or hours of a patient's life.

Critical care nurses have a key position in providing end of life care for critically ill patients and their families since they are the health care professionals who spent most of their working time with the patients and the focus of their work is to act as a point of connection between the patients, families and their physicians (Thompson et al., 2006). Several roles and

responsibilities have been identified in research about nurses in providing end of life care in critical care units. Critical care nurses seek to provide a holistic approach, regard the care of patients' families as an integral part of their role and seek to advocate for their patients (Badger, 2005). Accumulated literature highlights that communication with patients and their families is a crucial nursing role, which is especially important in end of life decision making (Clayton and Kissane, 2009; Cohen et al., 2005). Generally, most of communication in critical care units takes place with the patient's family reasons include:

1. Limitations in clinician-patient communication since most critical care patients are unconscious.
2. Some critical care patients are supported with assistive devices that interfere with their communication.
3. Some patients experience an episode of delirium and psychosis and/or lose their ability to communicate.

In end of life care, clinicians rely on consultation with families to inform decisions about the treatment options because patients who are approaching death in the critical care units are almost always unable to communicate and lack capacity (Boyle et al., 2005). However, there is little information about communication practices between nurses and medical staff and how these influence end of life care planning and decision making with family members, especially in the Jordanian context. In addition, there is limited knowledge about the perspectives of health care professionals about the recognition and management of the transition from curative to end of life care in critical care units (Badger, 2005; Thompson, 2006). This study seeks to gain the perspectives of critical care health professionals in Jordan, where there has been little or no research into these issues.

1.2 Aim and research questions

Aim

To develop Jordanian critical care practice by identifying barriers and facilitators to the transition to end of life care from the perspective of health care professionals working in critical care units.

To work with critical care nurses to develop recommendations to improve the process and outcomes of palliative care for patients at high risk of dying and their families in the critical care units.

Research Questions

1. How do Jordanian critical care staff recall their experiences of providing care for critically ill patients and what difficulties do they narrate?
2. What are the perceived roles and responsibilities that Jordanian critical care staff have when communicating with families of critically ill patients who are likely to die?
3. What barriers and facilitators do Jordanian critical care staff identify that influence transitions to end of life care in critical care units?
4. What are the suggested recommendations to ease the process of transition to end of life care and to improve communication between clinical staff and patients' families and between different categories of professionals?

1.3 Terminology explained

Palliative care

This study operationalises 'palliative care' in line with the World Health Organization (WHO) definition "an approach to care, which improves quality of life of patients and their families facing life-threatening illness, through the prevention and relief of suffering by mean of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" (WHO, 2004).

End of life care

According to the National Council for Palliative Care (2006), end of life care may be defined as the "provision of supportive and palliative care in response to the assessed needs of the patient and family during the last phase of the life".

Transition to end of life care

The term transition in this study will be defined as a change in the direction of care for a critically ill patient from treatment focusing on cure and disease remission or "active

treatment", to treatment that focuses on symptom management, relief suffering and maximizing quality of death or "palliative care" (Gott et al., 2011).

Culture

The term culture in this study is used in the sense of a "social construct, which is characterised by the behaviours and attitudes of a social group based on their individual beliefs and choices" (Carey and Cosgrove, 2006). However, Bisin and Verdier (2000) point that culture is a "melting pot" which changes in a continuous manner based on social and environmental factors.

This study will obtain the views of health care professionals about end of life care in a highly patriarchal culture, where the presence of the extended family strongly affects end of life care and where families have a key role in decision-making and care for their terminally ill loved one in the hospital or in their home.

1.4 Research design

This study adopted a mixed methods approach (Creswell, 2003). In mixed methods research, a researcher combines quantitative and qualitative research methods at different stages of the research in order to get an in-depth as well as a broad picture about the topic being studied (Johnson et al., 2007; Creswell, 2003). This approach is considered to be an innovative and appropriate method of obtaining the views of health care professionals about the provision of end of life care and particularly to get a full picture of the transition phase to end of life care in Jordanian critical care units. This study is divided in to two phases. The first phase employed the "National Survey of Critical-Care Nurses' Perceptions of End-of-Life Care" questionnaire to elicit the views of critical care staff about the possible obstacles and supportive behaviours to providing end of life care for critically ill patients and their families. In the second phase, qualitative interviews were conducted with staff to gain insight into how the issues reported in the survey were experienced; allow identification of otherwise unknown factors; and enabled exploration some cultural meanings which were very particular to Jordanian context. Interview participants were recruited from critical care units' nurses, heads nurses and junior doctors who were in direct contact with critically ill patients.

1.5 End of life care in Jordan

Jordan is located in the Eastern Mediterranean region and is one of the members of the Middle East Cancer Consortium (MECC). The population of Jordan is approximately 6.316 million people. Life expectancy has risen in the recent past to 69 years in men and 78 years among women (WHO, 2009). The primary causes of death across the MECC region are cardiovascular and heart disease, with cancer the second commonest cause of disease-related death. Health care systems in Jordan are represented by: Ministry of Health, Royal Medical Service, university hospitals and a number of private hospitals; each of these systems provide services for approximately one-third of the population (Stjernswärd et al., 2007). The Ministry of Health operates 1,245 primary health-care centers and 27 hospitals; the military's Royal Medical Services runs 11 hospitals; two university hospitals and private hospitals distributed among 56 hospitals (Metz, 2009). The great majority of Jordanians have medical insurance. Jordan does not have hospice units for dying patients in the hospitals. Two university-affiliated hospitals have an oncology department, but no palliative care unit or hospital-based consultation service (Stjernswärd et al., 2007).

In Jordan, there is a comprehensive cancer centre called King Hussein Cancer Centre (KHCC) in Amman providing palliative care for in-patients, out-patients and patients at home. The centre provides care solely for cancer patients who present with advanced disease. Only a small number of these patients are cared in KHCC; most cancer patients have no access to palliative care services since these are both privately provided and only available in the capital of the country (Bingley and Clark, 2009).

Jordan is lacking of any laws or policy around providing end of life care that govern health care professionals practice in different health care setting. Health care professionals work under the general umbrella of health care which declares that it is the right of all patients to receive the care that they deserve or need and any health care decision to be made there should be a mutual agreement with patient's family members. At the educational level, until recently there were no any courses in relation to palliative end of life care on Universities curriculum for either undergraduate or post graduated; doctor or nurses. Recently, the first Master degree on palliative care was launched in the University of Jordan and palliative care courses were added to the undergraduate curriculum. At the research level, a very limited number of studies were

conducted in Jordan; most of these studies were about end of life care for patients who have cancer (Al-Tamimi and Bushnaq, 2011; Qaddoumi et al., 2009; Tarawneh et al., 2009).

Generally, the Oriental trends of life are different from the Occidental trends; family relationships are closer and the extended family is a common feature of Arabic family life; religious beliefs play an important role in social life and particularly in life and death issues. In addition, the ethical values, medical practices and the financial status of Middle East Arab Countries are to some extent different from those in western countries (Yazigi et al., 2005; al-Awamer and Downar, 2014). In a recent study in Jordan al-Awamer and Downar (2014) interviewed thirteen palliative care physicians who have experience in both Western and Middle East countries and identified four themes that present the palliative care practice differences between Western and Middle East:

1. Cultural differences including the communication style; the role of family; the importance of religion; and the societal view of palliative care in general.
2. Policy and legal issues. The participants perceived a lack of legal clarity a round end of life medical issues and a lack of consistency in health policies among hospitals.
3. Different understandings of palliative care. It is reported that many patients, families and even medical staff and policy makers are unaware of core concept of palliative care.
4. Limited palliative care resources.

All of these differences highlight the importance of investigating the transition to end of life care in a country with a different culture and religious beliefs to those in the west.

1.6 Significance of the study and personal motivation

This study will add to the body of knowledge related to the provision of end of life care in critical care units, and contribute to the development of end of life care knowledge and practice development within and outside of critical care in the Middle East more generally. I hoped at the outset that this study would meet what I was looking for when I worked as a critical care nurse in Jordanian critical care units, and answer the questions that my colleagues and I were always talking about during our work and indeed outside of the workplace. In my experience, the continuous use of aggressive treatments for dying patients and the needless suffering that critically ill patients endured with these treatments places critical care nurses in a stressful and

paradoxical situation and makes them feel guilty. We commonly experienced conflict with patients' relatives, for many reasons. We perceived that false hope was given by patients' physicians, that families had an un-realistic picture about the role of critical care unit; they were often neither aware of the prognosis of their loved ones nor the reasons for use or likelihood of success of different types life-sustaining treatments.

The provision of end of life care in Middle Eastern Arab Countries is not well developed. Clinical studies related to end of life care in critical care units in the Middle East region have been reported from Israel and Turkey (Eidelman et al., 1998; Iyilikci et al., 2004). These studies have examined the clinical practices associated with withholding and withdrawing life sustaining treatments from critically ill patients in critical care units. Because these two countries have different social values, social traditions and religious beliefs from the Middle Eastern Arab Countries, other studies have been conducted in Oman, Saudi Arabia and Lebanon, and all of these studies were focused on the same topic (Yazigi et al., 2005; Da Costa et al., 2002; Iyilikci et al., 2004).

Moreover, very few studies have examined the transition from curative and aggressive care to end of life care in critical care units from the perspective of health care professionals, and of those that do exist, they have been conducted in western countries. In a prospective observational study of European critical care units, Sprung et al. (2007) reported that there is a significant effect from religious affiliation and culture on the end of life decision making process and recommended studies to be conducted in Islamic cultures. In addition, dying patients and their families and health care professionals will experience death differently not only because of particular disease but as a product of cultural, ethnicity, spirituality and socio-economic factors.

Finally, this research study may provide a base for development of strategies to enhance the provision of end of life care in critical care units in Jordan and in Middle East region by identifying and managing the obstacles in providing end of life care. In addition, hopefully this study will inform current practice and policy in delivering palliative and end of life care in Jordanian critical care units where the palliative care services are available for patients with malignant disease (Bingley and Clark, 2009).

The next chapter presents a review of existing research regarding providing end of life care for critically ill patients in critical care units, and points out gaps in the available evidence, which are relevant to this study.

Chapter2:   Literature Review

2.1 Introduction

This chapter presents a review of existing research on end of life care in critical care units. The review sought to identify existing research studies that have explored issues around providing end of life care for critically ill patients in critical care units from the perspective of healthcare professionals. Since end of life care is a multidimensional and broad area, the review explored research contingent to the research questions, covering the following areas in critical care: (1) the experiences and perceptions of staff toward providing end of life care; (2) the barriers and facilitators to providing end of life care for dying patients and their families; (3) end of life care communication between healthcare professionals and patients' families and among professionals themselves; and (4) the transition process from curative trajectory to end of life care trajectory. The following section describes the process of searching the literature. The subsequent four sections present the results of the literature review. I conclude the chapter by pointing out the gaps in the available evidence, which are related to this study.

2.2 Review of the research relating to end of life care in critical care

In order to obtain a comprehensive overview of the research literature on end of life care in critical care units, a broad search strategy was used. A wide range of data bases were searched, including: EMBASE, MEDLINE, PSYCInfo, AMED, CINAHL (Cumulative Index to Nursing and Allied Health), Web of Science and the Cochrane Library. Table 2.1 below presents the keywords that were used in the literature searching across all the data bases. In addition, hand searching was conducted to examine the reference list of some studies and to follow up authors. The search was between from the January 1995 and December 2011. Later in the course of the study, the review was updated to include any recent research using narrative methods.

Table 2.1: Search strategy

Included
An electronic search of: EMBASE, MEDLINE, PSYC Info, AMED, CINAHL (Cumulative Index to Nursing and Allied Health), Web of Science, Cochrane library.
The following Key terms were used: `critical care nurse*` or `perception` or `role` or `experience*` and `intensive care unit*` or `critical care unit*` or `ICU*` or `ITU*` and `transition*` or "end- of -life care` or `cure to comfort care` or `care transition` or `communication` or `end of life communication` or `transition*` or `Barrier*` or `facilitator*` or difficult*` or challenge*` family*` or `critically ill patient* family*` or Relative*`.
Hand search.
Reference list examined and author name search.

"* " was used in the literature searches as it signifies that the research will include the search string with any character.

2.3 Results of the literature review

Four themes emerged from this body of research: the importance of end of life communication with patients' families in end of life decision making, the process of transition to end of life care, the experiences of critical care staff toward providing end of life care and finally the obstacles and supportive behaviours experienced by the staff to providing end of life care for dying patients and their families. These issues are discussed below:

2.3.1 End of life care communication

Accumulated studies in the literature have examined the crucial role that interdisciplinary, multi-professional and family-centred end of life care communication has in contributing to high quality of end of life care in critical care units and has also shown a range of difficulties accompanying such communication (Puntillo and McAdam, 2006; Lofmark et al., 2005; Levin et al., 2010; Hickey and Quinn, 2012; Pavlish et al., 2014). Effective end-of-life communications among critical care health professionals themselves and with patients and their families are powerful facilitators of good quality end of life care and the primary means of protection from conflict within critical care teams and with patients or families (Pavlish et al.,

2014; Nelms and Eggenberger, 2010). End of life care communication has been shown to be one of the primary roles for critical care nurses since they spend most of their working time with patients and families and act as intermediaries between physician and patients/families (Schulman-Green et al., 2005; Aslakson et al., 2012). The importance of end of life care communication is highlighted by the evidence that the majority of patients' family members have a poor understanding of diagnosis, prognosis and treatment options (Azoulay et al., 2000; Scherer et al., 2006; Selecky et al., 2005). For example, Azoulay et al. (2000) surveyed 102 relatives of patients who were admitted to an intensive care units for more than 2 days and reported that fifty four per cent have a poor understanding of their patients' condition. Ineffective communication between health care professionals and patients and / or families about the realistic picture of prognosis and treatment options can delay the transition to end of life care by making it more likely that there is continuing use of aggressive treatments. This can increase patients' suffering and impact negatively on both patients' families and critical care staff (Schulman-Green et al., 2005; Kirchhoff and Beckstrand, 2000).

Effective end of life care communications among critical care health professionals are associated with reducing patients and families' psychological distress, depression and anxiety and improving the quality of death and dying; it also has been shown to lead to limiting provision of futile aggressive treatments which consume staff time, effort and staff focus (Levin et al., 2010; Wiedermann et al., 2012; Kompanje et al., 2013). Critical care units represent an expensive, limited resource the use of which can be maximised with better inter-staff communication (Ahrens et al., 2003). Ahrens et al. (2003) conducted a controlled study to evaluate the effect of a communication team that include a physician and a clinical nurse specialist on length of stay and costs for dying patient in critical care units. Ahrens and colleagues found that improving communication and team work reduced critical unit lengths of stay and resource utilization. A range of other studies have highlighted the benefits of interdisciplinary communication and team-based approaches in attaining timely and effective transition to end of life care and in providing palliative care in different health care settings (Kirby et al., 2014; Coombs et al., 2012; Gott et al., 2011). However, over many years inter-professional collaboration and communication are the most problematic areas in the process of transition to end of life care for nurses health care professionals working in critical care units (Fridh, 2014; Ferrand et al., 2003). There is a need for more research evaluating interventions to enhance interdisciplinary communication in critical care units (Kryworuchko et al., 2013).

In terms of the communication between health care staff and families, the research evidence shows that that honest conversations that are sensitively navigated, strengthen the relationship between the two sides and build a trust (Rushton et al., 2007; Gordon and Daugherty, 2003). It has been well documented that there is a strong reciprocal relationship between trust and end of life care communication. On the other hand, where mistrust exists, this is a key barrier to end of life care communication (Lynn-sMcHale and Deatrick, 2000; Farmer, 1992). Communication is also reported to be crucial to manage families' hope and reach a balance between clinical realism and families' optimism (Gelling, 1999; Sullivan, 2003; Verhaeghe et al., 2007). Effective communication between physicians and critically ill patients' families addressing questions about the patient's current health status; prognosis and responding to families with empathy and respect are highly correlated with family satisfaction (Low, 2012).

To have questions answered honestly; to have explanations given that are understandable; to know the expected outcome; and to know specific facts concerning the patient's progress have been shown to be among the most important of families' needs in critical care units (Al-Hassan and Hweidi, 2004; Omari, 2009; Jovanovic, 2011). While some health care professionals perceive that patients and families do not desire or cannot accept information and conversations about end of life care, the research literature documents that the opposite is true (Caldwell et al., 2007; Apatira et al., 2008; Azoulay et al., 2011). Pierce (1999) elicited the perspective of 29 bereaved relatives of peaceful death and found that the majority wanted health care professionals to provide full, direct and frank information about the patients' health status. Hickey and Quinn (2012) surveyed 304 members of the general public in South West Essex (UK) and found that 87 percent of participants would wish for earlier discussion about end of life care.

A number of barriers to effective end of life care communication have been identified in the review. These include:

1. Physicians' desire to continue with aggressive treatments as a result of ambiguity and uncertainty in prognostication (Barclay and Maher, 2010; Sprung et al., 2008).
2. Critical care staff not having suitable knowledge and skills to carry out end of life care communication (Kamel et al., 2014; Gibbins et al., 2011).
3. Staff desire to maintain hope for patients and their families (Gutierrez, 2012; Schulman-Green et al., 2005).

4. Staff uncomfortable in carrying out end of life care communication (Pavlish et al., 2014; Panagopoulou et al., 2008).

5. Unexpected patient death and perceived unwillingness of some patients' families to accept their patients' prognosis (Schulman-Green et al., 2005; Aslakson et al., 2012).

2.3.2 The transitions to end of life care in critical care units

Most deaths within critical care units occur after a decision to withhold and withdraw life–sustaining treatments has been made (Lautrette et al., 2006; Espinosa et al., 2008). End of life care decisions about withholding and withdrawing life–sustaining treatments take place when the critical care professionals recognise that recovery is not a viable outcome and continuation with treatments would just prolong the dying process. After that, communication between patients, healthcare professionals and families should be directed towards reaching a common shared agreement that the subsequent focus should be on palliation and ensuring dignity and comfort (Sprung et al., 2003). However, managing this process of transition from curative care to a palliative care approach can often be difficult and challenging for health professionals (Coombs et al., 2012; Pattison, 2004). The complexity surrounding this process relates in part to uncertainty and ambiguity associated with the onset of the terminal phase of disease (Badger, 2005a; Badger, 2005b; Coombs et al., 2012; McAndrew and Leske, 2014). Additionally, the life-saving philosophy of critical care critical care units; its acute care culture and the many different parties involved add to the challenges in achieving timely, planed and smooth transition, making the "good death" difficult to attain (Trankle, 2014; Coombs et al., 2012; O'Connor and Aranda, 2003). Further key factors in the process of transition are staff beliefs and attitudes, including religious and cultural beliefs. These shape end of life practice and emotional experiences among staff when caring for dying patients and their families (Trankle, 2013; Sprung et al., 2007; Trankle, 2014; Badger, 2005).

While there has been a sustained focus internationally on education and policy in palliative care, leading to wide ranging recommendations to improve the transition to and provision of quality end of life care for all patients regardless of diagnosis and in all care settings, the majority of knowledge available in wider palliative care literature remains cancer care based and relates to settings other than critical care units (Gott et al., 2007; Bingley and Clark, 2009; Coombs et al., 2012). Research in critical care units to date has focused on managing the process of withholding and withdrawing life–sustaining treatments (Baggs et al., 2007; Curtis

and Vincent, 2010; Halcomb et al., 2004), with little known about the process of transition to palliative care (Gardiner et al., 2011; Coombs et al., 2012; Pattison, 2006). Gardiner et al. (2011) conducted a systematic review of the literature concerning the transition from curative care to palliative care within health care setting in UK and found that only two papers referred to transition in critical care settings (Pattison, 2004; Pattison, 2006).

The review of literature demonstrates that only three studies have explicitly explored issues in the process of transition to end of life care in critical care units from the perspective of health professionals (Badger, 2005a; Coombs et al., 2012; Badger, 2005b); although transition to end of life care can be seen to be a major theme in providing quality end of life care in other studies (McAndrew and Leske, 2014; Hov et al., 2007). Among the studies that explored explicitly the transition process, Badger (2005a) explored the experience of moving to end of life care from the perspective of nurses working in a medical intensive care unit and describe the barriers and facilitators to transition. The same author explored the coping strategies used by nurses during transition (Badger, 2005b). Nurses perceived that the transition from curative treatment to end of life care is unclear and its boundaries are not clearly defined (Badger, 2005). In a later study, Coombs et al. (2012) studied the challenges in the process of transition from intervention to an end of life care from the perspective of 13 medical staff and 13 nurses associated with 17 decedents. They found that managing the transition to end of life care is the most challenging and complex stage in the end of life trajectory. Coombs and colleagues reported that unrecognised and unplanned transition to end of life care can lead to continuing use of aggressive treatments which interferes with quality of end of life care.

The literature suggests that little clear guidance exists worldwide about how palliative end of life care in critical care should be implemented (Pattison, 2006; Truog et al., 2008; Nelson and Danis, 2001; Truog et al., 2001). As a result, initiation and continuation of futile interventions and support therapies is common in western countries (European and North American) contributing to negative effects for patients, families and staff (Kompanje et al., 2013). Studies investigating distress among critical care health care professionals reveal that the situations causing most distress to staff relate to provision of futile treatments that prolong the dying process (De Villers and DeVon, 2013; Wiegand and Funk, 2013; McAndrew and Leske, 2014). Additionally, variation in care practice at end of life exists between countries and between critical care units in the same country (Ravenscroft and Bell, 2000; Wunsch et al., 2005; Poulton et al., 2005; Wilkinson and Truog, 2013). For example, Ravenscroft and Bell (2000)

surveyed all clinical nurse managers for critical care units in the Yorkshire region (UK) and found inconsistency in the initiation, continuation and withdrawal of life-prolonging procedures.

Several factors have been identified that interfere with clear, planned and smooth transition to end of life care. The most commonly cited factors are (1) uncertainty of prognostication, (2) ineffective end of life care communication between physicians and patients or families, (3) families' misunderstanding about palliative care and the nature of the illness, (4) younger patient age and (5) lack consensus between staff in health care teams on the direction of care (Norton and Bowers, 2001; Coombs et al., 2012; Badger, 2005). In contrast, factors adopted by critical care staff to facilitate the transition process include: providing patients and their families with good quality and honest information regarding patient prognosis and current health status based on staff assessment and experiences (Hov, 2007; Badger, 2005); enhancing the roles of nurses in as mediators between patients, their families and physicians to enhance end of life care focused communication (McClement and Degner, 1995; Coombs et al., 2012); and finally, working to attain consensus about care direction (Badger, 2005; Coombs et al., 2012; Norton and Bowers, 2001).

2.3.3 Obstacles and supportive behaviours to providing end of life care

Several studies have reported on the barriers and facilitators to providing care for terminally ill patients in critical care units. Quantitative studies using questionnaires and surveys were most commonly (Espinosa et al., 2008; Beckstrand et al., 2006). Among these five studies have used the 'National Survey of Critical Care Nurses Perception of End of Life Care' to explore nurses' perspectives toward the challenges, obstacles and facilitators to providing end of life care in critical care units (Kirchhoff and Beckstrand, 2000; Beckstrand et al., 2006; Crump et al., 2010; Gross, 2006; Attia et al., 2013). Attia et al. (2013) have conducted the only study in the Middle East (Egypt); all the other studies were conducted in United States. This questionnaire has been used also with emergency nurses (Heaston et al., 2006); paediatric critical care nurses (Iglesias et al., 2013); and hospital and cancer unit nurses (Lee et al., 2013). Other qualitative approaches have been also used and mostly to elicit the experiences of medical critical care toward the barriers to providing end of life care in critical care units (some barriers are presented below under the section of medical experiences) (Coombs et al., 2012; Norton and Bowers, 2001).

Several obstacles to providing end of life care for critically ill patients in are identified in the literature. These relate to factors that are intrinsic to critical care staff and their relationships with patients, families, as well as to environmental factors related to critical care units. Beckstrand and Kirchhoff (2005) report that nurses frequently identify the following as key obstacles: physicians' avoidance of end of life care communication with patients and families; lack of consensus among staff on the direction of care; and families who continually ask nurses for information about the patient's status. Other barriers identified in related research include: nurses' lack of time; misunderstanding of the concept of life saving measures by patients and families; families not accepting poor prognosis; and poor design of critical care units (Attia et al., 2013; Crump et al., 2010; Coombs et al., 2012). Espinosa et al. (2008) provided systematic reviews of evidence relating to the problems and obstacles experienced by nurses when caring for critically ill patient who are dying. The most cited problems are limiting nurses' involvement in curing and comfort healthcare planning; lacking of consensus among physicians and between critical care health professionals; lacking of appropriate knowledge and skills; unrealistic families expectations; staff shortage; lack of support; and problem related to critical care units as a place for providing quality end of life care. The medical staff perceptions of barriers and facilitators to providing end of life care medical are discussed under the next section.

In contrast, behaviours that aid the provision of end of life care include: consensus among health care staff on the direction of patient care; the family accepting that the patient is dying; clear understanding among families of the disease process and its likely outcomes; planned cessation of futile care and provision to critical care staff of the knowledge and skill needed to provide appropriate end of life care (Beckstrand and Kirchhoff, 2005; Thompson, 2006).

2.3.4 Critical care staff experiences of providing end of life care

Many studies have reported on the experiences of providing care for critically ill patients who are likely to die in different critical care units around the world from the perspective of nurses (Calvin et al., 2009; Espinosa et al., 2010; Valiee et al., 2012); physicians (Ahern et al., 2012; Shapiro et al., 2011; Bowden et al., 2012); and nurses and physicians together (McAndrew and Leske, 2014; Festic et al., 2012). Studies of nurses' experiences are more frequent in the literature. Most of these studies concern experiences of end of life decision making i.e. withholding and withdrawing life–sustaining treatments (McAndrew and Leske, 2014;

Vanderspank-Wright et al., 2011; Boyd et al., 2011; Trankle, 2013) and its related communication (Boyd et al., 2011; Deep et al., 2008). Other studies identify how both doctors and nurses conceptualise 'good death' and explore their experiences of providing such a death (Trankle, 2014; DelVecchio Good et al., 2004); and others explored nursing staff perceptions only (Costello, 2006; Beckstrand et al., 2006). There is a considerable nursing literature that explores the roles and responsibilities of nurses towards patients and their families in end of life in critical care setting (Adams et al., 2011; Adams et al., 2014) and small number of other studies explore both physicians and nurses roles (Baggs et al., 2007; Sorensen and Iedema, 2007).

A number of themes can be identified that summarise critical care staff experiences in end of life care from the literature review:

Practical experiences of end of life care and inter-professional communications and collaboration: Initiation and continuation of futile life-sustaining treatments that prolong dying process have been reported in the literature to be common in critical care units (Kompanje et al., 2013; Calvin et al., 2009; Badger, 2005). Studies have documented that nurses and physicians struggle to balance their commitments for their patients and the ethical, moral and legal issues associated with providing life-sustaining treatments (McAndrew and Leske, 2014; Coombs et al., 2012). Additionally, end of life decision making is the most common source of ethical conflict among health care providers (Puntillo and McAdam, 2006; Cronqvist and Nyström, 2007). Nurses perceive that they have essential roles in communication with, and care of, dying patients and their family (Ranse et al., 2012; Efstathiou and Clifford, 2011), but they acknowledge physician authority in end of life care communication and decision making and their limited roles in it (Ferrand et al., 2003).

Psychological experiences of providing end of life care communication and decision making: Critical care nurses and physicians describe feelings of frustration and distress when aggressive treatments are introduced that can no longer benefit the patient and increases their suffering. The atmosphere of uncertainty in critical care units; communication with patients and families about end of life decision making and responsibilities for the delivery of bad news are associated with high levels of anxiety and distress (Kongsuwan et al., 2010; Espinosa et al., 2010; Calvin et al., 2009; McAndrew and Leske, 2014). Because nurses are in the front line of care provision they have especially high levels of distress (Piers et al., 2014; Fridh, 2014).

Nurses role and responsibilities in end of life care communication and decision making: The importance of critical care nurses involvement in planning, communicating and providing end of life care for critically ill patients and their families in critical care units has been extensively discussed in the literature and different roles have documented (Kongsuwan et al., 2010; Ranse et al., 2012; Sheward et al., 2011; Adams et al., 2014). Adams et al. (2011) provide a systematic review of evidence relating to nursing roles in providing end of life in critical care units, including: providing patients' families with adequate information about prognosis and possible treatments; providing comfort care, avoiding isolation; keeping patients free from pain, giving patients and families a sense of control over the dying process and advocating for patients.

Medical perceptions of Barriers and facilitators to providing end of life care: For physician, the negative end of life experiences that mostly associated with uncertainty and ambiguity and loss of control over decision-making due to patient, families and system factors may (Blomberg and Sahlberg-Blom, 2007; McCann et al., 2013). Among the other most reported problems or challenges were balancing between families' expectations and patient's prognosis; delivering bad news; managing difficult communication with families and other physicians colleagues and medical uncertainty toward prognosis (Ahern et al., 2012; McAndrew and Leske, 2014; Coombs et al., 2012; Piers et al., 2014; Kamel et al., 2014). In a Canadian study Ahern et al. (2012) elicited the experiences of 19 critical care senior medical residents with end-of-life decision making and found that the physician feel more distressed when patients' families insist to continue with providing inappropriate care despite a poor prognosis while on the other hand desire to respect patient's wishes and alleviate suffering. The negative end of life experiences have documented that it leads to physicians burnout, affect their health adversely, and distancing themselves from patients (Shapiro et al., 2011).

Critical Healthcare professionals' perceptions of good death: Nurses and physicians experiences account agreed that the ability to deliver a "good death" is particularly inhibited critical care settings. "Good Death" as a major theme for quality end of life care was conceptualised by the healthcare professionals as multidimensional. The key features of a good death identified in the literature (Kongsuwan et al., 2010; Trankle, 2014; Beckstrand et al., 2006; Kongsuwan, 2011) were:

1. Symptom control and alleviate suffering; all critical care staff, regardless of domain, emphasised the importance of good symptom control in order to achieve a 'good death'.

2. Preparing for death and timely and effective management of the transition phase which was reported to be problematic in critical care settings

3. Communication with patients if possible and their families was regarded by critical care staff as crucial in a good death. Effective end of life care communications provide patients and families with a sense of control and help in meeting patient preferences and wishes for end of life care.

4. Families' acceptance of impending death.

5. Keeping patient surrounded by family and friends and not leaving them alone.

2.4 Appraising the quality of the existing evidence

The review has demonstrates that while there is a body of research on staff roles, interactions, relationships, experiences and perceptions toward providing end of life care, there is only a very small body of evidence specifically related to their experiences and perspectives on transition to end-of-life care in critical care contexts (Gardiner et al., 2011; Coombs et al., 2012; Pattison, 2006); moreover, those studies that do exist are all from the western world. The majority of the studies about critical end of life care practice are from the United States of America, followed by the United Kingdom. A small number of studies come from Sweden, Australia, Thailand, Japan and New Zealand. In addition, there is a very small body of research that has explored the provision of end of life care in Middle Eastern countries (Eidelman et al., 1998; Iyilikci et al., 2004; Yazigi et al., 2005; Da Costa et al., 2002; Iyilikci et al., 2004).

The great majority of the qualitative studies included interviews; a small number of studies used a focus group and observation approach (Badger, 2005; Espinosa, 2010; Hov, 2007; Aslakson, 2011). Studies vary in their capture of nurses' and physicians' perspectives. The review demonstrated that the vast majority fail to mention essential methodological procedure such as ethical approval, timing of data collection and analysis, criteria for completing the analysis and approach to corroborate key findings (Hansen, 2009; Calvin, 2009; Espinosa, 2010; Thompson, 2006; McClement, 1995; Gross, 2006). Although almost all of the qualitative studies report the research setting and participants clearly, methodological issues with setting and sampling were also reported, including: non-representative settings i.e. one critical care unit (Simpson, 1997; Calvin, 2009; Ranse, 2011; Hov, 2007; Crump, 2010), or one geographical area (Reinke, 2008; Aslakson, 2011); small sample of respondents (McClement, 1995; Bushinski, 2007); high withdrawal rate (Reinke, 2008); convenient sampling (Bushinski,

2007; Gott, 2011); and other selection bias problems e.g. certain group of participants (only female, only white, or only non-Muslim participants) (McClement, 1995; Bushinski, 2007; Thompson, 2006; Kongsuwan, 2010). Thus, most of the existing research may need caution with regard to generalization to critical care units within different organisational, financial, cultural and legal systems.

The 'National Survey of Critical Care Nurses Perception of End of Life Care', which was used most frequently in the literature, has been used in the literature to elicit the perspectives and experiences of nursing healthcare professionals only. The reliability and validity of this scale has been assessed and measured in different studies, suggesting that it is a robust survey that has a good reliability and validity (Crump et al., 2010; Beckstrand and Kirchhoff, 2005). Other quantitative assessment tools are documented in the literature, but these have been more recently developed and are yet to be tested in terms of reliability and validity (Kinoshita, 2011; Sheward, 2011; Lofmark, 2005; Hansen, 2009). Although these quantitative studies have shed light on the central obstacles and supportive behaviours to providing end of life care in critical care units worldwide, some of the quantitative studies reported issues related to the generalisability of their result, including: small sample size (Kinoshita, 2011; Gross, 2006), low to moderate response rates (Lofmark, 2005; Hansen, 2009; Beckstrand, 2006), and non-representative sampling (Crump et al., 2010; Attia, 2011; Gross, 2006). Other issues relate to ambiguity of questions and lack of clarity have been reported (Sheward, 2011; Schulman-Green, 2005). The literature review has demonstrated that mixed methods approach has not been used previously to explore issues around end of life care in critical care units.

2.5 Justification for the Study

The transition from curative care to end of life care is the most difficult and complex phase that critical care professionals experience when providing care for critically ill patient (Coombs et al., 2012); effective management of this phase is considered as the most important factor in providing quality end of life care. However, there is limited knowledge about the perspectives of healthcare professionals about the recognition and management of such transition and those studies that exist have been conducted in western contexts. Additionally, there has been no research into issues of transition in Jordan with little attention paid to palliation of critically ill patients, especially those with non-malignant disease. The differences between the Oriental and Occidental trend underpin the importance of investigating the transition to end of life care

in a country with a different culture and religious beliefs to those in the west. This study fills a gap in the literature surrounding the transition to and providing end of life care in critical care units by examining this issue from the perspective of health care professionals working in Jordanian critical care units. The next chapter describes and discusses the methodological approach, methods and procedure used in designing and developing this study.

Chapter3:   Making Sense of Mixed Methods Paradigm: Methodology and Methods

3.1 Introduction

'Methodology' has been defined as a set of strategies adopted by the researchers to answer their research questions (Backman and Kyngäs, 1999; Polit and Beck, 2006). The literature review has demonstrated that there is only a small body of evidence that explores transition to end-of-life care in critical care contexts; all the existing studies are from the western world. This study therefore examines this issue from the perspective of health care professionals working in Jordanian critical care units. This chapter presents the methodological plan that was applied in this study and discusses issues encountered in its implementation.

This study examined the transition to, and provision of, end of life care for dying patients and their families in Jordanian critical care units; it was divided into two phases:

- Phase one: addressed critical care staff's experience and perception of the obstacles and supportive behaviours to providing end of life care for dying patients and their families using a questionnaire survey.
- Phase two: used semi-structured interviews to elicit the experience of critical care staff about transition to end of life care and to evaluate their perceptions of factors that enable or hinder transition.

This chapter begins with the presentation of my rationale for adopting a mixed methods design for this study and the philosophical aspects relating to combining quantitative and qualitative research approaches (Feilzer, 2010). The details of the qualitative and quantitative methods of data collection are then described, and the sampling, setting, recruitment strategies and data analysis for the methods explained. This chapter also examines the procedures undertaken to ensure the validity and the reliability of the quantitative data and the rigour of the qualitative data. Finally, the ethical issues surrounding the planning and conducting the study are examined.

3.2 Methodology overview

This study adopted an explanatory mixed methods research design. Mixed methods research is a research paradigm in which qualitative and quantitative research approaches are integrated with one another at different phases in any research project (i.e. study design, data collection, data analysis and inference) in order to get both depth and breadth of understanding of the phenomenon of interest (Johnson et al., 2007). In this explanatory mixed methods study the quantitative aspect informed the qualitative aspect to address the research questions (Creswell and Plano Clark, 2011).

In this study there were two elements: a preliminary quantitative survey and a subsequent and complementary qualitative interview phase. Whereas the quantitative element enabled understanding of the prevalence of issues and their relative frequency and weight, the qualitative element enabled exploration of participants' views of obstacles and/or supportive behaviours in more depth, eliciting experiential and perceptual knowledge about transition to end of life care for dying patients and their grieving families (Tashakkori and Teddlie, 1998). In addition, the quantitative phase provided descriptive data about the participants characteristics which enabled and guided purposive sampling for the qualitative phase (Creswell, 2003). The results from the two phases were mixed in the interpretive stage to identify key findings (Creswell, 2003; Creswell and Plano Clark, 2011).

Survey

Surveys are widely used in nearly all social science disciplines across different research topics. Using survey research in social sciences produces representative and generalizable information which provides an opportunity to study the whole population but compared to other methods, less time and lower cost. In addition, using survey allows replication in different settings, times and with different populations. Survey design has been recognised to be more transparent and accountable than many of the other methods used by other research designs.

On the other hand, the main criticism for using surveys is that they involve structured questions that limit the depth, sensitivity and quality of its results. Additionally, using survey provides a little insight into the connection between factors or the patterns of relationships between them and limits the opportunity of studying action and context. Thus, linking survey with other types

of research designs is a common means to address these weaknesses. Linking qualitative research with a survey is a common combination (Kremelberg, 2011). Using this combination can serve a range of different purposes:

1. A qualitative study provides details for and extends the results of a survey.

2. A quantitative survey provides a framework for selecting participants for the qualitative design.

3. Qualitative results inform the analysis of survey results which help minimize inaccurate conclusions.

4. A qualitative study allows the study of the relationship, process and social issues between factors in the ground.

3.3 Philosophical framework

3.3.1 Quantitative-qualitative Debate

There has been a long standing epistemological debate about the relative merits of qualitative and quantitative research paradigms. Both quantitative and qualitative researchers tend to see 'their' paradigm as the ideal method for research studies and many adhere to the "incompatibility thesis" (Howe, 1988) which holds that the paradigms cannot and should not mix since they have a different philosophical underpinnings: those located in the qualitative paradigm emphasise the importance of deep and rich observational and interview data and those located in the quantitative paradigm emphasise the importance of 'hard' and generalizable data (Sieber, 1973).

Although quantitative and qualitative paradigms differ from each other, there are similarities between them. For example, both of them try to answer research questions using empirical observation, describe and summarize data, build an explanation argument from these data and explain why the results happened as they did (Sechrest and Sidani, 1995). In addition to that, both quantitative and qualitative researchers try to minimize bias and other sources of threats to validity (Sandelowski, 1986). Another similarity between these two paradigms is that all

research in social science is directed towards providing information about human beings, their environment and their interactions (Biesta and Burbules, 2003).

3.3.2 Pragmatism

This study adopted pragmatism as an underpinning philosophical framework to inform the choice of methodology and methods. Pragmatism is a philosophical movement that originated in the late 19th century and early 20th century in the United States; its popularity waned but re-emerged in the last part of the 20th century (Putnam, 2009). The most important philosophical figures of the pragmatism were Charles Sanders Peirce (1839–1914), William James (1842–1910), John Dewey (1859–1952) and George Herbert Mead (1863-1931). The pragmatic method is firstly delineated as a way of clarifying one's thoughts, of defining one's terms. Pragmatists perceive thought as a tool or instrument for prediction, problem solving and action instead of describing, representing or mirroring reality (James, 1975). Pragmatism is not a single philosophy as there is no simple doctrine that unifies it as in the cases of naturalism, realism, or idealism (i.e. no single epistemology, no single metaphysics, and no single theory of truth). Instead it is more a style or way of doing philosophy. As such, it allows a variety of views on almost any philosophical topic.

Pragmatism considers practical consequences or real effects of any idea, concept or theory to be vital components of both their meaning and truth. In general terms, pragmatism argues that the meaning of any idea or concept can be equated with the conceivable operational or practical consequences of whatever the concept represents. It also asserts that any theory that proves itself more successful in predicting and controlling our world than its opponents can be considered to be nearer the truth. Pragmatists contend that most philosophical topics—such as the nature of knowledge, language, concepts, meaning, belief, and science are all best viewed in terms of their practical uses and successes. Pragmatism differs from positivism in that it focuses on the consequence of action in particular situations to make claims for knowledge while positivism focuses on the action itself (Patton, 1990).

Pragmatists identify that there are many different ways of interpreting the world, that no single point of view can ever give the entire picture and that there may be multiple realities (James, 1975). Additionally, Pragmatists believe that truths are provisional tools used to solve particular problems thrown up by life; truth is not "ready-made", but that truth is made jointly

by us and reality. This idea has two senses (1) truth is mutable: beliefs can pass from being true to being untrue and back again depend on different persons, times, context and situations, and (2) truth is relative to a conceptual scheme: there can be no truths without a conceptual scheme to express those truths. In summary, the pragmatic approach uses the principles of (1) 'what works': an ideology or proposition is true if it works reasonably, and (2) Truth is prediction: the truth makes better predictions and proper solution for problems (James, 1975; Peirce, 1998).

The philosophical approach of pragmatism in research methodology developed in response to the debates between quantitative and qualitative paradigm. However, pragmatism does not aim to solve the epistemological differences between the quantitative and qualitative paradigms and it doesn't provide the perfect solution for bridging these differences, but it uses philosophy to try to fit together the insights from both qualitative and quantitative to gain a practical solution (Johnson and Onwuegbuzie, 2004). Pragmatism argues that both quantitative and qualitative approaches may be used in one study in order to attain the goal of the study. According to this perspective, the focus must be on the research questions and how they can be addressed, rather than prioritising one particular approach or philosophical assumption. In addition to that, the methodological choices should be guided by a practical and applied research philosophy (Creswell, 2003). In pragmatism the researcher has a freedom to choose the method and procedure that best fit the research question; truth in pragmatism is what works at that time. Thus pragmatism opens the door to multiple methods, different worldviews and different assumptions as well as different forms of data collection and analysis (Creswell, 2003).

Pragmatism has been identified as the best paradigm for mixed methods research because of its focus on answering research questions and using pluralistic approaches to gain knowledge about the research problem (Morgan, 2007; Patton, 1990; Tashakkori and Teddlie, 1998). This perspective states that multiple paradigms can be used in mixed methods research study to address research problems (Tashakkori and Teddlie, 1998)

.

In addition to "what works" as a way to solve the disputes between the quantitative and qualitative philosophical paradigm, pragmatism reject the common disputes which focus on dualisms (e.g. rationalism versus empiricism, subjectivity versus objectivity) and weight these contrasting paradigms based on how well they work in solving research problem and answering research questions. In addition, pragmatism recognises the important and the existence of both the natural or physical world and social and psychological world that includes language, culture and subjective thoughts and refusing reductionism which look to culture thoughts and beliefs as nothing more than neurobiological processes (Benton and Craib, 2001).

3.4 Mixed methods research

The history of mixed methods research as a generic concept began in the 1950s with the intent of the researcher to use more than one method of data collection in the same study: simply the combination of multiple quantitative or qualitative methods in the same study (Creswell and Tashakkori, 2007). For example, it could be using both participant observation and in depth individualised interviews or it could be using a survey with a quantitative experiment research in same study. This notion follows closely what is called today as a 'multi-method' research or within method triangulation (Tashakkori and Teddlie, 2003).

Several factors have been reported as contributors to the emergence of mixed methods research, including: the need for complex research designs in order to capture the complexity of some research problems, the need for multiple forms of evidence to inform the formulation of research problem and the recognition from both quantitative and qualitative researchers of the important role that different research methods can play in expanding the scope of studies and deepening insights from data (Creswell and Plano Clark, 2011; Sandelowski, 2000).

Although there are many challenges with using mixed methods research and the paradigm debates surrounding mixing the quantitative and qualitative methods continue, mixed methods research has been called "a new star in the social science sky" (Mayring, 2007, p.1) and a "third methodological movement" (Tashakkori and Teddlie, 2003). These relate to the perceived advantages that mixed methods research has, including: addressing the weaknesses of both quantitative and qualitative when used alone, providing more evidence to inform the research problems; and helping to address communication and collaboration between quantitative and qualitative researchers (Creswell and Plano Clark, 2011). Finally, mixed methods research is a

practical method in the sense of using both words and numbers, and inductive and deductive approaches.

3.4.1 Justification for adoption of mixed methods design

In this study, the justification for adoption a mixed methods design was that there is an existing standardised survey tool (See section 3.8.2), which has been used for more than fifteen years in western countries to gather critical care nurses experiences and perceptions of the obstacles and supportive behaviours to providing end of life care. A study in the Middle East using structured interviews, an Arabic translated form of this questionnaire was used to elicit the perceptions of nurses in an Egyptian critical care setting regarding the obstacle and the supportive behaviours to providing end of life care (Attia et al., 2013). In the study reported in this thesis, the questionnaire assesses both the experience and the perceptions of the obstacles and supportive behaviours among nurses and medical critical care staff working in Jordan.

Using this tool gave an opportunity for obtaining comparative data and providing a baseline about how Jordanian nurses and medical critical care staff might experience and perceive end of life care. Additionally, it was anticipated that the results of this study would lead to recommendations about the future use or further adaptation of the survey to be used in the Middle East countries. On the other hand, because the questionnaire has rarely been used in the Middle East, it was expected that the survey may not captured all those issues of relevance to the Jordanian context. Conducting qualitative interviews allowed identification of otherwise unknown factors and enabled exploration some cultural meanings which were very particular to Jordanian context. They also showed how individuals experienced the issues explored in the survey and enabled a detailed description of those experiences. In addition, the combination of the two methods maximised data interpretation (Tashakkori and Teddlie, 2003; Creswell and Plano Clark, 2011).

3.4.2 Mixed methods designs

3.4.3 The explanatory mixed methods design

This design is a mixed methods design in which the researcher conducts a qualitative method informed by a specific results of quantitative method (Creswell and Plano Clark, 2011;

Tashakkori and Teddlie, 2003). This design is conducted in two distinct interactive phases: the quantitative phase and the qualitative phase and the emphasis is on the second, qualitative phase of the study (Creswell, 2003; Tashakkori and Teddlie, 1998) (see Figure 3.1).

In this study, the first phase was started with collecting the experiences and the perceptions of critical care staff toward the obstacles and supportive behaviours to providing end of life care for dying patients and their families using a questionnaire survey. After the data collection was completed, the data were analysed. In the second, qualitative phase of this study the data were collected by using an in-depth individualized interviews with a sample of surveyed critical care staff along with head nurses to get an in-depth understanding about the survey results and particularly to elicit their experiences and perceptions on the subject of transition from focusing on curing and disease remission care to end of life care. The interviews were tape-recorded and transcribed verbatim and then analysed.

The second qualitative phase was informed by the results of the quantitative phase by two ways. First, the quantitative data analysis provided data that was explained by the qualitative method (Morse, 1991; Creswell and Plano Clark, 2011). This data include: the obstacles and the supportive behaviours that perceived by critical care staff to be frequent and have a high intensity; the additional obstacles and/or supportive behaviours, the changes needed to improve end of life care and the comments added by critical care staff as a responses to the open ended questions; missing data or multiple answer to the same question and any questions the critical care staff have about the study.

Second, the quantitative method enabled and guided purposive sampling for qualitative phase (Creswell and Tashakkori, 2007). After the quantitative data were collected, the descriptive data of the surveyed participants including demographic, clinical and professional characteristics were analysed. These data provided an overview about the critical care staff included in the study which helped in planning and conducting the sampling process of the next qualitative phase and in attaining a representative sample. For example, the participants' age and experience data were used to recruit participants having different years of experience in critical care units and the data of critical care staff job title to recruit junior, senior and in-charge ones. Additionally, male and female participants were also recruited in this study.

Figure 3.1: Study design: explanatory mixed methods design in two phases

3.5 Setting

Health care systems in Jordan are represented by: Ministry of Health, Royal Medical Services, University Hospitals and a number of private hospitals, each of these systems provide services for approximately one-third of the population (Stjernswärd et al., 2007). This study was conducted in five medical critical care units at the major two teaching affiliated hospitals in Hashemite kingdom of Jordan: King Abdullah University hospital and University of Jordan hospital.

King Abdullah University Hospital, located in the second largest city of the country after the capital (Irbid city), is the largest hospital in the north of the country. The hospital contains four critical care units; two of them are adult medical critical care units (General Intensive care unit and Coronary care unit). Each unit contains twelve beds with seventy five critical care staff (including nurses, resident physicians and head nurses), with different positions and qualification levels, working in these units.

The University of Jordan Hospital is located in the capital of the country (Amman) and is the largest hospital in the middle of the country. This hospital contains seven critical care units; four of them are adult medical critical care units (Male and Female Coronary Care Units, General intensive care unit, and Medical intensive care unit). Each unit contains from five to seven beds with eighty three critical care staff (including nurses, resident physicians and head nurses) working in these units. This hospital provides care for patients from nearby cities in addition to those from the capital. Full details about the staff are described below under the section of sample and population. The reasons for choosing these hospitals a study sites were:

1. These hospitals are the largest hospitals in the country, located in the centre of the country and they are easily accessible.

2. These hospitals are staffed with many physicians from other health care system (Ministry of Health and Royal Medicine Service) and serve more than two million of the Jordanian population (one third of the population).

3. The critically ill patients from other cities in the country and from the Ministry of Health hospital are transferred to these hospitals to benefit from the advance technology and highly qualified staff present in these hospitals.

4. Regarding the Royal Medical Services, there are very particular challenges with accessing these settings because they are military based and their services are provided only for military members and their relatives.

This study was conducted in only the medical critical care units in these two hospitals for two reasons. Firstly, these are the place where people more likely to die if compared with surgical ones. Secondly, five units are much more manageable to conduct a survey and recruit participants for qualitative interviews.

3.6 Population and sample

The study population refers to the total number of the target population that meet the inclusion and exclusion criteria defined to delimit the study sample (Polit and Beck, 2006). In this study the population were all critical care staff (nurses, physicians and head nurses). The sample was drawn from the five medical critical care units in the pre-defined setting. In these units, there were 149 staff members (nurses and physicians) who actually involved in direct patients care. Of these staff, there are 116 critical care nurses and 33 physicians working in these units. Socially, the nurses divided in to three categories based on their length of stay in critical care units: junior, senior and charge staff nurses. According to their professional experiences, the physicians also divided in to three categories: first year (junior physicians), second year and third year (senior physicians). Finally, there are six heads nurses allocate in these six critical care units in the predefined setting.

In the quantitative phase, the sample was all the critical care staff, whether nurses or physicians, working in the five critical care units and providing direct care to dying patients. For the interview phase, the aim of sampling was to recruit a diverse and representative sample of

critical care staff working in the critical care units including: nurses with different age, gender and levels of educational qualification; physicians of different positions and experience and head nurses. The desired sample characteristics were described in the eligibility criteria in the table below the interview's section (Table 3.4). The participants took part in the qualitative interviews and their details are described later on.

In this study, the reasons behind including the physicians were:

1. The physicians are the key and final decision maker with regard to the direction of care for the critically ill patients. Therefore, obtaining their perspectives enhanced the understanding of the research problem.
2. Several studies that examine the critical care nurses' perspectives have reported that some physicians' behaviours are perceived by nurses as obstacles to providing end of life. Therefore, it was interesting to determine which of these behaviours applied in Jordanian context and to seek to access the physicians' perspectives about the reasons behind their behaviours.
3. Culturally in Jordan, patients and their families rely mainly upon physicians in making difficult decisions. In addition, according to health care policy in Jordan, nurses are unable to start prognosis-related or end of life care communication until they have a 'green light' from the patient's doctor.

3.7 Methods and data collection

Research methods refer to the ways that data are collected and analysed by the researcher in answering his or her research questions (Johnson et al., 2007).

3.8 Phase one: quantitative

3.8.1 Introduction

In this phase, a questionnaire survey was used to assess the obstacles and supportive behaviours to providing end of life care from the perspective of critical care physicians and nurses; permission to use the questionnaire was obtained from the author.

3.8.2 Survey

A questionnaire, the National Survey of Critical Care Nurses Perception of End of Life Care, was used (A copy of nurses and doctors questionnaire is attached in the appendix A and B). Other questionnaires were also found in the literature that investigate the perceptions of nursing and medical critical care staff other than the one used in this study (Nelson et al., 2006; Festic et al., 2010; Festic et al., 2012). However, this particular questionnaire was used for several reasons:

1. This survey is a robust survey that has good reliability and validity, therefore it forms an excellent basis for the soundness of this research (Crump et al., 2010; Beckstrand and Kirchhoff, 2005).

2. Whereas other questionnaires were developed recently and are yet to be tested in terms of their reliability and validity, this survey has been used worldwide for more than fifteen years to gather critical care nurses' experiences and perceptions of the obstacles and supportive behaviours to providing end of life care. Using this survey will therefore provide the opportunities to compare the results of this study to the international literature.

3. After a careful look at the various questionnaires and after discussion with supervisors, it was anticipated that this survey would be effective in answering the research questions as it captures the most important issues related to providing end of life care in critical care unit, and also is feasible to distribute and easy to complete.

The survey was originally designed to assess the obstacles and supporting behaviours to providing end of life care to dying patients and their families. It was developed, pretested, and administered in 1998 in the United States of America (Kirchhoff and Beckstrand, 2000). The original version was subsequently used in two studies (Gross, 2006; Attia et al., 2013). In the latter study, the original version of the questionnaire was used with a sample of 23 critical care nurses working in one community hospital in north-eastern USA (Attia's study as mentioned earlier).

By the same authors (Kirchhoff and Beckstrand, 2000), the questionnaire then was adapted and used with a randomly selection of 1500 members of the American Association of Critical- Care Nurses (after adaptations) to elicit their perceptions and practices of end of life care (Beckstrand and Kirchhoff, 2005). The major change was adding the experience part of the

questionnaire. The experience part in both obstacles and supportive behaviours' section in the questionnaire was designed to measure how frequently nurses experienced obstacles or supportive behaviours on a scale from 0 (never occurs) to 5 (always occurs). The questionnaire version used in this study involves three parts. Table 3.1 below present a summarised description of the three parts.

Table 3.1: Survey parts

The first part assesses the obstacles perceived by critical care nurses in providing end of life care to dying patients and their families including how large each obstacles they perceived, with range from 0 (not an obstacle) to 5 (extremely large obstacles) and their experience of the frequency of occurrence with range from 0 (never occurs) to 5 (always occurs). This part also provides an open-ended question at the end, allowing the participants to describe in detail any additional obstacles they have perceived or experienced and not reported in the questionnaire including how large the obstacle is and how frequently it occurs.

The second part of the questionnaire seeks to elicit critical care nurses' perceptions of possible helpful behaviours in providing end of life care to dying patients and their families including the extent to which they have found each behaviour is helpful with range from 0 (not a help) to 5 (extremely large) and the frequency they have experienced each one with range from 0 (never occurs) to 5 (always occurs). At the end of this part there is also a question allowing the participants to describe additional supportive behaviours in detail, including how large the supportive behaviour is and how frequently it occurs.

The third part of the questionnaire includes questions about the demographic characteristics of the participants including age, gender, years of professional experience, work experience in critical care units, job titles, end of life care experience and the type of critical care unit they are working in. Additionally, with other open-ended questions the nurses were asked to report the changes that they would like to see in any aspect of end of life care for dying patients and their families and/or any comment about the study.

The reliability of the National Survey of Critical Care Nurses Perception of End of Life Care scale has been assessed and measured in different studies (Beckstrand and Kirchhoff, 2005; Kirchhoff and Beckstrand, 2000). For instance, in United States, the internal consistency of the 29 obstacles items was estimated by computing Cronbach's α (0.89). Internal consistency estimates of reliability were also computed for 29 obstacle items (0.89). For the 24 helpful

behaviours items reliability was (0.86), and for the 24 helpful behaviours items reliability was (0.81). This suggests that the scale is internally consistent.

3.8.3 Survey adaptation and administration

In order to utilize this survey to elicit both physicians and nurses' perceptions of end of life care and the results of this survey to be comparable, this questionnaire survey was adapted since it was originally designed to obtain only the perceptions of critical care nurses. The approval for adapting the questionnaire was gained from the original author of the questionnaire. The author was contacted via email and the permission was also given as an electronic email response in which the author asked whether the survey would be translated to another language other than English. At that time, he was informed that the questionnaire will be used in the same language it was designed with some adaptation. A copy from the email is attached in the appendix H. In addition, the questionnaire items have been adapted to fit with cultural issues particular to the Jordanian context.

The adaptations were made at different levels. First, the title and the introductory message of the questionnaire were formulated to be more general and fit with both nurse and doctors. A subtitle was also added showing the different type of the questionnaire (nurses' or the doctors' questionnaire). Second, the obstacle items were formulated to be appropriate for both doctor and nurse participants. The supportive items were kept as they are. In addition, minimal issues with English language were also managed to make the items more understandable to the staff. Third, the demographic section was minimally adapted to fit with the Jordanian context; thus some of the demographic characteristics questions were deleted because they were not applicable in the Jordanian context.

The adaptation of the survey was conducted by myself and was revised by my supervisors. For the purpose of validity testing, two different things were done. First, the adapted questionnaire along with the original was sent to a doctor here in the United Kingdom, who is a Jordanian immigrant. Second, in order to make final adjustments to the questionnaire, two Jordanian critical care nurses were asked to fill the questionnaire in front of me before its distribution to the participants of the study.

Each member of critical care staff was asked to complete either a physician's questionnaire or a nurse's questionnaire, according to their role. The difference between the two questionnaires was that the nurses' questionnaire included all the three parts (obstacles, supportive behaviours and demographic characteristics parts), while the physicians' questionnaire include only the obstacles and the demographic characteristics aspects.

3.8.4 Sampling

Through the sampling design and procedure the researcher decides which sample from the study population is appropriate to provide information that can address the research questions (Creswell and Tashakkori, 2007). In the quantitative part of this study the aim of the sampling procedure was to choose participants who were representative of the population, in order to enhance generalizability (Creswell and Tashakkori, 2007; Coyne, 1997).

In the quantitative phase the sample was all critical care staff who providing direct care for dying patients in the five critical care units. So in this study the questionnaires were distributed to all critical care nurses (junior, senior and charge nurses) and physicians (second year and senior) working in the five critical care units. All staff involved in providing care for dying patients was given the opportunity to complete the questionnaire including the demographic characteristics. Finally, in this phase of the study head of nursing were not surveyed because the questionnaire items are directed toward staff engaging in providing bedside care for critically ill patients who are likely to die and their families.

3.8.5 Recruitment

Quantitative data collection was started directly after getting the ethical approval from both Jordanian hospitals and the ethical review letter from the University of Nottingham. Quantitative data collection lasted for four months (some interviews were also conducted during this time). For the purposes of survey distribution, the head nurses of each unit were contacted individually. They were informed about the purpose of the study, the target participants and the stages of the study. Lists of the names of the nurses working in the critical care units were also obtained. In term of doctors' recruitment, the medical director in each hospital was asked about the number of physicians who worked in critical care units, their job titles and their work shifts; thus a list of medical critical care staff was obtained.

Since the work shifts for critical care nurses and physicians were different depending on the institution's policy, the most feasible way to approach them was to contact them individually or in groups at different times. When I contacted the potential participants face to face, I introduced myself, explained the purpose of the study and responded to their questions. After that, the invitation letter, the information sheet (A copy of invitation letter and information sheet are attached in the appendix D and E) and the survey document were administered to the health care professionals by putting them in a numbered special envelope; they were asked to return the questionnaire in the same envelope if they were willing to participate in the study.

Moreover, in the first meeting with potential participants, I went through the different parts of the questionnaire and other documents explaining what they would have to do if the decide to take part in the study. This was to minimize the chance of confusion the participants might encounter when start filling in the different parts and sections of the questionnaire. Namely, they were informed that for the obstacles and supportive behaviours sections there were two parts: a perception element and an experience element. They were asked to add any comments about obstacles or supportive behaviours that the questionnaire might not cover and to respond in any language they preferred.

Just before ending the introductory meeting, the best contact details (phone number, emails or address) for the participants were obtained. The potential participants were informed that they would receive three reminder messages, with one week between each. These messages were to remind them about the questionnaire, to remind them where to put the returned questionnaire and to thank them for participating in the study. The participants were told that they did not need to respond to the messages. Through the invitation letter, the critical care staff were asked to read the information sheet and to fill the survey if they are willing to take part in the study. At the end of the survey a question asking the participants if they would be willing to be approached to take part in the follow up interview was added. Respondents were asked to fill their details in the participant's confirmation form (Appendix F) that is enclosed, and to return this with their survey questionnaire in the same envelope.

In order to enhance the response rate, a formal cover letter with the participant's name was included inside the envelope. This letter talked about the importance of the study by informing the participants that all the information that is available in the literature about this subject is from western country so their participation will be extremely valuable and worthy. In the

formal letter, the participants were thanked for their time in filling in the questionnaire and taking part in the study. In addition, the participants were informed that they will receive a participation certificate after returning the survey and the confidentiality will be maintained.

I choose the off-peak work shifts to distribute the questionnaires so the staff would be more likely to have time to talk to me. These 'off-shifts' were mostly the after-noon and night shifts. Before starting distributing the questionnaire in these shifts the supervisors and the directors covering the hospital during these shifts were contacted to gain their permission to distribute the questionnaires. When I contacted them, I gave them a general overview about the study including: the purpose, the target units, the participants, the process of recruitment, the time needed and the methods of data collection; they were also shown the letters of ethical approval I had received from the hospitals. Sometimes they gave me some information about the units and how that might affect my data collection, such as: nurse shortage and overload. Sometimes I felt that they were worried that I might distract the staff from their jobs. Thus, they were assured that the staff's duties would not be affected and they were informed that I would be flexible with timing to ensure suitability. Every time I went to distribute the questionnaires, I started by examining all the critical care units and started with the unit where the nurses were not too busy. In each unit, the unit charge nurse was contacted to obtain permission to talk with the nurses. Once the permission is granted, the unit charge nurses were contacted. With contacting the units' charge, an overview about the study was given; they were asked about their suitable time for conducting the study and were asked about the feasible way to contact the nurses either individually or in groups.

3.9 Phase two: interviews

3.9.1 Introduction

This section of the chapter explores the qualitative phase of the study. Semi-structured interviews were conducted with a sample of critical care staff to elicit their experiences and perceptions on the subject of transition from curing and disease remission to end of life care. This section of the chapter begins with the rationale for adopting semi-structured interviews as a method of data collection. The sampling, recruitment strategies and data analysis are then explained.

3.9.2 An overview of qualitative interviews

Qualitative research interviews explore meanings and perceptions and seek to gain rich descriptions of the life world of the interviewees and their interpretations of the meaning of the phenomena under investigation (Kvale, 1983). Qualitative research interviews seek to enable participants' narrations about the topic and to discover new thoughts or ideas that were not anticipated at the outset of the study (Britten, 1995).

Qualitative interviews have been categorised in different ways in the literature. One contemporary categorisation is to refer to: unstructured, semi-structured and structured interviews (Bernard, 1988; Fontana and Frey, 2005). Structured interviews often produce quantitative data by use of standardised questions and analyses to test prior hypothesis. Semi-structured and unstructured interviews are used to explore meanings and get a detailed understanding of the phenomena being studied from the point of view of the interviewees (DiCicco-Bloom and Crabtree, 2006; Britten, 1995).

No qualitative research interview can completely be considered unstructured, but some interviews are, to greater or lesser extent, more like guided conversations. The ethnographic tradition in anthropology employs unstructured interviews alongside participant observation and field note recording (Margaret, 1928; DiCicco-Bloom and Crabtree, 2006). During this process the ethnographer identifies one or more "key informants" to interview.

In this study semi-structured interviews were used to gain the staff accounts about providing end of life care in critical care units. During the interviews the critical care team were encouraged to recall their experiences, express their feelings, thoughts and ideas about end of life care and their perceptions of death and dying. Particular attention was placed on their experiences of moving from the treatments aimed at curing and disease remission to treatments aimed at provision of care and comfort. This involved the factors they perceived that might interfere with planned and smooth transition; factors that might facilitate the transition; their ideas about good and bad death and the roles and responsibilities they perceived in communication with families of dying patients.

3.9.3 Sampling

Coyne (1997) points to the profound effect of sample selection on the quality of qualitative research. However, there are continuous debates regarding sampling in qualitative research secondary to a lack of clear guidelines and principles for selection of a sample (Morse, 1991).

In this study and for the purpose of the interviews, selecting interviewees was based on purposive sampling to maximize richness of information when addressing the research questions (Kuzel, 1992). Purposive sampling involves intentionally selecting participants who have experience with the central phenomena of interest or the key topic being explored (Coyne, 1997). The selection of participants in the qualitative phase was based on the type of the five medical critical care units included in the study (e.g. Medical Intensive Care Units, Coronary Care Units, and General Intensive Care Units) by choosing participants spread fairly across these units. In addition, the sampling process was guided by obtaining a mix of perspectives in order to give the breadth of data, for example, a mix of gender, a mix of experiences and a mix of educational level. Moreover, the first interviews guided the sampling process after which additional participants were recruited for the purpose of answering the evolving question. These evolving questions covered new topics or issues mentioned by participants already interviewed, topics or issues already mentioned but needing more clarification or explanation, issues of data saturation, and the relationship between previously mentioned issues and new ones. Finally, a participants' selection was also informed by the quantitative results, for example the individuals who vary on a selected answer; participants with different demographic characteristic and participants who respond to the open ended questions. In this

study, a total of thirty interviews were conducted with critical care staff. Of these interviews, 15 were with nurses; ten were with physicians and five were with head nurse (Figure 3.2).
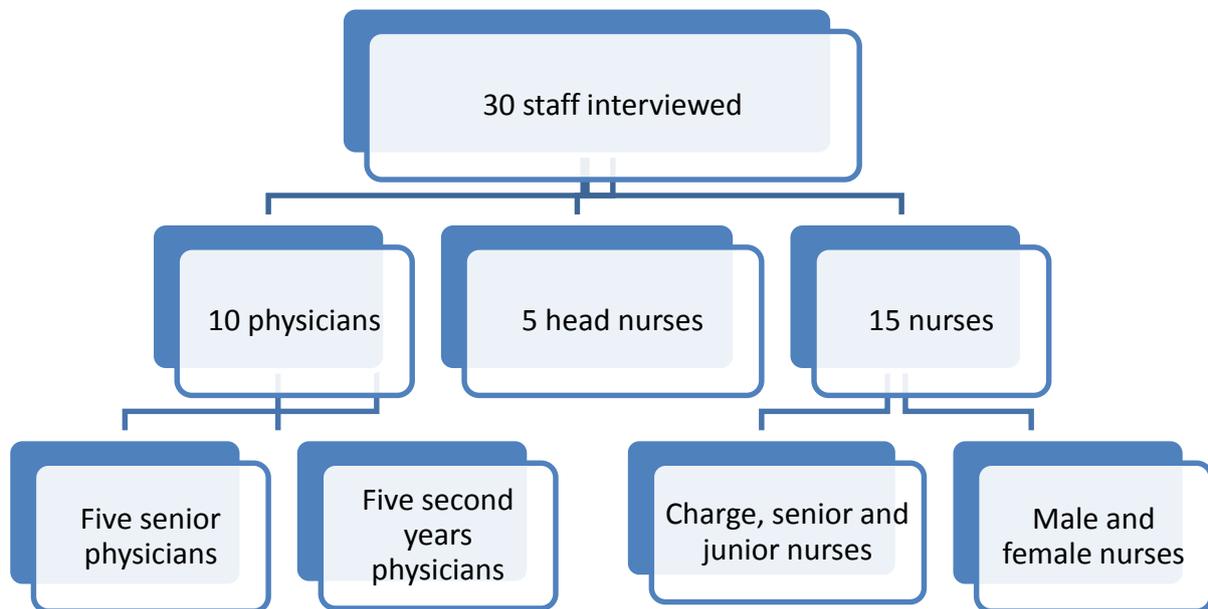
Figure 3.2: Qualitative data interview sample

3.9.4 Interview guide

The interviews started with a critical incident technique involving a recall of a specific death. The interviewees were asked about the last person they could remember who died including whether a decision was made to commence end of life care, the communications conducted and the challenges faced. This facilitated further discussion and consideration of issues relating to the participants care of dying patients. Using an in-depth semi-structured interview helped the respondents to share their ideas, thought and experiences (DiCicco-Bloom and Crabtree, 2006). The interview guide used in this study is presented in Table 3.2 and Table 3.3.

Table 3.2: Interview guide for nurses and doctors

Overview:

1. Thanks for taking part in interview.
2. Going through information sheet (confidentiality, withdraw at any time, stop taping any time and specific needs)
3. Obtaining signed consent where applicable.
4. Do you have any question about the study before we start?

Key questions were asked, with a series of additional prompt questions used only when participants do not refer to these issues.

5. Let us begin our interview by taking a few minutes to talk about yourself: professional experience, critical care experience, how long do you work here? How often do you take care of dying patient?
6. Let us now focus our discussion specifically on the last death experience you have. Can you tell me about the last person' who died that you were caring for? Can you remember? What illness s/he had? How long s/he spent in critical care unit? etc.
7. What the care s/he received before death? What (if any) treatments were changed once you recognise that you are losing the patient?
8. **Probe response:** what type of treatment change decisions? When they happened in relation to the patients' death/ dying process? What was the family role in these changes? What was the nursing role in these changes?
9. What types of communications have been carried out related to the patient's care?
10. **Probe response:** Between health care professionals and patients/families and among the health care professionals themselves; timing of these communications in relation to the patients' death/ dying process; the occurrence of family meeting and conference in the units; problem of power position between the medicine and nurses and within medicine itself and whom of patient's family members were involved?
11. What were your roles as a nurse/doctor with communication with the patient's families before and after the patient's death?
12. **Probe response:** Family understanding of events; prognosis related communication and the direction of care; the skill, knowledge and willingness to conduct this type of communication; their feeling with these communications; any obstacles or challenges; preparing families for end of life discussion; advocate role and liaising between the family and patients' physicians.
13. What are the sources of conflicts that you have experienced regarding this dying patient? What about other patients?
14. **Probe response:** Prognostication; the conflict of futile care; conflict with families about the patient' direction of care (curing or end of life care).
4.

Then, as you know the main focus of this study is about the transition from aggressive care to end of life care critically ill patients who are likely to die. So, let us now focus our discussion specifically on the issue of transition.

15. What are your experiences with transition to end of life care?
16. **Probe response:** time for transition (reasons and conditions); planning for transition; emotional labour involved in transition and quality of dying

17. From your perspective, what make the transition to end of life care smooth and swift and what make it difficult?
18. **Probe response:** making the diagnosis of dying; achieving consensus about the transition decision and in effective communication at different level.
19. In what way are families helpful or not helpful in planning and achieving the transition to end of life care?
20. **Probe response:** family member relationship; family expectation; religion; making the diagnosis of dying and effective end of life communication.

Ending:

21. We come to the end of the interview. Do you have any question, comment or suggestion about the study?
22. Thank you very much for the time you have given. You have my contact details if you need to discuss or ask anything please feel free to do that.

Table 3.3: Interview guide for head nurses

1. How do you see the critical care environment as a place of death?
2. **Probe response:** visiting hour and the ability of families to be with their loved one; professional emotional support provided to a family and staff and Unit design and if there is a special room for dying patients.
3. What are the strategies that adopted in your unit to enhance the care of dying patients?
4. **Probe response:** nurses education and family and patients education.
5. About the idea of having some sort of an intervention or tool. What do you think might be worthwhile to have in order to improve the care of dying patients?

Although the above interview guide were used while conducting the interviews with the critical care staff, I gave a space to the participants to share, discuss and comment on any topic that might be related to the study purpose. I also used probes to elicit more details.

One of the issues I encountered in my data collection was how to deal with my interview guide or where the position of the interviews guide should be during first interviews since this was the first experience for me with conducting qualitative interviews. For example, during my first interview I stuck too much to the guide. Rather than follow the participant while sharing his account, I was very busy in preparing for the next questions using the guide. At that time, once I finished the interview, initially I felt satisfied with what I did, but after transcribing the interview I realised that I missed so much detailed information from the participant's account.

3.9.5 Recruitment

Qualitative data collection lasted for four months. The recruitment of the participants for the interviews was started while the survey was going on (during the distribution of the surveys and once the participants started to return the survey). Once the participants returned the survey documents and the data were analysed, other participants were recruited for the purpose of explaining the statistical results. There were two reasons to invite participants while survey was going on:

1. The two methods are gathering different kinds of knowledge in which the survey helped in answering one of the research questions, while the other research questions were informed by the interviews.
2. Rather than spending most of time waiting for survey results and after that compressing the interview phase within a short period of time, this approach saved time and offered enough time to conduct the interviews.

With every returned questionnaire, I checked the willingness of the participant to take part in qualitative interview; the willing participants were added to a volunteer list designed by me for this purpose. Then, the volunteer's eligibility to participate in the interview phase was assessed on the bases of their demographic information (Table 3.4). The eligible participants were contacted in their work shift and during distribution of the questionnaires (in the same visit) to arrange a suitable time and location for the interview. The location of the interviews was near the critical care units so that the staff were available for any help or any emergency events in the unit; this was likely to be more acceptable to female participants (as discussed in the ethical issues section later on).

Once fifteen volunteers were recruited, I checked the achieved sample to make sure that there was spread across the five critical care units and that it included both nurses and physicians. The rest of the participants were selected purposively from among the other volunteer to balance the sample and according to the survey results. I contacted all other volunteers who do not fit with eligibility criteria telling them that they would not be interviewed giving them the reasons. At the end of the quantitative part, the total number of participants who volunteered to participate in the qualitative phase of this study was 40 participants (nurses and physicians).

Table 3.4: Eligibility criteria

Eligibility criteria for nurse
• Work as a nurse more than one year. • Working on critical care units for more than six month. • Providing direct care to critically ill patients.
Eligibility criteria for physicians
• Working as a full time doctor in the hospital. • Second year and senior physicians working in critical care units or the physicians who are caring/covering critical care units. • Providing direct care for critically ill patients.
Eligibility criteria for head nurse
• Working as a head nurse more than one year in the same critical care unit.

3.9.5.1 Interviews with nurses

3.9.5.1.1 Interviews with critical care nurses

Fifteen nurses were interviewed from across the five units (Table 3.5). Of those nurses who were included: 7 were female; 8 were male; five were charge nurses (more than five years of experience in critical care units); 6 of these nurses were a Master's degree holder and the rest were bachelor degree holders; five were senior nurses (more than three years of critical care units experience and less than five) and five were junior nurses (less than three years of critical care units experience).

When I got the first five eligible volunteers, I examined the biographies of these volunteers and arranged for the first appointment for an interview with the nurse who had the longest experience in critical care units; this was to attain abroad and deep account about the end of life care and to guide other interviews. The appointment was changed three times because the participant was very busy and this was a common challenge I encountered.

Table 3.5: Characteristics of Nurses

P#	Participant Code	Hospital	Gender	CCUs experience	Education level	Position CCU
N1	CCN1.2.10	H1	Male	3.8	Master	Senior Nurse
N2	CCN1.2.9	H1	Male	5.0	Master	Charge Nurse
N3	CCN1.1.19	H1	Female	1.8	Master	Junior Nurse
N4	CCN1.2.20	H1	Female	2.9	Bachelor	Junior Nurse
N5	CCN1.1.2	H1	Female	5.0	Bachelor	Charge Nurse
N6	CCN1.1.7	H1	Male	3.9	Bachelor	Senior Nurse
N7	CCN1.1.9	H1	Male	3.4	Bachelor	Senior Nurse
N8	CCN2.2.2	H2	Male	15	Master	Charge Nurse
N9	CCN2.1.3	H2	Male	6.0	Bachelor	Charge Nurse
N10	CCN2.2.4	H2	Male	10.0	Bachelor	Charge Nurse
N11	CCN2.2.10	H2	Female	3.0	Bachelor	Senior Nurse
N12	CCN2.3.10	H2	Female	2.3	Master	Junior Nurse
N13	CCN2.5.13	H2	Female	2.5	Bachelor	Junior Nurse
N14	CCN1.2.8	H1	Male	4.0	Bachelor	Senior Nurse
N15	CCN1.1.8	H1	Female	2.9	Master	Junior Nurse

In the time of this meeting and the following interviews, I prepared my audio- tape recorder with extra batteries and my field note diary. Before starting the interviews, I went through the information sheet with the participants and responded to their questions. After that, if the participants were still interested in taking part in the study, their consent was gained. During the interviews all needs and requirements for the respondents involved were addressed and they were free to withdraw from the study at any time or to arrange another meeting at a more

convenient time. The interviews were conducted in Arabic, with technical terms in English. The consent and information forms were in English, as this is the professional language (A copy of consent form and information sheet are attached in appendix G and E). Additionally, most of the interviews were conducted in evening and night shifts.

Just before conducting the next interviews, the previous interviews was translated to English and then sent to my supervisors gaining their perspectives. The supervisors provided me with comments and suggestions that help in conduction the next interviews. This was the way of recruitment for and conducting the entire qualitative interview

Another issue I sometimes encountered was frequent interruption of the interviews. As feasible and available places were chosen to conduct the interviews, this issue was anticipated. For instance, the first interview was conducted in the unit's store room; it was a small room, but at that time it was the only place available (the interview conducted during the day shift). The interview was interrupted three times by other staff need some stuff from the room. In order to get the participant back again in the interview, I draw in my field note to tell the participant what he said and where we stop. This was a lesson I learned for next interviews where I tried to do the interviews in afternoon or night shift and avoid such places where interruption is anticipated as possible.

3.9.5.1.2 Interviews with head nurses

In this study, five heads nurses were included in this phase of the study (Table 3.6). Interviewing head nurses provides an opportunity to get a different sort of knowledge that connects to management level and revealed knowledge not mentioned by the medical team or hidden from view of nurses as most of times, the relationship between medical team and the head nurses is very strong.

As mentioned earlier, the plan was to start with medical critical care staff interviews after completing the nurses' interviews. However, because of the challenges mentioned below, I decided to carry on with head nurses and leave physicians' interviews to the end hoping that the situation becomes better. When conducting the second set of the nurses' interviews, the heads nurse were contacted in person individually to arrange for interviews. The head nurses were unable to give exact appointments for interviews because of their job nature; the

agreement was to set a suitable time in principle and to contact them one day before the day of interview to verify their availability and confirm the time and place.

P#	Participant Code	Hospital	Gender	CCUs experience (Years)	Education level	Position CCU
H1	HN1.1	H1	Female	13	Bachelor	Head Nurse
H2	HN1.2	H1	Female	10	Bachelor	Head Nurse
H3	HN2.1	H2	Female	13	Master	Head Nurse
H4	HN2.2	H2	Female	17	Bachelor	Head Nurse
H5	HN2.3	H2	Female	17	Bachelor	Head Nurse

3.9.5.2   Interviews with physicians

The most challenging recruitment was for medical critical care staff. At the start, the recruitment was by contacting the volunteers, setting date, time and place for interview. Several times, the interviews were cancelled. After that, it was agreed to call the potential interviewee once s/he starts the work shift to determine if an interview could be made. After many unsuccessful appointments, five full interviews were conducted over three months.

With interviewing medical critical care staff, I experienced an issue that to some extent has affected my data collection. One of the settings where the study was conducted is in a city has a shared border with Syria and secondary to the Syrian crisis many injured Syrian refugees were admitted there. This resulted in an exceptionally high workloads for physicians and after a while I realised it was going to be difficult, if not impossible to get another full interview with doctors having spent a long time getting the first five full interviews.

At that time, when I realised that getting more interviews was going to be very difficult I contacted my supervisors. They gave me some different ways to think about this issue, either to spend some more time to get a few more interviews or if the interviews that were done are saying the same thing and there is no a lot to be gained by doing some more interviews, to draw

a line under those interviews. In addition, they suggested that I could supplement the interviews that I already had by talking more informally and briefly to some doctors to ensure a range of perspectives but not take too much of their time, given the problem with the refugee crisis. So, five additional brief interviews were conducted and focused on selective topics to check the saturation of the data. Within some of these brief interviews we discussed some cases present in the unit at the time of meeting.

Most of these brief interviews were conducted at morning and afternoon work shifts and were with medical staff who had volunteered to participate. In order to conduct these interviews, I used to spent most of the time in the critical care units examining all the cases in the units to identify the dying ones with help from nurses; once a medical critical care staff approach the department and after finishing his or her work I contacted him or her asking for a brief and short interview rather than a long and detailed one. The participants were very cooperative and they apologised for the inability to make full interviews.

In these interviews I used to either select topics to check the saturation of the data or to discuss some cases present in the unit I already identified. To identify the topics to be discussed in the brief interviews, I transcribed all the physicians' full interviews which I already did before starting with theses brief interviews and selected topic where the saturation needed to be checked or detailed to be obtained. I focused most of my question on the topic of transition to end of life care including: the imminence of patient's death; any treatments that were changed because the patient is dying; the obstacles they are encountered to provision of end of life care; how the transition could be eased and if they have any different transition experiences with other patients. The brief interviews lasted on average around 20 minutes.

Finally, the physicians' interviews were across all critical care units. Of those physicians: six were male and four were female; four were from first setting and six from second setting; five were senior doctors (more than three years of experience as a professional doctor) and five were in their second year of experience as a doctor. Table 3.7 below presents the detailed information about the interviewed medical critical care staff.

Table 3.7: Doctors' characteristics

P#	Participant Code	Hospital	Gender	CCUs experience (Years)	Professional experience (Years)	Position
D1	MD1.3.38	H1	Female	1.3	2.3	Second year
D2	MD2.4.17	H2	Male	2.0	3.5	Second year
D3	MD1.3.33	H1	Male	2.2	4.2	Senior Doctor
D4	MD1.3.16	H1	Female	2.5	4.4	Senior Doctor
D5	MD2.4.1	H2	Male	2.5	4.6	Senior Doctor
D6	MD2.4.6	H2	Male	1.3	2.1	Second year
D7	MD1.3.11	H1	Male	2.3	3.8	Senior Doctor
D8	MD2.4.9	H2	Female	1.5	2.4	Second year
D9	MD1.3.8	H1	Female	2.5	3.8	Senior Doctor
D10	MD2.4.12	H2	Male	1.6	2.8	Second year

3.9.5.3   Power in qualitative research

Power in terms of research is a dynamic, fluid and moving force (O'Brien and Moules, 2007). All qualitative paradigms and traditions with a considerable disparity between them (Mantzoukas, 2004) share a common epistemological principle of redistribution of power in which the researcher seeks to minimize the distance between the researcher and the participants (Creswell, 1998; Ebbs, 1996; Karnieli-Miller et al., 2009). Power in research has different aspects: power of knowledge, power of language and power of status (class, gender and ethnicity). The power moves between the researcher and the participants at different stage of the research process (Karnieli-Miller et al., 2009).

Both researcher and participants are major and complementary parts in qualitative research: the participants are the key provider of the data; story tellers who provide their experiences, feelings and beliefs for investigation and the researcher is the collector, analyser, writer and publisher of the participants' experiences, feelings and beliefs. Additionally, participants have diverse motivations to take part in study: they wish their voice to be heard or wish to gain some advantage (e.g. money or other profit) while the researcher seeks to fulfil his or her own motivations (earning an academic degree, publishing or receiving funding). Thus, there is an inherent complexity in power relations between participants and researcher which impacts on the quality of the qualitative research. Empowering participants may create a feeling of empathy that enables them to open up about the data they have but this might not allow the researcher to obtain the data they need. On the other hand, empowering the researchers may give them the chance to control over research and ask questions they want but this may create a negative perspective in participants and a sense of being controlled by others which affect the quality of data they give (Torres and Magolda, 2002).

In qualitative interviews the aim of power distribution between interviewer and interviewees is to create a friendly and non-threatening context in which the interviewees are willing to open up about their experience, stories and beliefs (Taylor and Bogdan, 1998). In this study, interviewing participants in different levels with different positions, qualifications and titles including doctor, nurses and head nurses made the issue of power relations quite recognizable and made maintaining the power balance between me and the participants a challenging process. In the recruitment stage the control over the research was in my hand in which I decided how to introduce the study, what to tell about the study and explaining who I am. In this stage I was very careful about how to introduce myself and my affiliations to participants and how to response to the question of "Who are you" to gain maximum cooperation and minimize the distance (Christensen, 2004). With nurses I introduced myself as a critical care nurse doing a research about end of life care in critical care units. This was to make the participant feel more comfortable to accept to share their experiences openly supposing that I can understand their account due to my professional background.

With head nurses, who had more power, I used to use the statement of "I was one of your critical care staff and I'm now doing a PhD research study about end of life care in critical care units" frequently when introducing myself to the head nurses in order to balance power between us. With medical critical staff I disclosed my professional, academic and institutional

affiliations in order to encourage them to pay me attention and agree to take part in the study. I tried to empower participants by informing them that they had valuable experiences and important information to give; I also handed over to them the subject of the best arrangements for interviews.

In the data collection stage, I tried to gain access to participants' own experience and accounts by building rapport and trust with them. For instance, for nurses' participants, I often used to say "I completely realise what you're talking about since I'm a critical-care-nurse and I have across some of these issues".

3.9.6 Data Analysis in mixed methods research

Data analysis in mixed methods research consists of analysing the quantitative and qualitative data separately as well as analysing both sets of data using techniques that mix the quantitative and qualitative results (Creswell & Plano Clark, 2011). In this study, the data analysis was conducted in three phases: (1) the analysis of the quantitative data, (2) the analysis of the follow-up qualitative data and (3) in the interpretive phase in this design, integrative analysis was used to answer the research questions about whether and how the qualitative data help in explaining the quantitative results (Creswell and Plano Clark, 2011; Tashakkori and Teddlie, 2003). In the section below the quantitative data analysis of this study was discussed and the qualitative data analysis is presented in the qualitative section.

3.9.7 Quantitative data analysis

This section sets out the statistical analysis carried out for all available quantitative data on the obstacles and supportive behaviours to providing end of life care to dying patients and their families, under headings such as: screening and cleaning the data: validity, reliability and factor analysis for the used questionnaire; the skewness and kurtosis of the data; descriptive and inferential statistical analysis were performed.

3.9.7.1   Screening and cleaning the data

Screening the data from nurses' showed that the data were within three standards deviation from the mean scores except for one participant. This participant was a man in his fifties working as a bedside staff nurse. His "years of experience as a registered nurses", "years of

experience in critical care unit" and "age" variables have a more than three standard deviation from the variable's data mean (Z=3.93, Z=4.67, Z=5.8 respectively). Different recommendations have been reported in the literature about the value of the Z score in order to consider a variable as an absolute outlier (Hoaglin and Iglewicz, 1987). In this study, any variable data have a Z score of above 3.29 or below -3.29 was considered as an absolute outlier. So the participant's values of the variables mentioned above were considered as an outlier in the subsequent quantitative data analysis by considering them as missing values.

The literature has suggested three different ways to deal with outliers (Hoaglin and Iglewicz, 1987). Firstly, the Winsor-zings way in which the researcher replaces the outlier value with the mean of the other values. Secondly, the trimming way in which the researcher removes the entire data of the participant who has outlier values from the database. Thirdly, consider the outlier values as a missing data so they will not be included in any of statistical analysis.

Although the literature has reported if the trimming way of dealing with outlier values is done for less than five percent of the data, it will not affect the hypothesis, this way was not adopted for two reasons: Firstly, these values are for demographic data and will not affect the main part of the quantitative data analysis in this study which is looking for the intensity and frequency of occurrence of (1) obstacles to provide end of life care in critical care units and (2) supportive behaviours that help in providing end of life care. Secondly, adding the perception of this participant might be important to represent the data especially that he has an extensive experience as a nurse.

In this study, and in order to clean the data, the absolute outlier values of the variables are considered as missing values. So, the number of values for these variables is seventy five instead of being seventy six. After screening the medical critical care staff data, all variables' values were within 3.29 and -3.29 (-3.29<Z<3.29) standard deviation from the mean. So no value was recognized as an outlier.

3.9.7.2 Reliability and factor analysis

The reliability of the research instrument refers to the issue of getting the same results using the same instrument when it is used each time with the same person and in the same setting. The two types of reliability were commonly used is the internal consistency reliability and the split half reliability. In this study, the internal consistency estimate of reliability was used. The

internal consistency for the intensity and frequency scores of both obstacles and supportive behaviours to provide end of life care were computed.

For nurses data, the reliability for the twenty nine obstacles intensity items' scores, the Cronbach's Alpha was computed to 0.8 which classified as a good reliability items (George and Mallery, 2012). The reliability of the twenty nine obstacle items' frequency scores was acceptable; almost good with Cronbach's Alpha was computed to be 0.8 (George and Mallery, 2012). In addition, the internal consistency estimate of reliability for the supportive behaviour items' scores was also computed. The reliability for the twenty four supportive behaviour items was good, almost excellent with Cronbach's Alpha of .88 for intensity scores and .86 for frequency scores (George and Mallery, 2012).

For the respondent medical critical care staff, the reliability of the obstacles intensity and frequency scores were computed using internal consistency estimate of reliability. For the twenty nine intensity scores, the Cronbach's Alpha was 0.81 which classified as a good reliability items (George and Mallery, 2012). For the twenty nine frequency scores, the reliability of the items were poor (Cronbach's Alpha was 0.54).

The principle component analysis was run for the revised questionnaire to determine whether the questionnaire was still a reliable tool after a revision was made. The analysis indicated that the measure of end of life care was multidimensional. The items rotated into seven clearly defined factors that demonstrate that the questionnaire is still a reliable tool for use in measuring the perceptions and the experiences of critical care staff of obstacles and supportive behaviours to providing end of life care to dying patients and their families. The questionnaire's reliability results and factor analysis suggest that the questionnaire used still works in the way that it did previously even it was adapted.

3.9.7.3 Kurtosis and skewness of the data

The skewness of the data refers to the shape of the data distribution and shows whether the distribution of the data is left skewed (more negative value for skewness) or right Skewed (more positive value for skewness). In the other hand, the kurtosis of the data refers to how flat or peaked the distribution is. The literature has suggested that any value for kurtosis and skewness between -1 and 1 is excellent (George and Mallery, 2012). The kurtosis and skewness

were calculated for critical care staff data and showed that there was neither skewness nor kurtosis issues.

Another criterion or rule to analyze the normality of the data distribution has been mentioned in the literature is to multiply the value of the standard error of skewness or kurtosis by three and if the absolute value of the skewness or kurtosis is less than the value of skewness or kurtosis, they will be considered as an acceptable value (George and Mallery, 2012). In this study, according to this rule all values of skewness and kurtosis for the scaled variables for the respondent critical care staff were acceptable.

3.9.7.4   Descriptive and inferential statistical analysis

In this study, quantitative data analysis focused on identifying the obstacles and supportive behaviours with the highest intensity and frequency perceived by critical care staff to providing end of life care to dying patients and their families and how these results relate to the their demographic data.

The data were entered for all returned questionnaires and analysed using 19.0 Statistical Package for Social Science software (SPSS Inc., Chicago, IL). A general description of respondents' characteristics including frequency, mean, standard deviation and range were calculated. In addition, frequencies, measures of central tendency and dispersion were computed for all obstacles and helpful behaviours items. Items then were ranked on the basis of their mean scores to determine which items were perceived as the biggest obstacles or helpful behaviours and which ones were reported to occur most often. After that, a perceived intensity score for the obstacles and helpful behaviours items were calculated to determine which items are perceived as having both the most intensity and the most frequent occurrence (Sawatzky, 1996). Finally, the obstacle and helpful items intensity scores were ranked from highest score to lowest score.

Moreover, independent sample t test was used to test the hypothesis which states that there is no significant difference between and among critical care staff perceptions and experiences of obstacles to providing end of life care (George and Mallery, 2012; Agresti and Finlay, 2009). In this study, this test was used specifically to address such questions: is there any significant difference between nursing and medical critical care staff perceptions toward the obstacles to providing end of life care. The result of the t test is indicated as statistically significant if the

significant level is equal or less than .05. If it is ≤ .05, one concludes that the two set of mean scores are statistically significant.

3.9.8 Qualitative data analysis

This study used insights from grounded theory to approach qualitative data analysis, applying it as a set of flexible guidelines to enable a systematic method. Grounded theory is a qualitative research method that was originally developed by Glaser and Strauss in the 1960s (Glaser and Strauss, 1967). The intended purpose of grounded theory is to develop theory about phenomena of interest. Strauss introduced this approach as a form of qualitative data analysis after publishing the book: Qualitative Analysis for Social Scientists (1987). In this study, the data analysis process conformed to the set of flexible principles and practices described by Charmaz (2006). The following steps was adopted:

1. Constructing initial codes using line-by-line coding to identifying anchors that allow the key points of the data to be gathered.
2. Grouping the data by collecting codes of similar content.
3. Constructing sub-theme and themes.

Analysis started with the very first line of the very first interview. I started constructing the codes by attaching labels to segments of data that depicted what each was about (Charmaz, 2006). This step was repeated until all interview transcripts were coded. During this process, I used what has been described as the constant comparison method involving comparing codes and grouping codes of similar content (Glaser and Strauss, 1967). Over time, distinct sub-themes were identified and then named. The above mentioned steps were repeated, with the introduction gradually of theorizing which involved thinking about how each sub-theme related to a more inclusive theme or construct. For example, appendix K describes the process undertaken to develop the theme and sub-themes 'staff-families trust relationship'.

In the qualitative phase of this study, data collection and analysis were conducted concurrently with myself generating an emerging understanding about the research questions which then inform the sampling process and the question being asked. Data collection and data analysis process then continued until no more new information emerge (Silverman, 2004). Finally, the data were transcribed for thematic analysis and reflective notes were made after the interview.

One of the advantages of using in-depth interview is that dialogue between the interviewer and interviewee can be recorded so accurate and comprehensive data management is enhanced. In this study, the interviews were digitally recorded with the permission of the interviewee, so that the interview data would be more accurate than note taking and allow for further revision (Opdenakker, 2006). However, note taking during the interviews is very important even the interview is totally recorded, because it helps in checking to see if all areas of questioning have been addressed and helps in the case of recorder or interviewer malfunction. It was planned that if the participant refuses to record his or her voice the interview data will based on note taking. However, I did not encounter this issue.

Audio-recording is the most common way to record interviews beside video-recording and note taking (Owen, 2001). Several issues with using tape-recording were considered. For example, tape-recorded data can be perceived as dangerous or risky by interviewees so they were assured that the recordable material would be carefully managed and destroyed after the transcription or when the data analysis completed.

During analysis the data were transcribed verbatim. Transcribing tape-recorded interview into text gives rise to some issues that can interfere with the accuracy of the data. Transcribers often have difficulties in capturing the interview dialogue because of sentence structure and mishearing words; sometimes they have to make judgments in transcription which may lead to a change in meaning and affect the overall accuracy of data (Meadows and Dodendorf, 1999). Seale (1999) pointed that listening to the audio-tape while reading the transcript and checking notes taken during the interview may help the researcher to check accuracy during interpretation.

The analysis was conducted in Arabic language for several reasons. First, conducting data analysis in the original language in which it was collected helped in grasping the context of data collection (Temple et al., 2006). Second, allowing me to catch the nonverbal responses or slang expressions and words helped to ensure comprehensiveness and encouraged a more reflexive analysis. Third, avoiding the methodological issues accompanied the translation including the translators and researcher power and role issues (Berman and Tyyskä, 2011). However, in order to enhance the confirmability of the findings a professional translator was used to translate a number of interviews from Arabic to English to be checked by my supervisors and the translation was reviewed by me and another health care professional

3.9.9 Rigour and trustworthiness: qualitative perspectives

The soundness or quality of any research study regardless of the approach adopted is always critically assessed by others including readers, decision makers, peer and grant reviewers. The evaluator of the scientific soundness of quantitative research adopts reliability, validity and generalizability as essential markers (Agresti and Finlay, 2009). Even though these concepts to some degree correspond with factors in qualitative research evaluation, different terms, notions and principles are considered to fit with the qualitative, naturalistic and pluralistic endeavour. Additionally, even though there are some basic principles in evaluating the qualitative work, not all qualitative approaches should be evaluated with the same strategies (Lincoln, 1985; Krefting, 1991).

Rigour is many things. It is dissatisfaction with uncertainty, with erroneous answers, and with imprecise measurements. Rigour in research inquiry implies a structured and controlled way of planning, developing, analysing and evaluating our research and a special care in presentation of the result in order to establishes the authenticity of the research process regardless of the research method applied (Aroni et al., 1999). Rigour is indispensable principle in research endeavour, because without rigour the worth or sound of the research is in danger (Morse et al., 2002). In the scientific process of qualitative research, using rigorous methods was identified as a mean to ensure that the findings represent the reality by evaluating their truth and consistency (Slevin and Sines, 2000). With complex debate in the literature about whether the rigour fit with the qualitative research or not, the idea of trustworthiness as an application of rigour throughout research study introduced by Guba and Lincoln (1985) as a new way to apply the essential markers of reliability, validity and generalizability out of the rationalistic quantitative paradigm to naturalistic one. Trust worthiness of the qualitative research methods refers to judging the extent to which the information acquired from these methods is true, real and genuine picture for personal perspectives, views or lived experiences of participants about a phenomenon under search (Mays and Pope, 2000; Lincoln, 1985; Guba, 1981). The importance of learning of how to ensure the rigour, thus the quality, of qualitative research in order to its relevance to inform the day to day practice has been well-known in the literature (Carpenter and Suto, 2008; Hammell and Carpenter, 2004).

In order to ensure the trustworthiness of the qualitative research, several frameworks about how qualitative research might be evaluated are reported in the literature (Fitzpatrick and

Boulton, 1994; Secker et al., 1995; Blaxter, 1996). In this study, Guba (1981) and Lincoln (1985) framework was used to evaluate the qualitative approach. Under this framework, four criteria should be considered in evaluating the trustworthiness: credibility, dependability, transferability and confirmability (Guba, 1981; Lincoln, 1985).

3.9.9.1 Credibility

Credibility of the qualitative research refers to the degree to which the research findings are present a real or 'true' picture of informants' accounts. Different strategies have been reported to enhance the credibility of the qualitative research findings (Krefting, 1991; Guba, 1981; Lincoln, 1985). Of these, the strategies used in this study included: triangulation, member checking, prolonged engagement, interview technique and reflexivity. In triangulation the findings were compared between two different data collection methods (interview and survey) or between different data sources (Curtin and Fossey, 2007). In this study different data sources were used to enhance the credibility of the qualitative findings. The data were collected from more than one level of person including critical care nurses, physicians and heads nurses (person triangulation); The data were also collected from two different setting (space triangulation). In this study, two different methods were used to complement and confirm each other and compensate the weakness of each other. The triangulation approach has been seen as a way of ensuring the comprehensiveness of the data and promotes the reflexivity of the data analysis (Curtin and Fossey, 2007; Farmer et al., 2006; Mays and Pope, 2000).

Respondent validation or member checking is a technique used to enhance the accuracy and credibility of a study. In member checking, the researcher shares all of the findings with the participants involved the study participants in order to check the authenticity of the work; the participants either affirm that a study result reflect their views, feelings, and experiences or not (Lincoln, 1985; Shenton, 2004; Silverman, 2006). This serves to decrease the incidence of incorrect data and the incorrect interpretation of data. In this study, I did not have the opportunity to involve the participants in the data analysis. However, in this study the member checking technique was used during the data collection. Once I finished one question or topic and just before moving to the next one, I summarised the main points or ideas and then asked for participants' verification and for any further comments they wished to add.

Reflexivity refers to being sensitive toward how the researcher's role, assumptions and personal and intellectual characteristics shape the findings (Finlay, 1998). Importantly, Guillemin and Gillam (2004) reported that the reflexivity does not have a specific time in the research process, but it is in itself a process take place through research. In this study, in the interviews I identified my role as data collector of others' accounts and presenting realities reported by study participants setting aside my professional and clinical experiences as critical care nurse and the assumptions I might have about the topic of the study. However, I sometimes referred to my experiences and assumptions to assure the comprehensiveness of data collection and to assure a more reflexive analysis of the data. In addition, I tried to minimize the effect of my personal characteristics on data collection by redistribution of power between him and the participants as mention in power relation section (Section 3.9.5.3 above). This was an opportunity to enrich the qualitative interviews findings. My details were provided in first chapter of this study, including personal, professional, clinical and educational back ground and my interest in the study topic. In addition, with the discussion and dialogues between me and my supervisors about the way of data analysis, I found an opportunity to share my points, assumptions and experience.

Another way to enhance the credibility in this study was by prolonged engagement in the critical care units while conducting data collection. This helped in building rapport with the participants and helped to ensure voluntary participation

3.9.9.2   Dependability

Dependability corresponds to reliability criterion in quantitative research evaluation. In the literature, it is reported that meeting this marker is difficult in qualitative research (Shenton, 2004). It involves providing the reader with a clear and full account about how the data were collected (including setting, participants, intensions, process and interactions) and analysed (including steps, interpretations, validation and data presenting) in order to allow them to evaluate whether data are supported by the mechanisms of its collection and analyses. In this study, I have tried to provide a clear and detailed account about the methods used in the data collection including access, recruitment, interview conduction and ethical and methodological issues (Higgs, 2001: citen in Byrne-Armstrong et al., 2001; Curtin and Fossey, 2007). In addition, a clear exposition of the method of data analysis has been provided. Moreover, limitations are acknowledged (See chapter 7).

3.9.9.3   Transferability

Transferability refers to the extent to which the findings of the qualitative research can be applied to other settings other than the one where they are produced. In this study, in order to enhance the transferability of the qualitative findings full details about the qualitative inquiry were provided to the readers that allow them to compare between methods, principles and findings (Mays and Pope, 2000). These details include the informants' details, the research context and setting where the study was conducted.

3.9.9.4   Confirmability

Conformability refers to the neutrality of the qualitative research findings and whether they represent a balance of perspectives, views and experiences among the participants (Lincoln, 1985). In this study, my supervisors examined the process and the production of data analysis step by step. This was to verify that the finding explanation, recommendation and conclusion are supported by the data and not the result of my biases or assumptions.

3.10 Ethical considerations

Studying highly sensitive issues such as end of life care is fraught with several ethical issues that should be taken in consideration in order to attain the benefits of the research while maintaining participant wellbeing and preserve their rights (Seymour and Skilbeck, 2002).

3.10.1 Ethical principles of participation

Freedom of participation

In order to avoid the feeling among the potential participants that the participation is mandatory, the prospective participants for both quantitative and qualitative phases were invited by invitation letter included in the envelope along with all other document that discuss the research objectives and benefits within their hospital. After that, the participants decided whether to participate or not. Then, the participants who were willing to participate returned the completed survey and indicated whether they were willing to participate in the qualitative part. The consent form was filled as needed and a proper time and location for the study interview were defined. However, one female nurse in the second hospital refused even to take

the envelope containing the survey and letter saying that she has own reasons not to enrol in any research project. Her stance was respected and gave me a valuable lesson to be considered while contacting other staff, namely asking if they were happy to be contacted to talk about the study and if they are willing to take the envelope or not.

In long interviews, the participant was always asked if s/he feel happy to continue with the interview or not. Finally, a participant's permission was taken toward using a digital voice recorder to record the interview conversations and a notes were planned to be taken if the participant refuses using the audiotape. For example, D7, a female doctor, sought more information about the digital recorder by saying "could you please tell me who will listen to the tape and in what form you will used the recorded information"; her questions were answered and clarified.

Right for information

There is a consensus that participants have a right to be adequately informed about the study including the objectives, the benefits and the methodology (Seymour and Skilbeck, 2002). Individualised and group meetings with the potential participants were conducted in which written and verbal information were given. Written information was given in the form of information sheet. The sheet explained the benefits and general information about the study and a verbal interpretation was provided if necessary. These strategies enabled the potential participants to be fully informed about the study. Finally, some participants expressed preferences to have the results of the study. A summary of the available results, especially after doing a preliminary analysis for the quantitative data, was provided.

3.10.2 Principle of respect for human dignity

Informed consent

- ❖ The study participants provided written or verbal consent to participation, recording of the interviews and the publishing of findings.
- ❖ The consent was in English language and has not been translated as this is the professional language.
- ❖ The participants were informed that they have the right to withdraw their consent at any time without giving a reason.

❖ Privacy was maintained by conducting the interviews in a place chosen based on common agreement with the participants and available places.

Signing informed consent was applied in the second hospital only. In the first hospital I was requested not to do that in the ethical approval, so verbal consent was gained

Data confidentiality

Some participants were worried about the confidentiality of their accounts. They saw that their information could be harmful for them and to their relationship with other staff. Thus, during the study, the participants were assured that their confidentiality of will be preserved including the audiotapes, transcripts and the personal data by a set of strategies:

❖ The personal data were stored on a separate sheets accessible by me only.
❖ The audiotapes and the transcripts were stored securely and accessible only by me and my supervisors. The data were stored in a password protected university computer and the hard copy was stored in a locked filling cabinet.
❖ After the study completion, all information will be moved in to the university archives storage.
❖ Any use of the study data in any conferences, presentations or publications will be anonymised to protect the participant confidentiality.

3.10.3 Ethical approval

The study proposal was ethically reviewed by the Medical School Ethics Committee in the University of Nottingham. Formal ethical approval to conduct this research study in the critical care units of the two hospitals was obtained from the Ethics Committees of the two hospitals. In addition, I also contacted each of the critical care unit managers, and they issued me with a brief letter of approval to conduct my research study. A copy of ethical approval letters are attached in the appendix C.

3.10.4 Potential ethical issues for this study

Table 3.8 below shows some ethical issues were encountered that are very particular to this study and the strategies adopted to deal with them.

Table 3.8: Potential ethical issues in this study and planned strategies

Ethical issues encountered	Strategies adopted
Some participants asked whether his/her name will be adding in the final study results.	I provided enough information to participants about the research process and that the anonymity of the participants should be reserved.
In Islamic culture, some female staff may feel uncomfortable to be in a separate and closed venue with the researcher.	The interviews were conducted in a quiet place so there is no interruption for the audio-recording and they were near to the participant's unit and the door kept open.
One a female doctor participant preferred to conduct a joint interview with her doctor friend.	Ethically it was responsible to act as they wish. So joint interview was allowed. Joint interview was done and impacted positively on the interviews data because her friend was a senior resident doctor working in critical care unit as well.
Some participants asked what other staff said about them.	To keep the anonymity of the participants and the hospital as well, general and neutral picture about the results of both hospitals were provided to the participants and they were informed that these results are not just for your hospital.
Sometimes, volunteered participants may initially agree to participate but may later decline (a matter of time).	Keeping in contact with the participants; built a rapport relationship with the participants in recruitment phase and work within a pre-scheduled plane with participants.
Some participants may share negative impressions about other staff during the interviews and may mention their names.	Enough information about the endeavour of the study and the anonymity of the participants was provided before the interviews. Any name mentioned by the interviewee during the interviews was deleted during the transcription.

3.11 Conclusion

This chapter has provided the methodological plan that was applied in this study and discusses issues and challenges encountered in its implementation. This study adopted an explanatory mixed methods research design in two phases: a preliminary quantitative survey and a subsequent and complementary qualitative interview phase. The first phase employed the "National Survey of Critical-Care Nurses' Perceptions of End-of-Life Care" (adapted with permission) to elicit the views of critical care staff (N=104) about the possible obstacles and helps to providing end of life care for critically ill patients and their families.

In the second phase, complementary qualitative interviews were conducted with staff (15 nurses; 10 junior doctors; 5 head nurses) to gain insight into how the issues reported in the survey were experienced, to allow identification of otherwise unknown factors and enable exploration some cultural meanings which were very particular to Jordanian context. The study took place in two University hospitals in two cities. The next chapter presents the results from the first phase of the study using the adapted "National Survey of Critical-Care Nurses' Perceptions of End-of-Life Care". The two following chapters report the finding of the interviews with the critical care staff.

Chapter4: Perceived Obstacles and Supportive Behaviours to Providing End of Life Care: Survey results

4.1 Introduction

This chapter reports the results from the first phase of the study using the adapted "National Survey of Critical-Care Nurses' Perceptions of End-of-Life Care". The participants were medical and nursing critical care staff working in the critical care units and providing direct care to dying patients. The survey was used in order to gather some data related to a range of perceived issues among doctors and nurses and to be able to compare those result to the international literature. It was also used to inform the qualitative aspect of the study.

Using the adapted questionnaire to elicit both doctors' and nurses' perceptions, the results show important similarities and differences in staff perceptions toward obstacles to provide end of life care. The findings also outline the importance of supportive behaviours to provid end of life care as perceived by critical care nurses.

This chapter starts by describing the social, professional and clinical demographic characteristics of the respondent participants. Then, the obstacles to providing end of life care to dying patients and their families perceived and rated by the medical and nursing staff respectively are reported. After that, the rated supportive behaviours as perceived by nurses are also presented. Finally, the similarities and the differences between nursing and medical staff perceptions are outlined and discussed.

4.2 Demographic characteristics of the respondents

From one hundred and fifty two critical care staff (doctors and nurses) who were working in the current study setting, one hundred and forty three critical care staff were invited to fill in a survey. In this sample the nurse participants were 110 and the doctor participants were 33. The critical care staff who could not be contacted were nursing staff and included: three nurses who did not provide direct patient care; three nurses on maternity leave; two nurses on annual leave before leaving employment. In addition, one nurse refused to take part in the study.

Figure 4.1 below shows a flowchart for recruitment of critical care staff.
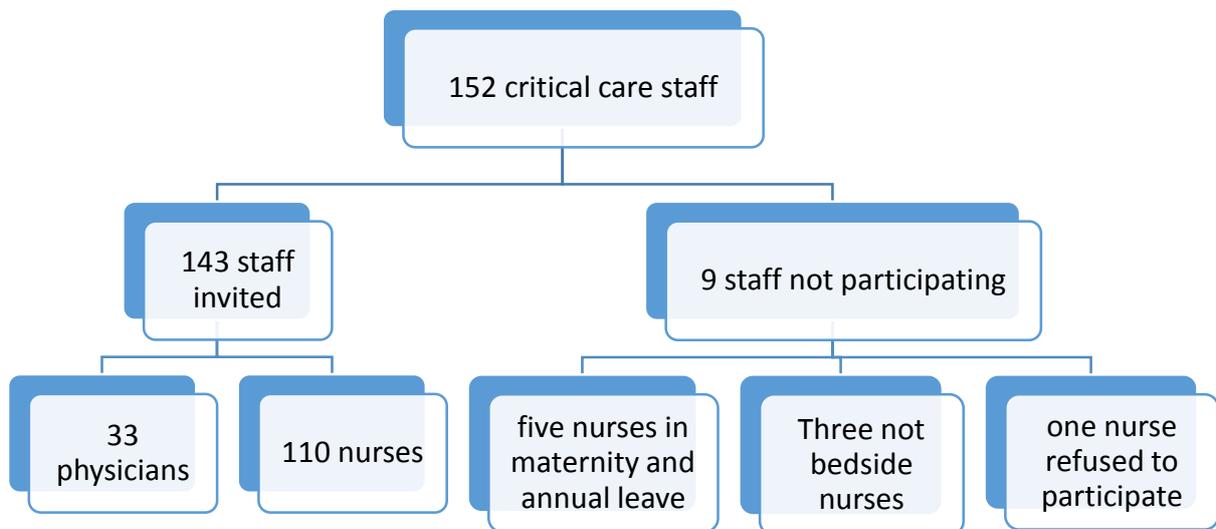
Figure 4.1: Recruitment flowchart for critical care staff

The overall response rate was 72.7%. There was an 84.5% (N=28) returned data for medical staff and 69.1% (N=76) for nursing critical care staff. All returned questionnaires were included in the analysis. Table 4.1 below reports the demographic characteristics of the respondent participants.

Table 4.1: The complete demographic characteristics

Social, Professional and Clinical Characteristic	Nursing Staff			Medical Staff		
Gender, Number. (%)						
Male	38 (50)			18 (64.3)		
Female	38 (50)			10 (35.7)		
Scaled variables	Mean	SD	Range	Mean	SD	Range
Age, Years	26.4	(2.9)	(23– 38)	27.25	(0.96)	(26 – 30)
Years as registered nurse or doctor	4.1	(2.4)	(1 - 11.9)	3.14	(1.06)	(1.6 - 4.6)
Years in critical care units	3.4	(2.0)	(0.1 –10)	1.39	(0.81)	(0.1 – 3)
Hours worked per week	45.	(3.8)	(40 – 48)	62.78	(14.65	(36 – 90)
Number of bed in unit	9.2	(3.2)	(5 – 13)	-	-	-
Dying patients cared for over the participant's career, (%)						
>30		42.1			39.3	
21-30		10.5			10.7	
11-20		25.0			17.9	
5-10		11.8			21.4	
≤5		9.2			10.7	
Other		1.3			0.0	
Highest Degree, (%)						
Bachelor's degree		85.5			-	
Master degree		14.5				
Working area, (%)						
ICUs		35.5			3.6	
CCUs		35.5			10.7	
Combined ICUs/CCUs		7.9			78.6	
MICUs		15.8			7.1	
SICUs		2.6			0	
Other		2.6			0	
Position, (%)						
Direct Care/ Bedside Staff		39.5			-	
Charge Nurse/ Staff Nurse		60.5			-	
Senior doctor		-			53.6	
Second year doctor		-			46.4	

Abbreviations: CCUs, Coronary Care Units; MICUS, Medical Intensive Care Units; SICUs, Surgical Intensive Care Units

4.2.1 Nurses' demographic characteristics.

The nurses respondents were 23 to 38 years old (M=26.49 years, SD= 2.9), had been registered as a nurse for a mean of 4.17 years (SD=2.4) and ranged from 1 year to 11.9 years. Of those respondents, 50% were male and 50% female. The respondents had worked in critical care units for a mean of 3.47 years (SD= 2.05) with a range from 1 month to 10 years. The range for the number of hours worked per week for the nurses was between 40 to 48 hours with a mean of 45 hours (SD=3.82). The number of units' bed ranged from 5 to 13 beds (M=9).

From the respondent nurses, 85.5% were holding a bachelor's degree (n=65) and 14.5% (n=11) of them held a master's degree level of education. In terms of the type of critical care units where the nurses' participant primarily employed, 35.5% (n=27) of the respondent nurses were working in intensive care units and the same percent were working on coronary care units; 7.9% working in combined intensive care units and Coronary care units; 15.8% working in medical intensive care units; 2.6% working in surgical intensive care units, and 2.6% working in other critical care units. The nurses sample were employed as a bedside staff nurse 39.5% (n=30) or a charge bedside nurse 60.5% (n=46).

4.2.2 Doctors' demographic characteristics

In this study, 84.5% (n=28) of the medical critical care staff returned the questionnaire. Of those respondents, 64.3% (n=18) were male and 35.7% (n=10) were female. The age of the respondent doctors ranged from 26 to 30 years (M= 27.25 years, SD= 0.967). The respondent participants average years of experience as a doctor was 3.14 years (SD= 1.06) and they had worked in intensive care units for 1.39 years (SD=.81) on average. Most of the doctors (78.6%) were working in both intensive care units and coronary care units; 7.1% (n=2) working in medical intensive care units and 3.6% (n=1) working in intensive care units only.

The respondents worked on average 62.78 hours (SD=14.65) weekly with a range between 36 to 90 hours. From the respondent doctors 39.3% (n=11) had provided end of life care for more than thirty patients; 10.7% (n=3) provide that care for number of patients between 21 to 30 patients; 17.9% (n=5) between 11 and 20; 21.4% between 5 and 10, and 10.7% (n=3) of the doctors sample have provided end of life care for less than five patients over their career. According to the system in both hospitals in which the study was conducted, the resident

doctors who cover the intensive care units or other critical care units should be at least a second year doctors. So, the sample doctors were second year doctors 46.4% (n=13) or senior (more than three years of experience as a professional doctors) doctors 53.6% (n=15).

4.3 Nurses' perceptions of obstacles

This section discusses the perception of critical care nurses toward the intensity and the frequency of obstacles to providing end of life care to dying patients and their families. It also presents the perceived intensity scores which refer to the obstacles that were perceived both to be the highest intensity and most commonly encountered by the respondent nursing staff. Additional obstacles reported by critical care nurses are then presented. The perception of medical critical care staff are presented under the next section.

4.3.1 Obstacles intensity, occurrence and perceived intensity score

Highest Intensity Obstacles: Using a Likert scale from 0 (not an obstacle) to 5 (extremely large obstacle) the mean intensity scores for the obstacle items as perceived by nursing critical care staff was calculated. The mean scores ranged from 4.12 to 2.93. Table 4.2 below presents the top ten obstacle items along with their intensity mean scores. The items in the table were in descending according to the values of mean of intensity. In this chapter only the top ten obstacles and supportive behaviours items in terms of intensity and frequency are reported; the detail is reported in appendix J.

The two largest perceived obstacles to providing end of life care were having family members that don't understand what "life-saving measures" really mean, i.e., that multiple needle sticks cause pain and bruising, that an endotracheal tube won't allow the patient to talk etc. (M= 4.12) and the poor design of critical care units which do not allow for privacy of dying patients or grieving family members (M= 3.89).

Examining the items perceived to be the most intense obstacles to providing end of life care, the critical care nurses in this survey talked about critical care clinicians' stances, behaviours and characteristic obstacles. Four out of the top ten obstacles involved issues with critical care clinicians. These obstacles take place when the clinicians focus on activities that are trying to save the patients' life and didn't have enough time to provide quality end of life care (M= 3.86);

71

when they lack proper education and training regarding family grieving and quality end of life care (M= 3.84); when they are evasive and avoiding conversation with family members (M= 3.71); and when multiple clinicians are involved or providing care to one patient and differ in opinion about the direction of care (M= 3.59).

Table 4.2: The mean scores for obstacle intensity reported by nurses

Obstacles	Intensity mean
Family members not understanding what "life-saving measures" really mean, i.e., that multiple needle sticks cause pain and bruising, that an endotracheal tube won't allow the patient to talk etc.	4.12
Poor design of units which do not allow for privacy of dying patients or grieving family members.	3.89
Not enough time to provide quality end-of-life care because the clinicians focus is on activities that are trying to save the patient's life.	3.86
Lack of clinician's education and training regarding family grieving and quality end-of-life care.	3.84
Clinicians who are evasive and avoid having conversations with family members.	3.71
Clinicians' having to deal with angry family members.	3.68
Families not accepting what the clinicians are telling them about the patient's poor prognosis.	3.59
Multiple clinicians, involved with one patient, who differ in opinion about the direction of care.	3.59
The unavailability of an ethics board or committee to review difficult patient cases.	3.57
No available support person for the family such as a social worker or religious leader.	3.49

The most frequent obstacles: On a scale from 0 (never occurs) to 5 (always occurs) the frequency mean scores to the twenty nine obstacle items as perceived by nursing critical care staff ranged from 1.78 to 4. Table 4.3 below presents the top ten obstacle items along with their frequency mean scores. Of the twenty nine obstacle items sixteen items had a mean of three or more, meaning that they were perceived as fairly often occurring.

The three obstacles perceived as the most frequent occurring to providing end of life care were respectively the poor design of the critical care units which do not allow for privacy of dying patients or grieving family member (M= 4); family members not understanding what is meant by "life-saving measures" i.e., that multiple needle sticks cause pain and bruising, that an endotracheal tube won't allow the patient to talk etc. (M= 3.89); and dealing with angry family members (M= 3.76).

Table 4.3: The mean scores for obstacle frequency reported by nurses

Obstacles	Frequency mean
Poor design of units which do not allow for privacy of dying patients or grieving family members.	4
Family members not understanding what "life-saving measures" really mean, i.e., that multiple needle sticks cause pain and bruising, that an endotracheal tube won't allow the patient to talk etc.	3.89
Clinicians' having to deal with angry family members.	3.76
Not enough time to provide quality end-of-life care because the clinicians focus is on activities that are trying to save the patient's life.	3.75
Families not accepting what the clinicians are telling them about the patient's poor prognosis.	3.5
Family and friends who continually call the clinician wanting an update on the patient's condition rather than calling the designated family member for information.	3.42
Lack of clinician's education and training regarding family grieving and quality end-of-life care.	3.38
Clinicians' knowing about the patient's poor prognosis before the family is informed.	3.38
The clinician not knowing the patient's wishes regarding continuing with treatments and tests due to the patient's inability to communicate.	3.37
Continuing treatments for a dying patient even though the treatments cause the patient pain or discomfort.	3.33

As well as being perceived to be among the most intense obstacles, medical critical care staff issues were also reported to be of the most frequent issues to have been experienced by critical care nurses. Of the ten obstacles reported to be most frequent, medical critical care staff issues

were manifest in five items: insufficient time to provide quality end of life care because the clinicians focus on activities that are trying to save the patients' life (M= 3.75); clinicians lack proper education and training regarding family grieving and quality end of life care (M= 3.38); the clinician not knowing the patient's wishes regarding continuing with treatments and tests due to the patient's inability to communicate (M= 3.37); the treatments were continued for a dying patient even though the treatments cause the patient pain or discomfort (M= 3.33) and clinicians knowing about the patient poor prognosis before the family is informed i.e. late family informing of patients poor prognosis (M= 3.38).

The perceived intensity scores (PISs): To identify which obstacle items were perceived by the respondent nurses as being both the most intense and the most frequently occurring, the perceived intensity scores of the obstacle items were calculated. The PISs were calculated by multiplying the mean score of intensity by the mean score of frequency for each obstacle item individually (Kanner et al., 1981; Sawatzky, 1996).

Looking at the PISs data (Table 4.4), the first two items had the highest PIS were family members not understanding what "life-saving measures" really mean, i.e., that multiple needle sticks cause pain and bruising, that an endotracheal tube won't allow the patient to talk etc. (PIS= 16.02) and that the design of the critical care units is poor as it does not allow for privacy of dying patients or grieving family member (PIS= 15.56).

Of the top ten obstacles items in terms of intensity and frequency, four incorporated issues with medical critical care staff behaviours and characteristics. These obstacles took place when clinicians focus on activities that are trying to save patients' life so there not enough time to provide quality end of life care (PIS= 14.4); clinicians lack of proper education and training regarding family grieving and quality end-of-life care (PIS= 12.9); not knowing the patient's wishes regarding continuing with treatments and tests due to the patient's inability to communicate (PIS= 11.76); and when they continue intensive treatments for a dying patient even though the treatments cause the patient pain or discomfort (PIS= 11.48).

Table 4.4: The perceived intensity scores critical care nurses

Obstacles	PISs
Family members not understanding what "life-saving measures" really mean, i.e., that multiple needle sticks cause pain and bruising, that an endotracheal tube won't allow the patient to talk etc.	16.02
Poor design of units which do not allow for privacy of dying patients or grieving family members.	15.56
Not enough time to provide quality end-of-life care because the clinicians focus is on activities that are trying to save the patient's life.	14.47
Clinicians' having to deal with angry family members.	13.83
Lack of clinician's education and training regarding family grieving and quality end-of-life care.	12.97
Families not accepting what the clinicians are telling them about the patient's poor prognosis.	12.56
The clinician not knowing the patient's wishes regarding continuing with treatments and tests due to the patient's inability to communicate.	11.76
No available support person for the family such as a social worker or religious leader.	11.51
Continuing treatments for a dying patient even though the treatments cause the patient pain or discomfort.	11.48
The unavailability of an ethics board or committee to review difficult patient cases.	11.10

Obstacles related to patients' families such as dealing with angry family members and who not accepting what the clinicians are telling them about the patient's poor prognosis also featured in among the first ten highest PIS scores. In addition, other items in the top ten involved systems issues such as unavailability of a support person for the family such as a social worker or religious leader and unavailability of an ethics board or committee to review difficult patient cases.

4.3.2 Additional obstacles reported by critical care nurses

In addition to the obstacles and supportive behaviours items, the surveyed participants were invited to respond to open ended questions to report any additional obstacles or supportive

behaviours to providing end of life care they have perceived or experienced. They were also asked to identify the most needed changes to improve end of life care in critical care units they would like to see if they have the ability to do so. At the end of the questionnaire, a question eliciting comments that the participant might have about the study was also included. Under this section the additional obstacles reported by critical care nurses are presented.

Fifteen nurses (19.7%) added responses to the additional obstacles open ended question. These nurses reported twenty eight additional obstacles to providing end of life care. Content and thematic analyses were applied to analyze these responses. The additional obstacles that could not be categorized, they were grouped under "other obstacles". These added responses were distributed to five categories including staff attitudes, knowledge and behaviours; religious issues; environmental constrains; setting specific issues and family issues. The most common obstacles identified by the respondent nurses were related to staff attitudes, knowledge and behaviours. These obstacles were reported by nine nurses (60%) and they were "Incompetent staff", "Ineffective communication between doctors and patients families", "Improper pain relief due to worries about addiction", "Poor religious understanding", "Poor culture understanding", "Palliative and end of life care are not part of some staff consideration". Table 4.5 below lists the reported the additional obstacles and the categories they belong to

Interestingly, some of the additional obstacles reported by nurses were included in the questionnaire, such as open design and no privacy, rushing the post death care because of patients over load and families nervousness. One possible reason that the respondent repeated items already mentioned on the questionnaire is that the respondent wished to emphasise the importance of these items.

Another explanation might be that the items mentioned in the questionnaire did not fully address the respondents' concerns. For example, one participant who added comments about the problems posed by open design and lack of privacy explained that open design of critical care units interfered with patients' rest time and made other patients extremely stressed and uncomfortable when the death of other patients occurred. Additionally, some of the respondents (n=3) commented that the questionnaire was too long and time consuming; this may have meant that some respondents may have missed some items and preferred instead to write about issues that were important to them.

Table 4.5: Additional obstacles to providing end of life care from the perception of nurses

Additional obstacles reported by staff in the questionnaire

Staff attitudes, knowledge and behaviours
Incompetent staff
Ineffective communication between doctors and patients families
Improper pain relief due to worries about addiction
Poor religious understanding
Poor culture understanding
Palliative and end of life care are not on some staff consideration

Religious issues
Religious thoughts and stances about end of life care
Islamic religion and compunction
Religious sometimes come against some end of life care issues

Environmental constrains
Staff shortage
Staff work load
Rushing the post death care because of patients over load
Open design and no privacy

Families issues
The concept of do not resuscitate is not acceptable
Large families
Families nervousness
Families always repeated question about patient's condition
Poor religious understanding
Lack of knowledge about patient condition
Families members reluctant to take decisions about patient condition

Setting specific issues
Don't have a do not resuscitate policy in the hospital
Because this hospital is a large and centre one most of referral cases are poor prognosis

Other
Dealing with young patients death

4.4 Doctors' perceptions of the intensity and occurrence of obstacles

This section presents the intensity and frequency of obstacles to providing end of life care as perceived by medical critical care staff. The obstacles were perceived as both most intense and most frequently occurring are offered by presenting the obstacle items' perceived intensity scores. Additional obstacles reported by medical staff are also presented in this section.

4.4.1 Obstacles intensity, occurrence and perceived intensity score

Highest Intensity Obstacles: The intensity mean scores for the obstacle items as perceived by medical critical care staff were calculated. The mean ranged from 3.92 to 1.85. Table 4.6 below presents the top ten obstacle items along with their intensity mean scores ordered in descending manner. The first obstacle was rated by respondent medical staff to be the largest obstacle in term of its intensity was the same as the respondent nurses. This obstacle took place when the family members don't understand what is "life-saving measures" really mean", i.e., that multiple needle sticks cause pain and bruising, that an endotracheal tube will not allow the patient to talk, or that ribs may be broken during chest compressions (M= 3.92).

Similar to nurses' data, most of the items receiving the highest intensity mean scores incorporated issues related to the critical care clinicians' behaviours and characteristics. Of the top obstacles items, five items incorporated clinicians' issues. These obstacles are continuing treatments for a dying patient even though the treatments cause the patient pain or discomfort (M= 3.85); clinicians who are evasive and avoid having conversations with family members (M= 3.46); clinicians failing to elicit patient's wishes regarding continuing with treatments and tests due to the patient's inability to communicate (M= 3.42); clinicians lack of education and training regarding family grieving and quality end-of-life care (M= 3.42) and finally clinicians being away from the patient and family because of the need to deal with a new admission or consultation (M= 3.38).

Table 4.6: The mean scores for obstacle intensity reported by doctors

Obstacles	Intensity mean
Family members not understanding what "life-saving measures" really mean, i.e., that multiple needle sticks cause pain and bruising, that an endotracheal tube won't allow the patient to talk, or that ribs may be broken during chest compressions.	3.92
Continuing treatments for a dying patient even though the treatments cause the patient pain or discomfort.	3.85
Clinicians' having to deal with angry family members.	3.77
Family and friends who continually call the clinician wanting an update on the patient's condition rather than calling the designated family member for information.	3.65
Poor design of units which do not allow for privacy of dying patients or grieving family members.	3.65
The unavailability of an ethics board or committee to review difficult patient cases.	3.5
Continuing intensive care for a patient with a poor prognosis because of the real or imagined threat of future legal action by the patient's family.	3.46
Clinicians who are evasive and avoid having conversations with family members.	3.46
The clinician not knowing the patient's wishes regarding continuing with treatments and tests due to the patient's inability to communicate.	3.42
Lack of clinician's education and training regarding family grieving and quality end-of-life care.	3.42

The most frequent obstacles: The obstacles frequency means scores were between 1.23 and 3.85. Table 4.7 below presents the top ten obstacle items in terms of their occurring frequency along with their frequency mean scores. The highest rated item was seen as a most frequent obstacle the medical critical care staff have experienced while providing care for dying took place when family members not understanding what is meant by "life-saving measures", i.e., that multiple needle sticks cause pain and bruising, that an endotracheal tube will not allow the patient to talk, or that ribs may be broken during chest compressions (M= 3.85). The next highly frequent items were that critical care unit design do not allow for privacy of dying patients or grieving family members (M= 3.77) and family and friends who continually call the clinician

wanting an update on the patient's condition rather than calling the designated family member for information (M= 3.69).

Of the remaining top ten obstacles received high intensity mean scores, four involved critical care clinicians' issues. These frequently happening obstacles took place when physicians continuing treatments for a dying patient even though the treatments cause the patient pain or discomfort (M= 3.50); when they not knowing the patient's wishes regarding continuing with treatments and tests due to the patient's inability to communicate (M= 3.31); when they called away from the patient and family because of the need to deal with a new admission or consultation (M= 3.27); and they are lacking of education and training regarding family grieving and quality end-of-life care (M= 3.23).

Table 4.7: The mean scores for obstacle frequency reported by doctors

Obstacles	Frequency mean
Family members not understanding what "life-saving measures" really mean, i.e., that multiple needle sticks cause pain and bruising, that an ET tube won't allow the patient to talk, or that ribs may be broken during chest compressions.	3.85
Poor design of units which do not allow for privacy of dying patients or grieving family members.	3.77
Family and friends who continually call the clinician wanting an update on the patient's condition rather than calling the designated family member for information.	3.69
Continuing treatments for a dying patient even though the treatments cause the patient pain or discomfort.	3.5
Continuing intensive care for a patient with a poor prognosis because of the real or imagined threat of future legal action by the patient's family.	3.46
No available support person for the family such as a social worker or religious leader.	3.42
Clinicians having to deal with distraught family members while still providing care for the patient.	3.42
The clinician not knowing the patient's wishes regarding continuing with treatments and tests due to the patient's inability to communicate.	3.31
Being called away from the patient and family because of the need to deal with a new admission or consultation.	3.27
Lack of clinician's education and training regarding family grieving and quality end-of-life care.	3.23

The perceived intensity scores (PISs): To identify which obstacle items were perceived by the respondent medical staff as having both the most intense and the most frequent of occurring, the perceived intensity scores of the obstacle items were calculated. The item with the highest perceived intensity score (PIS) was actually rated to be number one in term of the obstacle's intensity and also number one in term of how frequent it occurred. This obstacle happened when family members not understanding what is meant by "life-saving measures" (PIS= 15.09). The next item with the highest PIS score was poor design of the critical care units which do not allow for privacy of dying patients or grieving family members (PIS= 13.76).

Of the top ten obstacles in terms of reported perceived intensity of obstacles scores, four incorporated issues with medical critical care staff. These obstacles took place when clinicians continue treatments for a dying patient even though the treatments cause the patient pain or discomfort (PIS= 13.47); when clinicians not knowing the patient's wishes regarding continuing with treatments and tests due to the patient's inability to communicate (PIS= 11.32); when clinicians called away from the patient and family because of the need to deal with a new admission or consultation (PIS= 11.05); and lack of clinician's education and training regarding family grieving and quality end-of-life care (PIS= 11.04).

Obstacles related to patients' families also featured in among the first ten highest PIS scores (Table 4.8). These obstacles include dealing with angry family members while providing care for critically ill patients (PIS= 11.87); real or imagined threat of future legal action by the patient's family which impose the staff to continue with intensive care for a patient with a poor prognosis (PIS= 11.97), stopping clinician from providing care because of family and friends who continually call the clinician wanting an update on the patient's condition rather than calling the designated family member for information (PIS= 13.46)

Table 4.8: Doctors' perception of obstacles intensity and frequency intensity scores

Obstacles	PISs
Family members not understanding what "life-saving measures" really mean, i.e., that multiple needle sticks cause pain and bruising, that an endotracheal tube won't allow the patient to talk, or that ribs may be broken during chest compressions.	15.09
Poor design of units which do not allow for privacy of dying patients or grieving family members.	13.76
Continuing treatments for a dying patient even though the treatments cause the patient pain or discomfort.	13.47
Family and friends who continually call the clinician wanting an update on the patient's condition rather than calling the designated family member for information.	13.46
Continuing intensive care for a patient with a poor prognosis because of the real or imagined threat of future legal action by the patient's family.	11.97
Clinicians' having to deal with angry family members.	11.87
The clinician not knowing the patient's wishes regarding continuing with treatments and tests due to the patient's inability to communicate.	11.32
Being called away from the patient and family because of the need to deal with a new admission or consultation.	11.05
Lack of clinician's education and training regarding family grieving and quality end-of-life care.	11.04
The unavailability of an ethics board or committee to review difficult patient cases.	10.92

4.4.2 Additional obstacles reported by doctors

Five respondent critical care doctors (17.85%) added a response to the additional obstacles open ended question. These doctors reported five additional obstacles to providing end of life care. These obstacles were (1) the concept of do not resuscitate or do not intubate is not acceptable in this society, (2) doctors shortage with high responsibilities and accountability, (3) because the hospital is a large and central one, most of referral cases are poor prognosis (4) because hospital is a highly prestigious one, so many time we have to meet the family expectation and (5) medical uncertainty. Interestingly, some of these obstacles were also added by critical care nurses as mentioned earlier.

4.5 The difference between doctors' and nurses' perceptions

This part of the analysis chapter assesses the difference between medical and nursing critical care staff perceptions of obstacles (29 obstacles) to providing end of life care using independent-samples t tests.

4.5.1 The differences in staff perceptions of obstacles intensity and frequency

The difference in obstacles intensity between doctors and nurses: The perceptions of nursing and medical critical care staff were compared using the obstacles' intensity data. Using independent-samples t tests, three items were found to have a significant difference. Firstly, the nurses found the intensity of the obstacle of employing life sustaining measures at the family's request even though the patient had signed advanced directives requesting no such care as more of an obstacle (M= 2.93, SD= 1.10) than the doctors did (M= 2.46, SD= 1.43). Secondly, the physicians group found having clinicians will not allow the patient to die as more of an obstacle (M= 3.04) than the nurses group did (M= 2.99). Thirdly, the nurses again found having multiple clinicians, involved with one patient, who differ in opinion about the direction of care as more of an obstacle (M= 3.59) than the physicians group did (M= 3.04). Table 4.9 below shows the three obstacle items along with their mean, standard deviation, number of nurses and physicians respond to these questions and reports the t test results and the level of significant (p values) for each of the items. With these obstacles, even though there are significant differences, they have fairly small differences in terms of their intensity means

Table 4.9: Significant difference obstacle items intensity between doctor and nurses

Independent t tests for obstacle items that differ significantly between doctor and nurses in term of their intensity.						
Items	**Groups**	**t test**				**P***
		N	**Mean**	**SD**	**t**	**values**
Employing life sustaining measures at the families' request even though the patient had signed advanced directives requesting no such care	Nurses	76	2.93	1.10	-1.579	.024
	Physicians	28	2.46	1.43		
Clinicians who won't allow the patient to die	Nurses	76	2.99	1.48	.196	.018
	Physicians	28	3.04	0.96		
Multiple clinicians, involved with one patient, who differ in opinion about the direction of care	Nurses	76	3.59	1.05	-1.857	.029
	Physicians	28	3.04	1.45		

* Confidence level 95%

The difference in obstacles frequency between doctors and nurses: The independent-samples t tests were conducted to evaluate the differences between the nurses and physicians critical care staff with regard to obstacle frequency of occurring. The test was significant for three obstacle items. With these obstacles, even though there are significant differences, they have fairly small differences in terms of their frequency means. These items were (1) pressure to limit family grieving after the patient's death to accommodate a new admission to that room, (2) lack of clinician's education and training regarding family grieving and quality end-of-life care, and (3) opinions of other critical care staff about the direction of patient care not being requested, valued, or considered. These items were perceived by nurses group to have a higher frequency of occurring than physicians group did. Table 4.10 below shows the three obstacle items along with their statistical details.

Table 4.10: Significant difference obstacle items frequency between doctor and nurses

Independent t tests for obstacle items that differ significantly between doctor and nurses in term of their frequency						
Items	Groups	\u200b	t test			P* values
		N	Mean	SD	t	
Pressure to limit family grieving after the patient's death to accommodate a new admission to that room	Nurses	76	2.88	1.36	-1.465	.048
	Physicians	28	2.50	1.11		
Lack of clinician's education and training regarding family grieving and quality end-of-life care	Nurses	76	3.38	1.19	-.518	.010
	Physicians	28	3.21	1.55		
Opinions of other critical care staff about the direction of patient care not being requested, valued, or considered	Nurses	76	2.47	1.51	-0.782	.022
	Physicians	28	2.25	1.21		

Confidence level 95%

85

4.6 Nurses' perceptions of supportive behaviours to providing end of life care

This part presents the intensity and the occurring frequency of the supportive behaviours to provide end of life care listed in the second section of the questionnaire. The perceived supportive scores for the supportive behaviours (the supportive behaviours that perceived to be the highest intensity as well as the most commonly encountered by the respondent nursing staff) are then presented. Additional supportive behaviours reported by nurses are also presented in this section.

4.6.1 Supportive behaviours intensity, occurrence and perceived score

This section begins by reporting the intensity and the occurrence frequency of the supportive behaviours to providing end of life care as critical care nurses perceived. The perceived supportive behaviours scores are then presented.

Highest intensity supportive behaviours: Using a Likert scale ranged from 0 (not a help) to 5 (extremely large help), the mean scores for the supportive behaviour items intensity were between 2.47 and 4.12. The supportive items received the largest mean scores were when having family members accept that the patient is dying (M= 4.12) and when the nurses have enough time to prepare the family for the expected death of the patient (M= 3.91). The first ten items which were perceived to be the most supportive behaviours had close mean scores which were more than 3.5 on the same scale.

Of the remaining top ten supportive behaviours, six items surround supportive behaviours that took place after patient death and were in some way helpful to the patients' families as well as for critical care nurses and were usually behaviours under critical care nurses control (Table 4.11). Those supporting patients' families after death were: allowing adequate time for family members to be alone with the patient after he or she has died (M= 3.83); having the physician meet in person with the family after the patient's death to offer support and validate that all possible care was done (M= 3.75); when a peaceful, dignified bedside scene was provided for family members once the patient has died (M= 3.53); and when a critical care unit designed so that the family has a place to go to grieve in private (M= 3.51).

The other two helpful items that happened after death and support critical care nurses were: having family members thank nurses or in some other way show appreciation for nurses' care of the patient who has died (M= 3.75); and having a fellow nurse tell you that, "you did all you could for the patients," or some other words of support (M= 3.63).

Table 4.11: The supportive behaviours intensity mean scores reported by nurses

Supportive behaviours	intensity mean
Having family members accept that the patient is dying.	4.12
Having enough time to prepare the family for the expected death of the patient.	3.91
Allowing family members adequate time to be alone with the patient after he or she has died.	3.83
Having the physician meet in person with the family after the patient's death to offer support and validate that all possible care was done.	3.75
Having family members thank you or in some other way show appreciation for your care of the patient who has died.	3.75
Having one family member be the designated contact person for all other family members regarding patient information.	3.67
Having a fellow nurse tell you that, "you did all you could for the patients," or some other word of support.	3.63
Having the physicians involved in the patient's care agree about the direction care should go.	3.59
Providing a peaceful, dignified bedside scene for family members once the patient has died.	3.53
A unit designed so that the family has a place to go to grieve in private.	3.51

The most frequent supportive behaviours: The second section for the supportive behaviours' part of the questionnaire measures how frequently the critical care nurses have experienced the supportive behaviours as they have cared for dying patients. On a Likert scale from 0 (never occurs) to 5 (always occurs), the mean scores for the supportive items frequency ranged from 1.23 to 3.03. Allowing family members adequate time to be alone with the patient after he or she has died (M= 3.03) and having family members accept that the patient is dying (M= 2.82) were seen to be the most frequent two supportive behaviours the respondent critical care nurses have experienced.

Of the top ten frequent supportive behaviours (Table 4.12), three surround providing support to critical care nurses after patient's death: family members thank nurses or in some other way show appreciation for nurses' care of the patient who has died (M= 2.54); nurses supporting each other such as having a fellow nurse tell you that, "you did all you could for the patients," or some other word of support (M= 2.41); or having support staff compile all the necessary paper work for you which must be signed by the family after the patient's death and before they leave the unit (M= 2.38).

Other three supportive behaviours of the remaining top ten items related to providing support to family after their family member's death and the nurses have a control over them. These behaviours include allowing families unlimited access to the dying patient even if it conflicts with nursing care at times (M= 2.32), providing a peaceful, dignified bedside scene for family members once the patient has died (M= 2.49) and nurses drawing on his/her own previous experience with the critical illness or death of a family member (M= 2.78).

Supportive behaviour	Frequency mean
Allowing family members adequate time to be alone with the patient after he or she has died.	3.03
Having family members accept that the patient is dying.	2.82
The nurse drawing on his/her own previous experience with the critical illness or death of a family member.	2.78
Having the physicians involved in the patient's care agree about the direction care should go.	2.71
Having family members thank you or in some other way show appreciation for your care of the patient who has died.	2.54
Providing a peaceful, dignified bedside scene for family members once the patient has died.	2.49
Having a fellow nurse tell you that, "you did all you could for the patients," or some other word of support.	2.41
After the patient's death, having support staff compile all the necessary paper work for you which must be signed by the family before they leave the unit.	2.38
Having enough time to prepare the family for the expected death of the patient.	2.36
Allowing families unlimited access to the dying patient even if it conflicts with nursing care at times.	2.32

Perceived supportive behaviours scores: To identify which supportive items were perceived by the respondent nurses as having both the most intense and the most frequent of occurring, the perceived supportive behaviours scores were calculated. Instead of examining the intensity and the frequency scores for the supportive behaviours separately, calculated the perceived supportive behaviours scores will help in identifying the most intense and most frequent supportive behaviours to providing end of life care to dying patients and their families from the perspective of critical care nurses (Kanner et al., 1981). The perceived supportive behaviours scores (PSBSs) were calculated by multiplying the mean score of the intensity by the mean score of the frequency for every single supportive behaviour item.

The top ten supportive behaviour items with the highest perceived supportive behaviours scores have almost identical scores (Table 4.13). The supportive behavior with the highest PSBSs take

place when family members accept that the patient is dying (PSBSs=11.61). Of the top items, seven surround helpful behaviours that happened after patient death and to some degree support both nurses and families. Four of these items relate to support nurses by themselves and by patients families: (1) having family members thank nurses or in some other way show appreciation for nurses' care of the patient who has died (PSBSs= 9.52); (2) having a fellow nurse tell you that "you did all you could for the patients" or some other words of support (PSBSs= 8.74); (3) after the patient's death, having support staff compile all the necessary paper work for you which must be signed by the family before they leave the unit (PSBSs= 7.42); and (4) having fellow nurses take care of your other patient(s) while you get away from the unit for a few moments after the death of your patient (PSBSs= 7.32).

The other three items relate to bereavement support for families by nurses: providing a peaceful, dignified bedside scene for family members once the patient has died (PSBSs= 8.78) and having the physician meet in person with the family after the patient's death to offer support and validate that all possible care was done (PSBSs= 8.40); and offering family members adequate time to be alone with their patient after he or she has died (PSBSs= 11.60)

Table 4.13: The perceived intensity scores for supportive behaviours in end of life care

Supportive behaviours	PSBSs
Having family members accept that the patient is dying.	11.61
Allowing family members adequate time to be alone with the patient after he or she has died.	11.60
Having the physicians involved in the patient's care agree about the direction care should go.	9.72
Having family members thank you or in some other way show appreciation for your care of the patient who has died.	9.52
Having enough time to prepare the family for the expected death of the patient.	9.22
The nurse drawing on his/her own previous experience with the critical illness or death of a family member.	9.11
Providing a peaceful, dignified bedside scene for family members once the patient has died.	8.78
Having a fellow nurse tell you that, "you did all you could for the patients," or some other word of support.	8.74
Having the physician meet in person with the family after the patient's death to offer support and validate that all possible care was done.	8.40
Having one family member be the designated contact person for all other family members regarding patient information.	7.74

4.6.2 Additional supportive behaviours reported by critical care nurses

Six respondent nurses (7.89%) added responses to the additional supportive behaviours open ended question. These nurses reported eight additional behaviours that help in providing a quality end of life care. Of these items, two were related to medical critical care staff: diminish false hope or unreal expectations and prepared the families emotionally about the outcome from the first days of admission. Of the remaining items, three items were related to dying patient's families: accept the death as a possible outcome, decrease the number of patient family members in critical care units and presence of a support person to help with managing the family visit (security member). The remaining supportive items were presence of religious referral in the hospital; involve patients' families in palliative care before patients' death and visiting hour policy adaptations.

As in nurses' additional obstacles some of the additional supportive behaviours were already a questionnaire items such as having a family members accept that the patient is dying; physicians who put hope in real tangible terms; and having the family physically help care for the dying patient. Possible reasons that the respondent repeated items already mentioned on the questionnaire might be the same ones have been mentioned above for additional obstacles.

Changes needed to improve end of life care in critical care unit reported by nurses

At the end of the supportive behaviours part of the questionnaire, the critical care nurses were asked in an open ended question to report the changes that they would like to see in any aspect of end of life care for dying patients and their families in critical care units. Ten nurses (13.15%) added responses. These nurses reported seventeen changes to improve end of life care. Using content and thematic analysis, three categories were identified: changes in physicians' attitudes toward patients; changes in physicians' attitudes toward families; and changes at the institutional level. Table 4.14 below lists the reported changes that need to be made and the four categories they belong to.

Table 4.14: Changes needed to improve end of life care providing

Additional changes reported by staff in the questionnaire

Changes in physicians' attitudes toward patients

Let the patients die peacefully
Working non-medically with dying patients to last point of their life
Engage competent patients in discussion about the type of management
Discussion about the place of death

Changes in physicians' attitudes toward families

Debriefing family member after traumatic death
Educate families members about end of life care issues
Give end of life care as a treatment option
Engage families in discussion about the type of management

Institutional level changes

Decrease nurse-patient ratio
Presence of applied pain management policy
Present of ethical committee to deal with difficult cases
Presence of social support committee (e.g. psychiatric physicians)
Presence of specialized palliative and end of life care unit

4.7 Strengths and limitations

This study is the first to explore the obstacles and facilitators to providing end of life care in critical care units in Jordan and the first to elicit the perception of medical critical staff using "National Survey of Critical-Care Nurses' Perceptions of End-of-Life Care" which have used in the literature to pertain the viewpoints of critical care nurses. To maximise the diversity of participants all doctors and nurses worked in the two University hospitals were selected. Additionally, the study had a high response rate. However, certain limitations are acknowledged. Caution is required in interpreting and generalising from this data as it represents the perception of critical care staff working in one health care sector in Jordan. The adaptation and use of the survey with almost excellent reliability in this study would open the door for this questionnaire to be used with different sample in different settings and compare the result between and among the staff in this study with other studies. Future studies may look at ways to survey a larger group of health care professionals working in different health care sectors in Jordan including private hospitals and Ministry of Health hospital to have a national view of end of life care practice in Jordan. The survey was criticized by some staff to be too

long, time consuming and have some language difficulties and some questions were ambiguous and lack of clarity.

4.8 Conclusion

In conclusion, the critical care staff perceived the obstacles to providing end of life care to be frequent and have a large intensity than the other studies have documented. This suggests that the doctor and nurses in this study perceived that there are deficiencies in end of life care in Jordanian critical care units or at least in the units where the study was conducted. In the other hand, the supportive behaviours to providing end of life care were perceived by critical care nurses to be less frequent.

In this study, barriers related to clinicians' behaviours, characteristics and attitudes were perceived by doctors and nurses to be the most common barriers to providing end of life care in critical care units. Along the professional dimension of barriers, this study adds a new dimension for the most intense barriers to provide end of life care in. This dimension was related to environmental constraints which prevent critical care staff from providing quality end of life care to dying patients and their families. Moreover, the supportive behaviours were perceived highly by nurses in terms of intensity, but the frequencies of these behaviours were much lower (almost never occurring to fairly often occurs). Most of the supportive behaviours that received the highest frequency scores were related to bereavement support for families or critical care staff and were usually behaviours that critical care nurses could control.

The results in this study validate the results of other studies investigated the perceptions of critical care nurses toward the obstacles of providing end of life care in critical care units. This suggest that these shared obstacles and supportive behaviours are central when providing care for dying patients and their families in critical care units regardless the type of the unit or setting. The survey results in this study allude to the importance of identifying the possible area of developments to improve end of life care in Jordanian critical care units and working on these areas to meet the expectations of patients, families and critical care staff.

Finally, the survey findings demonstrate the importance of conducting a qualitative study in exploring issues surrounding end of life in Jordan as self-reported survey may not reflect the actions of the respondents. Thus, the key findings of this survey inspired and inform the

analysis of the qualitative work by exploring the issues behind clinicians' behaviours, characteristics and attitudes which present the key difficulties experienced by staff in the survey. The next two chapters report the findings from the qualitative interviews with Jordanian critical care staff.

Chapter5: Critical Care Staff Experience of Providing Care for Dying Patients

5.1 Introduction

This chapter and the following chapter report the findings from the qualitative interviews with the critical care staff. This chapter focuses on the experiences of staff in caring for critically ill patients who are likely to die and the challenges and barriers that they encounter. The next chapter explores how staff seek to communicate with, and care for families of dying patients and identifies the barriers and challenges to family focused care that they experience.

This chapter starts by exploring experiences of providing care for dying patients reported by staff and their perceptions of 'normal practice'. This exploration is set in the context of a description of policies related to end of life care in each hospital and is followed by an examination of some legal and religious issues surrounding end of life care that are commonly encountered by staff. The chapter then moves to explore patterns of interaction and communication between staff when caring for dying patients and their experiential accounts of the challenges and barriers to provision of end of life care. In this chapter, issues that staff encounter in the care of critically ill patients' families are briefly mentioned, with a more sustained focus on these provided in the following chapter.

Throughout this chapter, aspects from one detailed interview with a doctor are used to introduce the key issues in each section. The interview is used as a representative 'case study', since it captured the most important and recurring issues in all the interviews conducted with staff. Following the use of the case study interview, data from other interviews are presented to highlight any similarities and differences. The case study interview used throughout this chapter relates to an interview with 'doctor three' who was a senior resident doctor working in the first city hospital. This doctor had four years clinical experience since he qualified and a two and a half years' experience in critical care. As a senior doctor his role was to cover the two critical care units and the emergency department in the hospital, working closely with more junior doctors assigned to each unit.

5.2 Experiential accounts of critical care staff

In this first section of the chapter, I examine the frequency with which participants experienced death and dying and describe the normal practices that staff reported to be associated with care of the dying, highlighting some exceptions to this that staff identified.   I also explore how staff perceived the hospital policies that had relevance for end of life care and how they sometimes found ways to 'work around' these in order to deviate from the normal practice of carrying on as usual and thus move towards end of life care for patients.

5.2.1 Death frequency and certainty

> *So many cases my friend. Yes, as an estimated number I can say that they were at least 100 cases; this is in the intensive care unit alone. As a whole, I mean all critical care units; actually I can't really even count them.* (Senior Doctor 3, H1, P[1]1, L[2]15)

Doctor three talked about the large number of dying patients he dealt with during his clinical experience; this was also the reported experience of other interviewees. Staff perceived that death is a predictable event and also a common outcome in medical critical care units. The staff spoke about the large number of dying patients they had experienced in medical critical care units and general intensive care units compared to coronary care units. For example, in a shared interview in hospital one, where a second year doctor one covering a coronary care unit and a senior doctor four covering all critical care units were interviewed together, the doctors talked about the number of dying patients that they cared for during their career. Doctor four in the quote below reported that more than half of patients who settled in general intensive care unit at the time of interview are 'end of life'. From her wider account, it seems that the doctor used the term 'end of life' here to refer to patients whose death is imminent (including those patients whose death was imminent and those who had a longer critical care stay, but whose death was clearly anticipated: e.g. patients who are brain dead).

> *D4: Oh! Large numbers. We always deal with dying patients.* (Senior Doctor 4, H1, cover all critical care units)

> *R: In terms of you D1?*

---

[1] P: page number in the interview transcript.
[2] L: Line number in the page.

D1: Too many cases we are dealing with. (Second Year Doctor 1, H1, Coronary Care Unit)

D4: I mean in intensive care unit, most of the cases you can say…[3].You know we have usually 13 beds in general intensive care unit. From these beds, there are 7-8 patients we consider them end of life and this happens frequently and always. I mean I had two years of experience in intensive care unit, very often, very often we deal with such a type of cases. (Senior Doctor 4, H1 cover all critical care units)

D1: Because I am a second year, I have just nearly one year in coronary care unit, not like intensive care unit, in coronary care there are not too many cases like that. (Second Year Doctor 1, H1 Coronary Care Unit)

The same experience was echoed by a head nurse three from a medical intensive care unit:

For example, I have six beds in my unit. Among these six patients, there is one, two, three and four (participants counting); at least four patients who I am sure that they will be transferred to floor -2 (where is the mortuary). (Head Nurse 3, H2, Medical Intensive Care Unit)

A shared feature across the staff interviews, was that staff reported being able to predict the patients' death. Their certainty about the likelihood of patients' deaths was mostly based on patients' clinical presentation, but also on their previous experiences and knowledge of particular types of diseases and cases. For example, nurse two shared his story of a dying patient, explaining how the patient's clinical presentation led him to be certain that death was approaching. His account included: the chronic serious diagnosis; the patient's clinical signs and hemodynamic instability; the aggressive supportive treatments the patient was receiving; complicated disease progression; recurrent admissions to critical care unit and previous health history:

He was a 60-62 years old male; he had end-stage renal disease and he had a permacath (catheter for hemodialysis); he was on haemodialysis. The perm catheter sit became infected and after that the patient developed septic shock. Before his last admission to Intensive care unit, he had recurrent visits to our unit in his early stage of sepsis; the visits were for courses of antibiotics and then discharge. You know admission, treatment and then discharge and so on so forth. In his last visit (where he died) the patient had sever septic shock; the patient had a severe fever and hypotensive; on maximum blood support, dopamine, adrenalin and his Glasgow-coma-scale was three (patient on deep coma). There was no good progression for that case. You know he was well known for us due to his recurrent visit, old, unconscious hemodynamic unstable

---

[3] "…" Means skipped irrelevant data.

and maximum support he was surly dying. He stayed less than one week in that state and then he died. (Charge Nurse 2, H1, Intensive Care Unit)

This experience was echoed by nurse five, who reported that based on her experience with working with critically ill patients; she felt that she could now easily identify those who were dying. This was clear in her account of one particular case:

N5: We had an old man patient; he was recurrently admitted to our unit. He was under supervision of Doctor X; his case was a heart block, heart failure and his ejection fraction was within twenties. His heart rate was between 30 and 40beat/minute. They (physicians) inserted an internal-cardio-defibrillator 3 weeks before his death. Last week he again admitted with a congested heart failure; he is actually transferred from hospital X. He stayed for one week on maximum support. (Senior Nurse 5, H1, Coronary Care Unit)

R: When did you realise that the patient is dying?

N5: Actually, from the first time he was admitted since he was clinically 'tired'[4]; it was apparent that he was dying. You know by experience, you could know the dying patients once you see the patients. (Senior Nurse 5, H1, Coronary Care Unit)

In summary, the staff interviews showed that they worked very frequently with dying patients and that based on a combination of their clinical experience and knowledge about patients' clinical presentations, they felt able to identify those who were dying. The next section describes how staff cared for patients whom they realised were dying and what their normal practice is with such cases.

5.2.2 Normal practice

The last patient who died and I cared for was a cancer patient, but as for the last non cancer patient (Silent for a moment) the patient was an elderly man who had a stroke. The problem was initially an ischemic stroke, then after receiving the anticoagulants treatment, which we had prescribed, the patient developed a hemorrhagic stroke. The patient then deteriorated more and more as he became de-saturated and experienced minor aspiration; as a result he get an aspiration pneumonia, namely, lung infection. Thus, the chest infection plus the decrease in the level of consciousness were the indications to intubate the patient until he regains his health so then we can extubate the patient, The

---

[4] 'Tired' has a very specific meaning in the Jordanian critical care units' context. In discussion with my supervisors, I realised that this is not a term that is commonly used elsewhere. On reflection, this word is used to refer obliquely to a dying patient. The staff commonly use this word instead of using the word of 'dying' because of their difficulties in being open with families that a patient is dying.. Thus the word 'tired' is used to communicate information that is otherwise not permissible to provide.

problem was that his chest infection deteriorated more and because of his chest infection he developed sepsis, septic shock, multi-organ failure, disseminated intravascular coagulopathy, and subsequently he died, God bless his soul. (Senior Doctor 3, H1, P1, L20)

Doctor three in the quote above recalled his experience of working with the last person who died and for whom he provided care. The patient was in the intensive care unit for 10 or 11 days before death. The doctor recalled that the patient was an elderly man who had had a stroke and deteriorated very rapidly and unexpectedly. However, he went on to explain that as a medical team they realised that the patient was going to die in the early days of his stay in the intensive care unit, because of his clinical presentation:

> *We were aware that the patient will die when he first had aspiration pneumonia. Namely, (silent moments) it was in the 2ⁿᵈ to the 3ʳᵈ day of his admission.* (Senior Doctor 3, H1, P2, L24)

Nevertheless, the doctor reported (see quote below) that identifying that the patient was dying did not change anything in relation to the treatments provided; this followed the usual pattern of care provided for all others patients. The doctor makes a reference to the role of the family and their assumptions about the patient's condition (these issues are discussed in the next chapter), reporting that these make it impossible for any treatment to be limited or withdrawn. The doctor refers to potentially futile treatments as 'help'; in using this word, he appears to recognise that the supportive medical treatments were prolonging the dying process instead of being curative:

> *From the 3ʳᵈ day and to the last moment we kept same treatments and same management. There had not been any change in the care. You know there was no consent from the family. The family presumed that all what had happened to the patient were a hospital's mistake. So you can't, while the family has this presumption, and it is impossible to suggest on them to "withdraw any help from this patient". It is difficult. It was impossible for us to suggest such a suggestion even though we knew that "he will die".* (Senior Doctor 3, H1, P2, L22)

As shown by the data above, all the staff viewed caring for almost all critically ill patients whose death was imminent as 'ordinary' rather than 'extraordinary'. They described a general pattern in which aggressive modalities of treatment are pursued for all patients, with some rare exceptions. For example, nurse three, an oncology master degree holder nurse, commented on the type of medical treatments that the dying patients usually received:

Generally, there are no changes. On the contrary, they continue with aggressive care to the last moments of death. There are no decisions that this patient is end of life and we have to change the care or to stop or withdraw any treatments. There are no such things in intensive care unit. Here everything will be stopped and removed when the death in confirmed. Even normal or regular care e.g. daily blood test and daily chest x-ray will continue to last moments. There is not something like palliative care or end of life; all is aggressive care. (Junior Nurse 3, H1, Intensive Care Unit)

When it becomes clear that a patient is dying in spite of maximal treatment staff described how the actions taken usually involved keeping a patient on full medical support while withholding further escalation of intervention and at the time of death, the cardiopulmonary resuscitation would be attempted except for some circumstances mentioned under the next section. For instance nurse four described how in the medical intensive care unit, there was no category of 'dying patient':

For medically ill patients, here in intensive care unit actually and generally, we don't have something called dying patients. There are patients who reach maximum level of support, like tracheostomy, maximum vasopressor and BEG (percutaneous endoscopic gastrostomy). With these patients, you know, that's enough in terms of medical care. I mean we leave them as they are until death since there are still no treatments to be given except cardiopulmonary resuscitation at the time of death. (Junior Nurse 4, H1, Intensive Care Unit)

Interviewees reported that only when all medical treatments were exhausted was there sometimes a change in the focus. They reported that the level of general activity and attention for these patients was gradually decreased. This decrease in the level of care involved the care of both patients and their families and involved minimal attention to specific changes in patient's parameters; minimizing communication with families; minimal discussion between staff about a patient's condition and a decrease in a patient's medical supervision. This change occurred informally and without planning. Staff described how they felt that such a practice was reasonable in the context of patients whose situation they perceived to be 'hopeless', exhaustion of available treatments and time limitations. Table 5.1 illustrates how the issues described above featured widely among staff in their interviews.

Table 5.1: Normal practice

1. Other than cancer and brain dead patients no, no; there are no change. As a medical patients No! Everything is kept as normal. (Senior Nurse 1, H1, General-Intensive Care Unit)

2. Usually, for medical patients, there is no change. I mean usually the change occur either for surgical patients such as patient with a metastasis cancer or neurosurgery such as IVH (intra ventricular haemorrhage), ICH (intra cranial haemorrhage). These neurosurgery cases is a common cases where brain dead happened, but for medical patients usually or always No. No there is no change, I haven't experienced that. (Senior Doctor 9, H1, cover all critical care units)

3. In terms of medical treatments, there is no big change happening. I mean that the patients keep taking the treatments that they need to the last minutes of death. I haven't experienced something like a doctor stop any specific medication or anything else because it doesn't benefit the patients. No, no, no, there is nothing like this. Namely, the patients keep taking full managements and full medications. As medical patients there will never be any negligence or to deal with them as that is enough (in terms of care) or this treatment no need for it or that treatment doesn't help the patient. (Head Nurse 1, H1, Coronary Care Unit)

4. You know, for critically ill patients and after a while from exhausting treatments and nothing remains to do, they (doctors) start to give less care to these patients. For example, during morning medical round we (staff) don't give too much time or care for these patients, do you see what I mean?; keep everything as it is and don't change for example the antibiotic or increase the dose of medication and so on. They (lead doctors) used to say for these patients "don't push hard" for treatments and "don't push heart" for cardiopulmonary resuscitation. For example, we have a patient on bed number 4; I am sure that the lead doctor will come and say "don't push heart. (Head Nurse 3, H2, Medical Intensive Care Unit).

5. The last thing the doctor did I had experience is to leave the maximum support as it is. For example, if the temperature starts to increase or the white blood cell increase, the doctors don't increase the dose of antibiotic or change the antibiotic, in the medical round the specialist pass the dying patient to other patients, we (staff) used to use the same statement to patient's family and when endorse the patient between us " the same situation, nothing new or nothing changed" (Charge Nurse 9, H2, Coronary Care Unit)

5.2.3 Exceptions to normal practice

> *Let me makes it clear for you, with-holding and withdrawing treatment decisions are to some degree common for patients who had cancer or were brain dead. It is totally dependent on patient's lead physician, patient's condition and patient's family as well (if family members were accepting and understanding). Thus, end of life care for other dying patients most of time include withholding on maximum treatments and not withdrawing.* (Senior Doctor 3, H1, cover all critical care units)

Doctor three talked about some 'deviations' from the normal pattern of care that would take place if patients were brain dead or had advanced cancer. Additionally, the doctor mentioned factors that play a role in facilitating that deviation; these included family type, lead physician type and patient's condition (these issues are discussed later on in this chapter and in the next chapter). Even though exhausting medical treatments was a common pattern in the care of critically ill patients, other participants confirmed that deviation was possible in certain contexts: these are explored below.

5.2.3.1   Brain dead patients

> *Even if a patient is confirmed as being brain dead, I won't withdraw all treatments or remove him from the ventilator. What I do is not to add any new treatments. Like if the patient developed a nosocomial infection during his stay in the hospital, I won't add another stronger antibiotic besides the antibiotics he is already taking. I may avoid requesting septic work up or blood culture, since it would have no benefit. But I would not cut off something I'm already giving the patient.* (Senior Doctor 3, H1, P9, L32)

For the staff, patients who are brain dead are most clearly and quickly identified as "dying". Road traffic accidents, falls, congenital anomalies and cerebrovascular accidents were the most common causes of brain death that the participants encountered; often among young people. For brain dead patients, there were several patterns of responses in participants' interview data describing the care that was provided to these patients. Many staff like doctor three described how even brain dead patients were not treated any differently. For example, nurse 14 below reported that the same type of normal care is applicable for these patients.

> *Namely, what I'm going to tell you regarding these patients (brain dead) is that every specialist has his own protocol. Even though the patient is dying, he will continue with usual treatments and keep working with the patient to the last patient's breath.* (Senior Nurse 14, H1, Intensive Care Unit)

While doctor three reported that he hardly changed his usual practice with brain dead patients, there were different practices described by other staff. For example, nurse one below shared a discussion that happened between the nursing and medical staff about the variation in the care provided for different patients who are brain dead and also around providing futile treatments for such types of patients. The participants explained that this difference in the care provided was based upon patients' lead physicians' perspectives and type of patient's family (as described in chapter 6).

> *Actually, there is (futile care) and we always discuss these things with doctors (resident doctors); I mean suggesting that it is enough for such patients in terms of intensive treatments. One time we had a brain dead patient and at that time I had a discussion with one resident doctor saying: one patient had been admitted before one month and he was brain dead and at that time you (doctors) discontinue all medications and all lab and diagnostic tests, okay with this brain dead patient why you still doing all these things? We used to talk to residents doctors it is enough for these patients and you have to discontinue all treatments because really it is useless. Why is that? Why daily arterial blood gases? Why we need to puncture the patient's artery every day and that cause hematoma? What do you need from changing the ventilator setting? Nothing changed; it should be sufficient in terms of medications, diagnostic tests and other treatments. But they used to say that this is what the lead physician requests and if the lead physician wishes, he will stop them. (Senior Nurse 1, H1, Intensive Care Unit)*

Other medical staff talked about the experience of stopping everything that is unnecessary for patients who were diagnosed as brain dead. For example, doctor number four recalled her experience of withdrawing treatments from a confirmed brain dead patient:

> *Once they "neurological physicians" confirmed that the patient is brain dead and stop their treatments (brain saving measures), I ordered to stop all treatments except the ventilator, vasopressor and intra-venous fluid.* (Senior Doctor 4, H1, cover all critical care units)

When I asked her to explain what type of treatments she had withdrawn, she replied:

> *Because brain dead patient is in deep coma and the Glasgow Coma Scale is equal three so there is no need for sedation. Thus, I stopped all sedations. At that time, even the patient had a fever (40 ℃), I stopped all antibiotics because I realised that this fever in a central one. Also I stopped other treatments which we used to prescribe for brain injury patients like mannitol and dexamethasone. You know these treatments are useless for brain dead patients. It looks like throwing resources in a bin.* (Senior Doctor 4, H1, cover all critical care units)

Another nurse who similarly voiced the issue of withdrawing treatments from brain dead patients was nurse 15:

> *You know, here if the patient is confirmed to be brain dead and end stage, we discontinue all laboratory and diagnostic tests, all medications and all intravenous fluids. Namely just keep ventilator and the vasoactive drugs. I'm talking here about patients who are brain dead and most of them are post-neurosurgery. We came across many patients like this; after they were confirmed to be brain dead through the tests that they (neurologist) used to demonstrate in order to confirm brain dead, all tests, all medications and intravenous fluids were stopped.* (Junior Nurse 15, H1, Coronary Care Unit)

5.2.3.2   Cancer patients

> *The change usually occurs when we reach to the judgment that this patient has an advanced cancer, or it is non-treatable cancer. Any type of cancer reaches the 3rd or 4th stage is non-treatable. Otherwise, if it was 2nd stage for example it will extend further, even if it was complicated. Thus, the cutoff point is when the patient knows that he has cancer and it is in its end stage; but not before this point. At that time, we would counsel patients' families to intubate or not to intubate the patient.* (Senior Doctor 3, H1, cover all critical care units)

In this quote, doctor three talked about the second circumstance in which deviation could happen. This was with cancer patients who are admitted to critical care units at the end of life. The doctor reported that generally the deviation became possible at the point at which the patient would be considered for intubation; he would then try to speak with the patient's family and counsel against intubation.

The presence of patients with advanced cancer was a very common phenomenon in the study hospitals. Staff reported that patients admitted to intensive care with advanced cancer often received different care compared to other dying patients. In such situations, the option of limiting invasive treatments was often more openly discussed with families and seen as acceptable. Concurring with doctor three's report, most staff reported that the change took place when the patient was considered for intubation. By 'working around' the policy of against medical advice (discussed below) and where mutual agreement could be established with the patients' families, decisions were possible to withhold intubation and related invasive treatments. For instance, head nurse one shared a story where a decision not to intubate a cancer patient was made:

There was a female patient who came as a transfer to me from the 10th ward; she had cancer. For this patient I could say yes there was a decision. Form its transfer the patient was apparently "for dying" or for cardiopulmonary resuscitation. The physician spoke with the family and they asked not to put the patient on the mechanical ventilator and you just leave her. At that occasion, the doctor told us to leave the family with the patient and that the family was consulted and accepted not to put the patient on the mechanical ventilator for the time being. The doctor made the family sign that they didn't want that. (Head Nurse 1, H1, Coronary Care Unit)

The participants alluded to a number of possible explanations why there was a difference when working with dying cancer and non-cancer patients. They perceived that the families of dying cancer patients have had time to understand and accept their patients' condition and what the outcome will be. Thus they felt able to communicate to families that the patient is dying more openly and frankly. Additionally, the staff explained that the families' perception towards cancer plays an integral role. Staff described how many families perceived that cancer is not possible to cure and is correlated with death, while seeing other illnesses very differently. For example, doctor 8 talked about family perceptions towards cancer and other illnesses:

Because as I have told you before… the family keeps hoping that the patient's condition is treatable. It is a medical disease and it is treatable, not like cancer which has no cure. Cancer is socially known for having no cure. But medical conditions they (patient's family) just keep saying: "there is a treatment" for his condition. (Senior Doctor 8, H1, cover all critical care units)

5.2.3.3   Frail elderly patients

Now regarding other patients, their age plays an essential role. Namely, if the patient was in the extremes of age very elderly, it is possible to intubate or not intubate him/her. It is not the benefit of the treatment that counts, but we also inform the family of the risks of such procedure on the patient's wellbeing: we may lose the patient during intubation procedure itself. The family may take the decision to not intubate the patient if they were informed of the risks. (Senior Doctor 3, H1, P6, L33)

Doctor three described how a similar pattern of care followed with dying cancer patients would also be followed in the care of very frail and elderly patients. Across all conducted interviews where this issue was mentioned, staff explained that the change commonly occurred when a decision needed to be made about elective intubation and influenced the subsequent pattern of treatments provided to the patient. For example, this experience was voiced by nurse 8:

For example, one time, a night covering doctor did an intubation for a patient as the patient become tired; the doctor did not know about the criticality of the patient's condition. In the second day, the specialist doctor who is responsible upon the patient said it was better not to do that; the specialist means that it is better to leave the patient without intubation, especially because the patient was elderly. When a patient is of advanced years the family may accept the idea of inevitability of patient's death; accept the idea that according to his age the response to treatments will be very low. (Charge Nurse 8, H2, Medical Intensive Care Unit)

5.2.3.4   Family led care

It depends on how much the family understands the situation and how much they consent to it. It depends on them; they may even themselves ask you to do that (withholding or withdrawing). This actually possible and we have done it many times. (Senior Doctor 3, H1, P6, L12)

Another situation where deviation from what the staff reported as 'normal practice' occurred when the critically ill patients' families took the lead and asked for a limitation of invasive treatments in their relative's care. Staff described how this could sometimes happen when patients had a family member who was a health care professional or where family members were especially highly educated and insightful about the patient's situation or where there was a particularly good relationship between family members and the patient's specialist physician. Here, I will give just an example from the staff experience; fuller details about this issue are presented in the next chapter. This example was voiced by junior care nurse 12:

In the same time you distributed the questionnaire, there was a case. Actually, the patient was on maximum blood support, dopamine, adrenalin and his Glasgow-coma-scale was three (patient on deep coma). Then secondary to heart failure, he developed a renal failure. There was no good progression for that case. One of the patient's family members was a doctor and he didn't want a cardiopulmonary resuscitation to be carried out for the patient. The only thing that he did want is to keep the patient's blood pressure and respiration supported until he got a systole and this actually what happened. The patient stayed here in our unit nearly for one week or something like that and then he passed away. (Junior Nurse 12, H2, General Intensive Care Unit)

Staff experience of withdrawing life support treatments

Even though the staff reported that some invasive treatments might be limited in some groups of patients and in some circumstances, they also reported that that there are two treatments which are almost never stopped in any circumstances: mechanical ventilation and vasoactive drugs. While almost all staff agreed with giving up other active treatments which they

perceived would not lead directly to patient's death if they were stopped (this included such things as: antibiotic support, unnecessary blood samples and diagnostic tests); all were totally against withdrawing any treatments (including mechanical ventilation and vasopressors) which they perceived led to death quickly and directly. Removal of these treatments was seen to be akin to active euthanasia by the staff. Two patterns of responses were found in relation to this. While some staff perceived withdrawing ventilation and blood supportive treatments as a way of directly "killing" the patient, others used the word 'euthanasia' clearly. It seemed that the staff struggled with many of the issues and concepts related to non-treatment decisions and were confused about the potential overlap with euthanasia. This can be seemed from the interviews with nurse three and doctor four:

> *N3: In terms of myself, I'm with withholding and withdrawing the treatments that are useless and also contribute to unreasonable suffering to the patients like antibiotic, samples and screening tests. Yet, treatments which if removed will end the patient's life like ventilator or vasopressor; I'm worry about them because withdrawing them looks like killing patient; with this you switch the patient's life off.* (Junior Nurse 3, H1, Intensive Care Unit)

> *D4: Once family members accept that their relative is dying, between us as a staff we might withhold or withdraw some hopeless treatments except the life supportive ones like ventilator or vasopressor. This to avoid falling into what is called active Euthanasia which I think it is prohibited legally and religiously.* (Senior Doctor 4, H1, cover all critical care units)

Even though all participants reported that it was impossible for a mechanical ventilator to be withdrawn, one participant reported that she had experienced an occasion when there was a decision by a patient's family to withdraw all treatments including mechanical ventilator and vasoactive drugs. This participant described how the family was highly educated and well aware of the hopeless state of their relative's condition. In addition, the relationship between the family and the lead physicians was very close (this issue is examined in more detail in the next chapter):

> *The case was a neurosurgery one where brain-death had been confirmed at that time. Once they (family members) were informed that the patient will stay on same state (persistent vegetative state), and there is no hope for survival, they asked for everything to be withdrawn. You know, they were very respectful, minded and realistic families. I haven't seen any others like this family in my life, and they were always in contact with the patient lead physician by phone.* (Senior Nurse 11, H2, Medical Intensive care unit)

The hospital policies related to end of life care, together with staff's ethical and religious values and beliefs were the main issues that participants perceived greatly affected their management of patients. In terms of the hospital policies, the participants explained that Jordan lacks any national health care laws or policy in particular for palliative care and end of life care. There is thus no formal clinical or legal guidance about making end of life care decisions which might be applied in a setting like critical care unit. Therefore hospital policies that did exist did not necessarily reflect any wider framework of understanding about ethical issues in end of life care and decision-making. The next two sections describe the hospital policies and explore how the staff seek to 'work round' the policies when providing care to patients whom they recognise are dying. In the final section, the range of staff beliefs and values in relation to death are explored and discussed.

5.2.4 Hospitals end of life care related policies

> *From my perspective, the problem is that there are no standards to work according to them and this will make us suffer too much, all of us. Here in Jordan, there is a policy, I mean according to the Jordanian health laws, it is the right of all patients to receive the care that they deserve or need. Then, according to law, it is not permissible to demonstrate the option of do-not-resuscitate and it also forbids withdrawing the life support measures. However, we might withhold or withdraw the other active managements in some circumstances.* (Senior Doctor 3, H1, P13, L19)

A hard copy of the policy documents that might relate to providing care for dying patients in both hospitals was obtained before starting qualitative data collection. Although both hospitals have polices with similar titles, an examination of the documents showed somewhat different content. Within both hospitals there are general policies that are applicable to the care of all patients (including those who are dying) and others with particular relevance to the care of dying patients. For the purpose of this chapter, focus is placed on the policies that have particular relevance to dying patients. All policies documents were originally written in English and a summary of their contents is presented below. An anonymised copy of the policy is also included in Appendix I for reference. Below, is a description of the end of life care policies in each hospital: city hospital one and city hospital two.

In this hospital, there are two policies of relevance to the care of the dying patients:

1. "End of Life and Dying Patients Care".
2. "Do-Not-Resuscitate".

Policy: 'End of Life and Dying Patients Care'

This policy states that health care professionals should be aware of the specific needs of dying patients including:

1. Management of primary and secondary symptoms.
2. Pain management.
3. Responding to the unique individualised psychosocial, spiritual, emotional, religious, beliefs, cultural concerns needs of dying patients and their families and involving them in care decisions.

This policy is a four page document with four sections:

1. "Relieve the Dying Person's Pain". In this section a reference is made to the pain assessment and management policy.
2. "Keep the Patient Comfortable".
3. "Help the Patient to a Peaceful Death".
4. "Care after Death".

Under each section, there are a number of items (between 9 and 11). On the last page of the policy there is a three line paragraph that outlines the importance of nursing staff supporting and comforting each other when one of their patients die and signposts for referring the patients and their families to social services if they ask for that. Table 5.2 below presents a general overview of the four sections along with a summary of their items.

Relieve the dying person's pain:

1. Relieve and stop suffering is one of the main goals of health care professionals. Measures to relieve pain are fully described in the policy of pain assessment and management policy.
2. Trust patients saying about his / her pain rather than just draw on your own evaluation.
3. Give proper pain medications in proper doses that give the most pain control.
4. Combine pain medication to increase their effectiveness (giving examples).
5. Use simplest rout to give medications (by mouth if feasible, sub coetaneous if not able to swallow and so on).
6. Using non pharmacological measures to control pain including music, comfortable position and so on.
7. No matter for addiction with dying patients.
8. Reduce breathing (respiratory depression) is not important for dying patients.

Keep the patient comfortable:

1. Treat any discomfort the patients would complain.
2. Some discomforts would result from pain management such as constipation. In that case give the patient high caloric diet, encourage him/her to drink fluid and laxative may be helpful etc. Don't force the patient to eat and provide food s/he wishes.
3. Keep the patient clean (frequent bath, mouth care and so on).
4. Keep the patient in a comfortable position. Help the patient to get out bed, set him/her in a chair if possible or change position every two hours if the patient is complete bed rest.
5. Ease patients breathe including helping the patient to be in setting position, giving oxygen and suctioning throat.
6. Even the patient's death is close; s/he can hear and still feel your touch.

Help the patient to a peaceful death:

1. Ask patients and their families about their preferred place in last days of patient's life. If they want go home teach the family how to care for their patients and in particular how to give pain medications. If the patient stay at hospital try, as much as possible to do what the patient and the family want.
2. Make the patients feel secure and safe that s/he will not be lifted alone and calm any fears by assuring that s/he will not suffer. Provide psychosocial support for families
3. Keep the family informed about the patient and let them know when death is near.
4. Allow the families to stay as much as they want with their patients.
5. Respect the patients' preferences (ex. s/he does not want to eat, to get out of bed etc.), accept their feeling and allow them to talk about themselves.
6. Support the patient if he has unfinished business and provide spiritual care.

Care after death:

All items are about: allowing the patient's family a time to say good bye; comforting the families and allow them to grieve, providing clean and non-complicated environment for families and prepare the patient's body by taking away all equipment and supplies from the bedside and put him/her in proper position (description provided).

Policy: 'Do-Not-Resuscitate'

This policy is a one page document. It declares that the do-not-resuscitate order (defined as not to perform cardiopulmonary resuscitation in case of cardiopulmonary arrest) is not allowed. This policy has three items.

1. All collapsed patients must be resuscitated according to guidelines.
2. If the patient/family requests that resuscitation is not carried out, they should be informed of the policy and offered the alternative of transferring the patient to another hospital which provides the do-not-resuscitate process.
3. The lead physician will arrange for the patient's referral.

5.2.4.2 City hospital two (H2)

In this hospital, there are two policies of relevance to the care of the dying:

1. "End of Life and Dying Patients Care".
2. "Do-Not-Resuscitate".

Policy: 'End of Life and Dying Patients Care'

This policy is a four page document that presents a general principle labelled as "during the end of life, there are lots of thing that we can offer to patients to improve the quality of life despite the fact that their disease is not curable". The rationale for this policy is documented to be "to support the dying client, family and care giver" and "to promote peaceful death". Additionally, they define both end of life and dying terms. This policy seems to be more open to limiting some invasive treatments for dying patients. Table 5.3 presents a summary for the heading and subheadings included in the policy:

All physicians and nurses at H2:

1. Always respect patient's autonomy, privacy and patients' and their families wishes.
2. Respect the patients' right to refuse treatments.
3. Respect the physician's professional responsibilities to discontinue some treatments when appropriate, with consideration for both patient and family preference.
4. Always provide comfort and symptom management especially the pain (refer to pain policy).
5. Assess the patient for discomfort every two hours or as order and report it.
6. Assess and manage psychosocial, social, spiritual and religious issues.
7. Offer continuity of care for the patients and work in multidisciplinary approach.
8. Educate patient/family to empower them in the stressful moment and to involve social worker as needed.

Procedure:

1. Keep patient in comfortable position and make continuous and individualised assessment of level of conciseness; respiratory system and ease patients' breath (sitting upright position suction, give oxygen); dehydration and maintain fluid and electrolyte balance.
2. Nurses should pay special attention to general hygiene; skin care and change position frequently and avoid the use of aggressive therapies.
3. Provide frequent and sensitive communication with the client and family to help them to cope.
4. Monitor sign of death and document all nursing interventions and notes.
5. Protection from injury by provided safety measures like side rails and restraints.
6. Help patients' families to cope with crisis and encourage them to provide sensory stimulation by talking and touching their patients.

Policy: 'Do-Not-Resuscitate'

This policy is a six pages document. The purposes of this policy are to disseminate to family members the seriousness of the patient's situation and to disseminate "No Cardiopulmonary Resuscitation" according to patients wish and self–determination to die with dignity. For this policy to be applied, it is also portrayed at the front page that the attending physician should elicit the opinion of at least two other consultants in the field or relevant field of the patient's condition to determine whether the policy should be applied or not. Table 5.4 presents the principles and procedures included in the policy.

The policy identifies a number of cases named as "futile health conditions" to which the do-not-resuscitate policy could be applied (such as advanced late stage cancer, irreversible multi organ failure, severe brain damage and congenital anomalies that are incompatible with life). Additionally, three pages of the policy discuss the do not resuscitate practice from a religious

perspective where it provides fatwas (Islamic scholar views) allowing do-not-resuscitate policy and allowing withdrawal of all resuscitative measures when brain death is confirmed.

Table 5.4: Policy of do-not-resuscitate (H2)

Policy principles:

1. Do not leave the burden to the family members to take the decision of do-not-resuscitate since it is a medical decision.
2. The diagnosis of brain death should be confirmed by three consultants, including the neurosurgeon, neurologist and an anaesthesiologist.
3. If the treating physicians find a certain modality of treatment useless or going to increase the patient suffering, it shouldn't enforced from the beginning. Namely, withhold certain useless or harmful modes of treatment.
4. The no cardiopulmonary-resuscitation policy should be reviewed regularly as appropriate.

Procedure:

1. The attending physician should identify the patient whom the resuscitation is inappropriate. In some instance others might prompt the physicians to consider "No cardiopulmonary-resuscitation" e.g. nurses.
2. Elicit the opinion of at least two other consultants concerning the "No cardiopulmonary-resuscitation".
3. The discussion concerning the "No cardiopulmonary-resuscitation" order shall be documented in the doctors' progress note sheet and signed by the three physicians.
4. Upon reaching an agreement, a doctor order of "No cardiopulmonary-resuscitation" should be hand-written in the order sheet along with full details of the patient condition, the reasons for that "No cardiopulmonary-resuscitation" decision and the patient's quality of life.
5. The dying patients (if conscious) and their families should be provided with on-going information regarding patients status and at the time of "No cardiopulmonary-resuscitation" decision, the patient or immediate family member should be informed.
6. The social worker shall support the physician, patients and families.
7. If there is a conflict between the patient's family and the treating physicians about the "No cardiopulmonary-resuscitation" decision, another consultant would be involved. If an agreement is not achieved other health care team might be involved either the Chief of the concerned speciality or the chief medical officer or both. If the conflict is still unresolved the case referred to the ethical committee. After that if still unresolved, the family should be informed of the option to transfer the patient to another health organisation.

5.2.5 Working around the available policies

> *There is a defect in this hospital's policies. The problem with the policy is that there must be some agreement between the patient's specialist and the family that this patient is dying and no cardiopulmonary resuscitation will be done. Despite the policy here prohibited the "do not resuscitate" order but we can do a "social cardiopulmonary resuscitation". If social cardiopulmonary resuscitation would be applied, the specialist and the family agree on making light cardiopulmonary resuscitation and the resuscitation team is informed that if resuscitation code was called don't make it strict resuscitation "just try". It will make things easier. This thing we lack here and if it is corrected, it will help us. But as I have told you before the most powerful person in the policy is the family.* (Senior Doctor 3, H1, P13, L19)

The doctor reported that there is a deficiency in the policies that hospital one has. From his perspective the difficulty in applying the policy is that it theoretically places the decisions about patients' care jointly in the hands of doctors and families. However, the doctor points out that he perceives that the families have the most power in the decisions (as discussed in the next chapter). As presented earlier, hospital one has a policy where the default position is 'do resuscitate' unless a patient's family disagree, in which case patients would have to be transferred; this is clearly often impossible in a critical care context. As a result, the doctor reports that although the hospital policy prohibits do not resuscitate practice, it was sometimes possible to reach a position of some limitation. He describes this as "social cardiopulmonary resuscitation". Other staff from the first hospital similarly described "social cardiopulmonary resuscitation", while others referred to "ineffective cardiopulmonary resuscitation" or "cardiopulmonary resuscitation according to knowledge". Staff in the second hospital also commonly used the phrase of "social cardiopulmonary resuscitation" or sometimes referred to "don't push [the] heart" to allude to the same phenomenon. Further discussion of the latter is presented below, in the context of staff perceptions of the policies relating to resuscitation.

The staff reported that the hospital policies did not really help with the situation that applied in the critical care units where most of patients are suffering from acute exacerbation of chronic conditions and are unconscious. This was reported to be because the policies are directed mainly to the care of terminally ill patients who retain consciousness and for cancer patients in particular. Moreover, it was also reported that the policy in general refers to nursing care, rather than providing guidance about the direction of medical treatment. For example, the head nurse two from the first city hospital commented:

Frankly speaking, the policy (end of life policy) refer to mainly about the patients who are conscious e.g. relieving pain, keeping family at bed side of the patient, keep patients' families involved with patient's care and allow families to perform their ritual and so on. However, as terminally ill patients on ventilator who are unconscious it is not applicable; I'm speaking frankly. Another thing, the policy is mainly for nursing care more than medical care; I mean that the policy is free from medical matters, and the doctors don't have a job or role in it. This is the point, basically, the physicians are not involved in the policy; all of it is for nursing; and you know it includes simple thing to be provided for patients and their families and we almost do it in our work before having the policy. (Head Nurse 2, H1, Intensive Care Unit)

Similar reflections were voiced by head nurse three in the second hospital:

The end of life care policy points mainly to "how to deal with these patients"; I mean that you need to provide a psychological support for the cancer patients who are terminally ill and for their families. Mainly, it is directed for this kind of patients. In addition, it is actually nursing care, have you seen what I mean? This is the policy of end of life care; it is a matter of something we already do in the unit as nurse. (Head Nurse 3, H2, Medical Intensive Care Unit)

The staff accounts show that to a large extent they apply the end of life care policy unconsciously during their daily work without making any references to it as the policy actually talk about usual nursing practices e.g. keep the patient clean; keep patient in a comfortable position and support patients and their families.

5.2.5.1 Do-not-resuscitate policy

The participants' accounts show that this policy is highly fraught with medico legal concerns for critical care staff (Table 5.5, 1, 2). In the first hospital the policy states that the default position is 'to resuscitate' all patients. The participants working in this hospital reported that all patients who died were resuscitated even if some families requested that a do-not-resuscitate order should be made. Among the thirteen interviews completed with staff in the first hospital, seven reported that they had experienced a situation where dying patients' families requested that resuscitation should not to be carried out, but that their requests were not considered because of policy stating that this was non-permissible and the corresponding lack of any formal document to log the families' request. For example, nurse one shared his story of the last patient who died and for whom he had provided care:

The last case died and I was assigned for was the day before yesterday or before three days. That patient had a pancreatic cancer and the cancer had

metastasised to liver and lung. The family was Christian and they requested that they don't need either intubation, I mean resuscitation, nor any further treatments. They wanted nothing except let him dies in peace, you know just caring and pain relief; they said that it is enough suffering for him. The doctors said no. they informed the family that they we don't have a policy in the hospital that permit their request and they also don't have a form to be document their request. (Senior Nurse 1, H1, Intensive Care Unit)

In this hospital, the participants reported that even they though don't have a policy that permits a do-not-resuscitate practice, they tried to limit some of the invasive treatments if the family are agreeable. The care for the patients where families either requested that resuscitation should not be attempted or where they were clearly accepting that their relative was dying was reported to be different from the care of other patients. This difference was reported to include both the care before the patient's death and at the time of cardiopulmonary resuscitation, as demonstrated by senior nurse one:

As I said because the family requested for their patient not to be resuscitated, and despite the doctors refuse their request because we don't have such a policy, surly the care was not like other patients and that because the family's request. For instance, when the patient started to be hypotensive, among us as an intensive care staff we know that the patient is do-not-resuscitate (I mean informally) as requested by family. Even we don't have a do-not-resuscitate policy but between the staff it means sufficient in term of care; like this we understand each other. Otherwise, if another patient get hypotensive, we will start the patient of intravenous fluids and vasopressors and such these things; for this patient, we didn't do these things. (Senior Nurse 1, H1, Intensive Care Unit)

As described above and alluded to by senior nurse one, the staff reported a practice which was variably called: "social cardiopulmonary resuscitation", "cardiopulmonary resuscitation according to knowledge", "ineffective cardiopulmonary resuscitation" or "light cardiopulmonary resuscitation". Doctor three in the case study presented in the beginning of this section referred to this phenomenon and later elaborated his meaning with a vivid description of his practice:

What happens: we know previously through our colleagues during shift endorsement that the so-and-so patient, in the specific ward, has a very poor prognosis and we expect him arrest. Thus, the senior resident informs the team in advance of the "very poor prognosis" of this patient; and if the cardiopulmonary resuscitation code was activated: don't perform strict resuscitation or don't be hard on him. But we don't just be sufficient of "doing nothing". The meaning of not performing a strict resuscitation is: ending the resuscitation after 10 minutes or doing resuscitation for 5 minutes and just give

one ampoule of Adrenaline while looking whether there is a response or not; and if not holding the resuscitation; all of that just because the policy stated that all patients should be resuscitated. (Senior Doctor 3, H1, cover all critical care units).

Such practice was also echoed by doctor five:

We have a medical knowledge and it depends on the case itself; there is a variation in care. For example, a patient who we know that he has a "very poor prognosis" and he is going to die imminently, I'll give him his right of care "according to knowledge"; I mean just slight five resuscitation cycle, little or no medications and something like that. However if I have a young patient, patient come to emergency department or unexpected dying, I will keep trying as long as I can; I might stay for more than one hour in resuscitation. (Senior Doctor 5, H2, cover all critical care units)

With regard to the do-not-resuscitate policy in the second hospital, the participants who were interviewed from this hospital reported that although there is a policy, it is vague and is not communicated with all dying patients or their families. Moreover, they perceived that it was rarely applicable to the critical care units context and then only at a very late stage. Additionally, they reported that there is no specific form to be completed if the do-not-resuscitate policy is to be applied. For example, head nurse five talked about the vagueness of the policy and the corresponding lack of formal document to apply it:

We have a do-not-resuscitate policy in this hospital, but it is really vague, frankly speaking, and it is not that much clear and directive. You know I read it and I don't understand it and it difficult to follow. The policy should give you something clear and detailed; even with cases the policy mentions (where we can apply the policy), they are no specifications. Another thing is that the family should sign for that order (do-not-resuscitate order), but we don't have a form for that purpose (Head Nurse 5, H2, Coronary Care Unit).

Head nurse three explained about the applicability of the policy of resuscitation in the second hospital. In her account, the head nurse explained that the policy is not applicable because of the difficulty in accomplishing its requirements, since it needs mutual agreement from many people including: the patient's lead physician, two consultants and the patient's family. As in hospital one, the head nurse talked about doing a "social cardiopulmonary-resuscitation":

We have a do-not-resuscitate policy, but it is not applicable. We didn't have any patient we applied this policy upon; I mean where a family signed for a do-not-resuscitate for their patient along with a three consultants; because the policy say that all of the principle doctor and other two consultants; because they

should consult two other doctors. In this way it is not applicable at all. May be that we have a patient for example a brain dead patient, a cardiopulmonary resuscitation would be done socially; I mean give some medications, slight compression for short time and that's enough. Whereas as a policy, it is not applicable at all. No one, I mean family, accept it at all…also may be with cancer patients; the end stage cancer patients. For these patients the social cardiopulmonary resuscitation could be applied. (Head Nurse 3, H2, Medical Intensive Care Unit).

Similarly to the first hospital, the participants in the second hospital reported that they use the resuscitation policy to a certain degree between themselves rather than following the policy of do-not-resuscitate to the letter; this means that it is conducted informally between the staff and will not be written down. When head nurse three talked about "social cardiopulmonary resuscitation" she also used other phrases including: "don't push hard", "just support" or "this patient just for support " and described how these phrases are used in daily practice:

*Because many people should be involved when demonstrating the do-not-resuscitate policy, it is very rare to reach a position where a do-not-resuscitate order is written on patients file. However, what we used to see is a verbal do-not-resuscitate order. For example, during morning medical round the lead physician for critically ill patient might say "don't push hard", "don't push heart", "just support" or "this patient for support just" and so on. This means keep the patient on usual treatment e.g. keep on mechanical ventilator; keep on blood pressure support drugs but not aggressively (e.g. no combination); if the temperature goes up start antibiotics but again not aggressively (e.g. the most expensive drug) and so on. However, if the patient develops anything new such as arterial fibrillation, we provide usual care because we cannot leave the patient without management, but then again not aggressively, you see? But until now nothing will be written……. Not aggressive mean for example in cardiopulmonary resuscitation, it will be just 5-10 minutes; if any medication given it will be very small dose; the cardiopulmonary resuscitation team will not be requested, just doctor and nurses will be there. In antibiotic, for example, don't change antibiotic many times; no expensive antibiotic or may be no combination. However, he cannot say don't start antibiotic or don't support blood pressure, do you see what I mean? (*Head Nurse 3, H2, Medical Intensive Care Unit).

Table 5.5, items 3-5 illustrates other staff perceptions of practice surrounding cardio-pulmonary resuscitation.

Table 5.5: Working around do-not-resuscitate policy

1. I always ask doctors, why this treatment? And why that treatment? They used to say "just do it for medico legal aspect in the case if someone ask after that". So we have to do everything and everything should be documented. (Head Nurse 4, H2, Intensive Care Unit).

2. The hospital draws this policy (no do-not-resuscitate) from the Jordanian health law. The law state that you have to give patients their right of receiving the health care and the resources regardless whether patient is conscious, unconscious or terminal; there is nothing prevents us from doing cardiopulmonary resuscitation. This is what in Jordanian health laws (Head Nurse 2, H1, General Intensive Care Unit).

3. The applicability of it (do-not-resuscitate policy is rare). Actually it is not applicable as it should be. We used to talk to families about this policy and 95% of them refuse the idea of do-not-resuscitate. You know, families used to say that no one has the authority to end a person's life and they can't do that because they thought that they might be responsible religiously. You know for me for instance, I put my mother on do-not-resuscitate order. (Head Nurse 5, H2, Coronary Care Unit).

4. In social cardiopulmonary resuscitation, they (doctors) could not give any medication, because the patient supposed to be already on a maximum support of dopamine and noradrenalin before cardiopulmonary resuscitation, so they just do chest compression for a short time and bag mask ventilation and that's all…..during my whole experience I haven't experienced a do-not-resuscitate was written in a patient's file (the researcher asked whether families used to be informed about social cardiopulmonary resuscitation)…..frankly not always. You know with these cases the doctors used to say "I have done everything for this patient; nothing left; he is multi-organ failure, on maximum support of medications and may be arrested before; so what shall I do for the patient more than what I did; Just do chest compression and don't give any drug because he is already on a maximum support" (Head Nurse 3, H2, Medical Intensive Care Unit).

5. In reality and what happened in that case, the resident doctors go to patient's family and asked them just few words "if the patient arrested in any time, should we resuscitate her" This was the question and this is what usually happened. There is nothing written and 90-99.9% of times I didn't see anything written even there is a policies in the hospital like do-not-resuscitate and end of life care. (Charge Nurse 9, H2, Coronary Care Unit)

5.2.5.2 Against medical advice form

Findings show that the critical care staff realise that the dying patient should be treated differently, but because of legal constraints, they put aside their realisations and work within the real life constraints surrounding their practice. However, they tried to deal differently with dying patients in both hospitals by using a form called "against medical advice form". This should be filled by the patients or families who refuse any medical or nursing intervention. By using this form, the medical staff tried to provide a different modality of care where possible

for dying patients. They found opportunities to do so when a dying patient's family started to accept that their family member was dying and an opportunity arose to talk to the family and inform them that to continue with aggressive care would do nothing except cause unnecessary suffering. In this situation, medical staff described how they did what they called "counselling" (more detail in chapter 6). During counselling, the staff confirm death as is an absolute outcome and communicate the negative physical and emotional impact of keeping the dying patient under aggressive curative treatments for both patients and family. If the patient's family accept the idea, they will be requested to complete and sign the "against medical advice form". In the rare situations that this occurred, patient care could then be limited to basic supportive interventions (vasopressor, mechanical ventilator) with no other medical treatments until death. Head nurse four reported that it is difficult for families to reach agreement in order to sign the necessary form; this was a key barrier:

> *No one, I mean doctor, could write don't start dopamine or don't start noradrenalin or do-not-resuscitate. However, this matter as I said to you become between us and in particular between medical staff like saying between each other "if the patient arrested do push heart". Sometimes the families themselves if they are educated or have a health care background might come to physician saying for example, don't work aggressively or don't resuscitate him or something like that. If that happen the family should sign for their request, but with the matter of signing most of time no one, I mean from family members, agree to sign.* (Head Nurse 4, H2, Intensive Care Unit)

This form was reported to be used in two different situations. Firstly, to document the 'do not resuscitation order' in the second hospital (where it is allowable) when a family accept or request that resuscitation is not to be carried out. This is because there is no particular form for the purpose of do not resuscitate orders. While some staff reported using this form to fill the family's request, others reported asking families to sign a hand written statement added to the "doctor progress note sheet" in the patient's file. For example head nurse four reported:

> *We don't have a special form to document the families' requests, but they (doctors) used to write in the sheet of "doctor progress note" like for example writing "as a son or whatever the relationship of (patients' name) I'm (person name) I requested that for example a cardiopulmonary resuscitation not to be done upon my father" or something like that you see? And then the signature.* (Head Nurse 4, H2, Intensive Care Unit)

Secondly, to document the 'do not intubate order' in the case of having an end stage cancer or frail elderly patient, as reported above. This was reported to happen in both hospitals. For

instance, doctor number three talked about the change that could be carried out when caring for cancer patients:

> *You may experience sometimes cases in which you have to take a decision to intubate or not to intubate, for example. This happens with cancer patients whom are in advanced cancer or have very poor prognosis; in these cases we may resort to this approach in which if I intubated the patient, I have to transfer him to the intensive care unit; and if I do so, the family won't be able to see the patient in the intensive care unit as in the ward. Furthermore, there is no benefit from the intubation. So, I "counselled" the patients' families and give them the choice: either to intubate the patient and put him in an isolated room in intensive care unit and thus there may be no space for the family to be with the patient, or I may let the patient in his own room with the family being around him without intubation while providing the other supportive care. In such situations the family has the choice to decide whether to intubate or not.* (Senior Doctor 3, H1, cover all critical care units)

In summary, the staff reported a number of obstacles with regard to the available end of life care policies to providing end of life care. However, they try to limit some invasive life-prolonging treatments by used these policies to a certain degree or working around them and in other situations to guide families to come to the decision of treatment limitation. The next section describes how staff beliefs and values affect their practice of caring for patients whom they realised were dying.

5.3 Staff beliefs and values

> *As I told you before; the family always has hope, which would be wrong for us to increase it. The family hopes that the patient will live, and you can't contradict this. Because we know that death is not in our (power) hands it is in the hands (power) of God; destined and it is beyond our comprehension and knowledge is the hope which they hold tight. So, you have to do your job and let the rest for providence (God). Also, you might know that the hope which families have is based upon rare cases, which they have heard it from an unknown place. The family may tell you "we have heard of a patient who stayed 100 days in coma and afterward he recovered".* (Senior Doctor 3, H1, P11, L22)

Doctor three talked about the religious perspective of the medical staff toward caring for dying patients by way of explaining why it was usual practice to continuing with care as usual even when recognising approaching death. From his perspective, the doctor sees that death and dying are matters that belong to God; no one can be completely sure that anyone is going to die, even if this is expected. He drew a line between his role as a professional doctor and what should be left to the authority of God.

As presented earlier, the experiences of the critical care staff show variations in the practice of providing care for critically ill patients who are approaching death. The staff reported that there would be situations where different care would be provided to patients with similar conditions. These variations were reported to rest with the preferences of the staff and were partly related to their religious beliefs and values[5].

End of life decisions (including withholding, withdrawing, do-not-resuscitate and do-not-intubate procedure) are subjects of heated religious and ethical debate for Muslim health care providers, patients, and patients' families in national Jordanian discussions (where the Islamic regulations are the main source for legislations). Through these debates, some clinicians believed that these decisions are "killing" and therefore are prohibited. There are "Fatwas" (Islamic scholar opinions or viewpoints) about these issues where some of them support end of life care decisions and others considered it as taboo ones because all death and dying issues belong to God and it is a patients right to receive full care. Thus, some staff prefer to do their job by continuing with aggressive treatments in order to avoid these conflicts and the risk of forbidden actions. For instance, nurse 9 from hospital two voiced the perspective of doctors

---

[5] It is noteworthy in addition that the policies in the second hospital had a section that explored the religious perspective towards withdrawal of life-sustaining treatments from patients who have "futile health conditions".

toward withholding and withdrawing treatments. The nurse reported that such decisions are considered as unethical and negligent from the perspective of medical intensive care staff:

> *Here the doctors considered it (withholding and withdrawing treatments) as unethical and other consider it as negligence.* (Charge Nurse 9, H2, Coronary Care Unit)

The findings show that there are great many perspectives on the applicability of religious issues in the care of the dying patient. The perspectives range from being completely against any change from the usual pattern of care to the viewpoint that seeking aggressive life-prolonging medical treatments is not compulsory; many perspectives fall in between. For instance, doctor five adopts the position that it is a religious mandate to work with all critically ill patients as usual and to the end. However, he is the only one who adopts this position and makes no exceptions:

> *Now myself as a care provider, at the end I am a son for this community and I want to go back home, put my head down on my pillow and sleep. So I don't want to come to the point of thinking in the night where I say if I gave that patient that medication or if I continue that medication for that one may God do thing? Yeah God may do thing; may do a miracle. I am different from those who don't consider these things, actually I do. Generally, I'm against these things e.g. do-not-resuscitate, withhold or withdraw.* (Senior Doctor 5, H2, cover all critical care units)*… For me, even with cardiopulmonary resuscitation, I used to say that nothing would prevent me from working to the end. In another way, the patient should take his/her right; this is the point taking their right. Namely, from my perspective this is a right for patients, this is my viewpoint. It is not me who decide whether this is patient right or not; my job is to do everything and our God who is the only one who can decide. Even though sometimes I identify that this medication is worthless or that treatment is useless, from my perspective, I am just a mean; I'm a means and the only one who cures is our God. I'm a person believe in miracles.* (Senior Doctor 5, H2, cover all critical care units)

In contrast, nurse 9 echoed that seeking aggressive life-supporting treatments from Islamic perspective is not a must that every Muslim should do and withholding/withdrawing treatment are not considered sins. The nurse 9 reported in their accounts some Hadiths[6] from where this rule was derived and support the viewpoint.

---

[6] Hadith In religious use is often translated as 'tradition', meaning a report of the teachings, deeds and sayings of Muhammad (the Islamic prophet)

The problem here is the misunderstanding of religion not the religious itself, because as I have said before that it is not compulsory to request the medicine and this is from my perspective (Allah is knower) and the below "Hadith" will prove that: Ibn 'Abbas once said to me ('Ata bin Abi Rabah), "Shall I show you a woman of the people of Paradise?"I said, "Yes."He said, "This black lady came to the Prophet (peace be upon him) and said, 'I get attacks of epilepsy and my body becomes uncovered; please invoke Allah for me.' The Prophet (peace be upon him) said (to her), 'If you wish, be patient and you will have (enter) Paradise; and if you wish, I will invoke Allah to cure you.' She said, 'I will remain patient,' and added, 'but I become uncovered, so please invoke Allah for me that I may not become uncovered.' So he invoked Allah for her"… And this is another "Hadith" at the time of our Prophet Muhammad death when he said "Laa Ilaaha Illaa Allaah (there is nothing worthy of worship except Allaah), indeed death contains agony" (Charge Nurse 9, H2, Coronary Care Unit).

This experience was also echoed by nurse 14:

Even in religion, they (physicians) didn't learn about these issues from religious perspective. In religion some "Olama" (the scientific person in religion of Islam) said that it is not compulsory to request medicine especially if the medical treatment is futile (Senior Nurse 14, H1, Intensive Care Units).

Based on these different accounts, some staff reported that they work actively with critically ill patients even in the face of an obvious decline in their condition in order to be on the safe side and to avoid self-blaming and guilt of committing sins. They reported that they don't want to start blaming themselves when the patient's condition and illness has deteriorated more or when death has occurred through their decision to limit intensive treatments. This observation was reported by the head nurse five:

Another thing, they (staff) need to finish their shift work hours and go back home with a comfortable conscious and that all what they want. So they provide maximum care that they can do for the patient whatever the patients are. (Head Nurse 5, H2, Coronary Care Unit)

Nursing staff tried to avoid the self-blaming and get rid of this feeling by leaving the decisions in resident doctors' hands and then following their instruction. At the same time, the resident doctors tried to do the same thing by handing over the role to the specialist doctors. The quote below details a conversation between nurse 9 and a resident doctor. The dialogue was about a patient who had an internal pacemaker which kept pacing even after patient death. The conflict point was whether to announce death and stop treatments or to continue with treatments as there is heart beats. At the end of the quote, the nurse put the accountability at resident doctor's hand.

In that time, the resident covering doctor said that it is an ethical case and my religious and ethical instance don't allow me to say that he is dying and I respond to him by saying it is a taboo and unethical what you are doing, just look at his face, he is dead. All of that and the doctors didn't believe in that and he think that he must do the maximum care for all patient, whatever the patient was. Anyway it is up to him, he will be the responsible for his sins (Charge Nurse 9, H2, Coronary Care Unit)

The experience where the resident physicians handing over the role to specialists was reported in nurse one account:

But they (residents' doctors) used to say that this is what the lead physician's request and if the lead physician wants, he will stop the aggressive treatment). (Senior Nurse, 1, H1, Intensive Care Unit)

The findings show that these differences in moral and religious standpoints were reported to be a source of conflict between and among health care staff. The staff reported that having different religious and ethical positions was a challenge that they commonly encountered and sometimes created conflict between them. For instance a story of an experience shared by nurse one shows a conflict that happened between a nurse and a resident doctor surrounding withdrawing a treatment for a dying patient. The nurse described how the doctor asked for a supportive vasoactive drug to be withdrawn, whereas the nurse, from his religious view, argued that the medication should be continued even though it was medically futile. The power relationship between nursing and medical staff, which the staff commonly refer to as "doctor dominant culture", is evident in the quote below and is discussed in the next chapter:

There was a patient with no sign of good prognosis at all. He was on norepinephrine infusion. The resident doctor came and asked to stop it. We as nurses and from religious perspective (prohibited and permitted issues), one of our colleagues replied to that doctor saying: no! These things (death and dying issues) are belong to the God; we have to work whatever we can do; the patient is hypotensive, so this medication should be kept on patient even the patient is dying; when his time of death come he will die. At that time, the doctor said no, and as a medical order stops the medication. (Senior Nurse 1, H1, Intensive Care Unit)

5.4 Inter-professional communication and collaboration

The participants alluded to how the health care related decisions including end of life ones are specialist led with other staff (including resident doctors) typically having few opportunity to have input. The resident participants reported that their role is to carry out the specialists'

recommendations and to communicate these recommendations to the patients and their families since the specialist spend very limited time in the critical care units. Thus, any end of life decision that needs to be proposed, discussed with patients or families or implemented is a specialist's responsibility, but this responsibility is rarely acted upon. Doctor 6 shared this experience:

> *These issues (end of life care issues) are the responsibilities of the patients' specialists. It is not our job even to discuss these matters with the patients' families. Most of our communications with families are treatments and prognosis focused; we work in between specialists and patients and their families. The only role that we would have is to present the patient's picture (including treatments, lab result and prognosis) to his or her specialist; specialist have more knowledge and experience* (Doctor 6, H2, Medical Intensive Care Unit)

In addition to the issue that some nurses tried to avoid getting involved in decisions surrounding providing care for dying patients with the technique of handing over the responsibilities as discussed earlier (staff beliefs and value section), nurse participants reported that they are usually not actively involved or take part formally and openly in these decisions. For example, in the quote below nurse 10 talked about his role as a nurse in the care that is provided for a dying patient. The nurse notes that nurses are not usually involved in decisions surrounding the care of dying patients. Their job was described to be as following to doctors' instructions even if they perceived that these would be harmful and futile for the patient:

> *As nurses and with experience, we do not have a problem of working with dying patients as doctors' instructions even if you have confidence in treatments uselessness and patient hopelessness in order not to put ourselves under accountability. At the end, the hospital, doctors and families will not excuse you; a patient family may launch a negligence complaint against you. So, with experience if there is an order for a medication, we will just give it; in this hospital, I came every shift to work my job. This because the hospital and doctors don't give you your role as a nurse; everything for doctor; he is the only one who take decisions in such these issues or even in anything else. As I said, if there is an order, you as a nurse you have to carry out the order* (Charge Nurse 10, H2, Medical Intensive Care Unit)

Another role for nurses in the care of dying patients was as an information resource for doctors about patients. Nurse two reiterated the point that nurses do not have an active role in the health care decisions that are taken about critically ill patients. The nurse described that their role is restricted to that of an information provider to doctors about patients' health status so that doctors can take a decision based on this information. In his quote, the nurse gives an example

of a patient who has a bedsore and shows how the nursing role is to describe for doctor the characteristic of that sore:

> *Regrettably, we didn't have a role. Generally, the lead physicians take decisions by themselves and with other consultants just; they would refer to nurses because they don't know about the bedsore that the patient has; he know that the patient has a fourth degree bedsore, but they don't know whether the sore is infected, granulated, have an exudate or what is the current size of the sore. This information, they take it from nurses in order to take a decision whether the patient is severely septic or not from the bedsore. So, the physicians' decision comes supported by nurse's information, but actually, the nurses don't have a role in taking any decision; the nurse is just a source for information. .*
> (Charge Nurse 2, H1, General Intensive Care Unit)

In terms of nurse-doctor communications, nursing staff reported that they are unable to directly speak with the specialist; they only have the opportunity of communicating with resident doctors who then pass the information to specialists. For example, nurse 11 articulated that they communicate their comments, viewpoints and suggestions to resident doctors who in in turn communicate with patients' specialists on their behalf:

> *Another thing, here in this hospital we don't have a direct contact with specialists except via his/her follower residents' doctors; if we need anything we have to talk to residents who then talk to the specialist; neither we nor the residents have a decision maker capabilities. We always say "why is that? What about this? It's enough with this patient" and the residents keep saying "we will talk to the specialist; why to call the specialist? If he wants this he will do it; it's the specialist recommendations and we have to follow". So I think to keep silent is a better thing* (Senior Nurse 11, H2, Medical Intensive Care Unit)

The staff reported that having critically ill patients who were supervised by more than one specialist would create an obstacle to providing end of life care for two reasons Firstly, because the specialists were likely to have different perspectives toward the patient's prognosis and life expectancy. This experience was reported clearly by doctor four:

> *Different perspectives frequently happen between us as a critical care team and other teams. One time I was working under the critical care team. At that time one patient had a cancer, so from the perspective of oncology specialist, the patient has a chance to live 4 to5 months more (based on cancer progression). However, for us as a medical critical care team and from the sepsis that the patient had then he developed a septic shock and neutropenia (zero neutrophils), we didn't expect the patient to live any more. For him (oncology specialist), because cancer was his focus other than the critical care specialist*

focus, he insisted to continue with full treatments. (Senior Doctor 4, H1, Intensive Care Unit)

The second reason was because it was perceived by staff that there was ineffective communication between the patient's specialists, particularly with regard to the handing over of the responsibilities for a patient's care between them. This was also reported to affect the quantity and quality of information provided to the families of critically ill patients, since families would 'fall between' specialists. Staff reported that it is rare for specialists to meet in person to discuss a patient's condition or to communicate with their family:

> *A practice we frequently see between specialists is that they rely on each other to take the decisions around the patient's care. Therefore, we (resident doctors) had been asked many times to see other specialist opinions like "what the specialist said? Ask another specialist and work upon his/her decision". You know they (specialists) should endorse patients to each other and get a mutual agreement; it's rarely happened that they set together and discuss cases or talk to families; we (residents) are the messengers between them. In consequence, sometimes the families keep in between the specialists; the first specialist says "let's see what another consultant said" and vice versa.* (Senior Doctor 5, H2, cover all critical care units)

5.5 Critical care staff experience of challenges and barriers

From the stories of their experiences, the critical care staff in this study revealed a number of challenges and barriers that they encountered while providing care for critically ill patients. These challenges and barriers vary according to many factors. To illustrate their experience of these challenges and barriers, I have categorised them into three categories: challenges and barriers related to the critically ill patients; challenges and barriers related to staff themselves and system related barriers. The challenges and barriers that are related to patients' families are reported and discussed in the next chapter

5.5.1 Challenges and barriers related to the critically ill patients

> *It also depends on the quality of the patient… other conditions or some things that makes the death very complicated such as: factors related to the patient's family, patient being a very important people patient, or the patient may be young.* (Senior Doctor 3, H1, cover all critical care units).

Across all interviews with staff, acute or sudden death and rapid progression of the disease were reported as major challenges for critical care staff while providing care for critically ill

patients. The participants accounts revealed that losing the control over a patient's death, either when the death happened suddenly or unexpected or when the disease progressed more quickly than it should, complicated the process of caring for both patients and their families. Staff explained that in these situations, they don't have enough time to prepare the family members for their loved one's death and the family don't have time to handle and accept their loved one's condition. For instance, the nurse 8 described his experience of this:

> *The last patient, who died and whom I cared for, died before two days. The case was for a female patient who was admitted to the unit with a diagnosis of warfarin toxicity. The patient was admitted conscious and oriented and we were talking with her and we built a strong relationship with her. She was very nice and polite person. The patient was young (40 years old). She stayed in the unit for two days, in the third day and suddenly she deteriorated and developed a respiratory failure with dyspnea and something like that. We did an elective intubation and entered a central venous line. After that, her heart's function start to decline and she was on a ventilator she stayed all that day and for the next day (nearly 36 hours) and after that she died after an ineffective cardiopulmonary resuscitation; it was really bad day; it was really difficult and a shock for us, she was doing well.* (Charge Nurse 8, H2, Medical Intensive Care Unit)

Nurse 8 above revealed another challenge which was also reported by most of the other participants interviewed in this study. This challenge is having critically ill patients who (from the families' perspective) appeared to be clinically stable on their admission to critical care units. The staff reported that having a patient who is critically ill and unconscious at the time of admission is less challenging than a patient who comes to the unit conscious and oriented and later deteriorates, since in the latter case, the patient's family members are poorly prepared to hear bad news and staff may have little time to prepare them for such news. For example, nurse three described this challenge:

> *It happens to me many times when family members came in the morning and they were very confused and angry because they did not know what happened to their patient in the night once they saw their patients intubated and mechanically ventilated. You know, for families the patient was talking one day before and he was normal, but for us we realised the full scenario the patient will follow and we know that the patient will be intubated and ventilated. So they become very angry in the morning asking what wrong you did for him and so on. The physicians should tell families before, what are the possible scenarios might be; this will ease our work.* (Junior Nurse 3, H1, Intensive Care Unit)

Having a young critically ill patient was reported to be among the most difficult situations that the participants have to deal with. This was because of the difficulty in accepting death by the family and their high and often unrealistic hopes, as well as the emotional feeling that staff have toward families. For example, doctor five talked about the type of care provided for young patients:

> *The care is also dependent on the type of case; yeah there is a difference between cases. For example, with a patient who I know in advance that s/he old chronically ill patient with a very poor prognosis and he is dying, I will demonstrate usual care, but if a young patients come to intensive care unit from emergency, I mean sudden and unexpected or something like that, the families and sometime myself still have a hope and I'll keep with a very aggressive care until the end; even sometime I know the outcome. You know I'm also willing to do a cardiopulmonary resuscitation for more than one hour and it happened one time when I spent more than one hour in cardiopulmonary resuscitation because the family will never accept to work for 15 minute and said the patient die.* (Senior Doctor 5, H2, cover all critical care units)

Sudden and unexpected death in addition to uncertainty about patient's prognosis were described as challenges that the critical care staff encountered on regular basis. The medical staff interviews revealed that the challenge is about what to communicate to patients' families and how much time to predict the prognosis and prepare families for patient's death they have. This was voiced clearly in the account of the critical care nurse 8:

> *Other challenges are when event happens suddenly and unexpectedly, and providing care for young age dying patient; it is very difficult… Sometimes, the patient transferred in from other hospital on a ventilator and the family are well prepared about the patient prognosis and sometimes you don't know whether the family are emotionally prepared or not. So in this situation the communication will be directed to make the family understand that the patient is in tired position. If the good prognosis is possible we told them that but if it is not we talk to them that the situation is critical and it's too difficult to be better than this and the situation may be….(Silence)....sometimes we don't know what will happened and sometimes it is a matter of guessing. You know sometimes, the patient is really tired and the recovery is not possible but the patient become well and it happens to us many times. In the other hand, sometimes there were patients who we expect that they will become better but suddenly develop a new complication, such as pulmonary embolism or something like that and suddenly dead.* (Charge Nurse 8, H2, Medical Intensive Care Unit)

5.5.2 Challenges and barriers connected to the critical care staff

Lack of staff education regarding end of life care was another barrier to providing quality end of life care. Findings show that the participants had different perspectives and perceptions about what end of life care is. Their accounts about end of life care were elicited when they were asked about the applicability of the end of life care policy that both hospitals have and how they comprehend these (including any deficiencies and how their care is affected by the policy). While some participants were aware of the fact there was a policy and were familiar with the contents and how it should be applied, many participants had different notions or ideas about the policy. I noticed that with some participants, the policy was their point of reference when talking about how they understood end of life care, whilst others who had an educational background about this issue (master degree holder) had a broader understanding of end of life care. Generally, the concept of 'end of life care' as a term was reported not to be commonly used or something that the staff talked about between themselves, with patients or their families; either in written or oral form. For instance, this observation was reported by head nurse one:

> *Frankly speaking, they (medical staff) don't adopt it (the policy) to a degree where we could say that there is an attention toward it; no not that attention. You know, as six years of experience as a head nurse, I have not experienced any doctor write on patient file for example end of life or this patient for end of life care; also the policy is less-known for them and they don't use it between themselves on their daily work.* (Head Nurse 1, H1, Coronary Care Unit)

Instead of using 'end of life care' as a term to deal with dying patients, the findings show that the staff commonly used terms which related to 'end of life care decisions' between themselves. These terms included: withholding, withdrawing, do-not-resuscitate and do-not-intubate. Some nurses linked end of life care with withholding or withdrawing treatments. For example, nurse three talked about her experience with application of end of life care policy for dying patients:

> *Her in this hospital, in all my experience of two years and with all dying cases I have dealt, they (physicians) did not stop any medication or treatment because the patient is dying or as you said receiving end of life care.* (Junior Nurse 3, H1, Intensive Care Unit)

Some of these staff perceived that end of life care is only for geriatric or cancer patients rather than critical care unit's patients because patients such units are most of time unconscious and

the policy doesn't apply to them. In addition, only one nurse participant saw end of life care as hospice care where dying patients should be supported and their symptoms relieved short of providing aggressive medical treatments. Whereas some nurses have these ways of comprehending end of life care, another nurse asked about the meaning of end of life care at the beginning of interview and comprehended it as palliative care. To illustrate these observations, I have drawn from a few nurses' interviews in Table 5.6 (1-4).

Moreover, end of life care was seen by some staff as nothing more than psychological care and pain management. Doctor four commented on their role toward dying patients and their families saying:

> *Actually, end of life care is a psychological care and pain management. First thing, no one of us adhere to…I mean we don't have clear pain management guidelines. There should be a pain clinic here in the hospital, but it is not functional at all; so (participant verifying) many times happened when patient either over medicated or under medicated. In the case of over medicated patients, they develop ileus, coma and other complications, or still have a pain if they are under medicated. You know the pain management here is very bad, very bad. The second thing is the psychological care for dying patients and their families; it is their wright to have such a type of support, but actually we don't provide it.* (Senior Doctor 4, H1, cover all critical care units)

The participants reported that from other staff's perspective end of life care is just home care and should be provided at home. Doctor four shared a story where she experienced a case that need end of life care and the patient was not admitted to the hospital adopting the position that the care will be provided in hospital is the same as in home:

> *…Another problem, when dying patients come to the emergency and there is nothing medically we can provide (for well-known patients who we used to see him in clinic) except the supportive care, specialists refuse to admit them. These doctors used to say that these patients need a supportive care which is the same care the families can provide at home. Most of times, the families refuse keeping patient to die at home saying "we cannot take care of him at home and we don't him to die at home, let him die here"* (Senior Doctor 4, H1, cover all critical care units)

Of the full interviews that were done with the medical intensive care staff, two participants reported the obstacle that doctors are more optimistic toward patients' recovery. This leads doctor to present things to families with more optimism and complicates the possibilities of limiting intensive treatments. For example, doctor five on his account reported:

You know, sometimes we used to be in a cardiopulmonary resuscitation for terminally ill patient where the outcome is 100% that the patient will die and we do that because we don't have a do-not-resuscitate policy. In situations as this, experience has shown me that death is the absolute outcome; hence I am amazed that some of my colleagues work aggressively with an expectation that the patient will walk on his/her legs. (Senior Doctor 5, H2, cover all critical care units)

Ineffective communication between physicians (including residents and specialists' physicians) and dying patients' families were seen as one of the major barriers across all interviews. Additionally, lack of appropriate staff training and knowledge towards working with critically ill patients and their families was voiced as an obstacle the staff experienced while providing care for critically ill patients and their families, as discussed in detail in the next chapter.

Table 5.6 provides insight into how end of life care was perceived by other staff in this study.

1. With regard to the end of life care policy that we have here in this hospital, the majority of our patients in the unit as you know are on ventilator and we don't have patients who are conscious and terminal in the same time to apply this policy. Here in our policies, we don't have a do-not-resuscitate policy, but sometimes, sometimes (participant verifying) there are specific cases not here in the intensive care unit, I am talking about patients on wards (cancer patients), there might be no active management upon them and they (doctors) don't work with these cases as a full management; and most of time it requested by patients' families themselves also. However, the patients we have here in intensive care unit as end of life ones, we deal with them like any other normal patients, completely active treatments. Frankly speaking. (head nurse 2, H1, Intensive Care Unit)

2. You know palliative care or end of life care should be at home not in the hospital. Why do families who have an elderly relative send them to hospital to be cared by others? Why they don't take care of their relative at home?...you know, you are talking with critical care sister, and I am not a ward one (where you can find a cancer and geriatric patients); actually, I don't know if the policy (end of life care policy) is applied for the ward patients; I mean for dying patients there. (Head Nurse 5, H2, Coronary Care Unit)

3. Here in intensive care unit, the majority of the patients to whom we provide end of life care or hospice care are the brain tumour patients and cancer patients. We keep them on the same treatments and provide them with usual nursing care until death. (Senior Nurse 14, H1, Intensive Care Unit)

4. First of all, what dose end of life care dose mean? You need to make me understand what end of life care as a concept mean, because there is nothing likes this here in the hospital….do you mean palliative care? (Junior Nurse 15, H1, Coronary Care Unit)

5.5.3 System related challenges and barriers

As seen from the participants' accounts, fear of legal liability, especially among medical staff was a major barrier to providing end of life care for critically ill patient. For instance, nurse 8 perceived that fear of having to explain their actions to families was a common reason why medical staff continued with futile medical treatments:

> *Here in this hospital, the doctors become afraid from medico legal aspect. For example, one time a covering doctor doesn't know about the patient condition and nothing is written in patient's file either do-not-resuscitate or not. So he does an intubation because the patient become tired and he said that I will not put myself under responsibility in the case if the family ask why he doesn't respond to the patient situation.* (Charge Nurse 8, H2, Medical Intensive Care Unit)

Another experience was reported by the same nurse:

Sometime I don't really believe in some treatments. For example, some doctors order to send a terminal patient who doesn't have a chance to survive to do brain computer topography (CT). I consider this as a futile care or to do Magnetic Resonance Imagination to patient who is on ventilator. In other hand, these treatments are so costly upon hospital, insurance and on patient if he is self-paid. Sometimes, the family say and ask for this type of treatments even you are not believe on them and the doctor also, but the doctor do it because of legal aspect, so because of that the doctor sent the patient to CT scan and after 2 days again sent the patient to CT for the second time. Do you think Issa that the patients tolerate to send them down and then up and to do CT? All this are useless. (Charge Nurse 8, H2, Medical Intensive Care Unit)

This fear of legal liability was aggravated by the lack of clear and detailed policies or standards that guiding the care of critically ill patients. For example, nurse 9 talked about the 'haphazard' nature of care:

They (doctors) take this subject in haphazard way, they don't have a proper knowledge, they don't have standards, and nobody put policies in the hospital how to deal with such type of cases like algorithms I mean. (Charge Nurse 9, H2, Coronary Care Unit)

High workload and staff shortage were among also amongst the barriers to providing care for critically ill patients. The staff realised that the critically ill and dying patients and their families had a particular need for help and support, however, they reported that these needs were often not met due to staff workload and shortage. For example, head nurse one referred to the importance of having a scheme that supported continuity of care for the dying patient by assigning patients to the same nursing staff and having well qualified nurses providing care for dying patients. However she reported that these were often not possible in the light of the resources she had:

From my perspective, these patients (dying patients) need such a different care from nurses. For example, each patient could be assigned to one nurse; I mean not all nurses work with the same patient because not all nurses are able to deal with these cases in proper way; the patient might become confused, and may suddenly become unconscious and many different situations could be happened to these patients. How to deal with these situations is totally different between nurses. Additionally, you have to give the assigned nurse enough time because s/he might spend hours with the patient. However, actually it is not the case. Namely, I have in coronary care unit 12 patients covered with four staff, so every staff should be assigned to other three patients or some time more. Thus the nurse doesn't have enough time. (Head Nurse 1, H1, Coronary Care Unit)

High work load was identified as a barrier to good care by residents and also for specialist physicians. This was reported to affect the time that physicians had to give to support families and the amount of information communicated to them:

> *D1: The lead physicians' workload and ours also plays a role. When you as a resident doctor have a 9 or 10 patients in addition to the consultations and clinic time and so on so forth; we as a resident doctors have that load of work, I don't have one hour of time to talk with every patient and every family. Sometimes I realise that this patient and that family I need to talk to them but really I don't have the time.* (Second Year Doctor 1, H1, Coronary Care Unit)

> *D3: So, the parsimony of information is better for some specialists, and it is time saving for them; spending 2 hours with every patient, when he has 14 or 15 patients. Thus, he sits with every patient for 15 minutes and he will be able to catch up and finish his daily services. The patient load also imposes on the specialist to do this kind of communication.* (Senior Doctor 3, H1, Intensive Care Unit)

Having physicians (residents and specialists) who avoid families was seen as creating an additional burden for critical care nurses. Nurses reported that families would often ask nurses questions to get the detailed information that they hadn't received from physicians. For instance, nurse 9 reported that the families were looking for detailed information from nurses who already have a high workload. The staff accounts show that there is a handing over of the responsibilities of caring for families between specialist, residents and nurses where the specialist physicians rely on residents who rely on nurses to carry out this job. The nurses have also a high workload and don't have a wide range of permissible communication with patients' families. These complex issues are discussed in the following quote:

> *The nature of our work (work load) is another issue. I mean that nurses generally cannot give families detailed follow up like doctors should do. Another thing is the nature of the families, I mean for example, families always have many questions and they need answerers for them, but once the doctor come, they got brief answers and a gain once the doctor leave the family starts to ask us. Actually, we don't have a time.* (Charge Nurse 9, H2, Coronary Care Unit)

5.6 Conclusion

This chapter reports the experiences of critical care staff while providing care for critically ill patients who are likely to die and examines the challenges and barriers that they encounter while doing so. The findings show that providing usual care by carrying on with aggressive

treatments even when it is futile to do so was the common practice. However, some deviations from usual practice were reported to be possible in certain circumstances, including where patients were brain dead, had advanced cancer, or were frail and elderly. In addition, patients with specific families were sometimes treated differently. The interviews with staff show also that 'end of life care' is a topic that the staff talk minimally about either in their daily work or when talking to patients and their families. Legal and religious issues were reported to have a key role in shaping the work of the critical care staff and their perspectives on matters of treatment limitation.

Overall, the data show that the families of dying patients' have a key role in shaping the care that is provided to their dying relatives and were perceived by staff to have leadership in directing patients' care. The next chapter describes how the staff relate to, work with and care for families of patients who are dying in critical care units.

Chapter6: Staff Practices in Family Care and Communication towards End of Life

6.1 Introduction

This chapter focuses in more detail on staff perspectives on and relationships with critically ill dying patients' families in their daily work. Communication, trust and hope emerged as central themes from the staff interviews; these are intertwined and overlap in a complicated and contradictory manner. A central paradox concerns how the staff perceive, on the one hand, that families should take decisions and that the power in decision-making lies with relatives, while on the other hand staff recognise and report a range of problems in communicating with families about death related issues which hinder families' ability to make such decisions. Moreover, the critical care staff recognise that fostering trust within family members is a vital aspect of their care delivery and they perceive that clear, honest and understandable communication has a key role to play within this. At the same time they identify that inadequacies in their communication process with critically ill patients' families can detract from the development of a trusting relationship. Together, communication and trust relationships are regarded by staff as essential in enabling families' hope: generation or sustenance of hope within families is a key goal that staff struggle to achieve. These issues and their complex relationships are discussed throughout this chapter.

This chapter starts by describing the communications that take place between the staff and families. This is followed by exploration of staff practice in building trust relationships when working with families and the roles and responsibilities that they seek to take on order to build such a relationship. The chapter then moves to examine the process and the meaning of hope for family members. The last part of the chapter explores staff experiences and perceptions of challenges in the care and communication process when working with critically ill patients' families.

6.2 Communication with families

As discussed above, the findings revealed a paradox where the staff recognise the essential role of communication with families but at the same time perceive it is difficult and sometimes

impossible to communicate openly. Accordingly, the first section of this chapter describes the essential role that staff perceive that the families have in determining the care to be provided for their dying relatives and how staff look out for or seek to detect the possibility of limiting invasive treatments from families' responses. The staff reports and perception of their 'usual' practices of communication with families of patients who are likely to die are then presented and described. This section also draws attention to some cultural issues, highlighting how death and dying is largely considered to be 'taboo' subjects.

6.2.1 The role of the family

Staff perceived that families were a crucial part of the decision-making process and should carry decision-making power regarding any changes in the course of treatment provided to dying patients. For example, senior doctor five talked about the decisive role of families in patients' care:

> *The power is usually in the hands of families. "The most dominant person about this patient and whether to apply a do-not-resuscitate order is not the consultant who is responsible upon the patient, the family is the dominant one.* (Senior Doctor 5, H2, cover all critical care units)

The doctor described how consultant medical staff are often willing to set on one side their preferred decisions and judgments and instead defer to a patient's family's view about the patient's care. He indicated that he perceived that the family should 'direct' do-not-resuscitate decision-making.

The staff however commented that most of these family interventions that resulted in limitations of treatment came very late in the course of the patient's illness and only after an exhaustive series of life sustaining treatments had been given. For example, head nurse three shared a story of the death of a man who was the father of health care colleague of hers. The colleague asked for resuscitation not to be done and requested that further treatments be withheld, but this was at a late stage and the patient died on the same day, soon after a decision was made to withhold treatments:

> *One week ago, we had here in the unit the father of the previous head nurse of this unit; she is now working abroad (Saudi Arabia). Her father was here and*

he was extremely tired[7]; he was a complicated case. Finally, he developed minimal EEG (Electroencephalography) activity and was suspected to be having a brain dead. At that time, she took a decision to let him die in a peaceful manner; she asked that neither cardiopulmonary-resuscitation nor any further treatments or investigations should be done; he was on maximum support before the decision. However, not all folks like her; she realised that what the quality of his dying will be or the quality of life will be if he reverted. You know the same day she decided the patient died, after ten days. (Head Nurse 3, H2, Medical Intensive Care Unit)

Within all the accounts narrated by staff where families were reported to take a lead in decisions to limit intensive treatments, families were described as able to exert influence over decisions about treatment only in certain situations. These included: if a family had a health care background family member (doctor, nurse or any other health care professionals); if the relationship between the patient's family and the patient's physicians was strong; if the patient had been in the unit for a long time and where staff perceived that the family had higher levels of understanding and education and a more realistic outlook on the likely outcome of the patient's illness. For example, doctor three commented about the effect of having a family member who had a health care background:

It is much related. It eases our work, why? Because he will know, especially if he is a paramedic, how the nature of the things in the hospitals and what happens usually in it. This is if he was a paramedic and not a doctor. As if he was a doctor, he will know the scenario of the disease or the prognosis for any disease how it may evolve to. So if you tell him that your patient has massive ischemic stroke, he will know that this patient, even if he lived, will become dependent on his family. Thus, he knows the prognosis and quality of, and he appreciates things that we perform to ameliorate the patient's condition. (Senior Doctor 3, H1, cover all critical care unit)

Even though having a family member who had a health care background was reported to be a major influence when decisions to limit invasive treatments were made, staff reported that relatives could not always successfully change the direction of patient care. In addition, having a family member with a health care professional background was sometimes regarded by staff as leading to complications in the management of a patient's death or seen as a problem or an interruption to the work of the staff. For example, doctor four talked about two different types of family members with a health related background: one who he perceived was very realistic, understanding and facilitated the work of the staff; and another who interrupted the work of

---

[7] 'tired', as discussed in the first chapter, is a colloquial term for 'probably dying'

staff by trying to get involved in patient's care inappropriately. In the quote below, the doctor perceived that that the latter relative would typically be someone who had some health related knowledge but not enough to be able to understand what was happening in critical care.

> *When there is someone who is medical professional personnel, this will be one out of two conditions: either an excellent thing or it is a tragedy; being in between like lay people it's difficult. Namely, either being an excellent thing where there is an understandable person is who understand everything and being realistic so it's easy to go along with him and he will be more accepting for end of life care, or a person who know but not too much such as having a patient who his son or his father is a nurse and don't know too much or a patient have a fourth degree heart failure and his son is a paediatrician and doesn't know about his father condition and even he couldn't understand about it; he has a little medical background but not enough to start arguing. In the latter case, those people start to interfere in everything related to their patient care and this is a tragedy; the time you could spend with the patient, you spend it with them instead. This is really a problem.* (Senior Doctor 4, H1, cover all critical care unit)

Counselling

The medical staff often referred to the term "counselling" when describing their attempts to communicate with families about end of life issues and when they sought to encourage families to decide about any medical treatment or when they perceived a need to gain a family's agreement to interventions such as an operation, elective intubation, tracheostomy or any other diagnostic procedure. The staff accounts show that "counselling" took place when staff perceived that there is a need to limit some invasive treatments and where they were concerned that families assumed the responsibility and accountability for decisions to limit treatments.

In this counselling, the medical staff tried to provide families with information around the decisions the families need to make, including: the futility of patient status, the treatments possible done; the futility of these treatments; the possible outcomes; how the futile treatments would affect the patients e.g. suffering and death of the patient due to treatments severe side effects; loss of contact with the patients. For instance, doctor four described her experience of 'counselling' a patient's family about elective intubation:

> *Here in Jordan there is nothing called do-not-resuscitate. With every patient whatever the case with whatever the life expectancy needs active managements to the last moments even with counselling. For example, the patient's family who I did counselling regarding the intubation (the participant talked before about an end stage cancer patient need elective intubation), according to*

Jordanian health laws I should intubate him because medically he needs intubation. However, as a physician, personally or as a matter that is well-known that he will not benefit from the intubation, but from medico legal aspect the family should sign the "against medical advice form" if they wish him not to be intubated. So at that time, I counselled them (family) that medically the patient needs to be intubated and you have two choices, either firstly to intubate the patient as usual but with this the patient might not tolerate the intubation and we might lose him and the intubation will not benefit him and furthermore if I intubate him I will send him to intensive care unit and you won't be able stay with him anymore; or secondly for legal purposes you sign that (the patient not to be intubated) was your request and take the responsibility. They refused to sign. You know it is not easy for family to fill this form (against medical advice form) and it's difficult for them to sign it as well. You know the time you ask for a signature all of family members draw back; so with this we have to work with active management. (Senior Doctor 4, H1, cover all critical care units)

6.2.2 Staff perception of effective communications

The staff talked frequently about the importance of "effective communication" in providing care for terminally ill patients. For the staff effective communication meant providing information about a patient's status at the right time (on admission and then continuously throughout the stay on the unit), in the right quantity (including detailed with clarity and frankly), with the right persons (including both right staff with right family members) and of the right type (emotionally and religiously supportive communication in addition to the medical related communication).

Head nurse three talked about the importance of the communication with critically ill patients' families by doctors, talking about the culture of 'doctor dominant'[8] in the community. This means that patients' families rely on and greatly respect communications with medical staff and decisions by medical staff. For many families, the medical staff is seen to be the primary decision makers about patients' care, even though medical staff perceive that the families should decide. However, the head nurse talked about the constraints upon doctors' communication with patients' families and the related difficulties for nursing communication:

So, families always don't have a full picture about the health status of their patients. You know we are in a community where people like to hear from doctors, to be assured by doctors and to be cared by doctors. So nurses are in the first line position for families, because they are always present with their patients. We as a nursing, we are not allowed to communicate with families that

---

[8] 'Doctor dominant' is a term used commonly among professionals in Jordan and it is quite clear in the Jordanian context.

much amount of information about their patients and we are always busy in addition to what I said that families like to hear from doctors rather than from nurses because they think that doctors will assure them or they have more information. (Head Nurse 3, H2, Medical Intensive Care Unit)

Another aspect of effective communication perceived by staff was the provision of detailed information. For example, head nurse two presented her perspective about the information that should be provided for families by doctors, while making it clear that in her experience this rarely happened. She perceives that the information should include: life and death expectancy; communication of hope in realistic and tangible terms; conveyance of both hopeful and difficult information and attainment of families' satisfaction in terms of communications.

> *You know the doctors don't sit with families and explain to them, for example as a doctor, after admitting any case and after doing the assessment, he is supposed to talk with the family about the life expectancy for the patient, the expectancy to restore his or her life or the expectancy to discharge from the unit; doctors should provide both the positive and negative side; provide realistic hope or how much we should hope; but they don't communicate these things; they just [do it] if families ask, [and then] they give them "short answers", you see what I mean? They don't meet families' expectations in terms of communications; they don't make families understand the health status of their patients in detail. Additionally, families expect and accept from doctors more than nurses; also their acceptance from resident doctor is different from when the specialists come and sit with them.* (Head Nurse 2, H1, General Intensive Care Unit)

In describing their perceptions of effective communication, the staff pointed to the importance of decreasing or minimizing the gap between what families know and expect about the patient's condition and what the staff know and expect. Nurse three shared her experience with this issue. She described how a potential for conflict with families is created from a combination of not allowing family members to stay with patients during the night or out of visiting hours, and ineffective communication from doctors about possible outcomes:

> *You know, because it is not allowed here in the unit for patients' families members to remain with their patients during the night, It happens to me many times when family members come in morning confused and angry because they did not know what happened to their patient in the night; that happens once they see their patient intubated and mechanically ventilated; we did it as an emergency response. You know, for families the patient was talking one day before and he was normal from their perspective, but for us we realised the expected full scenario that the patient will follow and we knew that the patient will be intubated and ventilated. So they become very angry in the morning asking what wrong you did for him and so on. The physicians should tell families*

before, what are the possible scenarios might be; this will ease our work. (Junior Nurse 3, H1, General Intensive Care Unit)

This issue of having a family member present continuously was also explained by nurse 8 when he was asked in the interview about a comment he wrote on his survey questionnaire about having one patient's family member stay with the patient through the night. His quote below alludes to another aspect of effective communication, which is keeping patients' families oriented about their patients all the times:

> *I mean it is better if one of patients' family members (not all family members) always remain with the patient all the time especially at night to tell them for anything new and to be oriented about the patient prognosis constantly- that will ease our work.* (Senior Nurse 8, H2, Medical Intensive Care Units)

Table 6.1 illustrates more experiences from staff interviews showing the aspects perceived to make up effective communications with critically ill patients' families.

Table 6.1: Effective communication

1. When doctors and even nurses talk with families step by step, for instance, with this patient we are talking about, if they have been told that the patient has a liver failure; his blood level of ammonia is high; this mean that the level of ammonia on brain will increase, the coagulation system will go down and as a result the patient is highly susceptible to bleeding and hypotension; all that will affect the heart. With communicating these things step by step, the family start to feel that they are involved and they are a part in health care that is provided, you see? And this is the mission of this hospital which is to provide the best care for patients and their families and to get families involved with patients care. (Second Year Doctor 10, H2, General Intensive Care Unit)

2. To get change, they (doctors) have to promote their communications with families; making them get the idea in simple and detailed way that the patient is dying; they don't need to teach them medicine; making them accept the situation. So, family's reaction will be different in a way that everything will be easy for doctors themselves and for us. (Senior Nurse 14, H1, General Intensive Care Unit)

3. The first thing is that their way of communication is not good. They took one of family member and just any one and talk with him by throwing two words and that set. The proposed way is to take a group of family member who are mature and can understand, we can said the older ones, the specialist sit with them along with the social worker (by the way there is a social workers here in the hospital but they don't perform their role or their role is not functioning) and the resident doctor. All the three set together and explain the case and the possible treatments and all things. In reality and what happened in that case, the resident doctors go to patient's family and talk just words "if something happened, do you need to do or not to do this and this" and usually this is what happened (Charge Nurse 9, H2, Coronary Care Unit)

4. If we could deliver religion correctly to the patient and the families, we will really improve their "Nafsit-hum"[9] and their cooperation with the staff. It is all about how you talk to the family and in a correct way that is it, and that will be at ease. (Head Nurse 1, H1, Coronary Care Unit)

5. The second thing is the psychological care for dying patients and their families. It is their right to have such a type of support, but actually we don't provide it. (Senior Doctor 7, H1, cover all critical care units)

6.2.3 Staff Usual Practices of Communicating With Families

According to normal practice in the hospitals where this study was conducted, for each patient there is at least one specialist doctor. Often there are several specialists, one lead specialist and other specialist to help or to "consult." Under every specialist there are doctors in training who are learning the skills of their specialty. These are called resident physicians. The staff reported

---

[9] "Nafsit-hum" a slang language means the psychological status.

that lead specialists usually visit their patients once daily, usually in the morning. After seeing a patient, the specialist talks to the patient's family who is usually waiting outside the unit. After that the family is left to relate to the particular specialist's resident physicians. These residents thus become the link between the families and the specialist. Except for their daily visits, most of the specialists' communications with residents and other staff occur via telephone.

When communicating with families, the staff reported that the communications are usually conducted with patients' first degree relatives: these might include the sons of an elderly patient, the husband of a female patient or the father of a young patient or brothers if the father is not available. For example, nurse 8 reported this experience:

> *We usually communicate with the first relative, I mean sons, brothers, daughters, wife and husband.* (Charge Nurse 8, H2, Medical Intensive Care Unit)

However, on rare occasions other people might be involved.

Head nurse one also elaborated on what she meant by patient's first relative when communicating with patients' of large families. The nurse talked about communicating with a specific person/s in the family members like the eldest son or the oldest two sons or wife. This was reported to be done when communicating bad news:

> *The next of kin, let us take an old age patient, I'm not going to sit with his son in law, his cousin, his nephew, and such that ! It may be the eldest brother in the family, the eldest son, the oldest two sons, or his wife. Those people concern me more and they are more helpful with the patient than other people.* (Head Nurse 1, H1, Coronary Care Unit)

From a staff perspective, this mode of communication was seen as appropriate for different reasons including: the difficulty sometimes in gathering all a patient's relatives at the same time; maintaining patients' confidentiality; minimizing the possibility of family members reaction by avoiding family member who cannot tolerate bad news and avoiding staff discomfort when communicating with a large number of people. Doctor three explained why medical staff don't like to communicate with extended families, describing this as a matter of confidentiality:

> R: Had it occurred that you communicated in a meeting room?

D3: No, why?! Because you can't know when all close family members are there. They may be 4, 5, 6, or 7 and not all of them have a close relation to the patient. You may have a cousin or any member that is not a first degree; there are usually 3rd or 2nd degree relatives. And the patient has his own privacies, and you can't expose his own secrets in front of all people. The family may prefer that this person or another (outside the family) not to know such information, so you have to avoid such communication. (Senior Doctor 3, H1, Cover all critical care unit)

In terms of communication of bad news, the staff reported that it is better to engage with just one or a few persons. These people are usually the eldest male individuals in a patient's first degree relatives and they are then responsible for informing the rest of the family members. The staff reported that they always avoid conducting a bad news discussion with a female relative. Below, nurse 9 talks about the most appropriate way for bad news communication where a large family is involved. This was through talking with only the person who is considered 'big'[10] in their family or clan:

You know, the good thing in the clan that when you need to tell them a bad news, you need just to search for first relatives people who are also 'big' in the clan and tell them that I need to talk with you, but if you talk to a young people, they wouldn't endure the news and may have a negative reaction. (Charge Nurse 9, H2, Coronary Care Unit)

Head nurse one talked about the importance of choosing one family member as a designated person to inform other family members of the bad news. The head nurse commented that this designated person will know better than the staff whom to inform and the way that they should be approached:

For example, doctors may communicate with one of the patient's brothers. This brother for example may inform the other brothers; the sister may be sick if she hears about her father, so he doesn't want the bad news to reach her. He knows better than I do. She may call here and I answer her that her father is tired; he will be more competent on whom to give the information and how. (Head Nurse 1, H1, Coronary Care Unit)

Staff reported that most of the communication carried out with families' takes place at the patients' bedside or other places in the unit e.g. nursing station or corridor rather than being in a meeting room. A few staff reported that they had experienced communication in a family

---

[10] 'Big' person in a family or a clan is a cultural concept which referred to the person who is valued by other family or clan members. Sometimes, this person would be the older one, the highly educated one or have a very important position in the community.

meeting context but this was rare. For example, the head nurse one reports the places where the communication with families could take place:

> *HN1: Sometimes in residents' room and sometimes in patient's room it (communication) happens. The physician may tell me "call for me his first relatives"; the conversation may take place near the patient's room.*
>
> R: Had it happened as meetings?
>
> *HN1: No meeting, No; in proper way, also no. The physician may take them to the resident's room and it is rarely happen and most of time may be just in patient's room or the doctor may walk with him along the corridor and that is all. But that he sit and talks with them in a correct way, if we may say, no.* (Head Nurse 1, H1, Coronary Care Unit)

6.2.4 Death as a taboo subject

The staff interviews show that death is a topic that they talk rarely about with dying patients' families. The findings demonstrate that what was important for critical care staff was to 'tell without telling' i.e. to let the family come to their own realisation about the approach of death without explicitly speaking to them about death. Rather than communicating about forthcoming death directly with families, the staff followed a sequence of indirect communication in order to try to disseminate bad news to patients' relatives. Once the staff acknowledged that a patient is dying, they reported how they sought to communicate uncertainty to relatives, by use of phrases such as: 'nothing clear to us, 'we don't know exactly' and 'we hope for the best'.

Medical staff only very rarely perceived that it is possible to communicate about death and dying clearly. For example doctor three talked about the nature of the death related communications with a patient's family from the day they knew that the patient is dying, through the 10 days of intensive care to the day of the patient's death. His quote displays the indirect manner in which the medical staff communicate the idea of dying to patients' families. The doctor describes how 'the facts started to uncover themselves', which means that rather than communicate patient's dying clearly, the staff rely on the family developing an understanding of the possibility of death from the use of general terms like 'very bad', 'no improvement' or -as in this example- the use of a drowning metaphor:

It is at this point when the facts started to uncover themselves to the family. How did it uncover? As you start to tell them "his condition is very bad", and this was our response whenever the family asked us and that "there is no improvement". We were trying to give the idea that the patient's condition is getting worse. We use this phrase very often: "as the patient is in the intensive care unit, he is drowned under 100 m, so whatever is the improvement it will be a 10 meters, thus he is still drowned!" It is this phrase what we try to get them to understand, or something that conveys such a meaning. (Senior Doctor 3, H1, cover all critical care unit)

The messages used by staff were reported to include: clinical terms, religious terms, hopeless facial expressions and instrumental or terms that express the exhaustion of life sustaining treatments. The following were phrases frequently reported: "we lose our control"; "the patient is extremely tired" "the patient is on maximum treatments and dose of medications"; "the patient's body doesn't respond to the treatments"; "the patient's heart and body is very weak"; "the situation is very critical"; "we did our best and the rest is up to God"; "let us pray for him/her" and "the hope only is in God's hands". Some critical care staff perceived that using these terms was as clear and as honest as it was possible to be with families; others regarded these as vague and ambiguous terms and felt uncomfortable about their use. For example, nurse three reported her perception that using these terms sent a clear message that the patient is dying:

When she (patient's daughter) asked me about her mother situation, or like this question (prognosis related question), I had been talking to her clearly that she is on maximum support but her body doesn't respond appropriately to this support. We do our best and hope the best; all things are in God's hands (power); let's pray for her. You know by communicating like this, she will understand that her mother is dying. (Junior Nurse 3, H1, General Intensive Care Unit)

Most of the nursing staff perceived that discussion with families of terminal status or dying may be delayed or may not happen at all. Consequently, the nurses in the study reported that having families who were not aware that their patient was dying is a common phenomenon. Nurses described how some families who never got to the point that they perceived their patient was dying until the time of death because they misunderstood what staff meant. For example, head nurse two describes the problems this leads to:

I feel that the problem is from the beginning; it is not communicated from the beginning; I mean communicating that a patient for example is dying; what you need to do is to communicate with families rather than telling them that your patient is clinically bad, bad prognosis or hopeless, just tell them that actually

the patient is on his or her end of life stage and dying. Sometimes families get shocked when their patient die saying that we don't know that the patient was dying; the families usually said: okay the doctor said nothing changed, but didn't mean that he is dying or the doctor doesn't tell us from the beginning that the patient is going to die. Frankly, this happens so many times. I don't know why doctors don't tell families from the beginning? They need to tell them that we do so and so and you find this and this; give them details so they can get the point that their patient is dying. (Head Nurse 2, H1, General Intensive Care Unit)

As discussed earlier, on the rare occasions where the communication of dying was carried out clearly, this took place only in very specific situations. For example, when one of the patient's family members was a health care provider, when there is a good and trusting relationship between the primary physicians and the families, when patients had been frequently admitted or if there was something special about the family.

The staff reported that a long critical care unit stay has a major role in preparing families for a loved one's death. This works by making families realise over time that everything is drawing to an end and by providing enough time for them to accept that the patient is dying though observing the changes in the patient's condition. Additionally, a long unit stay was perceived by staff to strengthen the relationship between staff and dying patients' families, enabling a better chance for staff to communicate about forthcoming death. For example, head nurse five compared a family's condition at the time of their patient's admission and after staying for some time in the unit. Whereas they were described as stressed, anxious and in denial at the time of admission, they were described as becoming calmer and more accepting later on. The head nurse also described how that it is more appropriate to talk to families after they have spent some time in the critical care unit:

Time. Only time and nothing else makes families become more accepting. I feel the time is enough for families to become calm and accepting. At the time of admission, they are much stressed, anxious and [in] denial; you will find all family members in the unit in a fearful manner. With time then, the things become more...I mean...become acceptable for them. At that time you can communicate with them otherwise you will fearfully rejected. (Head Nurse 5, H2, Coronary Care Unit)

Nurse 8 echoed the same perspective in his interview. He shared a story about a young patient who stayed in the medical intensive care unit for about six months. The nurse compares the family's response to their patient's situation at the time of admission and then six months later:

The acceptance of death goes with time no more any less. Just let me give you an example. We received a 26 years old patient from other hospital having an organ-phosphorus poisoning… During the first time his family were much stressed and emotionally hurt, you see they were losing a guy with 26 years old and it is not easy to accept that. With time, the family started to realize that their patient will stay on mechanical ventilator. This situation stays for nearly 6 months. You see the first 2-3 days they were very afraid and stressful, but after that they started some sort of adaptation. In late stage his father said that if he died in that time (before 6 months) it is better and I forgot him and the family started to wish the best for him (dying). In that time, the patient's family accepted the situation but if he died at the first time it will be very difficult and a big shock for them. (Charge Nurse 8, H2, Medical Intensive Care Unit)

6.2.5 Staff perceptions of their communication practices

In this section, I examine the perceptions of the staff about their communication practices with critically ill patient families. I explore the nursing staff perceptions of doctors' communications, and then examine doctors' perceptions of their own communication. Lastly I explore the nursing staff perceptions of their own practice.

6.2.5.1 Nurses' perceptions of doctors' communication practices with families

As discussed earlier, the nurses saw medical staff communication with families as essential and realised that good communication between doctors and families enables a trust relationship to be built with families. Nurses reported that most of the doctors' communications with the critically ill patients' families were about clinical issues: current health status, laboratory results and diagnostic tests, planned medical interventions and prognosis. However, they described that very little communication took place between doctors and families about patients' poor prognoses although nurses perceived that this was important and influenced the possibility of future communications about dying with patient's families. For instance, nurse four talked about the problem that some families don't realise that their relatives is dying until the time of death:

The problem is that the doctors should give them (families) the possible outcomes that would happened for their patients, for example it could happen one, two or three (participant mean different possibilities); it is totally depend on the communications that are conducted with families; families don't get their patients status clear 100%. With the point that patient is dying or may die, doctors don't talk about with families. So when patient dies, families will get surprised asking "how he dies? He was fine? (Junior Nurse 4, H1, General Intensive Care Unit)

The findings demonstrated that this occurred because medical critical care staff usually avoided communicating bad prognosis and possible poor outcomes. Below are quotes of a conversation with the charge nurse 9. The nurse explains that doctors usually avoid communication with dying patients' families because they fear families' reaction and legal claims. The nurse talks about the use of general and vague communications about patients and how doctors often avoid further communication:

> *N9: Yeah, I talked with the family many times. Of course, the doctor avoids any communication with the family, but I talked with them many times and there were very acceptable and religious people even I get surprised from their response; I mean the family.* (Charge Nurse 9, H2, Coronary Care Unit)

> R: "Tayeeb"[11], you said that the doctor avoid any communication with the family?

> *N9: Exactly, I don't know, I feel that they afraid from legal responsibility and from the "Towash"[12]. You know, doctors and we (nurses) are not protected, and nobody protect us and we were assaulted more than once and nobody, neither the hospital nor the nursing council or anyone else protect us. So we become afraid from the aggressive response of some families and in order to avoid that, sometimes we give a vague response. I mean we used to say that "there is nothing clear to us", "we don't know exactly", "we do hope that the patient will become better" and " just pray for God to choose the best for patient".* (Charge Nurse 9, H2, Coronary Care Unit)

In addition to using general and vague communication as a way of avoiding families, the nursing staff reported that some medical staff and the specialists in particular use false hope as an another way of avoiding families' questions. For example, head nurse one reports that some specialists avoid families and hand over the responsibilities of communication with families to other staff (including nurses and residents):

> *We (nurses) get the feeling and start to realize that he (the doctor who give the false hope) just wants to soothe them (the families), or to keep the status quo.. He gives hope and silences the family. He doesn't want to enter in many discussions and arguments with them. Too much questions, why this and why that. He doesn't want to go in the details with them, so by this he eases his mind. Besides that the specialist, basically, doesn't come often, doesn't have full details about patients and it is the resident and nurses whom in the face of the family. So they leave the communication for us and for residents as well.* (Head Nurse 1, H1, Coronary Care Unit)

---

[11] "Tayeeb" Slang term works like okay.
[12] "Towash" is a slang word means conflict with patients' families and being assaulted by them.

As doctors were perceived by nurses to avoid communication with families, the nurses reported that it was usually families who tried to initiate the communication process by asking medical staff questions. Nurse 13 described this, again referring to the use of general and vague terms:

Usually families ask for information about their patient's status and prognosis. When the doctor gets in to the unit, the family start asking, how is the patient? Any change? Is there is any sign for good prognosis? Usually their answer is "actually no changes". Families understand this answer as a good thing; they comprehend it as we have a control over everything. You know, there should be a change to the better side, so no change is not good sign; they have to give details. (Junior Nurse 13, H2, Coronary Care Unit)

Based on all of these things, all nursing staff in this study perceived that doctors' communication with families is ineffective. The quote below presents the head nurse three experience of ineffective doctors' communication with dying patients' families. The nurse comments on a conflict that often happens between nurses and doctors:

The conflicts always happen in the honesty of the information that is given to the families. It happens when a family is told that all is well with the patient, while the patient is on noradrenalin and dopamine and the patient is unconscious. For last moment that, they (lead physicians) keep saying that "the patient is well" and the family hold and stuck to the idea that patient is well and if things happen they (the families) ask why did that happen, the patient was well?. For example, when they ask why his oxygen has fallen, why his pressure is dropped, and they fall of surprise as the nurse tells them that the patient is on medications for pressure, on treatments that support his ventilation; they don't have such information and details from physicians. Thus, as they hear the actual patient's condition from the nurse, here starts the conflict. The physicians never give complete information to the patient's family, or even to patients themselves. Namely, complete information: no, sufficient information: no. At all: no. (Head Nurse 3, H2, Medical Intensive Care Unit)

Another experience that echoed the issue of ineffective medical staff communication was reported by head nurse one:

The problem is that there is no one explains to them (families) about their relative health status; because…You know we have social workers here, but the role is not functioning at all, or at least in my unit; I don't know if they are working with cancer patients in floors. Doctors don't explain; they really far away from families, families are in one place and they are in a different and far place; the last thing they think about is families. (Head Nurse 1, H1, Coronary Care Unit)

The nursing staff talked about the importance of having a particular person who takes on the responsibility of communication with patients' families other than medical staff. This was voiced by head nurse three who said that ideally this person should be a nurse who specialised in psychological support or a social worker:

> *If we have a person who is his/her duty is to communicate with families and articulate the patients' situation and make their hopes more realistic; this person may be either a nurse who specialised in psychological support or a social worker.* (Head Nurse 3, H2, Medical Intensive Care Unit)

6.2.5.2   Doctors' perceptions of their communication practices with families

The nurses and doctors in their interviews shared a common observation about the medical communication process with families. Firstly, although nurses reported more about the issue of ineffective medical communication with families in their accounts, the medical staff themselves perceived that their communication (including the specialists and residents communications) is ineffective. For example, doctor 7 talked about his experience in working with his medical colleagues in terms of their communication:

> *Some of them are good communicators with families, whereas some of them are very bad ones. Without telling names, some physicians have communication as their sole weapon, which they use when working with families. You know, not everybody have the talent of sending information in easy and acceptable way for families. Communication for some doctors is a really magic weapon while it is really a problem for others. Communication also is very important for families; they always evaluate doctors and their work based on their communications. You know, most families don't have that much of medical knowledge, so communications for them is the only sensible thing* (Senior Doctor 7, H1, Intensive Care unit)

Secondly, the observation that medical staff communications usually lack reference to prognostic outcomes and in particular the possibility of death was also clear in the interviews with the medical intensive care staff. For instance, doctor three confirmed the perception of nurses that specialists avoid communication with families by using general and vague terms:

> R: You have said earlier that the specialist should have explained the full scenario? (Interruption).

> *D3: Exactly, he should provide them with the best picture of the situation. He informs them that the patient has poor prognosis. But he doesn't explain to them how the poor prognosis will ensue in the hospital and what might be the*

possible outcomes, this is the point and this will ease our work dealing with families. (Senior Doctor 3, H1, cover all critical care units)

Thirdly, avoiding communication with families was also a feature of the medical staff interviews. For instance, doctor 6 voiced this observation while working under specialist physicians:

Most of the specialists avoid families? For example, they don't provide the full communication; they just saying that the patient has poor prognosis; we do the best; we all hope in God and nothing more. (Second Year Doctor 6, H2, Intensive Care Unit)

The staff talked about the issue that some doctors and in particular the specialists intend to delivered optimistic information toward patients' recovery while communicating with dying patients' families. Giving optimistic communication was seen by most of the nurses and doctors as a way to avoid families and avoid threat to their position. For example, doctor five talked that they as medical staff had experienced specialists giving false hope in a very frequent basis. The doctor perceived two explanations: family avoidance and incorrect evaluation of patients.

Some physicians, of course we see too much, give families a false hope. These types of physicians used this way in order to escape; I mean escape from families. This because our community is 'Lahoh'[13] in its nature; I always say community, but it is actually the nature of human being, for example if I give a family a hope, they will keep asking 'please assure us', 'dose this hope increase or decrease'; if I said his (patient) getting worse, the family will keep asking and in frequent why that deterioration, will he become better, what happen, how you know and so on so forth. In the other hand, theses physicians who give false hope used to say 'patient's condition is good' so patient's family get comfort without further questions and the doctor give his back and leave. Yeah! This is truth we used to see in our work; even so many specialists; they do that in order to get themselves comfort, of course not always (Researcher: any other reasons?) may be wrong decision; yeah, may be a wrong evaluation. No one is away from mistakes. You know, because specialists most of times are not in the unit, so most of their judgments are based on phone calls with residents; he may see the situation differently. (Senior Doctor 5, H2, cover all critical care units)

Wanting to assure families at the time when they are very anxious and stressed was another explanation cited by doctors for optimistic communication. For example, doctor three talked about his perceptions of hope in specialist communication with families. Interestingly, this

---

[13] 'lahoh' is a slang word. Here it means asking many questions repeatedly.

doctor has a different view in contrary to all other medical staff; he didn't refer it as false hope, instead likening it to the provision of hope based on a slight possibility; i.e. minimal hope based on prior experience of unexpected outcomes in some unusual cases:

> *No, not very much. Not all specialists resort to it; but some do what you may not call a false hope, instead those specialists may be convinced that the patient has a chance of a good outcome. Those specialists have more experience than me, have seen more cases, and have seen cases that was considered hopeless and actually got better and improved. So, such specialists sometimes from their experiences know that there would be a minimal hope for good outcome with a patient case. This minimal hope is the hope that would be communicated.* (Senior Doctor 3, H1, cover all critical care unit)

The idea of the ideal scenario of having a specialised person to take on the duty of communication with patients' families was also echoed by medical staff. Work load, time constraints and limited contact with families were reported to prevent medical staff from communicating with patients' families effectively. Thus, the medical staff see that other people for whom these factors might not be issues would do better in relating to families:

> *We could make educational campaigns especially in the hospitals. And we may assign a person to talk to the patients and their families and tell them about the disease and its consequences. This will improve their knowledge and we shouldn't constrain it to the doctor. The doctor may not have the time to inform the family of the whole details. This person, who may inform them more thoroughly, should be a person who is not related to the doctor or the family and this I think will make things easier.* (Senior Doctor 3, H1, cover all critical care units)

6.2.5.3 Nurses' perceptions of their communication practices with families

The nursing staff reported that as physicians are busy and avoid conversation with families, that they are the most convenient information source for the critically ill patients' families. They reported that the families refer to them for a full, detailed and continuous update on their patients' status source. Additionally, the nurses also saw themselves as the families' interpreter for doctors' communications and sometimes as 'care mentors' when families were counselled about care decisions. For instance, nurse one voiced this issue in the quote below:

> *Here, the communications between doctors and families are valuable but not enough. Valuable in the mean of that patients' families always don't convinced to hear from someone other than doctors; also to hear from specialist is better than residents. I mean even you as a nurse talk to them about patient all the day*

and night, but they (families) always ask for doctors. Although specialists talk just few words, but for families it's different. On the other hand, the communication of them is not enough, as I said they talked few words and they go. So families keep all the day asking nurses for details about their patients, their treatments and what will happen next. (Senior Nurse 1, H1, Intensive Care Unit)

Nurse 9 talked about the issue that nursing staff in critical care units work as a care mentor for critically ill patients' families toward end of life care and decisions. He narrated a story where a patient's family members referred to nursing staff and sought their views and guidance when the patient's doctor counselled the family toward do not resuscitate practice:

The family referred to us (nurses) many time. No one of them was able to take the decision. They were coming to us asking what is your opinion and what we should do and we said the same thing as doctor, because we cannot talk more than that. (Charge Nurse 9, H2, Coronary Care Unit)

Because of their long shifts and their proximity to the bedside, nursing staff perceived that it was important to get communication right with critically ill patients' families in order to avoid future conflict. Additionally, the nurse is in a convenient position for families to communicate with; for example, nurse three describes how they are in a more convenient position than doctors to communicate with patients' families:

Let me get that clear for you. On admissions or if something happen suddenly, you know in intensive care unit patient's health status would be changed in a minutes, families become very scared and distressed, okay? The family come and stand beside the patient's bed, of course the doctors are not always bedsides, because you know doctors have more than one patient; I mean that the intensive care unit doctor taking care for more than one patient and they don't have a time being provide time for families. Then family will come to the nurse assigned for their patient; if you as a nurse don't have a full picture about their patient case, be sure that they will get aggressive and become angry. On contrary, if the nurse is a good communicator, which is very important, and know with details about the patient status, they will accept the condition smoothly. (Junior Nurse 3, H1, General Intensive Care Unit)

In addition, most nursing staff expressed their ability to communicate effectively with patients' families if they have the legal 'green light'. For example, head nurse four talked below about her staff in terms of their ability to work and communicate effectively with critically ill patients' families. Another experience displaying this perspective was reported by nurse nine presented below:

HN4: There are a good percentage of the staff who can communicate with patients' families properly. Some of them are religious and they can talk with families from that aspect; other staff are good in building social relationship with families so they can communicate with them freely. However, we always say that it's not our responsibilities so we most of time keep ourselves away to avoid problem. (Head Nurse 3, H2, General Intensive Care Unit)

N9: I am one of the nurses who can deal with patients' families when the patient died and I can absorb their reaction. In term of other staff, most of them, yeah especially the senior ones for example, "y" nurse can deal with the families with a very beautiful way. (Charge Nurse 9, H2, Coronary Care Unit)

However, the nursing staff reported that they don't have a much scope to communicate with patients' families; they perceived that they are not allowed to communicate some forms of information to families, including: diagnosis; possible outcomes; disease progression and diagnostic results. However, they reported that they can discuss treatments provided to patients; patients' haemodynamic parameters; pathophysiology of disease or explanations of what that doctor has said about diagnosis, prognosis, outcomes or diagnostic examination results *if* the family asks about this. For example, head nurse three explains the type of communication that nurses are permitted to conduct with families:

They (families) usually come asking about their patients. We communicate with them according to what is permitted for us to communicate; I mean among my authority; we have to communicate according to our job description. For instance, I wouldn't communicate about the diagnosis; we would talk about patients' hemodynamic parameters according to the patient's monitor; we would talk about anything surround patients' bed including machines, medications and fluids provided for patient; you know something like why we start patient on fluoride, or why we start patient on this medication or that treatment, something like this; you know, like that you educate families about their patients. (Head Nurse 3, H2, Medical Intensive Care Unit)

The same experience was voiced by head nurse one, who talks about how nurses can indirectly communicate the 'un-allowed information':

Look as a nurse it is of my authority to give any information to the family if it is not pure medical; I can't, for example, give them a diagnosis. I can indirectly tell them about their patient, but not directly that there patient is end of life. I can tell them the following, "this patient is on high dose medication" or "the patient is on respirator which is indicated for critical patients". But we don't go into the details, like that the patient brain is this or that, or we will do this or that. No, honestly, we rarely go into details. As a nurse it is not part of my responsibility to do that. If the specialist says that he is suspecting something and he wants to do some imaging investigation and inform the first relative

about that, the family might ask me about it what would I answer: I'll say just that I don't know; like this I would answer: the image has been done and when the doctor comes he will tell you the results and so on. You can't give more than that. (Head Nurse 1, H1, Coronary Care Unit)

Nevertheless, most of the nursing staff in this study reported that they sometimes choose to communicate to families everything, as they perceived a doctor should do. They explained that the choice to do so is totally dependent on the type of families that they are communicating with i.e. whether they perceived them to be open-minded, good communicators and showing signs of accepting their patient's situation. For example, head nurse three talked about the amount of information that nurses provide for patients' families. The head nurse correlates the assessment that undertake of families and the quantity and quality of information would be communicated:

The quantity of the information we would provide depends on our assessment of patient's family members. For example if they are mature enough; I mean for instance, in the meantime, among the families who are outside the unit, there is families whom I haven't talk to them at all, because I feel that the quality of their brain or their mentality so much difficult; so I cannot deal with them, You see. On contrary, there are other families who are very polite and they accept nurses, so you can deal with them gradually. Namely, as a nurse, I teach them about their relatives' status, the criticality of their situation and then what myself as a nurse expect from my experiences, both positively and negatively; you will find them acceptable. However, there are folks who have a difficult mentality so you couldn't react with them or even to talk with them, so we always refer them to doctors. (Head Nurse 3, H2, Medical Intensive Care Unit)

In contrast, nurses reported that they sometimes avoided communications with families to avoid any possible discrepancies between nursing and medical staff communications which may lead to families' confusion and conflicts.

6.3 Staff-families trust relationship

6.3.1 Trust and Lacking of trust

Through their description of their practice, the staff perceived the importance of building a trust relationship with families and they used a variety of terms to communicate this. Some of the staff explicitly used the word trust, although not all. Establishing a trusting relationship with patients' families was perceived by the staff to be especially important when staff perceived

that it was likely that the best course of action is to limit life extending treatments and to avoid accusations of blame or negligence. For example, doctor one talked about the mistrust as a reason for providing futile care. The doctor pointed in the quote below that losing trust between specialist and patients' families compels doctors to carry on with futile treatments to avoid accountability:

> *It is a matter of trust between the doctor and the family. Without trust, families hold the perception that there has been a mistake and negligence has took place. So, if they perceive that there has been a mistake, it will be a problem. The specialist is the first person who is accountable to answer regarding his patient. So, the specialists usually acts proactively to prevent what may be perceived as negligence or a mistake. For example, a brain dead patient's family may ask, why this patient has not done a computed tomography (CT). You can't just say to the family that your patient is dying and it is useless to do so, so I don't have to do the CT; they will never believe you. Thus, trust plays a role in such condition.* (Second Year Doctor 1, H1, Coronary Care Unit)

Problems of blame and staff-family conflict were commonly reported by the staff. For example, head nurse five talks about how the staff are the appropriate target to be blamed when the family are grieving and struggle to accept the reality of their loss:

> *We always accused by families as we neglect their patients; they always blaming us for their patients deterioration. This, because they don't have a good idea about their patients' status; they don't know how much effort we do trying to restore their patients' life; they don't realise that if patient entered intensive care unit that mean that that patient is critical.* (Head Nurse 5, H2 Coronary Care Unit)

Doctor four reports that the family's lack of appropriate knowledge is the key driver behind mistrust. Interestingly, the doctors hold the perception of the importance of providing families with appropriate information in building trust even though they avoid giving this information:

> *There is an absence or little trust between a patient's family and patient's doctor. Our community, in its structure, lacks the trust and this affects us. There is no full trust that we are doing our job. The family keeps repeating that there is some defect in our job. So, the trust between you and the family is not 100%. There is always a doubt of negligence in care…the trust between families and patients' doctors is shaky and as I have told you before the family's lack of proper knowledge is the reason.* (Senior Doctor 4, H1 cover all critical care units)

One of the major reported reasons relating to mistrust was due to ineffective and minimal communication with patients' families. Detailed, honest and understandable communications

with patients' families were seen as vital strategy to have such relationship. However, while the staff perceived this to be important in abstract and ideal terms, they reported that in day to day interaction it was challenging and difficult to achieve. Nurse 9 alluded to the importance of trust by using different terms like "families become involved with us and accept us" and "we had a strong relationship":

> *From my perspective, explaining to patients' families the expected outcome; articulating the case itself, communicating patient's prognosis day by day and give families a follow up even it's a simple follow up and making families participate in their patients' care give us a sense that families become involved with us and accept us. This will also help the family to accept if the patient develop a complication and died. I remember relatives of a patient's; we had a strong relationship with them. They used to set with us 10-15 hours daily, drinking coffee with us and something like that and communicate with each other. After patient passed away they came to thank us and show appreciation for our care of the patient saying may Allah reward you, you do the best and something like that.* (Charge Nurse 9, H2, Coronary Care Unit)

6.3.2 Time and trust

Time in critical care units is very crucial because it can interrupt the development of trust. Whereas the nursing staff blamed doctors for families' lack of appropriate information, the doctors blamed time constraints for their lack of effective communication.

As reported in the system related barriers in the previous chapter, time constraints are a major challenge for staff while working with critically ill patients. Staff reported that time constraints would affect building trust relationship in two ways. Firstly, with limited time, the doctors described how they don't have an enough time to communicate with families and don't have a chance to get to know the patients and their families. Secondly, due to time constraints imposed by workload, most of the critically ill patients who are likely to die have a limited time in critical care units and the staff have no prior relationship with them which also makes things difficult in the establishing staff-family trust. This shows the importance of prior communication interaction between patients and their families and the health care staff.

6.3.3 Knowing patients' families

In order to build a relationship and work effectively with critically ill patients' families, the staff reported that they first need to become familiar with the families with whom they will

work during the patients' stay in the critical care unit. So, in addition to the formal assessment that the staff usually do for all critically ill patients including the dying patients, they described how they would do some sort of more informal assessment for the families of patients who are about to die. This assessment was reported to be carried out initially at the time of patients' admission and continued until the time of patient's death, and it was seen as an integral step towards working effectively with families. The staff reported that the assessment outcome was informed by staff experiences of caring for families.

While some staff talked about doing this type of assessment explicitly, others might not talk explicitly but their account show that they did it unintentionally or as a normal practice in the unit. For example, in the quote below, nurse 6 talked about the dialogue that had been carried out with a family of a dying patient in the story he narrated. In this dialogue, the nurse asked a series of questions and drew a number of conclusions. These questions were about: patient health history, patient-family relationship, family emotional status, family educational level, family member's temperament and emotional aspect. Interestingly, the nurse reported that he did this assessment once he realised that the patient was going to die.

> *When the patient was admitted to the unit and after I realised that he is dying, I started to ask the family about the patient, including: age, previous medical history, the number of his family, what his order in his brothers, smoker or not and so on. As I talked about other issues, I also examined their (family) emotional status and what type of family they are, namely, whether they were educated and understandable or not and such these things. They were much stressed, not acceptable for the situation, very worried and sad upon their patient.* (Senior Nurse 6, H1, Coronary Care Unit)

Normally, these questions wouldn't be asked in such detail and the focus is usually on patients themselves not their families. Thus, the nurse was asked about the purpose of this extensive assessment for both the patient and the family. The nurse described that in addition to building a rapport with patient's family where they can provide an appropriate support, this assessment was mainly in order to establish the possible reaction of the family to the patient's imminent death:

> *You know I did that even they (physicians) had already done and we already had some of these information in the patient file, but this was to build a rapport and provide an appropriate support for them by putting myself in their position. Additionally, I did that mainly to predict their response if death happened since the patient was very critical. Knowing this thing determine the type and how*

much information we as a staff could provide and what their response might be at the time of death. Also, we can build a picture about how they will react after the patient death. So we got prepared. (Senior Nurse 6, H1, Coronary Care Unit)

This assessment was also seen by nurses as well as doctors as an integral part in determining the type and level of care that would be followed; detecting the possibility for limiting some invasive treatments or the opportunity for deviation from the normal pattern of practice and determining the kind and the amount of communication that would be carried out with families. Thus this assessment was regarded as a sort of 'testing the water' to see if it is possible to suggest to the family that some limitation of treatment might be sensible. For example, in a brief interview with doctor 6, he talked about a patient who settled in the medical intensive care unit at the time of interview. The patient was an older woman who had been in the medical unit for long time and was perceived by staff to be dying. The patient was surrounded by her family members. The doctor pointed out that based on their assessment of the family assessment they did not communicate to the family openly the patient's dying state or discuss the do-not-resuscitate policy with the family. In this quote, this assessment includes the degree of the family's satisfaction about the care provided; the family acceptance of their patient's condition; their expectation or expected outcomes or their hope of recovery:

... For example, do you see the family surrounding that patient (the participant pointing to family members surrounding their patient in the unit and asking the researcher to look toward them)?they don't accept anything; very tough; the patient is dying and they still have a hope; they always convince themselves that there is a medical negligence behind their patients deterioration. How do you think that we can tell them that your patient is dying or asked if the patient arrested, should we resuscitate him (the participant mean 'do not resuscitate order'); it is impossible for them to comprehend that. (Second Year Doctor 6, H2, Medical Intensive Care Units)

6.3.4 Trust optimising behaviours

The findings demonstrate that the staff recognised that caring for the needs of the dying patients' families was an integral part of their work. The staff described that caring for families aids in attaining their trust and help them get through their traumatic experience of having their loved one in critical care. Although providing care for families was reported in the medical staff accounts, it was a major theme in the nursing staff accounts For example the head nurse three commented on the importance of providing care for critically ill patients' families:

Families for example, since we are talking about end of life care, in intensive care units basically you are not providing care for patients themselves; you are providing care for their families instead. Because when you have a 16 years old patient who is dying...or another time we had a female patient; the patient started on haemodialysis just 6 months before her death; she was healthy; she was admitted with pneumonia and then she electively intubated and within two days she passed away. You couldn't believe how extremely distressed her family members were and how very difficult it was for them to accept her dying and death. So these are the families whom you need to provide care for. (Head Nurse 3, H2, Medical Intensive Care Unit)

The nursing staff reported that although their care is almost the same for all families in critical care units, they tried to support the families of dying patients differently. In their accounts, the staff referred to this care difference as focusing on the 'simple things' that they have the opportunity to provide. Allowing families to perform their cultural and religious rituals; provide them a space for gathering together and supporting them emotionally are 'simple things' shown in the quote below from head nurse four interview:

There are 'simple things' we can do. So to speak, there is a little, i.e. being not strict about visiting; from our own experience we know that this patient is end of life so sometimes I may give the family our meeting room; I may set with them a little; I allow visitors to stay with their patient and I allow them to read "Quran" (Muslim Book) and this as an example. (Head Nurse 4, H2, General Intensive Care Unit)

Providing families with flexible visiting hours and enabling them to stay with their patients as much as possible was a response to the care that is provided to dying patients' families that appeared across all the staff accounts, in spite of this being contrary to institutional policies. Head nurse one voiced this in her interview, comparing the visiting system in the general intensive care unit and what she used to do in her unit:

Namely, according to the hospital's policies, the visiting hours are so limited here in the critical care units. For example, in the general intensive care unit the visiting system is on card which allows one visitor for every patient at a time. However, there is something special for these patients (dying patients) and their families and should be done for them. So, I may call the security members and tell them to let family members for such patients to enter in two persons each time, and even if it not the visiting time for and even though, it is against the policy to do so. (Head Nurse 1, H1, Coronary Care Unit)

The nursing staff when working with critically ill patients families tried to reduce the families' stress and anxieties by providing them with detailed permissible information about their patient

condition; working in between families and medical team and allowing families to participate in their patient's care. For instance, these roles are reported by nurse 9:

> *Explaining to families about their patient's prognosis day by day and give them a follow up even it's a simple follow up or we may call doctor if then request and make families participate in their patients care. We read in some studies to make the family witness the cardiopulmonary-resuscitation of their relatives and help in providing care for their patients. In term of myself, and even that there is a policy in the hospital said that no visitor stay more than five minute and no visiting after 7 pm, I allow the families of the dying patient to stay with their patient too much. You see? You know, their patient is dying and I separate between them in last moments of patient's life, it is not acceptable, is it?* (Charge Nurse 9, H2, Coronary Care Unit)

Teaching families how to deal with their unconscious patients was another role that is adopted by the staff while working with dying patients' families. Nurse 10 explained that helping families to be close to their patients was away nurses used to reduce the families' anxieties and stress:

> *When they (families) come, we told them to set with their patients, holding his/her hand, tries to talk and chat with him/her and so on. Sometimes the families ask us whether the patient hears them or not "can he/she hear us", we said yes. You will get the feeling that there had been a relationship between the patient and his/her family; I mean between patients at the end of life phase and their families, and this will ease things a bit* (Charge Nurse 10, H2, Medical Intensive Care Unit)

Some head nurses tried to assign the care of dying patients to a specific staff with certain behaviours. This was reported to be done to meet the patients and their families' needs. Head nurse one in the quote below voiced this role:

> *Sometimes I know that this nurse has these attitudes and that one has this communication for example. One may be composed, poised, and calm while someone else may not be. In my morning assignment distribution I assign this patient (mean dying patient) for this nurse, and I tell them on the night shift to assign the patient to that nurse. Or don't let that person care for this patient. I try to distribute those patients according my schedule. That is it; I do it intentionally according to families and patients.* (Head Nurse 1, H1, Coronary Care Unit)

6.4 Hopeful culture

Hope among families of critically ill patients' was a theme that is reported across all interviews with critical care staff and would affect their practice while working and communication with families of critically ill patients. Culturally, the staff reported that they are living in an emotional and hopeful culture where families always have hope regardless the criticality of their health care status and they always ask for hope even it is minimal. Thus the staff struggle to find a balance between sustaining authentic hope that the families need without presenting false hope. These observations were voiced in doctor five and doctor two interviews in the quote below. Interestingly, doctor two saw that even where any realistic hope of recovery is less than 5%, this shouldn't be neglected when communicating with families:

> *D5: Here in our culture, families keep hoping always; live on to hope always; holding on to hope always. As I said before, we are living in an emotional culture and most emotions are applied to females because they are emotional more than men. So if you are going to tell any female especially mothers that 'sorry the patient is very tired and actually there is no hope', unconsciously you feel that you don't met her need or what she is looking for, or she may make you feel that you deceit her since you suppose to give a hope.* (Senior Doctor 5, H2, cover all critical care units)

> *D2: Some specialists may know that there is just limited hope and the likelihood of the patient improving is less than 5%, he still has a hope. This hope, that some specialists might have, is what they give to the family and families always ask for this hope even though it is minimal.* (Second Year Doctor 2, H2, Intensive Care Unit)

On the other hand, from the staff's accounts, it seems that families seek hope even though it is slight as a response to the traumatic experience of having their loved one in critical care. For instance, nurse 10 in the quote below talked about the families' need to foster and maintain hope, and the point that families tried to build or seek hope even it is unrealistic along with denial in order to adapt with their experience of loss:

> *This hope is because of the excessive attachment between the family and the patient. I mean that sometimes some families ask you to give them a hope even it is false, the most important to them is to hear a hope and sometimes they don't accept that the patient is tired and they said that "our patient is on your unit to give him the care" and they don't realise that as long as the patient is on intensive care unit his/her situation is critical and that what make the patient's family afraid, so sometimes we enforce to talk anything to make them calm.* (Charge Nurse 10, H2, Medical Intensive Care Unit)

The staff also alluded to the importance of providing clear, understandable and detailed information on their patients' condition and the possible prognosis in order to help families to steer and control their hope. Head nurse three in the quote below talked about the importance of effective communication with patients' families in making their hope more realistic and avoiding future conflict:

> *If family understand their relative health status, there will be no conflicts between us (families and staff). The families usually come to the unit having the idea that their patients will discharged from the unit walking and that according to the picture that they have about the intensive care units. Communication surely makes things easier; it gives them the real view for their patients' condition. Surely, effective communication will make things easier.* (Head Nurse 3, H2, Medical Intensive Care Unit)

However, because the situation in critical care units is characterized by numerous uncertainties and unpredictable developments in addition to the ineffective information that is perceived by the staff, the families have unrealistic hope. The next section discusses how the staff tried to work with families in the context of their hope.

6.4.1 Working with families facing loss

The findings of this study demonstrate that the critical care staff tried to provide care for dying patients in the context of their relatives' hope when they are confronted with their patients' critical situation. The hope would change from the time of admission to the time of death. According to this, the staff reported that families at the time of admission are very shocked, distressed and in denial and the hope of recovery dominates everything. This was clearly reported by head nurse three who described the hope state of a family when their relatives admitted to the intensive care unit. This seems that the families adopt a hopeful stance as an adaptive response when they find it impossible to believe or to acknowledge the critical status of their patients:

> *I have a patient admitted recently to the unit; he is nearly brain dead (massive brain injury) and we are waiting for his death. However, the family still have a hope that the patient will be alright and he will get recovering, you see? So if someone comes now and wants to inform them that your patient is dying or asks them for not resuscitating the patients, absolutely they will never accept or agree unless the patient gets one more week in the unit or something like that. At that time, the family members themselves might get the point of dying and take off their dreams, and only at that time you might talk with them; but to give*

them these things as a one shot from the beginning, it is not an easy discussion to be made; I mean our culture still doesn't accept. (Head Nurse 3, H2, Medical Intensive Care Unit)

During this time, the staff try to handle the family distress and hope by providing the best care (in family terms) which the staff perceived to be "doing everything" and that this happens even 'doing everything' is futile. It seems that the staff tried to meet the families' expectations for the provision of aggressive treatments and thus to maintain the hope of recovery and reduce families' anxiety and stress. Once the staff realise that the families can cope with their patient's situation, they try to change their manner of dealing with the patient. For instance, doctor four talked about working with a female patient who had a massive brain injury over a one week time period. The patient was young, previously healthy and had arrested suddenly. The doctor reported that they took three days to prepare the family for the patient's dying. During these days, the care was reported to be very active even though the dying status of patient was clear to the staff. The doctor reported that the reasons behind the provision of aggressive treatment was in order for the family to experience that the treatments were futile and to give them enough time to accept the reality of the situation:

> *She had a ruptured aneurysm; she stayed here in the unit (intensive care unit) for nearly 6 or 7 full days…from the same day she came, we know that she is dying…look! Firstly, when she was admitted, even that we know that there was no hope with her case, but you know at that time we had to work to say that we did what should be done; I mean in the first 2-3 days, we worked actively upon her; active in terms of doing septic workup, antibiotic, vasopressors medications and mannitol; everything was done; even we give her lactulose, you imagine; everything was active. All that care (active care) continued for three days. After three days we stopped the sedation then the antibiotics and after that we stopped everything; the patient kept just on the vasopressor medications and on ventilator until death…to be honest, that delay in discontinuing the active treatments was to a large extent for family; this was in addition to that the computer tomography (CT) report take some time to be ready, of course we know the CT result from the first one hour of her admission but I'm talking about the report, but then again the family had a major role…you know they couldn't handle and accept to tell them that the patient is dying from the first time the patient was admitted; so that delay give them a time to understand the reality and comprehend what is going on. You know, a young patient, previously healthy and sudden arrest it is impossible for them to accept that.* (Senior Doctor 4, H1, cover all critical care unit)

6.5 Conclusion

This chapter has reported the experiences and perspectives of critical care staff toward working with families of critically ill patients who are likely to die. It explored how staff seek to care for and communicate with patients' families and explores the barriers and challenges to family focused communication and care. The findings show that families are perceived by staff to have an essential role in any end of life care decision where limiting life support treatment would take place but that barriers to the provision of effective end of life care and communication means that it is rarely possible to openly discuss these issues with families. Staff perceived that the doctors' communications with patients' families were rarely effective when they concerned death and dying. Although the role of nurses was considered to be important in the communication process, nurses perceived that they had a limited range of opportunities for communication. Cultural issues were reported to have a key effect on the critical care staff while communicating with dying patients' families. Collective decision-making (including communication with large families' members and the essential role of families), the culture of "doctor dominant" and an overarching perception of death as a taboo subject were common issues encountered by the staff in this study. The next chapter will discuss the findings of this study in the context of the present literature.

Chapter7:   Discussion

7.1 Introduction

This study explored the experiences of Jordanian critical care staff when providing care for patients whom they perceived were likely to die. It provides insight into the difficulties they encountered and how they sought to care for, and communicate with, the families of patients who were approaching the end of life. The concept of 'transition' was used a theoretical framework to enable understanding of end of life care practice. Existing evidence has highlighted the importance of identifying, managing and directing the process of transition to palliation and finally, to end of life care. Effective management of such transition facilitates the providing of quality care for people who are approaching their end of life. However, identification and management of the transition phase to end of life care is complex, challenging and difficult for all those involved within critical care. The issue of the difficulty in making such a transition for patients in the critical care units was frequently raised in this study; complexity surrounding this stemmed from prognostic uncertainty about whether patients were dying or not and the emotional experiences staff encountered when caring for dying patients and their families.

This chapter offers a discussion of the study findings in the context of the contemporary literature, identifies the contribution of the study to existing knowledge, practice and research and proposes recommendations for policy, practice, education and research. Finally, the strengths and limitations of the study are acknowledged.

The participants in this study were the resident doctors and nurses working in two University hospital critical care units in two cities in Jordan. The study was conducted between September 2012 and April 2013, using a mixed methods approach in two phases. The first phase employed the "National Survey of Critical-Care Nurses' Perceptions of End-of-Life Care" (adapted with permission) to elicit the views of staff (n=104) about the obstacles and facilitators they encountered when providing end of life care. In the second phase, qualitative interviews were conducted with a sample of the surveyed staff (15 nurses; 10 junior doctors; 5 head nurses). The interviews enabled insight into how the issues reported in the survey were experienced by

staff and allowed identification of otherwise unknown factors. They also enabled exploration some cultural issues in end of life care that were very particular to the Jordanian context.

An overarching finding is that the critical care staff experience moral distress when caring for critically ill patients whom they perceive to be dying. "Moral distress" refers to the visceral painful feeling experienced by some healthcare professionals when they act in a manner that is contrary to what they perceive to be the morally right course of action (Berlinger et al., 2013; Jameton, 1984; Wilkinson, 1987). The moral integrity of healthcare professionals who practice in critical care is potentially greatly susceptible to threat since bioethical and legal issues are encountered on a day to day basis and are especially brought to the fore in end of life care contexts (Elpern et al., 2005; Ferrell, 2006; Mobley et al., 2007). In a recent Jordanian study, Allari and Abu-Moghli (2013) surveyed 150 critical care nurses in twelve Jordanian (seven public and five private) hospitals to describe their level of moral distress and reported that the nurses reported moderate level of moral distress.

As a concept, moral distress is an umbrella term that refers to the range of psychological, emotional and physiological experiences of individuals when acting in ways that are inconsistent with deeply held ethical values, principles or moral commitments (McCarthy and Deady, 2008). Moral distress was firstly delineated by the philosopher Andrew Jameton, as it pertains to nursing, in 1984 and was used to indicate a situation in which nurses are restrained from acting according to their moral choice because of *institutional* factors such as time constraints, institutional policy or legal limitation (Jameton, 1984: P. 6). Since then, a number of accounts of moral distress have been developed along with a range of empirical tools to identify the sources of moral distress, to measure and assess its impact on nurses as well as other health professionals and to identify how individuals cope with and/or resist moral distress (De Villers and DeVon, 2013; Austin et al., 2005)

The growing literature on moral distress defines this concept, or notion, in different ways. Consequently there has tended to be an abstraction of this concept which makes it more difficult to find a common ground or a consensus definition. The literature demonstrates that there is a dearth of work that unpacks the concept of moral distress theoretically, while also   critically considering its meaning empirically, by delineating and measuring it (McCarthy and Deady, 2008). The theoretical literature available on moral distress has indicated that the ways in which moral distress is defined and operationalized in empirical studies is problematic and documents

concerns about the lack of clarity in the way in which the concept of moral distress is portrayed in nursing research (Corley, 2002; McCarthy and Deady, 2008; Repenshek, 2009). Additionally, it expresses concern about the fact that research, so far, has been largely narrowed to determining the prevalence of experiences of moral distress among nurses (Corley, 2002; McCarthy and Deady, 2008; Repenshek, 2009).

Moral distress has been revealed as a complex and debatable concept that draws attention to the moral labour of nurses and other health professionals (Austin et al., 2005). Various critiques are documented in the literature. Firstly, theorists and researchers differ in placing emphasis of different dimensions of moral distress: for example whether it is an inability to do what is known to be the right thing to do; or doing what it is believed is the wrong thing (McCarthy and Deady, 2008). Secondly, different views about how "morality" is conceptualized and which moral values ought to be valued by individuals and societies. Namely, explaining what we mean when saying that 'individuals know what is the morally right thing to do' and what are the particular set of moral values that the individuals use to evaluate the rightness or wrongness of an action (Repenshek, 2009). Thirdly, questions about how and why any given set of values which determine the rightness or wrongness of an action such as freedom, justice and dignity, happiness, peace and reconciliation are adopted by individuals or societies at any given time or place (McCarthy and Deady, 2008; Repenshek, 2009). Fourthly, the uses of word 'distress' and exploring moral distress and related concepts that link to one another e.g. stress of conscience, moral uncertainty, moral stress, moral discomfort and emotional distress (Lützén et al., 2010; Begley and Piggott, 2013). Finally, the issue of whether the moral distress concept should extend to consider the experiences of patients and relatives who must make hard ethical choices and its effect on patient care (Begley and Piggott, 2013).

Nevertheless, the concept of moral distress has been in existence for more than thirty years, and it has received much attention in the international literature in recent years. Additionally, the empirical research and literature reviews on moral distress affirm that moral distress is an issue of concern for nurses and other health professionals around the world and indicated some consensus in relation to the factors that contribute to moral distress and its impact on nurses and nursing care. Moral distress highlights the way in which responsibility and authority is divided out in healthcare settings and acknowledges the role that emotions play in having a moral life and being a moral agent.

Moral distress has serious implications extending to patients, and patients' families. It has been associated with healthcare professionals' stress, job dissatisfaction and lack of retention in the workplace and likewise from the profession (Elpern et al., 2005; Hamric and Blackhall, 2006; Ferrell, 2006). It has negative effects on staff psychological and physical well-being, self-image, and spirituality (Hamric and Blackhall, 2006; Badger, 2005). Experience of moral distress also influenced staff attitudes toward providing care for critically ill patients in critical care units (Wilkinson, 1987; Rubin, 1996; Elpern et al., 2005). Elpern et al. (2005) surveyed 28 nurses working in a medical intensive care unit to describe the experiences and implications of moral distress and found that the sense of moral distress among critical care staff influenced their attitudes towards advance directives and participation in blood donation and organ donation and led them to either avoid patients or be over-solicitous due to a sense of guilt. Effects extending to patients include: increased pain, longer time of hospital stays and care that is not in their best interests (Baggs et al., 1999). The majority of studies on moral distress have focused on nursing staff (Epstein and Delgado, 2010; Latour et al., 2009; Levin et al., 2010; Suliman and Abu Gharbieh, 1996; Mrayyan, 2007; Corley, 2002). However, it is essential to highlight that moral distress is not merely a nursing issue. It has been identified to be a phenomenon affecting all healthcare professionals (Epstein and Delgado, 2010).

An examination of the literature shows that there is range of situations that cause moral distress among healthcare professionals. Corley (2002) identified the common sources of moral distress for nurses:

- Feeling that they are providing inadequate care of patients or care that is not in the best interest of the patient;
- Poor end of life communication between health care professionals and patients' families;
- Staffing levels that are inadequate and being untrained to meet patients' needs;
- Inappropriate allocation of healthcare resources;
- Feeling that pain management is inadequate;
- Unrealistic and false hope offered to patients' and their families.

In this study, there were three main dimensions to the moral distress experienced by the staff. These dimensions represent the key findings of the study. The discussion in this chapter synthesises these key findings by identifying and presenting a discussion of them in relation to

the wider literature and identifying their implications for end of life decision-making in critical care units in Jordan and elsewhere. Below I briefly highlight each of these dimensions, before turning to a more detailed examination:

First, the study showed that nurses experience moral distress when they are aware when the patients are likely to die, know that continuing life sustaining treatment is futile and yet are expected to continue to provide treatment as normal. Aggressive modalities of treatments are the usual practice pursued for most terminally ill patients, with both nurses and doctors perceiving there to be no planned, clear or distinct transition from curative directed care to end of life care.

Second, with regard to their relationship with patients' families, the staff found themselves to be in a problematic and paradoxical situation. One the one hand, they expected (and it is culturally normative) patients' families to take the lead in the care decision making process and thus perceive that the power in decision-making should lie with patients' relatives; but on the other hand, they also perceived that it is difficult and sometimes impossible to disclose bad news openly to families. Therefore, patients' families are not fully informed in a way that would enable them to take the lead in decision making process.

Third, the staff have an appreciation of the principles of end of life decision making as a team activity and as a collaborative venture, but they are not able to put these principles into practice for reasons ranging from staff relationships with each other to health care system factors.

The following sections discuss these three dimensions in relation to the wider literature.

7.2 Moral distress-dimension 1: providing futile care and treatments

The findings in Chapter 4 show that staff were aware when a patient is likely to die because of their experience of other similar cases and that they also have awareness of the principles of good end of life care, based on some degree of understanding of international recommendations about best practice. However, the chapter also shows that the staff perceive that they cannot deliver 'end of life care'; rather the normal and expected course is that aggressive treatment is continued until all medical treatments are exhausted, even though this is recognised to be futile and to prolong the dying process. This contradictory situation was associated with the highest

degree of distress among staff. This finding resonates with an examination of the literature where it is shown that continuing with providing aggressive burdensome, costly and futile curative care even though is not in the best interest of the patient is the most common source of moral distress among healthcare professionals (Elpern et al., 2005; Epstein and Delgado, 2010; Ferrell, 2006).

Compared to the practice observed in the study, wider contemporary literature suggests quite marked differences with the West, although there are similarities in issues reported in an older literature from the West (1990s). However, the practice in this study resonates with other studies reported in the literature of end of life care in critical care units from Middle East countries.

First, treatment decisions towards end of life e.g. withholding and withdrawing life-sustaining treatments are a common practice worldwide to the degree that in most critical care units death takes place after a decision to limit intensive therapy including United State of America (Prendergast and Luce, 1997; Pochard et al., 2001; Prendergast et al., 1998); European intensive care units for example, France, Spain and United Kingdom (Sprung et al., 2003; Ferrand et al., 2001; Esteban et al., 2001; Wunsch et al., 2005); and Canadian intensive care units (McLean et al., 2000; Rocker et al., 2004). This study suggests that such decisions are rare in Jordan i.e. the aggressive modalities of treatments is the usual practice that is pursued for most of the terminally ill patients. This study also suggests that in some Middle East countries there is a similar picture i.e. Israel and Lebanon (Eidelman et al., 1998; Yazigi et al., 2005). It is interesting to notes that a fairly recent study from New Zealand report a similar finding to that this study observed (Sheward et al., 2011). Sheward et al. (2011) surveyed all (610) medical, nursing, and allied health staff working in a 194-bed hospital regional hospital in New Zealand toward their perceptions of end of life care practice. Sheward and colleagues found that one of the major themes emerged from the study was 'no change'; despite patient deterioration there would be no change in the direction of care.

Second, in this study, even though generally there was no change was perceived in the care practice for critically ill patients, chapter 5 shows that there were times when exceptions to the usual pattern of care occurred. These tended to involve patients with advanced cancer, or those who were brain dead or very elderly, or in certain family and patients contexts (for instance where relatives had high level of understanding and education, where they were particularly

realistic or had a health care background; or where the patient had been in critical care for an exceptionally long time). Such an exception with patients who are brain dead has been reported in two studies conducted in Middle East i.e. Israel (Eidelman et al., 1998; Ganz et al., 2006). In a descriptive study that evaluated prospectively the patients' diagnosis, type and reason for forgoing life sustaining treatments in a general intensive care unit of a university hospital in Israel, Eidelman et al. (1998) found that withholding treatments is very common in the study setting, while withdrawing treatments takes place with patients who are confirmed to be brain dead or in the situation where medications are deemed to be futile. The exception for brain dead patients was a common practice in America in the late 1960s and early 1970s when the withdrawing ventilator or hydration or nutrition was considered only for patients who were brain dead (Sprung, 1990; Meyer, 2011) before the time (between the late 1980s and early 1990s) had come when limitations of life support treatments become a more common practice.

Third, the findings in Chapter 4 show that the staff distinguish between withholding and withdrawing treatments and were more willing to withhold life-sustaining treatments over withdrawing it for patients who died in critical care units. However, these practices are bracketed together by many ethicists, physicians and judges and are suggested in international guidance and recommendations as being morally equivalent (Wellesley and Jenkins, 2009; Cook et al., 2006; General Medical Council, 2010; American Thoracic Society Bioethics Task Force, 1991). An examination of the literature from the Middle East and the Mediterranean show that clinicians seem to be more willing to limit intensive treatments and more reluctant to withdraw therapies. In addition to the Israeli study mentioned above (Eidelman et al., 1998), in a Mediterranean study, Iyilikci et al. (2004) found that the Turkish critical care clinicians have a preference to withhold rather discontinue treatment in terminally ill patients. In Lebanon, Yazigi et al. (2005) also found that while 38% of patients who died in a medical intensive care unit of a university hospital had therapies withheld, only 7% had life-sustaining treatments withdrawn. A similar trend was found in a study examining end of life practice in a neonatal intensive care unit conducted in Oman (Da Costa et al., 2002). This tendency to withhold rather than withdraw has also documented by some studies in western countries for example, in London and Sweden (Sprung et al., 2007); France (Ferrand et al., 2001); Canada (Keenan et al., 1997) and in United States (Prendergast, 2000)

Fourth, another difference between practice as revealed by the wider literature and this study is related to the withdrawal of ventilator support and vasoactive drugs. Withdrawal of ventilator

support and vasoactive drugs is both legally permissible and accepted practice in critical care units in other parts of the world such as North America (Emanuel, 1988; Sprung, 1990); Europe (Vincent, 1990); and Australia (Emanuel, 1988). However, this study has shown that albeit with some limited exceptions withdrawing these treatments almost never occurs and moreover the staff perceive that withdrawing such treatments is akin to passive euthanasia. This perception is a theme that was common some 20-25 years ago in studies of international critical care unit practice (Rosner, 1991; Truog and Berde, 1993; Mystakidou et al., 2005; Goodman, 2010). In contrast, contemporary literature highlights the importance of making a distinction between 'active' euthanasia and 'letting die' when dealing with withdrawing machines or life-sustaining treatments. International guidance states that withdrawing treatments should not be considered as a form of euthanasia as long as the intent is to relieve suffering and not to kill or hasten death (Garrard and Wilkinson, 2005; Rachels, 2007; McLachlan, 2008; Douglas, 2009). However, In Jordan to date there has been no culture of discussion and debate about these difficult issues and so neither the staff nor the policy makers understand the distinction.

Finally, this study has shown that fluid and nutrition therapy might be withheld but not withdrawn and are considered to be different to other medical treatments. In contrast, such therapies have been reported to be the most frequently forgone treatments in western countries including Belgium, Denmark, Italy, Sweden, and Switzerland (Martin and Thompson, 2000) and the Netherlands (Martin and Thompson, 2000; Moss et al., 2005; Nava, 2004). Again, the finding from this study resonates with other research studies conducted in some Middle East countries for instance Lebanon and Israel (Eidelman et al., 1998; Yazigi et al., 2005). Italy is one example from the European countries where it is not permissible to withdraw clinically assisted nutrition and hydration (Richards et al., 1996; Stefania Negri, 2013). This is largely for religious reasons since many religious traditions consider providing food and water in whatever form is basic needs and its provision is mandatory if the patients are unable to eat and drink Italy is largely a Roman Catholic country (Stefania Negri, 2013). Religious have a vital influence in the attitudes and behaviours of health care professionals towards decisions of limiting treatments at the time of end of life (Sprung et al., 2007).

7.3 Moral distress-dimension 2: paradoxical relationship with families

The findings in Chapter 5 reveal a contradiction in staff relationship with families that contributed to the distress the staff experienced. This contradiction occurs when the staff wait

for families to express their wishes about the treatment and care of the patient and thus direct the decision-making process, yet at the same time feel reticence and reluctance to initiate any conversations about the possibility of death and dying with patients' families which would help families make an informed judgement. In the next section I discuss the family's role in the decision-making process revealed by this study and how it relates to the research literature.

7.3.1 The Families Have the Power

The staff indicated that the families should lead or 'direct' any end of life decision-making and perceived that decisions to limit treatment can take place only with the consent of families when the patient lacks decision-making capacity. This empowerment of families comes under the umbrella of a wider cultural and legal context in which seeking consent from families is mandatory. Chapter 4 highlighted that Jordan lacks any national health care laws or policy in palliative or end of life care, either in relation to the process of end of life decision-making generally or when a patient lacks capacity to make treatment decisions. For example, there are no provisions for advance directives, appointment of surrogate decision makers or ethics committees for consultation in Jordan. However, Jordan does have a laws which formalises the decision role of families in healthcare[14]. It is to be expected then that healthcare professionals will apply such a law to end of life issues. Thus the view of families or relatives is sought and regarded as an essential part of process of making decisions.

In comparing the situation revealed in my study with the literature on families' roles in decision-making, it is clear that family involvement in end of life care decision-making in critical care units is valued worldwide (Sprung and Eidelman, 1996; Van der Heide et al., 2003). However, examining the international literature shows large variations in the extent to which families, relatives and other caregivers are perceived to have a role in the end of life decision-making process when a patient lacks decision making capacity and has no advance directive:

1. Physicians in the United States prioritise patient autonomy in making decisions to undergo or refuse treatment (Electronic Code of Federal Regulations, 2011). Consequently, many decisions for forgoing of life-sustaining treatments decisions are made by patients'

---

[14] For more information see http://www.lob.gov.jo/AR/Pages/default.aspx

relatives through surrogacy laws, using a substituted judgment or best interest standard, or with the agreement of families (Esteban et al., 2001; Luce and Alpers, 2000; Luce and Lemaire, 2001; Sprung and Eidelman, 1996). These decisions take place under the guidance and advice of the patients' lead physicians, with the consent of patients or their families. Asch et al. (1995) surveyed a national sample of 879 physicians working in adult intensive care units in United States with regard to their practice of limiting life-sustaining treatments and found that only 12-14% of in United State reported withholding or withdrawing life-sustaining treatments without the knowledge of relatives.

2. Most of European physicians believe that end of life decisions such as withholding or withdrawing life-sustaining treatments are predominantly biomedical and ethical issues, and are the responsibility of the lead physician to make, albeit with appropriate communication and consultation with families. In most European contexts there is no legal obligation upon physicians to continue with futile treatments even if families feel strongly that they should be continued (Sullivan, 2002; Truog et al., 2008; Sjökvist et al., 1999; Vincent, 1999; Esteban et al., 2001).

3. Some research in Europe shows a pattern in which physicians take over the responsibilities of decisions of forgoing of life-sustaining treatments with limited involvement of families and relatives or without patients surrogate knowledge or consent (Van der Heide et al., 2003; Ferrand et al., 2001; Sjökvist et al., 1998; Melltorp and Nilstun, 1996). For example, Van der Heide et al. (2003) investigating the characteristics of end-of-life decision-making practices in six European countries found that with more than 50% of all end of life decisions in Italy and Sweden were neither discussed with the patient nor with relatives.

Jordan is an Arab country where culture plays a primary role in the decisions around end of life care for the families of patients confronting life-threatening illnesses (Da Costa et al., 2002; al-Awamer and Downar, 2014). It is revealed in Chapter 5 that it is a culturally normative for family members to be the decision-makers regarding their patients' end of life treatment and the decisions will be negotiated between different family members (Giger et al., 2005; al-Awamer and Downar, 2014). Clearly culture also plays a major role in other countries but a different culture produces a different emphasis. In the United States the culture is one of individualism, with the resultant emphasis on surrogacy. Additionally, it is perceived by the staff in this study that some patients want their families to decide on their behalf even they

have the capacity to make treatment decisions and in another case the family members of elderly patient usually take over the decision-making role. These decision-making features are also the norm in many other cultures for example Koreans and Mexican Americans, Asians, Bosnian and Pacific Islanders (Giger and Davidhizar, 2002; Maly et al., 2006; High, 1988; Giger et al., 2005; Searight and Gafford, 2005). Working with patients and families in the context of their culture is an essential foundation that allows for the delivery of individualized palliative and end of life care (Giger et al., 2005; Kagawa-Singer and Blackhall, 2001; Koenig and Gates-Williams, 1995; Searight and Gafford, 2005). Additionally, providing culturally competent end of life care is vital in the development of a trusting relationship between health care provider, patient and family (Barton and Brown, 1995). Building families-staff trust relationship represented a central theme that the staff struggled to achieve in this study.

Different cultures also give rise to different perceptions towards the status and the authority of physicians in decisions about patients' health care (Kingsley, 2010; Searight and Gafford, 2005). In United States, for the Latino patients and families who have immigrated from Mexico, it is the physicians who make health care decision and it is not usual for the patients or their families to have an opportunity to choose among treatment options given by physicians (Kingsley, 2010). The patients and families hold an expectation that the making health care decisions is a physician's job (Searight and Gafford, 2005). For example, many Filipinos, patients and their families rarely have an input into health care decision-making as the doctor is perceived to have the authority to make all decisions; even questioning physicians about health care decisions or enquiring about treatments options may be perceived as challenging the physician's authority (Lynch et al., 2003).

7.3.2 Families are not empowered

In chapter 5 we saw that communication between staff and family members is characterised by a lack of clear and frank conversations about the approach of death and dying. The staff in this study reported that they usually hesitate and sometimes intentionally avoid having such conversations with the families of patients whom they perceive are likely to die. In this study, staff perceived that it was as a way to protect families from being stressed and anxious and to sustain their hope. Physicians in multiple studies with different countries and different places share such perceptions. For example, Almack et al. (2012) interviewed 15 healthcare professionals caring for patients in five services providing palliative care to cancer and non-

cancer patients in United Kingdom. In the latter study, the risk of taking away hope and causing distress were among the barriers perceived by the professionals to initiate end of life care preferences communication (Curtis et al., 2000; Gutierrez, 2012; Schulman-Green et al., 2005; Davison and Simpson, 2006). In the United States, Curtis et al. (2000) explored the barriers to end of life care communication for patients with advance acquired immunodeficiency syndrome and their primary care clinicians. Among the physicians' related identified barriers that were associated with less end of life communication was the physicians' assumption that patients are not ready to discuss end-of-life issues. In a Canadian study, Davison and Simpson (2006) explored hope in the context of advance care planning from the perspective of patients with end stage renal disease and found that while the doctors worried about initiating end of life discussions in order not to deprive patients of hope, the patients showed that clear and honest information is crucial in managing their hope. In a critical care setting, Gutierrez (2012) and Schulman-Green et al. (2005) found that critical care nurses in United States express reluctance to initiate end of life communication and see continuation of aggressive treatment as a means of maintaining hope.

Other physician and health care system related barriers for being reluctant to initiate any conversation about end of life care were also revealed in this study and resonate in wider research including:

1. Uncertainty about patients' prognosis (Barclay and Maher, 2010; Sprung et al., 2008)
2. Fearing from losing families' trust and damaging their relationship as it became clear that they were unable to meet their expectations for the patients' survival (Gordon and Daugherty, 2003; Christakis and Lamont, 2000).
3. Staff were anxious to attain families' satisfaction (Sleeman, 2013; Weeks et al., 2012).
4. Fearing liability or blame, since they did not perceive that it was as their job (either as junior doctors or nurses) to conduct such conversations (Ferrand et al., 2003; Yazigi et al., 2005; Schulman-Green et al., 2005).
5. Not trained to practice end of life communication (Bowden et al., 2012; Gibbins et al., 2011).

Moreover, in addition to the importance of communication with family members of a patient at the end of life for the practical aspect of a patient care in critical care units, staff-family communication is also essential for families themselves. Good information and communication

is established to be crucial in guiding and supporting family caregivers while caring for and working on behalf of their patients at the end of life and in bereavement time, helping them to cope, , improving satisfaction as well as perceived quality of care (Rabow et al., 2004; Truog et al., 2008; Jackson et al., 2012; Low, 2012). Several studies that examine the needs of family members of a patient with serious and life-threatening illness have documented that families desire good information and communication and tend to evaluate the quality of their interactions with clinicians based on the clinicians' communication skills, perhaps even more than their clinical skill. (Giger et al., 2005; Koenig and Gates-Williams, 1995; Caldwell et al., 2007; Russ et al., 2007; Clayton et al., 2008). Families desire clear, frank and honest communication at the end of life in order to anticipate and prepare for the outcome of a patient's illness, managing their hope and identify their roles in providing care that is in the best interest of the patient (Apatira et al., 2008; Hagerty et al., 2005; Davison and Simpson, 2006). Two Jordanian studies have explored the most important needs perceived by the families who have a member in critical care units (Al-Hassan and Hweidi, 2004; Omari, 2009), (Table 7.1). Interestingly, both studies identify that gaining assurance and information were rated very highly by families. However, Omari (2009) who also explored whether these needs were met or not, found that none of these identified needs were perceived as being met.

Table 7.1: Needs rated highly by families in critical care units

1. To be assured that the best care possible is being given to the patient.
2. To feel that the hospital personnel care about the patient.
3. To feel there is hope.
4. To have questions answered honestly.
5. To have explanations given that are understandable.
6. To know the expected outcome.
7. To know specific facts concerning the patient's progress.
8. To know how the patient is being treated medically.
9. To know exactly what is being done for the patient.

(Al-Hassan & Hweidi, 2004; Omari, 2009)

This issue was reported in this study to have a cultural and religious dimension. Culturally, the staff perceived that the frank communication of issues about death and dying was impossible as it would cause loss of hope and would exacerbate the grieving process of dying patients' families. Some studies of immigrants in the USA have found that talking about death and dying

issues is perceived to be unacceptable for a variety of reasons. For example, Somalians in Minnesota consider it disrespectful (Stratis Health, 2010); Bosnians perceive it to be associated with bad luck (Searight and Gafford, 2005), while Korean and Mexican Americans perceive it to be associated with loss of hope (Blackhall et al., 1995; Giger et al., 2005; Kagawa-Singer and Blackhall, 2001). Some staff in this study perceived communicating that a patient is dying as 'taboo' since they perceived that it contradicts with the belief that God can only decide a person's fate. That this is alluded to by other Middle Eastern authors (al-Awamer and Downar, 2014). Al-Awamer and Downar (2014) interviewed thirteen palliative care physicians who have experience in both Western and Middle East countries and identified the fearing of self-blaming and guilt of committing sins in the matter of discussing death and dying issues. There is a Muslim belief that death and dying are issues that belong only to God who controls all events; God is the only one who knows whether a patient is dying and the timing of his/her death; these are issues beyond human control. Although the staff could clearly identify the dying patients based on their experience and knowledge of previous patients, they perceived that they were not permitted to be open about this.

Religious faith play a vital role in patients and families' perception of illness and their response to death and dying issues (Mark and Lyons, 2010; Countries and Their Cultures, 2012; Zeilani and Seymour, 2010; Koenig and Gates-Williams, 1995). In other research religious issues also play a vital role in the attitudes and behaviours of health care professionals towards critically ill patients who are possibly dying (Sprung et al., 2007; Curtis and Vincent, 2010). For example, Sprung et al. (2007) compared the end of life practice in 37 intensive care units in 17 European countries by the religious affiliation of physicians and patients. Sprung and colleagues found that there were significant differences associated with religious affiliation and culture for the frequency and type of end of life decisions of limiting treatments; the discussion of therapy limitation with families; and patients and the time to treatments limitation and death. Of the results, withholding treatments happened more often that withdrawing if the physicians was Jewish, Greek Orthodox; more withdrawing and more discussion of decisions with patient families occurred more often if the physicians is Catholic, Protestant, or had no religious affiliation. Additionally, there were variations in other parameters by religious affiliation

7.4 Moral distress-dimension 3: lack of collaborative end of life decision-making

Another element to the moral distress experienced by the staff in this study occurred when they felt they were unable to put into practice the principles they acknowledged to be important in team-work, communication and end of life decision-making. In chapter 4 we saw that the staff perceived that there was a lack of collaborative discussion and communication about end of life care between them and the specialists involved in providing care for a patient. Rather, specialists were seen as having authority over decision-making, with few opportunities for other staff to have any input. This situation runs counter to international evidence that demonstrates the importance of interdisciplinary communication and collaboration in providing care in critical care units. Poor interdisciplinary communication and collaboration among critical care staff has multi-dimensional effects; it is associated with increased patients' mortality, length of stay and readmission rates (Baggs et al., 1999; Ahrens et al., 2003; Wheelan et al., 2003). Higher patient and family satisfaction is associated with good interdisciplinary communication (Gries et al., 2008; Larrabee et al., 2004; Buckley and Andrews, 2011; Jackson et al., 2012). In addition, better staff communication and collaboration has been associated with enhanced professional relationships, staff satisfaction, decreased job stress for staff and enhanced learning (Amos et al., 2005; Kalisch et al., 2010; Puntillo and McAdam, 2006).

In this study, the opportunities for nursing staff to have a role in end of life communication and decision-making were identified as particularly limited. The nurses reported that they are unable to directly speech with specialist; this minimizes any opportunity for nurses to facilitate effective communication between the specialists and the patients' families. This finding resonates with a diverse body of research showing the crucial role of nursing communication in transition to and provision of end of life care for terminally ill patients nevertheless they don't always assume this task; this mostly due to fearing of liability or blame since they did not perceive that it was as their job as nurses to conduct such conversations (Wilkinson et al., 1998; Schulman-Green et al., 2005; Ferrand et al., 2003; Fridh, 2014). Several studies have recommended the involvement of nurses in end of life decision making (Ferrand et al., 2001; Society of Critical Care, 1990; American Thoracic Society Bioethics Task Force, 1991). Nurses have legitimate roles in facilitating end of life decision making process due to their proximity to patients and their families and their role as intermediary between with the medical staff. Wider research shows that nurses have a range of roles:

1. Helping in determining when to initiate end of life discussions with family members by identifying when the treatments proved to have no effect (Thelen, 2005; Puntillo et al., 2001; Bach et al., 2009).

2. Assessing family's needs to ensure that the care is in the best interest of patient and family (Murphy et al., 2001; Bach et al., 2009; Baggs et al., 2007).

3. Building a trust relationship with families (Fry and Warren, 2007; Robichaux and Clark, 2006; Calvin et al., 2009).

4. Supporting and guiding families during decision-making and during implementing end of life decisions (Liaschenko et al., 2009; Robichaux and Clark, 2006).

5. Facilitate the communication of other critical care staff (Bushinski and Cummings, 2007; Heland, 2006; Calvin et al., 2007).

7.5 Contribution to theories of 'transition' to end of life care framework

The study used 'transition' as a theoretical framework to develop an understanding of Jordanian critical care end of life care practice from the perspective of health care professionals working in critical care units. This study adds to the scarce literature about transition from intervention to end of life care for people who are about to dying in critical care units. The findings prominently identify the moral distress that critical care health professionals experience as they seek to move from curative interventions to end of life care. This resonate with other research studies of transition in critical care units (Badger, 2005a; Coombs et al., 2012; Badger, 2005b). As reported, one of the distress source for the transition from cure to end of life care is continuing life sustaining treatments for patients not expected to benefit from that care. Participants in this study spoke of providing futile treatments to critically ill patients whom they perceived dying. Providing inappropriate aggressive life prolonging treatments has been reported as the major source of distress reported for health care professionals in critical care units (Zuzelo, 2007; Hamric and Blackhall, 2006; Mobley et al., 2007).

Another distress resources reported in this study is the difficulty for staff to disclose bad news openly to families even though it is perceived that it is a culturally and legally standard for family to be the leader in the end of life care decision making process. The study demonstrates that the most important factor in facilitating transition to end of life care is for the staff to be empowered to address and discuss end of life issues with critically ill patients families (Coombs et al., 2012; Pattison, 2004; Pattison, 2006). This empowerment would involve to be prepared

educationally and emotionally and to have the skill of working as a team in order to carry out such a difficult and distressed conversation and care. Additionally, the finding demonstrates the essential role and the priority of cultural factors in managing the transition to and providing a quality end of life care even in the countries of same religion or whose their people are from the same background or ethnicity. The findings in this study demonstrate the far reaching effect of poor end of life communication on all parties who are involved in end of life care e.g. the significant distress the staff experienced; intra-staff and staff-family conflict; families' dissatisfaction and mistrust; patients receiving unnecessary and futile treatment and longer time of hospital stays.

Lack of a team work was another source reported by staff in this study for the moral distress they experienced. This study findings affirm the acknowledged argument that identification and management of end of life transition phase is more complex, challenging and difficult for those patients within critical care units (Ravenscroft and Bell, 2000; Coombs and Long, 2008; Robichaux and Clark, 2006; Gott et al., 2007). Thus, attaining an effective and timely transition from curative intervention to end of life care requires complex team decision-making processes where critical care staff communicate and collaborate between and among each other. This resonates with other research studies that explore the process of transition to end of life care (Coombs et al., 2012; Marsella, 2009).

The qualitative and quantitative findings of this study revealed a number of challenges that contribute to the difficulty in attaining a smooth transition to end of life care. Among these challenges is the uncertainty toward patients' prognosis and the challenge of identifying the dying patients. This uncertainty relate to the diseases' trajectory nature for patients who admitted to critical care setting; the patients commonly admitted with complex conditions and experience an episodic of deteriorating and improving along disease' trajectory. Additionally, patients in critical care units may decline rapidly or die unexpectedly, thus the transition to end of life care is rapid which deprived families as well as critical care staff from required time to be prepared and have a control over patients' death. Other reported factors that make such a transition so challenging include different religious viewpoints and beliefs among critical staff. These barriers are documented in the literature (Coombs et al., 2012; Marsella, 2009).

7.6 Recommendations and policy, research and practice implications

This study sheds light on two central ethical problems in end of life decision-making in Jordan: the problem of disclosure of terminal prognosis at the end of life and limited involvement of nurses and resident doctors in the process of end of life communication and decision making. Thus, the key recommendations of this study can be summarised more toward identifying and establishing the practice of ethically sound end of life decision-making. This section describes the future research, policy and practice implications that follow this recommendation. As explained earlier in the literature review of this thesis, in Jordan, there is a very limited existing published work on the nature and practice of end of life decision-making in critical care units. Thus, there is a wider need for evidence in end of life care to inform the development of policies and practice in critical care units (Bingley and Clark, 2009). Findings of the study suggest several new directions of investigation for future research:

Families' experiences, needs and role in end of life decision-making: Making end-of-life care decisions in the context of critical care units is complex, stressful and challenging for families of the terminally ill patients. This would be augmented in Jordanian context where families are assumed legally and culturally to be the leader in deciding the best care for their loved one who is in capable of deciding about their own care. This indicates a need to put special emphasis on identifying the Jordanian family's needs and tailoring care and management of the end of life care in a way to meet these needs and empower families by provision of information about how best to support the patient. Thus, one important investigation for future research is to look at the decision-making experiences, needs, concerns and fears of family who assisted terminally ill family member who are no longer able to make their own healthcare decisions.

Families' perceptions of good end of life care and communication: The findings demonstrate that the staff have a poor awareness of what family perceptions toward good end of life care and communication are and their practice is not evidenced based. The staff interviews revealed that staff hold a presumption that patients' families are unwilling to accept any end of life conversation. This is really problematic because if their perception is right, it may be better not to try to conduct such conversations. However, if this perception is wrong, this means that there are opportunities for end of life care and communications have been missed. This indicates a need to understand more about families' perceptions of good end of life communication and care. Additionally, more research needs to be conducted to explore the perception of

Jordanian's families who had lost a loved one in critical care units toward good end of life care and peaceful death.

This study's findings revealed that there are no particular national healthcare laws or policies in Jordan that guide the process of end of life decision-making. Lack of clear standards and policies were perceived among the central constraints for staff in this study to communicate and practice end of life decision-making. This research suggests a need for policies about ethics, decision-making and advance planning for end of life care in critical care unit to promote a shared and ethical end of life decision-making; empower critical care staff and families with such decisions; and provides a meaningful context for quality care. The findings of this study and other future research (discussed above) will inform the development of such policies in critical care units in Jordan. This research suggests also a need for critical care staff to work and collaborate with stakeholders to identifying effective means to address ethical issues of decision making as a necessity to improve end of life care in critical care settings and implement interventions to promote the practice of ethically sound end of life decision-making. Addressing cultural, religious and legal issues is a great challenge, thus a concentrated, planned and collaborative work is required. Required policies should contain clear and detailed guidelines that set out a process for reaching end-of-life decisions.

Before such guidelines can be introduced it is imperative that health care professionals receive better education in ethical issues in end of life decision-making. This could be by including the ethical issues of end of life in all critical care units-orientation programs; providing continuous trainings and courses for staff (Millner et al., 2009; Attia et al., 2013); and expand the provision of ethical end of life care training and courses to colleges and Universities. This also includes the importance of patients and families to be familiar and educated to the importance or desirability of advance care panning if possible. This study revealed a paradox in the staff-family relationship in this study: staff want families to take the lead in decision-making but cannot talk to them about the probability of the patient's death. Frank disclosure of terminal prognosis and diagnosis are regarded as imperative in preparing for the end of life decision-making (Clarissa de Pentheny et al., 2011). However, such conversations in Jordanian's context are very complex as it fraught with great emotions, cultural and religious attitudes and behaviours.

Ethical decision-making also necessitates empowering critical care staff to both professionally and educationally giving bad news in a very sensitive way that fit with the contextual cultural and religious (Wenrich et al., 2001). Developing educational and training programs in end of life communication skills for health care providers and include them in the orientation program for new staff is essential to support delivering such communication to patients and families. On this sense, the staff need to empower and assist patients' families with the process of end of life care decision-making. The key for this is to have better communication between the family and the critical care staff where adequate information related to life support and patient's prognosis are provided. Better communication include: assessing families beliefs (cultural, spiritual, social and otherwise) which need to be considered in end of life decisions making; spending enough time with families to build rapport and trust; listening to families; sharing information and expectation with families by which end of life care decisions making become a shared responsibility between families and health care staff and providing clear communication without technical terminology the families might not understand.

This requires then a need to bridge between team members in critical care units; make more roles for psychosocial workers and religious leader (Table 7.2 draw a number of recommendations cited on literature would promote a team end of life communication and decision-making). By all of this, end of life care practice will be accustomed between staff in critical care units including when we talk about end of life care, who patients are involved, what are their needs and which treatments they shouldn't receive.

Table 7.2: Recommendation to promote intra-staff communication and decision-making

1. Providing a specialised training for critical care staff that incorporate: communication, coordination, problem solving, conflict management and team oriented culture (Boyle and Kochinda, 2004).

2. Improving intra-staff communication in the critical care units using daily goals worksheet that outline all roles of healthcare professionals who may be responsible for a patient care (Pronovost et al., 2003).

3. Use of joint grand rounds, patient care seminars, and inter-professional dialogues (Kennard et al., 1996).

4. Conduct action researches that target the changes in organizational cultures regarding end of life care practice by developing and testing interventions to improve communication and collaboration between healthcare staff and other interventions that support them.

7.6.1 Practice recommendations and future research

7.6.1.1 Family conference approach

Internationally, most of actual end of life decision-making take place through a series of family conferences that includes the interested family members and critical care staff including: physicians, nurses, and social workers (Swigart et al., 1996; Cook et al., 1999). Individualised meeting with a few family members was the most common communication mode the staff used in this study. This would because that legal next of-kin are those who hold responsibility for decisions and so they are is ultimate goal of critical care clinicians. It emerges from the staff interviews that due to several reasons (e.g. work load and time constraints), the staff meeting either together or with families to discuss patients' condition, prognosis and outcomes is rare. Family conference provides an opportunity to enhance the quality of end of life communication between staff and patients' families (Hudson et al., 2008; Curtis et al., 2001). Additionally, it promotes the communication and collaboration between critical care staff themselves where supposed to be a medical meeting before family meeting where staff describe and discuss the process of treatments-decision in advance. On the other hand and for some reasons family conference might be not the useful way so future studies may look at ways to test in clinical trials whether family conference approach is more effective to convey prognostic information and improve end-of-life communication and decision making in critical care units.

From my perspective, using a proactive, multidisciplinary family meeting that gather of a physician leader, nurse and other healthcare professionals with the family members (Lilly et al., 2000) seems to be the most a useful way for health care professionals to convey diagnosis and prognostic information and conduct end of life decision-making process in Jordanian context. Family conference would work in Jordanian context in several ways. First, end of life decision making toward limiting medical interventions usually involves detailed and culturally and religiously complex conversations with patients' families and fraught with as discussed earlier that need an inter-disciplinary team work. In such away, every member can deliver their role in supporting families and responding to their fears and concerns. Additionally, family conference is often the setting in which Islamic scholar could have a crucial role in response to families' religious concerns. Second, family conference represents an important setting for enhancing interdisciplinary staff communication, collaboration and learning. Third, family conference would works will with conveying information to a large number of families members and that would minimizing the incidence of interrupting staff by continuous family request for information. Fourth, collaborative interdisciplinary work will help in building families trust and attain their satisfaction.

7.7 Strengths and limitations

This study is the first to explore how transitions to end of life care approach are perceived to be managed in critical care settings in Middle East. In an innovative way, I used a mixed method design to provide an in depth as well as broad insight into the view and experience surrounding transition to and providing end of life care in critical care units. I used purposive sampling to maximise the diversity of participants in the qualitative study; two hospital settings were also selected.

Moreover, for the first time, this study used the 'National Survey of Critical-Care Nurses' Perceptions of End-of-Life Care' to elicit the perspective of medical critical care staff toward the obstacles to providing end of life care as it was originally designed and used for critical care nurses (Kirchhoff and Beckstrand, 2000). Additionally, this questionnaire was used for the first time in Jordan and for second time in Middle East to survey healthcare professionals' perceptions of obstacles and helps to providing end of life care for terminally ill patients and their families.

However, certain limitations are acknowledged. The available resources in terms of the time, budget in addition to the political issues of Syrian crisis, limited the number of interviews conducted with medical critical care staff and compelled me to conduct the quantitative and qualitative part concurrently. If I had more time available for my data collection, I would have taken more time to recruit more doctors and conducted the quantitative and qualitative part sequentially.

Participants reported on their end of life care practice and that of their colleagues, therefore this was not directly observed. Additionally, the findings of this study are limited, since all critical care staff recruited in this study are from the university affiliated hospitals in Jordan. Critical health care professionals from other Jordanian health care institutions including Ministry of Health and private hospitals, for example, may have different experiences and perceptions.

Additionally, the data related to lead specialists' views and practice, as well as data related to families' perspectives is secondary information. So, caution is also required in interpreting some of this data as it lacks the perspective of lead physicians who are the principal decision maker toward critically ill patients' direction of care and the perspective of families. Further studies of the lead specialists and the comparison between different staff accounts is recommended for future researchers. It is also recommended to explore the experiences and perspective of critically ill patients' families.

Even though the survey was adapted as described earlier, the new use of this survey reveals some of its shortcomings in eliciting the perceptions and the experiences of Jordanian critical care staff toward the obstacles and the supportive behaviors to providing end of life care. The shortcomings were related to its feasibility and the items included. The survey was criticized by some staff for being too long, time consuming and have some language difficulties. Additionally, the staff interviews and their responses to the open ended questions revealed additional obstacles and supportive behaviours to providing end of life care they have perceived or experienced and were not covered by the survey.

7.8 Reflection

As a Jordanian critical care nurse who has worked in critical care units for years, this study has changed aspects of my personal, professional and academic life. It has not been an easy journey, but has also been a thrilling and enriching experience. This study has affected me deeply; it might be because little attention is paid to palliative and end of life care in Jordan. It has provided me with new insights into critical care and all those providing and receiving the services. It will also inform my future clinical and teaching career by focusing of such obstacles in local, national and international seminars, workshops and conferences.

The study explored the experiences of critical care staff when working with critically ill patients and the factors that shape such experiences. This helps me to understand things I have encountered at work over a number of years; it answers a lot of questions that I and I'm sure a large number of other colleagues of Jordanian critical care staff always have in our minds. It explains the cultural, religious, legal and moral factors that shape our experience in critical care units; really I haven't realized these factors and its effect as much as I do during this study.

The study provides a picture of how Jordanian critical care staff work and communicate with critically ill patients, families. When I reflect on this I acknowledged that the families of critically ill patients in addition to being central and essential practically, they really deserve more than we used to give them in Jordan. Even though there are a lot of obstacles that increase the gap between us, we need to challenge these obstacles and help and support them during their difficult end of life time. I think we can be a changing agent where to put them among our priorities while working in critical care units. Additionally, this study launched issues that are related to patients' families need to be explored by further researches such as families' perceived and unmet needs when a member is dying in critical care units in Jordanian critical care units; families experience in critical units and the process family members go through to handle and process end of life decision-making.

Finally, as I come to the end of my PhD study at the University of Nottingham, when I look back I acknowledge the tremendous support and guidance that my supervisors provide me. I testify that they were the best who know what, when, how to support me during my study.

References

Adams, J. A., Anderson, R. A., Docherty, S. L., Tulsky, J. A., Steinhauser, K. E. and Bailey Jr, D. E. (2014) Nursing strategies to support family members of ICU patients at high risk of dying. **Heart & Lung: The Journal of Acute and Critical Care**.

Adams, J. A., Bailey, D. E., Jr., Anderson, R. A. and Docherty, S. L. (2011) Nursing Roles and Strategies in End-of-Life Decision Making in Acute Care: A Systematic Review of the Literature. **Nursing research and practice** 2011p. 527834.

Agresti, A. and Finlay, B. (2009) **Statistical methods for the social sciences / Alan Agresti, Barbara Finlay.** Pearson Prentice Hall.

Ahern, S. P., Doyle, T. K., Marquis, F., Lesk, C. and Skrobik, Y. (2012) Critically ill patients and end-of-life decision-making: the senior medical resident experience. **Advances in health sciences education** 17(1): pp. 121-136.

Ahrens, T., Yancey, V. and Kollef, M. (2003) Improving family communications at the end of life: Implications for length of stay in the intensive care unit and resource use. **American Journal of Critical Care** 12(4): pp. 317-323.

Al-Awamer, A. and Downar, J. (2014) Developing a palliative care service model for Muslim Middle Eastern countries. **Supportive Care in Cancer** pp. 1-10.

Al-Tamimi, A. A. and Bushnaq, M. (2011) Communication and Skills Workshops for Oncologists in Jordan. **Journal of palliative medicine** 14(4): pp. 387-387.

Al-Hassan, M. A. and Hweidi, I. M. (2004) The perceived needs of Jordanian families of hospitalized, critically ill patients. **International Journal of Nursing Practice** 10(2): pp. 64-71.

Allari, R. and Abu-Moghli, F. (2013) Moral Distress among Jordanian Critical Care Nurse and their Perception of Hospital Ethical Climate. **Journal of Natural Sciences Research** 3(5): pp. 144-153.

Almack, K., Cox, K., Moghaddam, N., Pollock, K. and Seymour, J. (2012) After you: conversations between patients and healthcare professionals in planning for end of life care. **BMC palliative care** 11(1): p. 15.

American Thoracic Society Bioethics Task Force. (1991) Withholding and withdrawing life-sustaining therapy. **Am Rev Respir Dis** 144(3 Pt 1): pp. 726-731.

Amos, M. A., Hu, J. and Herrick, C. A. (2005) The impact of team building on communication and job satisfaction of nursing staff. **Journal for Nurses in Professional Development** 21(1): pp. 10-16.

Angus, D. C., Barnato, A. E., Linde-Zwirble, W. T., Weissfeld, L. A., Watson, R. S., Rickert, T. and Rubenfeld, G. D. (2004) Use of intensive care at the end of life in the United States: An epidemiologic study*. **Critical Care Medicine** 32(3): p. 638.

Apatira, L., Boyd, E. A., Malvar, G., Evans, L. R., Luce, J. M., Lo, B. and White, D. B. (2008) Hope, truth, and preparing for death: perspectives of surrogate decision makers. **Annals of internal medicine** 149(12): pp. 861-868.

Aroni, R., Goeman, D., Stewart, K., Sawyer, S., Abramson, M. and Thein, F. (1999) **Concepts of Rigour: When Methodological, Clinical and Ethical Issues Intersect.** [Online]. Available at: http://www.latrobe.edu/www/aqr/offer/papers/RAoni.htm [Accessed May 2013].

Asch, D. A., Hansen-Flaschen, J. and Lanken, P. N. (1995) Decisions to limit or continue life-sustaining treatment by critical care physicians in the United States: conflicts between physicians' practices and patients' wishes. **American journal of respiratory and critical care medicine** 151(2): pp. 288-292.

Aslakson, R. A., Wyskiel, R., Thornton, I., Copley, C., Shaffer, D., Zyra, M., Nelson, J. and Pronovost, P. J. (2012) Nurse-perceived barriers to effective communication regarding prognosis and optimal end-of-life care for surgical ICU patients: A qualitative exploration. **Journal of palliative medicine** 15(8): pp. 910-915.

Attia, A. K., Abd-Elaziz, W. W. and Kandeel, N. A. (2013) Critical Care Nurses' Perception of Barriers and Supportive Behaviors in End-of-Life Care. **American Journal of Hospice and Palliative Medicine** 30(3): pp. 297-304.

Austin, W., Rankel, M., Kagan, L., Bergum, V. and Lemermeyer, G. (2005) To stay or to go, to speak or stay silent, to act or not to act: Moral distress as experienced by psychologists. **Ethics & Behavior** 15(3): pp. 197-212.

Azoulay, E., Chevret, S., Leleu, G., Pochard, F., Barboteu, M., Adrie, C., Canoui, P., Le Gall, J. R. and Schlemmer, B. (2000) Half the families of intensive care unit patients experience inadequate communication with physicians. **Critical Care Medicine** 28(8): pp. 3044-3049.

Azoulay, E., Lautrette, A., Peigne, V. and Pochard, F. (2011) Meeting the needs of families of patients in intensive care units. **Bulletin De L Academie Nationale De Medecine** 195(2): pp. 367-375.

Bach, V., Ploeg, J. and Black, M. (2009) Nursing roles in end-of-life decision making in critical care settings. **Western Journal of Nursing Research** 31(4): pp. 496-512.

Backman, K. and Kyngäs, H. A. (1999) Challenges of the grounded theory approach to a novice researcher. **Nursing & Health Sciences** 1(3): pp. 147-153.

Badger, J. M. (2005) A descriptive study of coping strategies used by medical Intensive Care Unit nurses during transitions from cure- to comfort-oriented care. **Heart & Lung** 34(1): pp. 63-68.

Badger, J. M. (2005) Factors that enable or complicate end-of-life transitions in critical care. **American Journal of Critical Care** 14(6): pp. 513-521.

Baggs, J. G., Norton, S. A., Schmitt, M. H., Dombeck, M. T., Sellers, C. R. and Quinn, J. R. (2007) Intensive care unit cultures and end-of-life decision making. **Journal of Critical Care** 22(2): pp. 159-168.

Baggs, J. G., Schmitt, M. H., Mushlin, A. I., Mitchell, P. H., Eldredge, D. H., Oakes, D. and Hutson, A. D. (1999) Association between nurse-physician collaboration and patient outcomes in three intensive care units. **Critical care medicine** 27(9): pp. 1991-1998.

Barclay, S. and Maher, J. (2010) Having the difficult conversations about the end of life. **Bmj** 341.

Barton, J. A. and Brown, N. J. (1995) Home visitation to migrant farm worker families: An application of Zerwekh's family caregiving model for public health nursing. **Holistic nursing practice** 9(4): pp. 34-40.

Beckstrand, R. and Kirchhoff, K. (2005) Providing end-of-life care to patients: critical care nurses' perceived obstacles and supportive behaviors. **Am J Crit Care** 14(5): pp. 395-403.

Beckstrand, R. L., Callister, L. C. and Kirchhoff, K. T. (2006) Providing a "good death": Critical care nurses' suggestions for improving end-of-life care. **American Journal of Critical Care** 15(1): pp. 38-46.

Beckstrand, R. L. and Kirchhoff, K. T. (2005) Providing end-of-life care to patients: Critical care nurses' perceived obstacles and supportive behaviors. **American Journal of Critical Care** 14(5): pp. 395-403.

Begley, A. and Piggott, S. (2013) Exploring moral distress in potential sibling stem cell donors. **Nursing ethics** 20(2): pp. 178-188.

Benton, T. and Craib, I. (2001) **Philosophy of Social Science: Philosophical Issues in Social Thought.** Palgrave Macmillan.

Berlinger, N., Jennings, B. and Wolf, S. M. (2013) **The Hastings Center Guidelines for Decisions on Life-Sustaining Treatment and Care Near the End of Life: Revised and Expanded Second Edition.** Oxford University Press.

Berman, R. C. and Tyyskä, V. (2011) A critical reflection on the use of translators/interpreters in a qualitative cross-language research project. **International Journal of Qualitative Methods** 10(2): pp. 178-190.

Bernard, H. R. (1988) **Research methods in cultural anthropology.** Sage publications Newbury Park.

Biesta, G. and Burbules, N. C. (2003) **Pragmatism and educational research.** Rowman & Littlefield Pub Inc.

Bingley, A. and Clark, D. (2009) A Comparative Review of Palliative Care Development in Six Countries Represented by the Middle East Cancer Consortium (MECC). **Journal of Pain and Symptom Management** 37(3): pp. 287-296.

Bisin, A. and Verdier, T. (2000) "Beyond the melting pot": cultural transmission, marriage, and the evolution of ethnic and religious traits. **The Quarterly Journal of Economics** 115(3): pp. 955-988.

Blackhall, L. J., Murphy, S. T., Frank, G., Michel, V. and Azen, S. (1995) Ethnicity and attitudes toward patient autonomy. **Jama** 274(10): pp. 820-825.

Blaxter, M. (1996) Criteria for the evaluation of qualitative research papers. **Medical Sociology News** 22(1): pp. 68-71.

Blomberg, K. and Sahlberg-Blom, E. (2007) Closeness and distance: a way of handling difficult situations in daily care. **Journal of clinical nursing** 16(2): pp. 244-254.

Bowden, J., Dempsey, K., Boyd, K., Fallon, M. and Murray, S. (2012) Are newly qualified doctors prepared to provide supportive and end-of-life care? A survey of Foundation Year 1 doctors and consultants. **The journal of the Royal College of Physicians of Edinburgh** 43(1): pp. 24-28.

Boyd, D., Merkh, K., Rutledge, D. N. and Randall, V. (2011) Nurses' perceptions and experiences with end-of-life communication and care. **Oncology Nursing Forum** 38(3): pp. E229-239.

Boyle, D. K. and Kochinda, C. (2004) Enhancing collaborative communication of nurse and physician leadership in two intensive care units. **Journal of Nursing Administration** 34(2): pp. 60-70.

Boyle, D. K., Miller, P. A. and Forbes-Thompson, S. A. (2005) Communication and end-of-life care in the intensive care unit: patient, family, and clinician outcomes. **Critical Care Nursing Quarterly** 28(4): pp. 302-316.

Britten, N. (1995) Qualitative research: qualitative interviews in medical research. **BMJ** 311(6999): pp. 251-253.

Buckley, P. and Andrews, T. (2011) Intensive care nurses' knowledge of critical care family needs. **Intensive & critical care nursing : the official journal of the British Association of Critical Care Nurses** 27(5): pp. 263-272.

Bushinski, R. L. and Cummings, K. M. (2007) Practices of effective end-of-life communication between nurses and patients/families in two care settings. **Creative nursing** 13(3): pp. 9-12.

Byrne-Armstrong, H., Higgs, J. and Horsfall, D. (2001) **Critical moments in qualitative research.** Butterworth-Heinemann Medical.

Caldwell, P. H., Arthur, H. M. and Demers, C. (2007) Preferences of patients with heart failure for prognosis communication. **Canadian Journal of Cardiology** 23(10): pp. 791-796.

Calvin, A. O., Kite-Powell, D. M. and Hickey, J. V. (2007) The neuroscience ICU nurse's perceptions about end-of-life care. **The Journal of neuroscience nursing : journal of the American Association of Neuroscience Nurses** 39(3): pp. 143-150.

Calvin, A. O., Lindy, C. M. and Clingon, S. L. (2009) The cardiovascular intensive care unit nurse's experience with end-of-life care: a qualitative descriptive study. **Intensive & critical care nursing : the official journal of the British Association of Critical Care Nurses** 25(4): pp. 214-220.

Carey, S. and Cosgrove, J. (2006) Cultural issues surrounding end-of-life care. **Current Anaesthesia & Critical Care** 17(5): pp. 263-270.

Carpenter, C. and Suto, M. (2008) **Qualitative research for occupational and physical therapists: A practical guide.** Blackwell Pub.

Charmaz, K. (2006) Constructing grounded theory: A practical guide through qualitative research. London: Sage.

Christakis, N. A. and Lamont, E. B. (2000) Extent and determinants of error in physicians' prognoses in terminally ill patients: prospective cohort study. **Western Journal of Medicine** 172(5): p. 310.

Christensen, P. H. (2004) Children's participation in ethnographic research: Issues of power and representation. **Children & society** 18(2): pp. 165-176.

Clarissa de Pentheny, O. K., Urch, C. and Brown, E. A. (2011) The impact of culture and religion on truth telling at the end of life. **Nephrology Dialysis Transplantation** 26(12): pp. 3838-3842.

Clayton, J. M., Hancock, K., Parker, S., Butow, P. N., Walder, S., Carrick, S., Currow, D., Ghersi, D., Glare, P. and Hagerty, R. (2008) Sustaining hope when communicating with

terminally ill patients and their families: a systematic review. **Psycho-Oncology** 17(7): pp. 641-659.

Clayton, J. M. and Kissane, D. W. (2009) Communication about transitioning patients to palliative care. **Handbook of Communication in Oncology and Palliative Care** p. 203.

Cohen, S., Sprung, C., Sjokvist, P., Lippert, A., Ricou, B., Baras, M., Hovilehto, S., Maia, P., Phelan, D., Reinhart, K., et al. (2005) Communication of end-of-life decisions in European intensive care units. **Intensive Care Medicine** 31(9): pp. 1215-1221.

Cook, D., Rocker, G., Giacomini, M., Sinuff, T. and Heyland, D. (2006) Understanding and changing attitudes toward withdrawal and withholding of life support in the intensive care unit. **Critical care medicine** 34(11): pp. S317-S323.

Cook, D. J., Giacomini, M., Johnson, N. and Willms, D. (1999) Life support in the intensive care unit: a qualitative investigation of technological purposes. **Canadian Medical Association Journal** 161(9): pp. 1109-1113.

Coombs, M. and Long, T. (2008) Managing a good death in critical care: can health policy help? **Nursing in critical care** 13(4): pp. 208-214.

Coombs, M. A., Addington-Hall, J. and Long-Sutehall, T. Challenges in transition from intervention to end of life care in intensive care: A qualitative study. **International Journal of Nursing Studies** pp. (2011), doi:2010.1016/j.ijnurstu.2011.2010.2019.

Coombs, M. A., Addington-Hall, J. and Long-Sutehall, T. (2012) Challenges in transition from intervention to end of life care in intensive care: a qualitative study. **International journal of nursing studies** 49(5): pp. 519-527.

Corley, M. C. (2002) Nurse moral distress: a proposed theory and research agenda. **Nursing ethics** 9(6): pp. 636-650.

Costello, J. (2006) Dying well: nurses' experiences of 'good and bad'deaths in hospital. **Journal of advanced nursing** 54(5): pp. 594-601.

Countries and Their Cultures. (2012). Available at: http://www.everyculture.com [Accessed 29.8 2014].

Coyne, I. T. (1997) Sampling in qualitative research. Purposeful and theoretical sampling; merging or clear boundaries? **Journal of advanced nursing** 26(3): pp. 623-630.

Creswell, J. W. (1998) **Qualitative inquiry and research design : choosing among five traditions / John W. Creswell.** Sage.

Creswell, J. W. (2003) **Research design : qualitative, quantitative, and mixed methods = approaches / John W. Creswell.** Sage Publications.

Creswell, J. W. and Plano Clark, V. L. (2011) **Designing and conducting mixed methods research / John W. Creswell, Vicki L. Plano Clark.** SAGE.

Creswell, J. W. and Tashakkori, A. (2007) Editorial: Developing publishable mixed methods manuscripts. **Journal of mixed methods research** 1(2): pp. 107-111.

Cronqvist, A. and Nyström, M. (2007) A theoretical argumentation on the consequences of moral stress. **Journal of nursing management** 15(4): pp. 458-465.

Crump, S. K., Schaffer, M. A. and Schulte, E. (2010) Critical Care Nurses' Perceptions of Obstacles, Supports, and Knowledge Needed in Providing Quality End-of-Life Care. **Dimensions of Critical Care Nursing** 29(6): p. 297.

Curtin, M. and Fossey, E. (2007) Appraising the trustworthiness of qualitative studies: Guidelines for occupational therapists. **Australian Occupational Therapy Journal** 54(2): pp. 88-94.

Curtis, J. R., Patrick, D. L., Caldwell, E. S. and Collier, A. C. (2000) Why don't patients and physicians talk about end-of-life care?: Barriers to communication for patients with acquired immunodeficiency syndrome and their primary care clinicians. **Archives of Internal Medicine** 160(11): pp. 1690-1696.

Curtis, J. R., Patrick, D. L., Shannon, S. E., Treece, P. D., Engelberg, R. A. and Rubenfeld, G. D. (2001) The family conference as a focus to improve communication about end-of-life care in the intensive care unit: Opportunities for improvement. **Critical Care Medicine** 29(2): pp. N26-N33.

Curtis, J. R. and Vincent, J.-L. (2010) Ethics and end-of-life care for adults in the intensive care unit. **The Lancet** 376(9749): pp. 1347-1353.

Da Costa, D., Ghazal, H. and Al Khusaiby, S. (2002) Do not resuscitate orders and ethical decisions in a neonatal intensive care unit in a Muslim community. **Archives of Disease in Childhood-Fetal and Neonatal Edition** 86(2): pp. F115-F119.

Davison, S. N. and Simpson, C. (2006) Hope and advance care planning in patients with end stage renal disease: qualitative interview study. **Bmj** 333(7574): p. 886.

De Villers, M. J. and DeVon, H. A. (2013) Moral distress and avoidance behavior in nurses working in critical care and noncritical care units. **Nursing ethics** p. 0969733012452882.

Deep, K. S., Griffith, C. H. and Wilson, J. F. (2008) Communication and decision making about life-sustaining treatment: examining the experiences of resident physicians and

seriously-ill hospitalized patients. **Journal of general internal medicine** 23(11): pp. 1877-1882.

DelVecchio Good, M.-J., Gadmer, N. M., Ruopp, P., Lakoma, M., Sullivan, A. M., Redinbaugh, E., Arnold, R. M. and Block, S. D. (2004) Narrative nuances on good and bad deaths: internists' tales from high-technology work places. **Social science & medicine** 58(5): pp. 939-953.

DiCicco-Bloom, B. and Crabtree, B. F. (2006) The qualitative research interview. **Medical Education** 40(4): pp. 314-321.

Douglas, C. (2009) End-of-life decisions and moral psychology: killing, letting die, intention and foresight. **Journal of Bioethical Inquiry** 6(3): pp. 337-347.

Duggleby, W. and Berry, P. (2005) Transitions and shifting goals of care for palliative patients and their families. **Clinical Journal of oncology nursing** 9(4): pp. 425-428.

Ebbs, C. (1996) QUALITATIVE RESEARCH INQUIRY: ISSUES OF POWER AND ETHICS. **Education** 117(2): pp. 217-222.

Efstathiou, N. and Clifford, C. (2011) The critical care nurse's role in End-of-Life care: issues and challenges. **Nursing in Critical Care** 16(3): pp. 116-123.

Eidelman, L., Jakobson, D., Pizov, R., Geber, D., Leibovitz, L. and Sprung, C. (1998) Forgoing life-sustaining treatment in an Israeli ICU. **Intensive Care Medicine** 24(2): pp. 162-166.

Electronic Code of Federal Regulations. (2011) **Title 42: Public Health. Part 489 - Provider Agreements and Supplier Approval Subpart 1 Advanced Directives.** [Accessed 13 November 2014].

Elpern, E. H., Covert, B. and Kleinpell, R. (2005) Moral distress of staff nurses in a medical intensive care unit. **American Journal of Critical Care** 14(6): pp. 523-530.

Emanuel, E. J. (1988) A review of the ethical and legal aspects of terminating medical care. **The American journal of medicine** 84(2): pp. 291-301.

Epstein, E. G. and Delgado, S. (2010) Understanding and addressing moral distress. **Online Journal of Issues in Nursing** 15(3).

Espinosa, L., Young, A., Symes, L., Haile, B. and Walsh, T. (2010) ICU nurses' experiences in providing terminal care. **Critical Care Nursing Quarterly** 33(3): pp. 273-281.

Espinosa, L., Young, A. and Walsh, T. (2008) Barriers to intensive care unit nurses providing terminal care: an integrated literature review. **Critical Care Nursing Quarterly** 31(1): pp. 83-93.

Esteban, A., Gordo, F., Solsona, L., Alía, I., Caballero, J., Bouza, C., Alcalá-Zamora, J., Cook, D. J., Sanchez, J. M. and Abizanda, R. (2001) Withdrawing and withholding life support in the intensive care unit: a Spanish prospective multi-centre observational study. **Intensive care medicine** 27(11): pp. 1744-1749.

Farmer, B. (1992) Ethics: the use and abuse of power in nursing. **Nursing standard (Royal College of Nursing (Great Britain): 1987)** 7(23): pp. 33-36.

Farmer, T., Robinson, K., Elliott, S. J. and Eyles, J. (2006) Developing and implementing a triangulation protocol for qualitative health research. **Qualitative Health Research** 16(3): pp. 377-394.

Feilzer, M. Y. (2010) Doing mixed methods research pragmatically: Implications for the rediscovery of pragmatism as a research paradigm. **Journal of mixed methods research** 4(1): pp. 6-16.

Ferrand, E., Lemaire, F., Regnier, B., Kuteifan, K., Badet, M., Asfar, P., Jaber, S., Chagnon, J.-L., Renault, A. and Robert, R. (2003) Discrepancies between perceptions by physicians and nursing staff of intensive care unit end-of-life decisions. **American journal of respiratory and critical care medicine** 167(10): pp. 1310-1315.

Ferrand, E., Robert, R., Ingrand, P. and Lemaire, F. (2001) Withholding and withdrawal of life support in intensive-care units in France: a prospective survey. **The Lancet** 357(9249): pp. 9-14.

Ferrell, B. R. (2006) Understanding the moral distress of nurses witnessing medically futile care. Onc Nurs Society.

Festic, E., Grewal, R., Rabatin, J. T., Divertie, G. D., Shannon, R. P. and Johnson, M. M. (2010) End-of-life care in the intensive care unit: the perceived barriers, supports, and changes needed. **Acta Medica Academica** 39(2): pp. 150-158.

Festic, E., Wilson, M. E., Gajic, O., Divertie, G. D. and Rabatin, J. T. (2012) Perspectives of physicians and nurses regarding end-of-life care in the intensive care unit. **Journal of intensive care medicine** 27(1): pp. 45-54.

Finlay, L. (1998) Reflexivity: an essential component for all research? **The British Journal of Occupational Therapy** 61(10): pp. 453-456.

Fitzpatrick, R. and Boulton, M. (1994) Qualitative methods for assessing health care. **Quality in health care** 3(2): p. 107.

Fontana, A. and Frey, J. H. (2005) The interview: From neutral stance to political involvement. **The Sage handbook of qualitative research** 3pp. 695-727.

Fridh, I. (2014) Caring for the dying patient in the ICU–The past, the present and the future. **Intensive and Critical Care Nursing**.

Fry, S. and Warren, N. A. (2007) Perceived needs of critical care family members: a phenomenological discourse. **Critical care nursing quarterly** 30(2): pp. 181-188.

Ganz, F., Benbenishty, J., Hersch, M., Fischer, A., Gurman, G. and Sprung, C. (2006) The impact of regional culture on intensive care end of life decision making: an Israeli perspective from the ETHICUS study. **Journal of medical ethics** 32(4): pp. 196-199.

Gardiner, C., Ingleton, C., Gott, M. and Ryan, T. (2011) Exploring the transition from curative care to palliative care: a systematic review of the literature. **BMJ Supportive & Palliative Care** 1(1): p. 56.

Garrard, E. and Wilkinson, S. (2005) Passive euthanasia. **Journal of medical ethics** 31(2): pp. 64-68.

Gelling, L. (1999) The role of hope for relatives of critically ill patients: a review of the literature. **Nursing standard (Royal College of Nursing (Great Britain): 1987)** 14(1): p. 33.

General Medical Council. (2010) Treatment and care towards the end of life: good practice in decision making. london: General Medical Council.

George, D. and Mallery, P. (2012) **IBM SPSS Statistics 19 step by step : a simple guide and reference / Darren George, Paul Mallery.** Pearson.

Gibbins, J., McCoubrie, R. and Forbes, K. (2011) Why are newly qualified doctors unprepared to care for patients at the end of life? **Medical education** 45(4): pp. 389-399.

Giger, J. N. and Davidhizar, R. (2002) The Giger and Davidhizar transcultural assessment model. **Journal of Transcultural Nursing** 13(3): pp. 185-188.

Giger, J. N., Davidhizar, R. E. and Fordham, P. (2005) Multi-cultural and multi-ethnic considerations and advanced directives: developing cultural competency. **Journal of cultural diversity** 13(1): pp. 3-9.

Glaser, B. G. and Strauss, A. L. (1967) **The discovery of grounded theory: Strategies for qualitative research.** Aldine de Gruyter.

Goodman, J. (2010) The case of Dr Munro: are there lessons to be learnt? **Medical law review** 18(4): pp. 564-577.

Gordon, E. J. and Daugherty, C. K. (2003) 'Hitting you over the head': oncologists' disclosure of prognosis to advanced cancer patients. **Bioethics** 17(2): pp. 142-168.

Gott, M., Barnes, S., Parker, C., Payne, S., Seamark, D., Gariballa, S. and Small, N. (2007) Dying trajectories in heart failure. **Palliative Medicine** 21(2): pp. 95-99.

Gott, M., Ingleton, C., Bennett, M. I. and Gardiner, C. (2011) Transitions to palliative care in acute hospitals in England: qualitative study. **BMJ** 342p. d1773.

Gries, C. J., Curtis, J. R., Wall, R. J. and Engelberg, R. A. (2008) Family Member Satisfaction With End-of-Life Decision Making in the ICU*. **Chest** 133(3): pp. 704-712.

Gross, A. G. (2006) End-of-life care obstacles and facilitators in the critical care units of a community hospital. **Journal of Hospice & Palliative Nursing** 8(2): pp. 92-102.

Guba, E. G. (1981) Criteria for assessing the trustworthiness of naturalistic inquiries. **ECTJ** 29(2): pp. 75-91.

Guillemin, M. and Gillam, L. (2004) Ethics, reflexivity, and "ethically important moments" in research. **Qualitative inquiry** 10(2): pp. 261-280.

Gutierrez, K. M. (2012) Prognostic communication of critical care nurses and physicians at end of life. **Dimensions of Critical Care Nursing** 31(3): pp. 170-182.

Hagerty, R., Butow, P., Ellis, P., Dimitry, S. and Tattersall, M. (2005) Communicating prognosis in cancer care: a systematic review of the literature. **Annals of Oncology** 16(7): pp. 1005-1053.

Halcomb, E., Daly, J., Jackson, D. and Davidson, P. (2004) An insight into Australian nurses' experience of withdrawal/withholding of treatment in the ICU. **Intensive & critical care nursing : the official journal of the British Association of Critical Care Nurses** 20(4): pp. 214-222.

Hammell, K. W. and Carpenter, C. (2004) **Qualitative research in evidence-based rehabilitation.** Churchill Livingstone Edinburgh.

Hamric, A. B. and Blackhall, L. J. (2006) Nurse-physician perspectives on the care of dying patients in intensive care units: Collaboration, moral distress, and ethical climate. **Critical care medicine** 35(2): pp. 422-429.

Harrison, D. A., Brady, A. R. and Rowan, K. (2004) Case mix, outcome and length of stay for admissions to adult, general critical care units in England, Wales and Northern Ireland: the Intensive Care National Audit & Research Centre Case Mix Programme Database. **Critical Care** 8(2): pp. 99-111.

Heaston, S., Beckstrand, R. L., Bond, A. E. and Palmer, S. P. (2006) Emergency nurses' perceptions of obstacles and supportive behaviors in end-of-life care. **Journal of Emergency Nursing** 32(6): pp. 477-485.

Heland, M. (2006) Fruitful or futile: intensive care nurses' experiences and perceptions of medical futility. **Australian critical care : official journal of the Confederation of Australian Critical Care Nurses** 19(1): pp. 25-31.

Hickey, D. and Quinn, S. (2012) 'I don't want to talk about it.'Raising public awareness of end-of-life care planning in your locality. **International journal of palliative nursing** 18(5): pp. 241-247.

High, D. M. (1988) All in the family: extended autonomy and expectations in surrogate health care decision-making. **The Gerontologist** 28(Suppl): pp. 46-51.

Hoaglin, D. C. and Iglewicz, B. (1987) Fine-tuning some resistant rules for outlier labeling. **Journal of the American Statistical Association** 82(400): pp. 1147-1149.

Hov, R. (2007) **Nursing Care for Patients on the Edge of Life**. PhD thesis, Karlstad University Studies 2007: 33, Karlstad.

Hov, R., Hedelin, B. and Athlin, E. (2007) Good nursing care to ICU patients on the edge of life. **Intensive and Critical Care Nursing** 23(6): pp. 331-341.

Howe, K. R. (1988) Against the quantitative-qualitative incompatibility thesis or dogmas die hard. **Educational researcher** 17(8): pp. 10-16.

Hudson, P., Quinn, K., O'Hanlon, B. and Aranda, S. (2008) Family meetings in palliative care: multidisciplinary clinical practice guidelines. **BMC Palliative Care** 7(1): p. 12.

Iglesias, M. E. L., Pascual, C. and de Bengoa Vallejo, R. B. (2013) Obstacles and helpful behaviors in providing end-of-life care to dying patients in intensive care units. **Dimensions of Critical Care Nursing** 32(2): pp. 99-106.

Iyilikci, L., Erbayraktar, S., Gökmen, N., Ellidokuz, H., Kara, H. and Günerli, A. (2004) Practices of anaesthesiologists with regard to withholding and withdrawal of life support from the critically ill in Turkey. **Acta anaesthesiologica scandinavica** 48(4): pp. 457-462.

Jackson, J., Derderian, L., White, P., Ayotte, J., Fiorini, J., Hall, R. O. and Shay, J. T. (2012) Family perspectives on end-of-life care: a metasynthesis. **Journal of Hospice & Palliative Nursing** 14(4): pp. 303-311.

James, W. (1975) **The meaning of truth.** Harvard University Press.

Jameton, A. (1984) **Nursing practice: The ethical issues.** Prentice-Hall Englewood Cliffs, NJ.

Johnson, R. B. and Onwuegbuzie, A. J. (2004) Mixed methods research: A research paradigm whose time has come. **Educational researcher** 33(7): p. 14.

Johnson, R. B., Onwuegbuzie, A. J. and Turner, L. A. (2007) Toward a definition of mixed methods research. **Journal of mixed methods research** 1(2): pp. 112-133.

Jovanovic, M. (2011) Cultural competency and diversity among hospice palliative care volunteers. **American Journal of Hospice and Palliative Medicine** p. 1049909111410415.

Kagawa-Singer, M. and Blackhall, L. J. (2001) Negotiating cross-cultural issues at the end of life: You got to go where he lives. **Jama** 286(23): pp. 2993-3001.

Kalisch, B. J., Lee, H. and Rochman, M. (2010) Nursing staff teamwork and job satisfaction. **Journal of nursing management** 18(8): pp. 938-947.

Kamel, G., Paniagua, M. and Uppalapati, A. (2014) Palliative Care in the Intensive Care Unit Are Residents Well Trained to Provide Optimal Care to Critically ill Patients? **American Journal of Hospice and Palliative Medicine** p. 1049909114536979.

Kanner, A. D., Coyne, J. C., Schaefer, C. and Lazarus, R. S. (1981) Comparison of two modes of stress measurement: Daily hassles and uplifts versus major life events. **Journal of behavioral medicine** 4(1): pp. 1-39.

Karnieli-Miller, O., Strier, R. and Pessach, L. (2009) Power relations in qualitative research. **Qualitative Health Research** 19(2): pp. 279-289.

Keenan, S. P., Busche, K. D., Chen, L. M., McCarthy, L., Inman, K. J. and Sibbald, W. J. (1997) A retrospective review of a large cohort of patients undergoing the process of withholding or withdrawal of life support. **Critical care medicine** 25(8): pp. 1324-1331.

Kennard, M. J., Speroff, T., Puopolo, A. L., Follen, M. A., Mallatratt, L., Phillips, R., Desbiens, N., Califf, R. M. and Connors, A. F. (1996) Participation of nurses in decision making for seriously III adults. **Clinical Nursing Research** 5(2): pp. 199-219.

Kingsley, C. (2010) **Cultural and socioeconomic factors affecting cancer screening, early detection, and care in Latino populations.** [Online]. Available at: http://ethnomed.org/clinical/cancer [Accessed 29.8 2014].

Kirby, E., Broom, A. and Good, P. (2014) The role and significance of nurses in managing transitions to palliative care: a qualitative study. **BMJ open** 4(9): p. e006026.

Kirchhoff, K. T. and Beckstrand, R. L. (2000) Critical care nurses' perceptions of obstacles and helpful behaviors in providing end-of-life care to dying patients. **American journal of critical care : an official publication, American Association of Critical-Care Nurses** 9(2): pp. 96-105.

Koenig, B. A. and Gates-Williams, J. (1995) Understanding cultural difference in caring for dying patients. **Western Journal of Medicine** 163(3): p. 244.

Kompanje, E. J., Piers, R. D. and Benoit, D. D. (2013) Causes and consequences of disproportionate care in intensive care medicine. **Current opinion in critical care** 19(6): pp. 630-635.

Kongsuwan, W. (2011) Thai Nurses' Experience of Caring for Persons Who Had a Peaceful Death in Intensive Care Units. **Nursing science quarterly** 24(4): pp. 377-384.

Kongsuwan, W., Keller, K., Touhy, T. and Schoenhofer, S. (2010) Thai Buddhist intensive care unit nurses' perspective of a peaceful death: an empirical study. **International journal of palliative nursing** 16(5): pp. 241-247.

Krefting, L. (1991) Rigor in qualitative research: The assessment of trustworthiness. **The American journal of occupational therapy** 45(3): pp. 214-222.

Kremelberg, D. (2011) **Practical statistics : a quick and easy guide to IBM SPSS = Statistics, STATA, and other statistical software / David Kremelberg.** SAGE.

Kryworuchko, J., Hill, E., Murray, M. A., Stacey, D. and Fergusson, D. A. (2013) Interventions for Shared Decision-Making About Life Support in the Intensive Care Unit: A Systematic Review. **Worldviews on Evidence-Based Nursing** 10(1): pp. 3-16.

Kuzel, A. J. (1992) Sampling in qualitative inquiry. (In: Crabtree BF, Miller WL, eds. Doing Qualitative Research, 2nd edn. Thousand Oaks: sage publication, 1999: 33-45.).

Kvale, S. (1983) The qualitative research interview: A phenomenological and a hermeneutical mode of understanding. **Journal of phenomenological psychology** 14pp. 171-196.

Larrabee, J. H., Ostrow, C. L., Withrow, M. L., Janney, M. A., Hobbs, G. R. and Burant, C. (2004) Predictors of patient satisfaction with inpatient hospital nursing care. **Research in nursing & health** 27(4): pp. 254-268.

Latour, J. M., Fulbrook, P. and Albarran, J. W. (2009) EfCCNa survey: European intensive care nurses' attitudes and beliefs towards end-of-life care. **Nursing in Critical Care** 14(3): pp. 110-121.

Lautrette, A., Ciroldi, M. and Ksibi, H. (2006) End-of-life family conferences: rooted in the evidence. **Critical care medicine** 34(11): pp. S364-S372.

Lee, J., Choi, M., Kim, S. s., Kim, H. and Kim, D. (2013) Korean nurses' perceived facilitators and barriers in provision of end-of-life care. **International journal of nursing practice** 19(3): pp. 334-343.

Levin, T. T., Moreno, B., Silvester, W. and Kissane, D. W. (2010) End-of-life communication in the intensive care unit. **General Hospital Psychiatry** 32(4): pp. 433-442.

Liaschenko, J., O'Conner-Von, S. and Peden-McAlpine, C. (2009) The "big picture": communicating with families about end-of-life care in intensive care unit. **DCCN - Dimensions of Critical Care Nursing** 28(5): pp. 224-231.

Lilly, C. M., De Meo, D. L., Sonna, L. A., Haley, K. J., Massaro, A. F., Wallace, R. F. and Cody, S. (2000) An intensive communication intervention for the critically ill. **The American journal of medicine** 109(6): pp. 469-475.

Lincoln, Y. S. (1985) **Naturalistic inquiry.** Sage.

Lofmark, R., Nilstun, T. and Bolmsjo, I. A. (2005) From cure to palliation: Staff communication, documentation, and transfer of patient. **Journal of Palliative Medicine** 8(6): pp. 1105-1109.

Low, M. M. (2012) **Patient satisfaction in the ICU: A multi-center study**. CALIFORNIA STATE UNIVERSITY, LONG BEACH.

Luce, J. M. and Alpers, A. (2000) Legal aspects of withholding and withdrawing life support from critically ill patients in the United States and providing palliative care to them. **American journal of respiratory and critical care medicine** 162(6): pp. 2029-2032.

Luce, J. M. and Lemaire, F. (2001) Two transatlantic viewpoints on an ethical quandary. **American journal of respiratory and critical care medicine** 163(4): pp. 818-821.

Lützén, K., Blom, T., Ewalds-Kvist, B. and Winch, S. (2010) Moral stress, moral climate and moral sensitivity among psychiatric professionals. **Nursing Ethics** 17(2): pp. 213-224.

Lynch, J., Appelboam, R. and McQuillan, P. J. (2003) Survey of abuse and violence by patients and relatives towards intensive care staff. **Anaesthesia** 58(9): pp. 893-899.

Lynn-sMcHale, D. J. and Deatrick, J. A. (2000) Trust between family and health care provider. **Journal of Family Nursing** 6(3): pp. 210-230.

Maly, R. C., Umezawa, Y., Ratliff, C. T. and Leake, B. (2006) Racial/ethnic group differences in treatment decision-making and treatment received among older breast carcinoma patients. **Cancer** 106(4): pp. 957-965.

Mantzoukas, S. (2004) Issues of representation within qualitative inquiry. **Qualitative Health Research** 14(7): pp. 994-1007.

Margaret, M. (1928) **Coming of age in Samoa.** New American Library.

Mark, G. T. and Lyons, A. C. (2010) Maori healers' views on wellbeing: The importance of mind, body, spirit, family and land. **Social Science & Medicine** 70(11): pp. 1756-1764.

Marsella, A. (2009) Exploring the literature surrounding the transition into palliative care: a scoping review. **International journal of palliative nursing** 15(4): p. 186.

Martin, C. R. A. and Thompson, D. R. A. (2000) **Design and analysis of clinical nursing research studies / Colin = R. Martin and David R. Thompson.=0A=.** Routledge,=0A=.

Mays, N. and Pope, C. (2000) Qualitative research in health care: Assessing quality in qualitative research. **BMJ: British Medical Journal** 320(7226): p. 50.

McAndrew, N. S. and Leske, J. S. (2014) A Balancing Act Experiences of Nurses and Physicians When Making End-of-Life Decisions in Intensive Care Units. **Clinical nursing research** p. 1054773814533791.

McCann, C. M., Beddoe, E., McCormick, K., Huggard, P., Kedge, S., Adamson, C. and Huggard, J. (2013) Resilience in the health professions: A review of recent literature. **International Journal of Wellbeing** 3(1).

McCarthy, J. and Deady, R. (2008) Moral distress reconsidered. **Nursing Ethics** 15(2): pp. 254-262.

McClement, S. E. and Degner, L. F. (1995) Expert nursing behaviors in care of the dying adult in the intensive care unit. **Heart & Lung: The Journal of Acute and Critical Care** 24(5): pp. 408-419.

McLachlan, H. (2008) The ethics of killing and letting die: active and passive euthanasia. **Journal of medical ethics** 34(8): pp. 636-638.

McLean, R. F., Tarshis, J., Mazer, C. D. and Szalai, J. (2000) Death in two Canadian intensive care units: institutional difference and changes over time. **Critical care medicine** 28(1): pp. 100-103.

Meadows, L. and Dodendorf, D. (1999) Data management and interpretation-using computers to assist. **Doing Qualitative Research. 2nd ed. Thousand Oaks, CA: Sage Publications** pp. 195-218.

Melltorp, G. and Nilstun, T. (1996) Decisions to forego life-sustaining treatment and the duty of documentation. **Intensive care medicine** 22(10): pp. 1015-1019.

Metz, H. C. (2009) Jordan: A country study. Library of Congress, Federal Research Division.

Meyer, H. (2011) Changing The Conversation In California About Care Near The End Of Life. **Health Affairs** 30(3): pp. 390-393.

Millner, P., Paskiewicz, S. T. and Kautz, D. (2009) A comfortable place to say goodbye. **DCCN - Dimensions of Critical Care Nursing** 28(1): pp. 13-17.

Mobley, M. J., Rady, M. Y., Verheijde, J. L., Patel, B. and Larson, J. S. (2007) The relationship between moral distress and perception of futile care in the critical care unit. **Intensive and Critical Care Nursing** 23(5): pp. 256-263.

Morgan, D. L. (2007) Paradigms lost and pragmatism regained. **Journal of mixed methods research** 1(1): pp. 48-76.

Morse, J., Barret, M., Mayan, M., Olson, K. and Spiers, J. Verification strategies for establishing reliability and validity in qualitative research. IJQM. 2002; 1: 13–22.

Morse, J. M. (1991) Approaches to qualitative-quantitative methodological triangulation. **Nursing Research** 40(2): pp. 120-123.

Moss, A. H., Demanelis, A. R., Murray, J. and Jack, J. (2005) Barriers to quality end-of-life care in West Virginia ICU units: physicians' and nurses' prospectives. **The West Virginia medical journal** 101(5): pp. 200-204.

Mrayyan, M. T. (2007) Jordanian nurses' job satisfaction and intent to stay: comparing teaching and non-teaching hospitals. **Journal of Professional Nursing** 23(3): pp. 125-136.

Murphy, P. A., Price, D. M., Stevens, M., Lynn, J. and Kathryn, E. (2001) Under the radar: Contributions of the SUPPORT nurses. **Nursing Outlook** 49(5): pp. 238-242.

Murray, S. A., Kendall, M., Boyd, K. and Sheikh, A. (2005) Illness trajectories and palliative care. **BMJ** 330(7498): pp. 1007-1011.

Mystakidou, K., Parpa, E., Tsilika, E., Katsouda, E. and Vlahos, L. (2005) The evolution of euthanasia and its perceptions in Greek culture and civilization. **Perspectives in biology and medicine** 48(1): pp. 95-104.

Nava, S. (2004) Ethics, attitude and practice in end-of-life care decision: an European perspective. **Monaldi archives for chest disease = Archivio Monaldi per le malattie del torace / Fondazione clinica del lavoro, IRCCS [and] Istituto di clinica tisiologica e malattie apparato respiratorio, Universita di Napoli, Secondo ateneo** 61(1): pp. 50-57.

Nelms, T. P. and Eggenberger, S. K. (2010) The essence of the family critical illness experience and nurse-family meetings. **Journal of Family Nursing** 16(4): pp. 462-486.

Nelson, J., Angus, D., Weissfeld, L., Puntillo, K., Danis, M., Deal, D., Levy, M. and Cook, D. (2006) End-of-life care for the critically ill: A national intensive care unit survey. **Crit Care Med** 34(10): pp. 2547-2553.

Nelson, J. E. and Danis, M. (2001) End-of-life care in the intensive care unit: Where are we now? **Critical care medicine** 29(2): pp. N2-N9.

Norton, S. A. and Bowers, B. J. (2001) Working toward consensus: Providers' strategies to shift patients from curative to palliative treatment choices. **Research in nursing & health** 24(4): pp. 258-269.

O'Connor, M. and Aranda, S. (2003) **Palliative care nursing : a guide to practice.** Radcliffe Medical Press.

O'Brien, N. and Moules, T. (2007) So round the spiral again: A reflective participatory research project with children and young people. **Educational Action Research** 15(3): pp. 385-402.

Omari, F. H. (2009) Perceived and Unmet Needs of Adult Jordanian Family Members of Patients in ICUs. **Journal of Nursing Scholarship** 41(1): pp. 28-34.

Opdenakker, R. (2006) Advantages and disadvantages of four interview techniques in qualitative research. **[Eloctronic Journal]. Forum: Qualitative Social Research, 7, Article 11. Retrieved December 28, 2011 from http:// www.qualitative-research.net/fas-texte/4-06/06-4-11-e.htm.** .

Owen, S. (2001) The practical, methodological and ethical dilemmas of conducting focus groups with vulnerable clients. **Journal of advanced nursing** 36(5): pp. 652-658.

Panagopoulou, E., Mintziori, G., Montgomery, A., Kapoukranidou, D. and Benos, A. (2008) Concealment of information in clinical practice: is lying less stressful than telling the truth? **Journal of Clinical Oncology** 26(7): pp. 1175-1177.

Pattison, N. (2004) Integration of critical care and palliative care at end of life. **British journal of nursing** 13(3): pp. 132-139.

Pattison, N. (2006) A critical discourse analysis of provision of end-of-life care in key UK critical care documents. **Nursing in critical care** 11(4): pp. 198-208.

Patton, M. Q. (1990) Qualitative evaluation and research methods.

Pavlish, C., Brown-Saltzman, K., Dirksen, K. M. and Fine, A. (2014) Physicians' Perspectives on Ethically Challenging Situations: Early Identification and Action. **AJOB Empirical Bioethics** (just-accepted): pp. 00-00.

Peirce, C. S. (1998) **The essential Peirce: selected philosophical writings.** Indiana University Press.

Pierce, S. F. (1999) Improving End-of-Life Care: Gathering Suggestions From Family Members. **Nursing forum**. Wiley Online Library.

Piers, R. D., Azoulay, E., Ricou, B., Ganz, F. D., Max, A., Michalsen, A., Maia, P. A., Owczuk, R., Rubulotta, F. and Meert, A.-P. (2014) Inappropriate care in European Intensive Care Units: confronting views from nurses, junior and senior physicians. **CHEST Journal**.

Pochard, F., Azoulay, E., Chevret, S., Vinsonneau, C., Grassin, M., Lemaire, F., Hervé, C., Schlemmer, B., Zittoun, R. and Dhainaut, J.-F. (2001) French intensivists do not apply American recommendations regarding decisions to forgo life-sustaining therapy. **Critical care medicine** 29(10): pp. 1887-1892.

Polit, D. F. A. and Beck, C. T. A. (2006) **Essentials of nursing research : methods, appraisal, and = utilization / Denise F. Polit, Cheryl Tatano Beck.=0A=.** Lippincott Williams & Wilkins,=0A=.

Poulton, B., Ridley, S., Mackenzie-Ross, R. and Rizvi, S. (2005) Variation in end-of-life decision making between critical care consultants*. **Anaesthesia** 60(11): pp. 1101-1105.

Prendergast, T. J. (2000) Withholding or withdrawal of life-sustaining therapy. **Hospital practice (1995)** 35(6): pp. 91-92, 95-100,102.

Prendergast, T. J., Claessens, M. T. and Luce, J. M. (1998) A national survey of end-of-life care for critically ill patients. **American journal of respiratory and critical care medicine** 158(4): pp. 1163-1167.

Prendergast, T. J. and Luce, J. M. (1997) Increasing incidence of withholding and withdrawal of life support from the critically ill. **American journal of respiratory and critical care medicine** 155(1): pp. 15-20.

Pronovost, P., Berenholtz, S., Dorman, T., Lipsett, P. A., Simmonds, T. and Haraden, C. (2003) Improving communication in the ICU using daily goals. **Journal of critical care** 18(2): pp. 71-75.

Puntillo, K. A., Benner, P., Drought, T., Drew, B., Stotts, N., Stannard, D., Rushton, C., Scanlon, C. and White, C. (2001) End-of-life issues in intensive care units: a national random survey of nurses' knowledge and beliefs. **American Journal of Critical Care** 10(4): pp. 216-229.

Puntillo, K. A. and McAdam, J. L. (2006) Communication between physicians and nurses as a target for improving end-of-life care in the intensive care unit: Challenges and opportunities for moving forward. **Critical care medicine** 34(11): pp. S332-S340.

Putnam, H. (2009) **Renewing philosophy.** Harvard University Press.

Qaddoumi, I., Ezam, N., Swaidan, M., Jaradat, I., Mansour, A., Abuirmeileh, N., Bouffet, E. and Al-Hussaini, M. (2009) Diffuse pontine glioma in Jordan and impact of up-front prognosis disclosure with parents and families. p. 20081210.

Rabow, M. W., Hauser, J. M. and Adams, J. (2004) Supporting family Caregivers at the end of life - "They don't know what they don't know". **Jama-Journal of the American Medical Association** 291(4): pp. 483-491.

Rachels, J. (2007) Active and passive euthanasia. **Bioethics: An Introduction to the History, Methods, and Practice** p. 64.

Ranse, K., Yates, P. and Coyer, F. (2012) End-of-life care in the intensive care setting: A descriptive exploratory qualitative study of nurses' beliefs and practices. **Australian Critical Care** 25(1): pp. 4-12.

Ravenscroft, A. J. and Bell, M. (2000) 'End-of-life'decision making within intensive care-objective, consistent, defensible? **Journal of medical ethics** 26(6): pp. 435-440.

Repenshek, M. (2009) Moral distress: inability to act or discomfort with moral subjectivity? **Nursing Ethics** 16(6): pp. 734-742.

Richards, D., Deeks, J., Sheldon, T. and Shaffer, J. (1996) Home parenteral nutrition: a systematic review. **Health technology assessment (Winchester, England)** 1(1): pp. i-iii, 1-59.

Robichaux, C. M. B. and Clark, A. P. (2006) Practice of expert critical care nurses in situations of prognostic conflict at the end of life. **American Journal of Critical Care** 15(5): pp. 480-491.

Rocker, G. M., Heyland, D. K., Cook, D. J., Dodek, P. M., Kutsogiannis, D. J. and O'Callaghan, C. J. (2004) Most critically ill patients are perceived to die in comfort during withdrawal of life support: a Canadian multicentre study. **Canadian Journal of Anesthesia** 51(6): pp. 623-630.

Rosner, F. (1991) Modern medicine and Jewish ethics.

Rubin, J. (1996) Impediments to the development of clinical knowledge and ethical judgment in critical care nursing. **Expertise in Nursing Practice: Caring, Clinical Judgment and Ethics. New York, NY: Springer** pp. 170-192.

Rushton, C. H., Reina, M. L. and Reina, D. S. (2007) Building trustworthy relationships with critically ill patients and families. **AACN advanced critical care** 18(1): pp. 19-30.

Russ, A. J., Shim, J. K. and Kaufman, S. R. (2007) The value of "life at any cost": talk about stopping kidney dialysis. **Social science & medicine** 64(11): pp. 2236-2247.

Sandelowski, M. (1986) The problem of rigor in qualitative research. **Advances in nursing science** 8(3): pp. 27-37.

Sandelowski, M. (2000) Combining qualitative and quantitative sampling, data collection, and analysis techniques in mixed-method studies. **Research in nursing & health** 23(3): pp. 246-255.

Sawatzky, J. A. V. (1996) Stress in critical care nurses: actual and perceived. **Heart & Lung: The Journal of Acute and Critical Care** 25(5): pp. 409-417.

Scherer, Y., Jezewski, M. A., Graves, B., Wu, Y. W. B. and Bu, X. (2006) Advance directives and end-of-life decision making: survey of critical care nurses' knowledge, attitude, and experience. **Critical Care Nurse** 26(4): pp. 30-40.

Schulman-Green, D., McCorkle, R., Cherlin, E., Johnson-Hurzeler, R. and Bradley, E. H. (2005) Nurses' communication of prognosis and implications for hospice referral: A study of nurses caring for terminally ill hospitalized patients. **American Journal of Critical Care** 14(1): pp. 64-70.

Seale, C. (1999) Quality in qualitative research. **Qualitative inquiry** 5(4): pp. 465-478.

Searight, H. R. and Gafford, J. (2005) "It's Like Playing With Your Destiny": Bosnian Immigrants' Views of Advance Directives and End-of-Life Decision-Making. **Journal of immigrant health** 7(3): pp. 195-203.

Sechrest, L. and Sidani, S. (1995) Quantitative and qualitative methods:* 1:: Is There an Alternative? **Evaluation and Program Planning** 18(1): pp. 77-87.

Secker, J., Wimbush, E., Watson, J. and Milburn, K. (1995) Qualitative methods in health promotion research: some criteria for quality. **Health Education Journal** 54(1): pp. 74-87.

Selecky, P. A., Eliasson, C. A. H., Hall, R. I., Schneider, R. F., Varkey, B. and McCaffree, D. R. (2005) Palliative and End-of-Life Care for Patients With Cardiopulmonary Diseases*. **Chest** 128(5): pp. 3599-3610.

Seymour, J. and Skilbeck, J. (2002) Ethical considerations in researching user views. **European Journal of Cancer Care** 11(3): pp. 215-219.

Shapiro, J., Astin, J., Shapiro, S. L., Robitshek, D. and Shapiro, D. H. (2011) Coping with loss of control in the practice of medicine. **Families, Systems, & Health** 29(1): p. 15.

Shenton, A. K. (2004) Strategies for ensuring trustworthiness in qualitative research projects. **Education for information** 22(2): pp. 63-75.

Sheward, K., Clark, J., Marshall, B. and Allan, S. (2011) Staff Perceptions of End-of-Life Care in the Acute Care Setting: A New Zealand Perspective. **Journal of Palliative Medicine** 14(5): pp. 623-630.

Sieber, S. D. (1973) The integration of fieldwork and survey methods. **American journal of sociology** pp. 1335-1359.

Silverman, D. (2004) **Qualitative research: Theory, method and practice.** Sage Publications Ltd.

Silverman, D. (2006) **Interpreting qualitative data: Methods for analyzing talk, text, and interaction.** Sage Publications Ltd.

Sjökvist, P., Nilstun, T., Svantesson, M. and Berggren, L. (1999) Withdrawal of life support– who should decide? **Intensive care medicine** 25(9): pp. 949-954.

Sjökvist, P., Sundin, P. O. and Berggren, L. (1998) Limiting life support. **Acta anaesthesiologica scandinavica** 42(2): pp. 232-237.

Sleeman, K. (2013) End-of-life communication: let's talk about death. **The journal of the Royal College of Physicians of Edinburgh** 43(3): pp. 197-199.

Slevin, E. and Sines, D. (2000) Enhancing the truthfulness consistency and transferability of a qualitative study. **Nurse Researcher** 7(2): pp. 79-97.

Society of Critical Care, M. (1990) Consensus report on the ethics of foregoing life-sustaining treatments in the critically ill. **Crit Care Med** 18(12): pp. 1435-1439.

Sorensen, R. and Iedema, R. (2007) Advocacy at end-of-life: Research design: An ethnographic study of an ICU. **International journal of nursing studies** 44(8): pp. 1343-1353.

Sprung, C. L. (1990) Changing attitudes and practices in forgoing life-sustaining treatments. **Jama** 263(16): pp. 2211-2215.

Sprung, C. L., Cohen, S. L., Sjokvist, P., Baras, M., Bulow, H. H., Hovilehto, S., Ledoux, D., Lippert, A., Maia, P. and Phelan, D. (2003) End-of-life practices in European intensive care units. **JAMA: The Journal of the American Medical Association** 290(6): p. 790.

Sprung, C. L. and Eidelman, L. A. (1996) Worldwide similarities and differences in the forgoing of life-sustaining treatments. **Intensive care medicine** 22(10): pp. 1003-1005.

Sprung, C. L., Maia, P., Bulow, H. H., Ricou, B., Armaganidis, A., Baras, M., Wennberg, E., Reinhart, K., Cohen, S. L. and Fries, D. R. (2007) The importance of religious affiliation and culture on end-of-life decisions in European intensive care units. **Intensive Care Medicine** 33(10): pp. 1732-1739.

Sprung, C. L., Woodcock, T., Sjokvist, P., Ricou, B., Bulow, H.-H., Lippert, A., Maia, P., Cohen, S., Baras, M. and Hovilehto, S. (2008) Reasons, considerations, difficulties and

documentation of end-of-life decisions in European intensive care units: the ETHICUS Study. **Intensive care medicine** 34(2): pp. 271-277.

Stefania Negri, J. T., Amina Salki, Anna Zwick. (2013) **Advance Care Decision Making in Germany and Italy: A Comparative, European and International Law Perspective.**

Stjernswärd, J., Ferris, F. D., Khleif, S. N., Jamous, W., Treish, I. M., Milhem, M., Bushnaq, M., Al Khateib, A., Al Shtiat, M. N., Wheeler, M. S., et al. (2007) Jordan Palliative Care Initiative: A WHO Demonstration Project. **Journal of Pain and Symptom Management** 33(5): pp. 628-633.

Stratis Health. (2010) **Somalis in Minnesota. *Culture Care Connection*.** 2014. Available at: www.stratishealth.org.

Suliman, W. and Abu Gharbieh, P. (1996) Jordanian nurses: job dissatisfaction and anticipated withdrawal from practice. **DIRASAT MEDICAL AND BIOLOGICAL SCIENCES** 23pp. 76-87.

Sullivan, M. D. (2002) The illusion of patient choice in end-of-life decisions. **The American journal of geriatric psychiatry** 10(4): pp. 365-372.

Sullivan, M. D. (2003) Hope and hopelessness at the end of life. **The American Journal of Geriatric Psychiatry** 11(4): pp. 393-405.

Swigart, V., Lidz, C., Butteworth, V. and Arnold, R. (1996) Letting go: family willingness to forgo life support. **Heart & Lung: The Journal of Acute and Critical Care** 25(6): pp. 483-494.

Tarawneh, M., Nimri, O., Arkoob, K. and Zaghal, M. A. (2009) Cancer Incidence in Jordan 2009. **Non-Communicable Diseases Directorate, Jordan Cancer Registry. Ministry of Health**.

Tashakkori, A. and Teddlie, C. (1998) **Mixed methodology : combining qualitative and quantitative = approaches / Abbas Tashakkori, Charles Teddlie.** Sage.

Tashakkori, A. and Teddlie, C. (2003) **Handbook of mixed methods in social & behavioral research / = editors Abbas Tashakkori, Charles Teddlie.** SAGE Publications.

Taylor, S. J. and Bogdan, R. (1998) **Introduction to qualitative research methods : a guidebook and resource / Steven J. Taylor, Robert Bogdan.** Wiley.

Temple, B., Edwards, R. and Alexander, C. (2006) Grasping at context: Cross language qualitative research as secondary qualitative data analysis. **Forum Qualitative Sozialforschung/Forum: Qualitative Social Research**.

Thelen, M. (2005) End-of-life decision making in intensive care. **Critical Care Nurse** 25(6): pp. 28-37.

Thompson, G. N. (2006) "Changing lanes": Facilitating the transition from curative to palliative care. **Journal of Palliative Care** 22(2): pp. 91-98.

Torres, V. and Magolda, M. B. B. (2002) The Evolving Role of the Researcher in Constructivist Longitudinal Studies. **Journal of College Student Development** 43(4): pp. 474-489.

Trankle, S. A. (2013) **End of life decisions and practices: the experiences of doctors in Australia**. PhD Thesis.

Trankle, S. A. (2014) Is a good death possible in Australian critical and acute settings?: physician experiences with end-of-life care. **BMC palliative care** 13(1): p. 41.

Truog, R. D. and Berde, C. B. (1993) Pain, euthanasia, and anesthesiologists. **Anesthesiology** 78(2): pp. 353-360.

Truog, R. D., Campbell, M. L., Curtis, J. R., Haas, C. E., Luce, J. M., Rubenfeld, G. D., Rushton, C. H. and Kaufman, D. C. (2008) Recommendations for end-of-life care in the intensive care unit: A consensus statement by the American College of Critical Care Medicine. **Critical care medicine** 36(3): pp. 953-963.

Truog, R. D., Cist, A. F., Brackett, S. E., Burns, J. P., Curley, M. A., Danis, M., DeVita, M. A., Rosenbaum, S. H., Rothenberg, D. M. and Sprung, C. L. (2001) Recommendations for end-of-life care in the intensive care unit: The Ethics Committee of the Society of Critical Care Medicine. **Critical care medicine** 29(12): pp. 2332-2348.

Valiee, S., Negarandeh, R. and Dehghan Nayeri, N. (2012) Exploration of Iranian intensive care nurses' experience of end-of-life care: a qualitative study*. **Nursing in critical care** 17(6): pp. 309-315.

Van der Heide, A., Deliens, L., Faisst, K., Nilstun, T., Norup, M., Paci, E., van der Wal, G. and van der Maas, P. J. (2003) End-of-life decision-making in six European countries: descriptive study. **The Lancet** 362(9381): pp. 345-350.

Vanderspank-Wright, B., Fothergill-Bourbonnais, F., Brajtman, S. and Gagnon, P. (2011) Caring for patients and families at end of life: the experiences of nurses during withdrawal of life-sustaining treatment. **Dynamics (Pembroke, Ont.)** 22(4): pp. 31-35.

Verhaeghe, S. T. L., Van Zuuren, F. J., Defloor, T., Duijnstee, M. S. H. and Grypdonck, M. H. F. (2007) How does information influence hope in family members of traumatic coma patients in intensive care unit? **Journal of clinical nursing** 16(8): pp. 1488-1497.

Vincent, J.-L. (1999) Forgoing life support in western European intensive care units: the results of an ethical questionnaire. **Critical care medicine** 27(8): pp. 1626-1633.

Vincent, J. L. (1990) European attitudes towards ethical problems in intensive care medicine: results of an ethical questionnaire. **Intensive care medicine** 16(4): pp. 256-264.

Weeks, J. C., Catalano, P. J., Cronin, A., Finkelman, M. D., Mack, J. W., Keating, N. L. and Schrag, D. (2012) Patients' expectations about effects of chemotherapy for advanced cancer. **New England Journal of Medicine** 367(17): pp. 1616-1625.

Wellesley, H. and Jenkins, I. A. (2009) Withholding and withdrawing life-sustaining treatment in children. **Pediatric Anesthesia** 19(10): pp. 972-978.

Wenrich, M. D., Curtis, J. R., Shannon, S. E., Carline, J. D., Ambrozy, D. M. and Ramsey, P. G. (2001) Communicating with dying patients within the spectrum of medical care from terminal diagnosis to death. **Archives of Internal Medicine** 161(6): pp. 868-874.

Wheelan, S. A., Burchill, C. N. and Tilin, F. (2003) The link between teamwork and patients' outcomes in intensive care units. **American Journal of Critical Care** 12(6): pp. 527-534.

WHO. (2004) **WHO definition of palliative care.** [Online]. World Health Organization. [Accessed November 21,2011, from http://www.who.int/cancer/palliative/definition/en/.

WHO. (2009) **Jordan: health profile.** [Online]. [Accessed November, 21 2011 from http://www.who.int/gho/countries/jor.pdf].

Wiedermann, C. J., Lehner, G. F. and Joannidis, M. (2012) From persistence to palliation: limiting active treatment in the ICU. **Current opinion in critical care** 18(6): pp. 693-699.

Wiegand, D. L. and Funk, M. (2013) Consequences of clinical situations that cause critical care nurses to experience moral distress. **Nursing Ethics** p. 0969733011429342.

Wilkinson, D. J. and Truog, R. D. (2013) The luck of the draw: physician-related variability in end-of-life decision-making in intensive care. **Intensive care medicine** 39(6): pp. 1128-1132.

Wilkinson, J. M. (1987) Moral distress in nursing practice: experience and effect. **Nursing forum**. Wiley Online Library.

Wilkinson, S., Roberts, A. and Aldridge, J. (1998) Nurse–patient communication in palliative care: an evaluation of a communication skills programme. **Palliative medicine** 12(1): pp. 13-22.

Wunsch, H., Harrison, D. A., Harvey, S. and Rowan, K. (2005) End-of-life decisions: a cohort study of the withdrawal of all active treatment in intensive care units in the United Kingdom. **Intensive care medicine** 31(6): pp. 823-831.

Yazigi, A., Riachi, M. and Dabbar, G. (2005) Withholding and withdrawal of life-sustaining treatment in a Lebanese intensive care unit: a prospective observational study. **Intensive Care Medicine** 31(4): pp. 562-567.

Zeilani, R. and Seymour, J. E. (2010) Muslim women's experiences of suffering in Jordanian intensive care units: A narrative study. **Intensive and Critical Care Nursing** 26(3): pp. 175-184.

Zuzelo, P. R. (2007) Exploring the moral distress of registered nurses. **Nursing ethics** 14(3): pp. 344-359.

Appendices

APPENDIX A: Survey Of Critical Care Clinicians' Perceptions of End-Of-Life Care: Survey for Doctors

SURVEY OF CRITICAL CARE CLINICIANS' PERCEPTIONS OF END-OF-LIFE CARE

SURVEY FOR DOCTORS

The end of life is recognized as an important life phase. Clinicians deal frequently with critically ill patients who are at the end of life and dying. Care dilemmas arise for clinicians as dying patients are placed in an environment created to support and sustain life.

The following items pertain to your perceptions of possible **obstacles** to providing end-of-life care to dying patients and their families. As you read each item, please mark the circle that most closely characterizes how **large an obstacle** you have perceived each item to be then mark the <u>box</u> for how **frequently** you have experienced the obstacle when working in critical care units.

0= Not an Obstacle
1= Extremely Small
2= Small Obstacle
3= Medium obstacle
4= Large obstacle
5= Extremely Large

0= Never Occurs
1= Almost Never Occurs
2= Sometimes occurs
3= Fairly Often Occurs
4= Very Often Occurs
5= Always Occurs

Item	Obstacle size (0 1 2 3 4 5)	Frequency (0 1 2 3 4 5)
1. Clinicians who are overly optimistic to the family about the patient surviving.	0 1 2 3 4 5	0 1 2 3 4 5
2. Families not accepting what the clinician is telling them about the patient's poor prognosis.	0 1 2 3 4 5	0 1 2 3 4 5
3. Clinicians having to deal with distraught family members while still providing care for the patient.	0 1 2 3 4 5	0 1 2 3 4 5
4. Intra-family fighting about whether to continue or stop life support.	0 1 2 3 4 5	0 1 2 3 4 5
5. Clinicians knowing about the patient's poor prognosis before the family is informed.	0 1 2 3 4 5	0 1 2 3 4 5
6. Not enough time to provide quality end-of-life care because the clinicians focus is on activities that are trying to save the patient's life.	0 1 2 3 4 5	0 1 2 3 4 5
7. Poor design of units which do not allow for privacy of dying patients or grieving family members.	0 1 2 3 4 5	0 1 2 3 4 5
8. Unit visiting hours that is too restrictive.	0 1 2 3 4 5	0 1 2 3 4 5
9. The patient having pain that is difficult to control or alleviate.	0 1 2 3 4 5	0 1 2 3 4 5
10. Dealing with the cultural differences that families employ in grieving for their dying family member.	0 1 2 3 4 5	0 1 2 3 4 5
11. No available support person for the family such as a social worker or religious leader.	0 1 2 3 4 5	0 1 2 3 4 5
12. Employing life sustaining measures at the families' request even though the patient had signed advanced directives requesting no such care.	0 1 2 3 4 5	0 1 2 3 4 5

THANK YOU FOR YOUR PARTICIPATION IN THIS STUDY

The following items pertain to your perceptions of possible **obstacles** to providing end-of-life care to dying patients and their families. As you read each item, please mark the circle that most closely characterizes how **large an obstacle** you have perceived each item to be then mark the <u>box</u> for how **frequently** you have experienced the obstacle as you have worked in critical care units.

Left scale (circle):
0= Not an Obstacle
1= Extremely Small
2= Small Obstacle
3= Medium obstacle
4= Large obstacle
5= Extremely Large

Right scale (box):
0= Never Occurs
1= Almost Never Occurs
2= Sometimes occurs
3= Fairly Often Occurs
4= Very Often Occurs
5= Always Occurs

Item	Obstacle (0 1 2 3 4 5)	Frequency (0 1 2 3 4 5)
13. Continuing intensive care for a patient with a poor prognosis because of the real or imagined threat of future legal action by the patient's family.	0 1 2 3 4 5 ☐☐☐☐☐☐	0 1 2 3 4 5 ☐☐☐☐☐☐
14. Pressure to limit family grieving after the patient's death to accommodate a new admission to that room.	0 1 2 3 4 5 ☐☐☐☐☐☐	0 1 2 3 4 5 ☐☐☐☐☐☐
15. Continuing treatments for a dying patient even though the treatments cause the patient pain or discomfort.	0 1 2 3 4 5 ☐☐☐☐☐☐	0 1 2 3 4 5 ☐☐☐☐☐☐
16. Family and friends who continually call the clinician wanting an update on the patient's condition rather than calling the designated family member for information.	0 1 2 3 4 5 ☐☐☐☐☐☐	0 1 2 3 4 5 ☐☐☐☐☐☐
17. Lack of clinician's education and training regarding family grieving and quality end-of-life care.	0 1 2 3 4 5 ☐☐☐☐☐☐	0 1 2 3 4 5 ☐☐☐☐☐☐
18. Clinicians who won't allow the patient to die.	0 1 2 3 4 5 ☐☐☐☐☐☐	0 1 2 3 4 5 ☐☐☐☐☐☐
19. The unavailability of an ethics board or committee to review difficult patient cases.	0 1 2 3 4 5 ☐☐☐☐☐☐	0 1 2 3 4 5 ☐☐☐☐☐☐
20. Being called away from the patient and family because of the need to deal with a new admission or consultation.	0 1 2 3 4 5 ☐☐☐☐☐☐	0 1 2 3 4 5 ☐☐☐☐☐☐
21. Unit visiting hours that are too liberal.	0 1 2 3 4 5 ☐☐☐☐☐☐	0 1 2 3 4 5 ☐☐☐☐☐☐
22. Family members not understanding what "life-saving measures" really mean, i.e., that multiple needle sticks cause pain and bruising, that an ET tube won't allow the patient to talk, or that ribs may be broken during chest compressions.	0 1 2 3 4 5 ☐☐☐☐☐☐	0 1 2 3 4 5 ☐☐☐☐☐☐
23. The clinician not knowing the patient's wishes regarding continuing with treatments and tests due to the patient's inability to communicate.	0 1 2 3 4 5 ☐☐☐☐☐☐	0 1 2 3 4 5 ☐☐☐☐☐☐

THANK YOU FOR YOUR PARTICIPATION IN THIS STUDY

222

The following items pertain to your perceptions of possible **obstacles** to providing end-of-life care to dying patients and their families. As you read each item, please mark the circle that most closely characterizes how **large an obstacle** you have perceived each item to be then mark the <u>box</u> for how **frequently** you have experienced the obstacle as you have worked in critical care units.

Obstacle size scale:
0= Not an Obstacle
1= Extremely Small
2= Small Obstacle
3= Medium obstacle
4= Large obstacle
5= Extremely Large

Frequency scale:
0= Never Occurs
1= Almost Never Occurs
2= Sometimes occurs
3= Fairly Often Occurs
4= Very Often Occurs
5= Always Occurs

Item	Obstacle size (0 1 2 3 4 5)	Frequency (0 1 2 3 4 5)
24. Clinician's having to deal with angry family members.	0 1 2 3 4 5 ☐☐☐☐☐☐	0 1 2 3 4 5 ☐☐☐☐☐☐
25. The family, not being with the patient when he or she is dying.	0 1 2 3 4 5 ☐☐☐☐☐☐	0 1 2 3 4 5 ☐☐☐☐☐☐
26. Clinicians who are evasive and avoid having conversations with family members.	0 1 2 3 4 5 ☐☐☐☐☐☐	0 1 2 3 4 5 ☐☐☐☐☐☐
27. Multiple clinicians, involved with one patient, who differ in opinion about the direction of care.	0 1 2 3 4 5 ☐☐☐☐☐☐	0 1 2 3 4 5 ☐☐☐☐☐☐
28. Continuing to provide advanced treatments to dying patients because of financial benefits to the hospital.	0 1 2 3 4 5 ☐☐☐☐☐☐	0 1 2 3 4 5 ☐☐☐☐☐☐
29. Opinions of other critical care staff about the direction of patient care not being requested, valued, or considered.	0 1 2 3 4 5 ☐☐☐☐☐☐	0 1 2 3 4 5 ☐☐☐☐☐☐

30. Please describe any missing obstacles in detail. Indicate how <u>large</u> each obstacle is and how <u>frequently</u> it occurs.

_____

_____

_____

THANK YOU FOR YOUR PARTICIPATION IN THIS STUDY

Demographic data sheet

Please tell a little about yourself by filling in the appropriate boxes below.

31. How long have you been qualified as a doctor? Years ❑ Months ❑
32. How long have you been worked in ICU? Years ❑ Months ❑

33. What is your gender? ❑ Male ❑ Female

34. What year were your born? 19❑❑

35. Over your career, how many ICU patients have you, yourself given immediate end-of-life care to?

| ❑ | Less than 5 | ❑ Between 11 and 20 | ❑ More than 30 |
| ❑ | Between 5 and 10 | ❑ Between 21 and 30 | ❑ Other ———— |

36. In which type of ICU are you primarily employed?

❑	Intensive Care Unit	❑ Medical ICU	❑ Neuro/Neurosurgical ICU
❑	Coronary Care Unit	❑ Surgical ICU	❑ Shock/Trauma Unit
❑	Combined ICU/CCU	❑ Respiratory ICU	❑ Cardiovascular/Surgical ICU
❑	Other (Please specify) ————————		

37. The position you hold at the facility is?

| ❑ Junior | ❑ second year |
| ❑ Senior | ❑ Other (Please specify) |

38. How many hours per week do you work in the hospital you are currently working on? ❑❑

39. Do you have any comments about this study? ❑❑

—————————————————————————

68. Would you be willing to consider taking part in an interview to talk with Issa Almansour about end of life care? ❑ Yes ❑ No

If yes please fill in the participant's confirmation form that is enclosed and return with your questionnaire in the same envelope.

THANK YOU FOR YOUR PARTICIPATION IN THIS STUDY

SURVEY OF CRITICAL CARE CLINICIANS' PERCEPTIONS OF END-OF-LIFE CARE

SURVEY FOR CRITICAL CARE NURSES

The end of life is recognized as an important life phase. Clinicians deal frequently with critically ill patients who are at the end of life and dying. Care dilemmas arise for clinicians as dying patients are placed in an environment created to support and sustain life.

The following items pertain to your perceptions of possible **obstacles** to providing end-of-life care to dying patients and their families. As you read each item, please mark the circle that most closely characterizes how **large an obstacle** you have perceived each item to be then mark the <u>box</u> for how **frequently** you have experienced the obstacle when working in critical care units.

Obstacle scale:
0= Not an Obstacle
1= Extremely Small
2= Small Obstacle
3= Medium obstacle
4= Large obstacle
5= Extremely Large

Frequency scale:
0= Never Occurs
1= Almost Never Occurs
2= Sometimes occurs
3= Fairly Often Occurs
4= Very Often Occurs
5= Always Occurs

Item	Obstacle (0–5)	Frequency (0–5)
1. Clinicians who are overly optimistic to the family about the patient surviving.	0 1 2 3 4 5	0 1 2 3 4 5
2. Families not accepting what the clinician is telling them about the patient's poor prognosis.	0 1 2 3 4 5	0 1 2 3 4 5
3. Clinicians having to deal with distraught family members while still providing care for the patient.	0 1 2 3 4 5	0 1 2 3 4 5
4. Intra-family fighting about whether to continue or stop life support.	0 1 2 3 4 5	0 1 2 3 4 5
5. Clinicians knowing about the patient's poor prognosis before the family is informed.	0 1 2 3 4 5	0 1 2 3 4 5
6. Not enough time to provide quality end-of-life care because the clinicians focus is on activities that are trying to save the patient's life.	0 1 2 3 4 5	0 1 2 3 4 5
7. Poor design of units which do not allow for privacy of dying patients or grieving family members.	0 1 2 3 4 5	0 1 2 3 4 5
8. Unit visiting hours that is too restrictive.	0 1 2 3 4 5	0 1 2 3 4 5
9. The patient having pain that is difficult to control or alleviate.	0 1 2 3 4 5	0 1 2 3 4 5
10. Dealing with the cultural differences that families employ in grieving for their dying family member.	0 1 2 3 4 5	0 1 2 3 4 5
11. No available support person for the family such as a social worker or religious leader.	0 1 2 3 4 5	0 1 2 3 4 5
12. Employing life sustaining measures at the families' request even though the patient had signed advanced directives requesting no such care.	0 1 2 3 4 5	0 1 2 3 4 5

THANK YOU FOR YOUR PARTICIPATION IN THIS STUDY

The following items pertain to your perceptions of possible **obstacles** to providing end-of-life care to dying patients and their families. As you read each item, please mark the circle that most closely characterizes how **large an obstacle** you have perceived each item to be then mark the <u>box</u> for how **frequently** you have experienced the obstacle as you have worked in critical care units.

0= Not an Obstacle
1= Extremely Small
2= Small Obstacle
3= Medium obstacle
4= Large obstacle
5= Extremely Large

0= Never Occurs
1= Almost Never Occurs
2= Sometimes occurs
3= Fairly Often Occurs
4= Very Often Occurs
5= Always Occurs

	Obstacle 0 1 2 3 4 5	Frequency 0 1 2 3 4 5
13. Continuing intensive care for a patient with a poor prognosis because of the real or imagined threat of future legal action by the patient's family.	☐ ☐ ☐ ☐ ☐ ☐	☐ ☐ ☐ ☐ ☐ ☐
14. Pressure to limit family grieving after the patient's death to accommodate a new admission to that room.	☐ ☐ ☐ ☐ ☐ ☐	☐ ☐ ☐ ☐ ☐ ☐
15. Continuing treatments for a dying patient even though the treatments cause the patient pain or discomfort.	☐ ☐ ☐ ☐ ☐ ☐	☐ ☐ ☐ ☐ ☐ ☐
16. Family and friends who continually call the clinician wanting an update on the patient's condition rather than calling the designated family member for information.	☐ ☐ ☐ ☐ ☐ ☐	☐ ☐ ☐ ☐ ☐ ☐
17. Lack of clinician's education and training regarding family grieving and quality end-of-life care.	☐ ☐ ☐ ☐ ☐ ☐	☐ ☐ ☐ ☐ ☐ ☐
18. Clinicians who won't allow the patient to die.	☐ ☐ ☐ ☐ ☐ ☐	☐ ☐ ☐ ☐ ☐ ☐
19. The unavailability of an ethics board or committee to review difficult patient cases.	☐ ☐ ☐ ☐ ☐ ☐	☐ ☐ ☐ ☐ ☐ ☐
20. Being called away from the patient and family because of the need to deal with a new admission or consultation.	☐ ☐ ☐ ☐ ☐ ☐	☐ ☐ ☐ ☐ ☐ ☐
21. Unit visiting hours that are too liberal.	☐ ☐ ☐ ☐ ☐ ☐	☐ ☐ ☐ ☐ ☐ ☐
22. Family members not understanding what "life-saving measures" really mean, i.e., that multiple needle sticks cause pain and bruising, that an ET tube won't allow the patient to talk, or that ribs may be broken during chest compressions.	☐ ☐ ☐ ☐ ☐ ☐	☐ ☐ ☐ ☐ ☐ ☐
23. The clinician not knowing the patient's wishes regarding continuing with treatments and tests due to the patient's inability to communicate.	☐ ☐ ☐ ☐ ☐ ☐	☐ ☐ ☐ ☐ ☐ ☐

THANK YOU FOR YOUR PARTICIPATION IN THIS STUDY

The following items pertain to your perceptions of possible **obstacles** to providing end-of-life care to dying patients and their families. As you read each item, please mark the circle that most closely characterizes how **large an obstacle** you have perceived each item to be then mark the <u>box</u> for how **frequently** you have experienced the obstacle as you have worked in critical care units.

0= Not an Obstacle
1= Extremely Small
2= Small Obstacle
3= Medium obstacle
4= Large obstacle
5= Extremely Large

0= Never Occurs
1= Almost Never Occurs
2= Sometimes occurs
3= Fairly Often Occurs
4= Very Often Occurs
5= Always Occurs

	Obstacle 0 1 2 3 4 5	Frequency 0 1 2 3 4 5
24. Clinician's having to deal with angry family members.	☐ ☐ ☐ ☐ ☐ ☐	☐ ☐ ☐ ☐ ☐ ☐
25. The family, not being with the patient when he or she is dying.	☐ ☐ ☐ ☐ ☐ ☐	☐ ☐ ☐ ☐ ☐ ☐
26. Clinicians who are evasive and avoid having conversations with family members.	☐ ☐ ☐ ☐ ☐ ☐	☐ ☐ ☐ ☐ ☐ ☐
27. Multiple clinicians, involved with one patient, who differ in opinion about the direction of care.	☐ ☐ ☐ ☐ ☐ ☐	☐ ☐ ☐ ☐ ☐ ☐
28. Continuing to provide advanced treatments to dying patients because of financial benefits to the hospital.	☐ ☐ ☐ ☐ ☐ ☐	☐ ☐ ☐ ☐ ☐ ☐
29. Opinions of other critical care staff about the direction of patient care not being requested, valued, or considered.	☐ ☐ ☐ ☐ ☐ ☐	☐ ☐ ☐ ☐ ☐ ☐

30. Please describe any missing obstacles in detail. Indicate how <u>large</u> each obstacle is and how <u>frequently</u> it occurs.

_____

_____

The following items pertain to your perceptions of possible **helps** to providing end-of-life care to dying patients and their families. As you read each item, please mark the <u>circle</u> that most closely characterizes how **large a help** you have found each item to be then mark the box for how **frequently** you have experienced the helpful behaviour as you have cared for dying patients.

0= Not a help
1= Extremely Small
2= Small Help
3= Medium Help
4= Large Help
5= Extremely Large

0= Never Occurs
1= Almost Never Occurs
2= Sometimes occurs
3= Fairly Often Occurs
4= Very Often Occurs
5= Always Occurs

	Help 0 1 2 3 4 5	Frequency 0 1 2 3 4 5
31. Having one family member be the designated contact person for all other family members regarding patient information.	☐ ☐ ☐ ☐ ☐ ☐	☐ ☐ ☐ ☐ ☐ ☐
32. Having enough time to prepare the family for the expected death of the patient.	☐ ☐ ☐ ☐ ☐ ☐	☐ ☐ ☐ ☐ ☐ ☐

THANK YOU FOR YOUR PARTICIPATION IN THIS STUDY

The following items pertain to your perceptions of possible helps to providing end-of-life care to dying patients and their families. As you read each item, please mark the <u>circle</u> that most closely characterizes how **large a help** you have found each item to be then mark the box for how **frequently** you have experienced the helpful behaviour as you have cared for dying patients.

Help scale: 0= Not an A help, 1= Extremely Small, 2= Small Help, 3= Medium Help, 4= Large Help, 5= Extremely Large

Frequency scale: 0= Never Occurs, 1= Almost Never Occurs, 2= Sometimes occurs, 3= Fairly Often Occurs, 4= Very Often Occurs, 5= Always Occurs

Item	Help (0 1 2 3 4 5)	Frequency (0 1 2 3 4 5)
33. A unit designed so that the family has a place to go to grieve in private.	0 1 2 3 4 5 ☐☐☐☐☐☐	0 1 2 3 4 5 ☐☐☐☐☐☐
34. Having the physicians involved in the patient's care agree about the direction care should go.	0 1 2 3 4 5 ☐☐☐☐☐☐	0 1 2 3 4 5 ☐☐☐☐☐☐
35. Having a unit schedule that allows for continuity of care for the dying patient by the same nurses.	0 1 2 3 4 5 ☐☐☐☐☐☐	0 1 2 3 4 5 ☐☐☐☐☐☐
36. The nurse drawing on his/her own previous experience with the critical illness or death of a family member.	0 1 2 3 4 5 ☐☐☐☐☐☐	0 1 2 3 4 5 ☐☐☐☐☐☐
37. Having the family physically help care for the dying patient.	0 1 2 3 4 5 ☐☐☐☐☐☐	0 1 2 3 4 5 ☐☐☐☐☐☐
38. Talking with the patient about his or her feelings and thoughts about dying.	0 1 2 3 4 5 ☐☐☐☐☐☐	0 1 2 3 4 5 ☐☐☐☐☐☐
39. Letting the social worker or religious leader take primary care of the grieving family.	0 1 2 3 4 5 ☐☐☐☐☐☐	0 1 2 3 4 5 ☐☐☐☐☐☐
40. Teaching families how to act around the dying patient such as saying to them, "She can still hear...it is OK to talk to her."	0 1 2 3 4 5 ☐☐☐☐☐☐	0 1 2 3 4 5 ☐☐☐☐☐☐
41. Allowing families unlimited access to the dying patient even if it conflicts with nursing care at times.	0 1 2 3 4 5 ☐☐☐☐☐☐	0 1 2 3 4 5 ☐☐☐☐☐☐
42. Providing a peaceful, dignified bedside scene for family members once the patient has died.	0 1 2 3 4 5 ☐☐☐☐☐☐	0 1 2 3 4 5 ☐☐☐☐☐☐
43. Allowing family members adequate time to be alone with the patient after he or she has died.	0 1 2 3 4 5 ☐☐☐☐☐☐	0 1 2 3 4 5 ☐☐☐☐☐☐
44. Having a fellow nurse tell you that, "you did all you could for the patients," or some other word of support.	0 1 2 3 4 5 ☐☐☐☐☐☐	0 1 2 3 4 5 ☐☐☐☐☐☐
45. Having a fellow nurse put his or her arm around you, hug you, pat you on the back or give some other kind of brief physical support after the death of your patient.	0 1 2 3 4 5 ☐☐☐☐☐☐	0 1 2 3 4 5 ☐☐☐☐☐☐
46. Having fellow nurses take care of your other patient(s) while you get away from the unit for a few moments after the death of your patient.	0 1 2 3 4 5 ☐☐☐☐☐☐	0 1 2 3 4 5 ☐☐☐☐☐☐
47. Having a support person outside of the work setting who will listen to you after the death of your patient.	0 1 2 3 4 5 ☐☐☐☐☐☐	0 1 2 3 4 5 ☐☐☐☐☐☐

THANK YOU FOR YOUR PARTICIPATION IN THIS STUDY

The following items pertain to your perceptions of possible helps to providing end-of-life care to dying patients and their families. As you read each item, please mark the <u>circle</u> that most closely characterizes how **large a help** you have found each item to be then mark the box for how **frequently** you have experienced the helpful behaviour as you have cared for dying patients.

0= Not an A help
1= Extremely Small
2= Small Help
3= Medium Help
4= Large Help
5= Extremely Large

0= Never Occurs
1= Almost Never Occurs
2= Sometimes occurs
3= Fairly Often Occurs
4= Very Often Occurs
5= Always Occurs

Item	Large a help	Frequency
48. Having family members thank you or in some other way show appreciation for your care of the patient who has died.	0 1 2 3 4 5	0 1 2 3 4 5
49. Having an ethics committee member routinely attend unit rounds so they are involved from the beginning should an ethical situation with a patient arise later.	0 1 2 3 4 5	0 1 2 3 4 5
50. Having family members accept that the patient is dying.	0 1 2 3 4 5	0 1 2 3 4 5
51. After the patient's death, having support staff compile all the necessary paper work for you which must be signed by the family before they leave the unit.	0 1 2 3 4 5	0 1 2 3 4 5
52. Physicians who put hope in real tangible terms by saying to the family that, for example, only 1 out of 100 patients in this patient's condition will completely recover.	0 1 2 3 4 5	0 1 2 3 4 5
53. Having the physician meet in person with the family after the patient's death to offer support and validate that all possible care was done.	0 1 2 3 4 5	0 1 2 3 4 5
54. Having un-licensed personnel available to help care for dying patients.	0 1 2 3 4 5	0 1 2 3 4 5

55. Please describe any missing helpful behaviors in detail. Indicate how <u>large</u> the help is and how <u>frequently</u> it occurs.

a. _____

b. _____

56. If you had the ability to change just one aspect of the end-of-life care given to dying ICU patients, what would it be?

_____

_____

_____

THANK YOU FOR YOUR PARTICIPATION IN THIS STUDY

Please tell a little about yourself by filling in the appropriate boxes below.

57. How long have you been qualified as an RN?   Years ❑ Months ❑
58. How long have you been worked in intensive care unit? Years ❑ Months ❑

59. What is your gender? ❑ Male   ❑ Female

60. What year were your born? 19❑❑

61. What is your highest completed level of education?

❑ Diploma in Nursing   ❑ Bachelors   ❑ Doctoral

❑ Associate degree, Nursing   ❑ Masters degree
                                                   ❑ Other _____

62. Over your nursing career, how many ICU patients have you, yourself given immediate end-of-life care to?

❑❑ Less than 5   ❑❑ Between 11 and 20   ❑❑ More than 30

❑❑ Between 5 and 10   ❑❑ Between 21 and 30   ❑❑ Other _____

63. In which type of ICU are you primarily employed?

❑   Intensive Care Unit   ❑ Medical ICU   ❑ Neuro/Neurosurgical ICU

❑   Coronary Care Unit   ❑ Surgical ICU   ❑ Shock/Trauma Unit

❑   Combined ICU/CCU   ❑ Respiratory ICU ❑ Cardiovascular/Surgical ICU

❑   Other (Please specify) ————————————————

64. The position you hold at the facility is?

❑❑ Direct care/Bedside/Staff Nurse ❑❑ Clinical Nurse Specialist

❑❑ Charge Nurse/Staff Nurse   ❑❑ Other (Please specify) ——————————

65. What is the number of beds in your unit?
66. How many hours per week do you usually work as an RN?   ❑❑

67. Do you have any comments about this study?   ❑❑

68. Would you be willing to consider taking part in an interview to talk with Issa Almansour about end of life care?   ❑ Yes   ❑ No

If yes please fill in the participant's confirmation form that is enclosed and return with your questionnaire in the same envelope.

THANK YOU FOR YOUR PARTICIPATION IN THIS STUDY

Direct line/e-mail
+44 (0) 115 8231063
Louise.Sabir@nottingham.ac.uk

The University of Nottingham

Faculty of Medicine and Health Sciences

27 July 2012

Medical School Research Ethics Committee
Division of Therapeutics & Molecular Medicine
D Floor, South Block
Queen's Medical Centre
Nottingham
NG7 2UH

Issa Almansour
PhD Student
c/o Professor Jane Seymour
Sue Ryder Care in Palliative and End of Life Studies
School of Nursing, Midwifery & Physiotherapy
QMC Campus
Nottingham University Hospitals
Nottingham
NG7 2UH

Tel: +44 (0) 115 8231063
Fax: +44 (0) 115 8231059

Dear Mr Alamansour

Ethics Reference No: A07062012 OVS SNMP
Study Title: From Aggressive Care to End-of-Life Care in Jordanian's Intensive Care Units: Health Care Professionals' Perspectives.
Lead Investigator: Issa Almansour, PhD Student, School of Nursing Midwifery and Physiotherapy.
Chief Investigators/Supervisors: Professor Jane Seymour, Dr Aimee Aubeeluck, Lecturer, Sue Ryder Care Professor in Palliative and End of Life Studies, School of Nursing Midwifery and Physiotherapy
Duration of Study: 8 months– 08/12-04/2013 **No of Participants:** 150

Thank you for your letter dated 10th July 2012 responding to the issues raised by the Committee and the following documents were received:

- Application form dated 16/07/2012
- Project proposal 1 16/07/2012
- Jordan University Hospital approval letter from CCU Supervisor 11/7/2012
- Jordan University Hospital approval letter from SICU Supervisor 11/7/2012
- Jordan University Hospital approval letter from General Director 12/7/2012
- Jordan University Hospital approval letter from MICU Supervisor 11/7/21012
- King Abdullah University Hospital approval letter CCU Head Nurse 11/7/2012
- King Abdullah University Hospital approval letter ITU Head Nurse 11/7/2012
- King Abdullah University Hospital approval letter ref10/2/5/2465 IRB Committee 5/7/2012.
- Appendix C participant's Confirmation Form 16/7/2012
- Appendix E Survey for Doctors 16/07/2012
- Appendix F Survey for Critical Care Nurses 16/07/2012

Documents previously received:

- Application form.doc 23 May 2012
- Letter for ethics issa.docx 23 May 2012
- Project proposal.docx 23 May 2012
- Consent form.docx 23 May 2012
- Information sheet.docx 23 May 2012
- Outline of interviews.docx 23 May 2012

- Questionnaire for critical care nurses.docx 23 May 2012
- Questionnaire for doctor.docx 23 may 2012

These have been reviewed and are satisfactory and the study is approved.

Approval is given on the understanding that the Conditions of Approval set out below are followed.

Conditions of Approval

You must follow the protocol agreed and any changes to the protocol will require prior Ethics' Committee approval.

Approval is given on the understanding that all appropriate ethical and regulatory permissions are respected for each overseas project in accordance with all local laws, and that the host organisation involved.

You promptly inform the Chairman of the Research Ethics Committee of

(i)   Deviations from or changes to the protocol which are made to eliminate immediate hazards to the research subjects.

(ii)   Any changes that increase the risk to subjects and/or affect significantly the conduct of the research.

(iii)   All adverse Events/drug reactions that are both serious and unexpected.

(iv)   New information that may affect adversely the safety of the subjects or the conduct of the study.

(v)   The attached End of Project Progress Report is completed and returned when the study has finished.

Yours sincerely

Dr Clodagh Dugdale
Chair, Nottingham University Medical School Research Ethics Committee

**Medical School Research Ethics Committee
Membership 2010/2011**

*denotes attendance at the Meeting on 7th June 2012

Chair	Dr Clodagh Dugdale, University Teacher in Sports and Exercise Medicine, Division of Orthopaedic and Accident Surgery, School of Clinical Sciences.*
School	**Representative**
Biomedical Sciences	Dr Vince Wilson, Reader and Basic Scientist.* Dr Liz Simpson, Chief Experimental Officer.*
Molecular Medical Sciences	Dr David Turner, Clinical Associate Professor in Microbiology.
Community Health Sciences	Dr Gillian Doody, Clinical Associate Professor & Reader in General Adult Psychiatry, Division of Psychiatry.*
Clinical Sciences	Dr Abdol Nateri, Lecturer, Pre-Clinical Cancer Studies Division of GI Surgery*
Graduate Entry Medicine, Derby	Dr Caroline Chapman, Associate Professor, Breast Surgery.
Clinical Sciences Human Development	Professor Harish Vyas, Consultant & Special Professor in Paediatric Intensive Care Unit and Respiratory Medicine, Children's Respiratory Unit, E Floor, East Block, QMC Campus, Nottingham University Hospitals Trust.
Primary Care	Dr Richard Knox, General Practitioner/ Part-time Lecturer Division of Primary Care, QMC Campus*
School of Nursing, Midwifery and Physiotherapy	Dr Stephen Timmons, Associate Professor/Senior Lecturer, School of Nursing Midwifery and Physiotherapy.*
Lay (Out of Faculty)	Professor Nigel White, Professor of Public International Law, School of Law, University of Nottingham.*
	Lydia Davies-Bright, PhD Student, School of Law.
	Dr Mary Stephenson, Research Fellow, SPMMRC, School of Physics and Astronomy.*
Medical Students nominated by ISC	To be appointed, 3rd Year Medical Student
Postgraduate Student Member	Prema Nirgude, PhD Student, IWHO, Division of Psychiatry* Catrin Middleton, PhD Student, Breast Surgery, Graduate Entry Medicine, Derby.
Administrator	Mrs Louise Sabir, Division of Therapeutics & MM, School of Clinical Sciences*

233

مستشفــى الجامعـة الأردنيـة
Jordan University Hospital

Ref.   **JUH/ 10/2012/ \\ o٢٢**   الرقـم : ....

Date: **\٢/7/2012**   التاريخ : ....

Jane Seymour

Sue Ryder Care Professor of Palliative and End of Life Studies

The University of

Nottingham

Fax:0044 (0) 115 82 31211

Reference to your e-mail dated May14[th], 2012 requesting that Mr Issa Mohammad Ali Almansour conducts a research project titled "From Aggressive Care to End-of-Life Care in Jordanian's Intensive Care Units: Health Care Professionals' Perspectives".

I would like to notify that your request is approved, as long as you mention Jordan University Hospital's name in the research (study).

With best regards,

Sincerely Yours,

General Director / Jordan University Hospital

Prof. Dr. Mujalli Mhailan

A.A

ISO 9001
DNV
REGISTERED

Ref: ————————————

Date:————————————

الرقم: —————————————

التاريخ: _11. 7. 2012_ —————

Dr Clodagh Dugdale
Chair Medical Research Ethics Committee
Division of Therapeutics & Molecular Medicine
D Floor
South Block
Queen's Medical Centre
Nottingham NG7 2UH

Dear Dr Dugdale

Research project for Issa Almansour: From Aggressive Care to End-of-Life Care in Jordanian's

Intensive Care Units: Health Care Professionals' Perspectives

I write this letter in my capacity as a supervisor of CCU at the Jordan University Hospital. Issa informed us that he wants to conduct his research study at the intensive care unit and we are ready to offer any support which he may need throughout the data collection period.

If you require any further information please do not hesitate to contact me

Yours sincerely

11. 7. 2012

Name: Ahlam Mustafa Abed
Position: CCU supervisor
Mobile: 00962- 795103174
E-mail:ahlam.abed@yahoo.com

تلفون 5353444 فاكس 5353388 تلكس 21629 صندوق بريد 13046 عمان -الأردن
Tel. 5353444 Fax. 5353388 Telex. 21629 Ju.Jo.P.O.Box 13046 Amman-Jordan

235

الرقم:

التاريخ:

Ref:

Date: 11/7/2012

Dr Clodagh Dugdale
Chair Medical Research Ethics Committee
Division of Therapeutics & Molecular Medicine
D Floor
South Block
Queen's Medical Centre
Nottingham NG7 2UH

Dear Dr Dugdale

Research project for Issa Almansour: From Aggressive Care to End-of-Life Care in Jordanian's

Intensive Care Units: Health Care Professionals' Perspectives

I write this letter in my capacity as a supervisor of SICU at the Jordan University Hospital. Issa informed us that he wants to conduct his research study at the intensive care unit and we are ready to offer any support which he may need throughout the data collection period.

If you require any further information please do not hesitate to contact me

Yours sincerely

Name: Laila Awad kharabsheh
Position: SICU supervisor
Mobile:00962- 799019760
E-mail:mah1982moud@yahoo.com

تلفون 5353444 فاكس 5353388 تلكس 21629 صندوق بريد 13046 عمان -الأردن
Tel. 5353444 Fax. 5353388 Telex. 21629 Ju.Jo.P.O.Box 13046 Amman-Jordan

236

مستشفى الجامعة الأردنية
Jordan University Hospital

Ref . _____

Date: 11/7/2012 _____

الـرقم :_____

التاريخ:_____ ١١/٧ ع.ت

Dr Clodagh Dugdale
Chair Medical Research Ethics Committee
Division of Therapeutics & Molecular Medicine
D Floor
South Block
Queen's Medical Centre
Nottingham NG7 2UH

Dear Dr Dugdale

Research project for Issa Almansour: From Aggressive Care to End-of-Life Care in Jordanian's

Intensive Care Units: Health Care Professionals' Perspectives

I write this letter in my capacity as a supervisor of MICU at the Jordan University Hospital. Issa informed us that he wants to conduct his research study at the intensive care unit and we are ready to offer any support which he may need throughout the data collection period.

If you require any further information please do not hesitate to contact me

Yours sincerely

Name: Khadeejh Naeem Faraj
Position: MICU supervisor
Mobile:00962- 798514033
E-mail:khadeejhneem@yhaoo.com

تلفون ٥٣٥٣٤٤٤ - فاكس ٥٣٥٣٣٨٨ - صندوق بريد ١٣٠٤٦ - عمان - الأردن
Tel. 5353444 Fax 5353388 - P.O.Box 13046 - Amman - Jordan

237
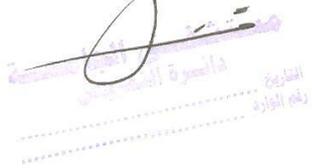
ص.ب (٦٣٠٠١) اربد (٢٢١١٠) الأردن

Ref. 10/2/5/2465
Date: 5-7-2012

هاتف: ٧٢٠٠٦٠٠ (٢-٩٦٢)   فاكس: ٧٠٩٥٧٧٧ (٢-٩٦٢)

الرقــم : ....
التاريخ : .... هـ
الموافق : .... م

D.r Jane Seymour,

Sue Ryder Care Center for the Study of Supportive, Palliative
And End of Life Care
Faculty of Medicine and Health Sciences
School of Nursing, Midwifery & Physiotherapy
The Medical School
Queen's Medical Center
Nottingham
NG7 2HA

Dear Dr.

In reference to your letter, in which you confirmed that Mr. Issa Mohammad Ali
Almansour is a Doctoral student in the School of Nursing at the University of
Nottingham and will be undertaking a project entitled:

" From aggressive care to end-of-life care in Jordanian's intensive care

unites: health care professionals' perspectives"

We would like to inform you that the IRB Committee has granted Mr. Issa Mohammad
Ali Almansour the approval to conduct her proposal at King Abdullah University
Hospital for the purpose mentioned above, under the following conditions:

1. Confidentiality is required while collecting data.
2. Informed consent is not required.
3. Provide us with the final results of the research before publishing.

Sincerely,,,

Prof. Hussein Heis

CEO KAUH

238

Ref. ....

Date : 11|7|2012

Dr Ciodagh Dugdale
Chair Medical Research Ethics Committee
Division of Therapeutics & Molecular Medicine
D Floor
South Block
Queen's Medical Centre
Nottingham NG7 2UH

11 July 2012

Dear Dr Dugdale

Research project for Issa Almansour: From Aggressive Care to End-of-Life Care in Jordanian's Intensive Care Units: Health Care Professionals' Perspectives

I write this letter in my capacity as the Head Nurse of coronary Care Unit at the King Abdullah University Hospital. Issa informed us that he wants to conduct his research study at the intensive care unit and we are ready to offer any support which he may need throughout the data collection period.

If you require any further information please do not hesitate to contact me

Yours sincerely

ABEER JAPITI
CORONARY CARE UNIT Head Nurse
(00962)-0799051320

Ref. ....   الرقـم : ....

Date : ____11/7/2012____   هـ .... : التاريخ

م .... : الموافق

Dr Clodagh Dugdale
Chair Medical Research Ethics Committee
Division of Therapeutics & Molecular Medicine
D Floor
South Block
Queen's Medical Centre
Nottingham NG7 2UH

11 July 2012

Dear Dr Dugdale

Research project for Issa Almansour: From Aggressive Care to End-of-Life Care in

Jordanian's Intensive Care Units: Health Care Professionals' Perspectives

I write this letter in my capacity as the Head Nurse of intensive care Unit at the King
Abdullah University Hospital. Issa informed us that he wants to conduct his research
study at the intensive care unit and we are ready to offer any support which he may
need throughout the data collection period.

If you require any further information please do not hesitate to contact me

Yours sincerely

NESREEN HILAT
INTENSIVE CARE UNIT Head Nurse
(00962)-0799051514

Issa .M.A. Almansour
B Floor, School of Nursing
Queen`s Medical Centre
Nottingham
NG7 2HA
ntxia1@nottingham.ac.uk

The University of
Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

An Invitation to Participate in Research

The Transition to End-of-Life care in Jordanian intensive care unit

Dear

I am a Jordanian CCN and I am now a postgraduate student in the University of Nottingham. I am interested in obtaining the perspectives of heath care professionals in ICUs toward the transition to and provision of end-of-life care for critically ill patients.

More complete information about this research study including the purpose of the study, what will involve, the participants involved and the dissemination of the result will be presented in the **"participants' information sheet"**. So please take your time and read the sheet carefully and I will be pleased to answer any question you have regarding the study; you can get in touch with me directly using my details given below.

Your participation will be extremely valuable and worthy because this is the first study in Jordan and all the information that is available in the literature about this subject is from western country. There is a survey document included in the envelop along with the information sheet, if you are willing to take part in this study, please fill up the survey and returns it back to the researcher. The participants will receive a participation certificate after returning the survey.

Thank you very much for taking your time to read this letter.

Your sincerely,

Issa M.A Almansour

00962-777-136172

Issa .M.A. Almansour
B Floor, School of Nursing
Queen`s Medical Centre
Nottingham
NG7 2HA
ntxia1@nottingham.ac.uk

The University of
Nottingham

UNITED KINGDOM · CHINA · MALAYSIA

Participant's information sheet

Title: The Transition to End-of-Life care in Jordanian intensive care unit

Names of investigators: Issa Almansour, Prof. Jane Seymour, Dr. Aimee
Aubeeluck

Dear

Before you come to a decision to take a part in the research study, it is important to understand the purpose of this study and what would be involved if you took part. Please take time to read the following information carefully and contact me if you have any inquiry or if you need further information.

Thank you for taking time to read this sheet.

What is the purpose of the study?

Providing comfort care is necessary, particularly when someone is dying. Providing quality end of life care in intensive care units requires a transition in the direction of care from focusing on curing and disease remission to providing comfort care and relieving suffering. The transition to end of life care is a challenging area of nursing and medical care.

This study aims to identify barriers and facilitators to the transition to end of life care from the viewpoints of health care professionals working in intensive care units. Your views are very important to help understand what difficulties staffs commonly encounter to provide end-of-life care and how best these difficulties can be managed.

Why have I been chosen?

You have been chosen because you are one of health care professionals providing care for dying patients in intensive care units in King Abdullah University Hospital and Jordan University Hospital. Health care professionals who are involved in this study are: critical care

nurses, doctor and head nurses of the intensive care units. Health care professionals who are not in direct contact with dying patients and those unable to provide their consent will be excluded.

Do I have to take part?

No. The participation in this study is voluntary. So it is up to you to make a decision whether to take part or not. If you agree to participate you will be provided by the information sheet and you will be asked to give your consent. In addition, if you feel uncomfortable or cannot complete the study at any time during the study, you are free to withdraw without giving any justification.

What does the study involve?

In this study, you are being invited to fill in a survey questionnaire that will take around 15-20 minutes to complete and is enclosed with the information sheet. In addition, some intensive care team will be contacted in the future to take a part in some qualitative interviews. The interviews will be conducted with particular participants depending on the findings of the survey and other interview data. The duration of the interview will depend on the topics to be discussed and will be approximately 60-90 minutes long.

The possible benefit of participation

Hopefully, by taking part in this study you may give some of your perspectives, preferences and experiences to be used in a constructive manner and aid in enhancing the provision of end of life care in Jordanian intensive care units, helping patients to experience a good death.

What are the possible disadvantages and risks of taking part?

This study will take a little bit of your time and this will be appreciated. In addition, because a sensitive issues (death and dying issues) will be discussed in the interview and may be concerned with some distressing experiences you have, this may cause some emotional disturbance. However, if you don't wish to discuss any of these experiences, you will never be required to do that and you can terminate the interview any time you feel uncomfortable. In addition, every effort will be adopted to make the interviews comfortable and anonymous and no given information will be shared with other members of staff including people at managerial level.

The interview place

The interview will be conducted in a convenient place and time near the intensive care unit so you will be near your work area to be available in the case of emergency. Once you give your consent I will contact you to arrange the convenient place and time for the interview.

Will my taking part in this study be kept confidential?

During the study, the confidentiality of the participants will be preserved including the audiotapes, transcripts and the personal data by a set of strategies:

- o The personal data will be stored in separate sheet in a study and it will be accessible by the researcher only.
- o The audiotapes and the transcript will be stored securely and it will be accessible by the researcher and his supervisors. The data will be stored in a password protected university computer and the hard copy will be stored in a locked filling cabinet.
- o After the study completion, all information will be moved in to the university archives storage.
- o You will not be identified in any report/publication.

What will happen to the results of the research study?

The result will be used to extend our understanding of end of life care in Jordanian intensive care units. The outcome of the study will be published as part of PhD thesis, Journal publications and conference presentations. The results are likely to be published by the end of academic year 2014/ 2015 and the thesis will be published as an electronic form at the website of university of Nottingham.

Who has reviewed the study?

This study has been approved by the King Abdullah University Hospital and Jordan University Hospital Research Committees.

What do I have to do?

If you agreed to participate, please fill up the survey document that is included in the envelope along with this sheet and returns it back to the researcher. If you need another copy, you can contact the researcher directly at the below address.

Contact for Further Information

Issa Almansour

Jordan

Irbid

Bayt Yafa

ntxia1@nottingham.ac.uk

i.almansour1985@yahoo.com

Mobile: 00962-777-136172.

* Thank you very much for taking part in the study.

Issa .M .A . Almansour
B Floor, School of Nursing
Queen`s Medical Centre
Nottingham
NG7 2HA
ntxia1@nottingham.ac.uk

The University of
Nottingham

UNITED KINGDOM · CHINA · MALAYSIA

Participant's Confirmation Form

The Transition to End-of-Life care in Jordanian intensive care unit

Dear Researcher

I am willing to participate in the research study to share my perspectives about providing End-of-Life care in ICUs. I know that I will be contacted shortly to arrange a convenient time and place to take apart in this study. My contact address is in the following:

Name: _____

Preferred method to contact: Phone   in personal   e-mail
(Please circle the preferable method)

Phone number: _____

E-mail: _____

Any specific needs or wishes to be considered

_____

Issa .M.A. Almansour
B Floor, School of Nursing
Queen`s Medical Centre
Nottingham
NG7 2HA
ntxia1@nottingham.ac.uk

The University of
Nottingham

UNITED KINGDOM · CHINA · MALAYSIA

Participant's Informed Consent Form

The Transition to End-of-Life care in Jordanian intensive care unit

Please check the box

1. I confirm that I have read and comprehend the participant's information sheet for this study.

2. I confirm that I have had the opportunity to ask and discuss any aspect of the study.

3. I realize that my participation is absolutely voluntary and I have the right to withdraw any time without any justification.

4. I agree to my interview being audio-recorded. I realize that I have the right to stop the recording at any time.

5. I agree to the use of some extract from my interview in results as published reports and presentations.

6. I realize that my personal information will be removed and I will be non-identifiable in any published report or any other output from the study.

7. I consent to contribute in this study.

_____   _____   _____

Name of the participant   Date   Signature

_____   _____   _____

Name of the researcher   Date   Signature

247

Permission to Use and Adapt the Questionnaire

Subject:	Critical Care Tool
From:	Renea Beckstrand (Renea_Beckstrand@byu.edu)
To:	i.almansour1985@yahoo.com;
Date:	Monday, 12 March 2012, 13:47

Issa Almansour,

You need to send me a fax number and I'll send you a faxed copy of the questionnaire. You have permission to use the questionnaire if you agree to send me any translations of the tool and if you notify me when you get your research published.

Renea L. Beckstrand, PhD, RN, CCRN, CNE

AACN RLN Steering Committee Communications Chair

Associate Professor and Research Coordinator

Brigham Young University, College of Nursing

Provo, UT 84602

renea@byu.edu

APPENDIX I: End of Life Care Policies

End of Life Care and Dying Patient Policy (Hospital One)

Policy Title **End of Life and Dying Patient Care**		
Policies and Procedures Manual **Clinical**	**Originating Department: Nursing Department**	
Policy No.: NR1002	**Page 1 of 3**	
Date Originated: 15/2/2009	**Last Revision: 11/10/2012**	**Issued No.: 2**
Approved by: General Director(CEO)	**Approval Date: 14/10/2012**	

Purpose:
- Support patient rights and responsibilities and deliver patient care in a respectful and compassionate manner.
- To provide awareness to health care providers of unique needs of dying patients

Policy:
- All health care providers shall be aware of dying patient unique needs that include treatment of primary and secondary symptoms; pain management; response to the patient's and family's psychological, social, emotional, religious, believes, cultural concerns, and involvement in care decisions

Procedure:
A. Relieve the dying person's pain
1. Measures to relieve pain are described fully in the policy on caring for the patient in pain. Patients who are in the last stages of illness, it is essential to remember that one of the main goals of HCP is to relieve or stop suffering. The following guidelines will be helpful:
    a. Always trust what patients say about their pain. And never just make your own judgment about how much pain they are suffering.
    b. Be kind when people express or show fear. And Comfort them and tell them that you can take care of the pain and that they do not need to fear.
    c. Give doses of pain medication that give the most pain control with the least side-effects as doctor order
    d. Give the appropriate pain killer to control pain such as (opioids)
    e. Giving some drugs together (in combination) increases their effectiveness. For example, non-steroidal anti-inflammatory drugs increase the effectiveness of opioids like morphine.
    f. Use the simplest route to give medicine. Give it by mouth, as long as the person can swallow. If the person cannot swallow, repeated boluses of opioids can be given under the skin (the subcutaneous route). Intramuscular routes are not as effective.
    g. Use other ways to control pain, including massage, music, and comfortable positioning of the patient. Sometimes a hot pad or hot water bottle is helpful with pain.
    h. Addiction to medication is never important for dying patients.
    i. Reduced breathing (respiratory depression) is not important for dying patients.
2. **Keep the patient comfortable**
    a. The patient may suffer from other discomfort, partly as a result of pain medication. such as(constipation a laxative may be helpful.
    b. As much as possible, give the patient a high-calorie, high-vitamin diet. Do not force the patient to eat. The patient should eat only what foods he/she wishes to eat.
    c. Encourage the patient to drink fluids.
    d. Keep the patient clean; (frequent baths, mouth care …)
    e. Help the patient to get out of bed and sit in a chair if he/she is able. If not, change the position every two hours and try to keep the patient in whatever positions are most comfortable.

F1GM6001

  f. If the patient has trouble breathing, help him or her to sit up a little.

  g. If the airway is obstructed, you may need to suction the patient's throat.

  h. If the patient feels short of breath or gasps for air, give oxygen.

  i. Even when patients are close to death, they can hear" so do not speak in a whisper". The patient will also still feel your touch.

3. **help the patient to a peaceful death**

  a. It is important to ask the patient and family whether the patient would prefer to stay in the hospital or to go home for the last days. Sometimes the family is not able to care for the patient at home, but often there is a choice. If the patient wants to go home, teach the family how to care for him or her. In particular, show the family how to give medication for pain. Make sure that they understand that it is very important to give the medicine in the right dose at the right times. Also explain to them how to make the patient comfortable, as listed above (establish hot line).

  b. If the patient stays in the hospital, try, as much as possible, to do what he/she and the family want. It is important to provide physical comfort. It is also important to make the patient feel secure to calm any fears, and give him or her hope.

  c. "Make the person feel safe and secure by showing that he/she will be taken care of, and will not be left alone"

  d. Calm any fears by assuring the patient that he/she will not suffer or die alone.

  e. (Give hope. Do not give false reassurances. Give smaller targets).

  f. Talk about the future of the patient's family, or suggest that the patient can hope for a good day tomorrow, or remind him or her that the children will soon be visiting.

  g. If the patient has unfinished business, give help with what he/she needs to do.

  h. The patient might need help with arrangements for his/her children or house. Provide spiritual care if the patient wishes, or speak to the family about having the religious leader visit.

  i. Respect the patient's decisions. and accept the patient's feelings. If he/she does not want to eat, or get out of bed, or be turned in bed, respects his/her desire. Listen and allow the person to talk about how he/she feels. If the patient or family is angry, try to calm them.

  j. Make it easy for the family to stay with the patient as much as they want. Show them how to take care of the patient and keep him or her clean and comfortable.

  k. "Keep the family informed about how the patient is. When death is near, let them know so that they can be with the patient at the time of death if they wish."

4. **Care after death**

  a. If the family is there at the death, allow them to stay with the patient after death, to say goodbye.

  b. If the families are not there, but they would like to see the body after death, make the person look as natural as possible. And make the environment clean. It is important to do this immediately, since the body will start to stiffen (rigor mortis) about two to four hours after death.

  c. Put the body in a flat position on the back, arms at the sides. Put a pillow or rolled towel under the head so that blood does not discolor the face. Close the eyelids and

F1GM6001

Policy Title		
End of Life and Dying Patient Care		
Policies and Procedures Manual Clinical	**Originating Department: Nursing Department**	
Policy No.: NR1002	**Page 3 of 3**	
Date Originated: 15/2/2009	**Last Revision: 11/10/2012**	**Issued No.: 2**
Approved by: General Director(CEO)	**Approval Date: 14/10/2012**	

hold them in place for a few seconds so that they will remain closed. Close the mouth, Wash soiled areas of the body. Take away all equipment and supplies from the bedside.

d. Comfort the family and let them grieve. (Refer to post mortem care policies adult and infant)

e. It is important for nurses who care for the dying to be aware of their own feelings about death and about their patients. It is difficult to see people die who you have cared for.

5. Many nurses feel frustration and grief when their patients die. It is important for you to recognize those feelings. You need to comfort and support each other in your care of the dying. Patient Ask foe help or comfort and talks to some body (psychological support or social services).

Definitions:

- Health care provider (HCP): are but not limited to physicians, nursing staff, dietitians, health educators, physical therapists, respiratory therapists, social workers…)

Documentation Requirements:

- NA

Approval:

- Nursing Director

References:

- Joint Commission International Standards Care Of Patient Chapter

F1GM6001

End of Life Care and Dying patient care Policy (Hospital Two)

POLICY AND PROCEDURE

Policy name: End- of –life and dying patient care	Policy Code: CLIN P017/3
Dept : Clinical	Originated Date : 4/4 /2009
	Implementation Date: 17/ 4 /2009
Scope : All patients at the end of life and dying Applies to: Physicians, nurses, social worker	Revision date: 13/3/2013
Written by :COP TEAM	Page No : (1 / 4)
Approved by: Date:.8.1.4.1.	Title: Sig:.....
Approved by: Date:19.14.1.7.1.	T... ...tor e'
Approved by: : Date...	1... ...tor Si...

Policy

All physicians and nurses at JUH will:

- Always respect patient's autonomy &privacy
- Always provide comfort and symptoms management especially for pain control refer to (pain management policy).
- Always assess for :
  - signs every 2hrs or as physician order& document it , such symptom as (Nausea & respiratory distress ..)
  - factors that alleviate or exacerbate physical symptoms
  - the need for an alternative setting or level of care.
  - psychological, social spiritual / religious issues
  - patient & family spiritual concerns such as despair, suffering, guilt, or forgiveness
  - Assess desires/ believes regarding organs and tissue donations.
  - Family coping mechanisms and the potential for pathological grief reactions.

- Be sensitive and respectful of the patients and family's wishes
- Offer continuity of care for the patient
- Provide access to any therapy which may realistically be expected to improve the patient's quality of life, including alternative of non traditional treatment
- Respect the right to refuse treatment
- Respect the physician's professional responsibility to discontinue some treatments when appropriate, with consideration for both patient and family preference
- Educate patient / family to empower them for stressful moment &to involve family in care giving by social worker if needed
- Always work in a multidisciplinary approach

Purpose:

- to adequately assess dying patient and their family & provide appropriate care.
- Keep the patient as comfortable as possible to improve the quality of life
- Prepare the family for patient's final hours
- Be aware about ethical issues regarding alternative therapies
- Prepare, support the patient, family & caregivers

Definitions:

End-of-life care is the term used to describe the support and medical care given during the time surrounding death. Such care does not happen just in the moments before breathing finally stops and a heart ceases to beat. An older person is often living, and dying, with one or more chronic illnesses and needs a lot of care for days, weeks, and sometimes even months.

Dying is the final portion of the life cycle for all of us. Providing excellent, human care to patients near the end of life, when curative means are either no longer possible or, no longer desired by the patient, is an essential part of medicine.

Equipment /Forms

- Emergency cart
- Monitor
- ECG machine
- O2 supply
- Suction
- Stethoscope
- Sphygnomanometer
- linens
- Pillows
- IV fluid

253

Procedure	Responsibility
-Keep patient in comfortable position 1. Assess level of consciousness 2. Assess respiratory system and maintain air way by positioning the patient in proper position chest physiotherapy suctioning applying air way and oxygen therapy as prescribed.	**Physician and Nurse**
3. Individualize the frequency of vital signs assessment for the dying client as much as possible within policy. Consider client and family preference and plan assessments to minimize disruption of family interactions and facilitate client comfort.	**Physician**

Procedure	Responsibility
4. Assess dying clients for dehydration, such as decreased ability to swallow and a subsequent decrease in blood volume. Consider the desires of the client and family, physician's orders and policy. 5. Maintain fluid and electrolyte balance by • hydration • administration IV fluid 6. Pain assessment & management.	**Physician and Nurse**
7. Pay special attention to general hygiene 8. Skin care and change position frequently 9. Avoid the use of aggressive therapies.	**Nurse**
10. Provide frequent and sensitive communication with the client and family to help them to cope.	**Physician**

254

12. Monitor signs of death:
  • absence of heartbeat, respirations
  • pupils fixed
  • color turns to waxen pallor as blood settle Body temperature drops
  • muscles, sphincters relax
  • release of stool, urine
  • eye can remain open
  • jaw falls open
 	
13. Documentation of all nursing interventions and notes
	Physician and Nurse

14. Help patients family to cope with crisis and encourage them to provide sensory stimulation by talking and touching their patients	**Nurse**

Rationale

- To support the dying client, family and caregivers
- To promote peaceful death

General Rules

- During the end of life, there are lots of things that we still can offer to patients to improve the quality of life despite the fact that their disease is not curable

References.

- Caring Connections (National Hospice and Palliative Care Organization.
- National and international standards.

Do Not Resuscitate Policy (Hospital One)

Policy Title Do Not Resuscitate		
Policies and Procedures Manual Clinical	Originating Department: Medical Department.	
Policy No. : MD1023	Page 1 of 1	
Date Originated: 18/6/2009	Last Revision: 11/10/2012	Issued No.: 2
Approved by: General Director(CEO)	Approval Date: 14/10/2012	

Purpose:
- To clarify the hospital policy regarding do not resuscitate.

Policy:
- Do Not Resuscitate process is prohibited at KAUH.

Procedure:
- A. All collapsed patients must be resuscitated as guidelines.
- B. If patient/ family wish to do not resuscitate, they will be informed about our policy and to offer them the alternatives of referral to another organization which provide the do not resuscitate process.
- C. The primary physician will arrange for patient referral to the hospital that provide do not resuscitate.

Definitions:
- **CPR:** the series of action that taken to prevent cardiopulmonary arrest.

- **DNR:** not to perform cardiopulmonary resuscitation in case of cardiopulmonary arrest.

Documentation Requirements:

- Transfer/ referral form F1GM1011

Approval:

- Medical Director

References:

- Joint Commission International Accreditation Standards for Hospitals.

F1GM6001

Do Not Resuscitate Policy (Hospital Two)

Policy name :DO NOT RESUSCITATE" (NO CPR) ORDER	Policy Code: CLIN P0037/2
Dept:clinical Division:	Originated Date : 1 /8 /2009
	Implementation Date: 10/8/2009
Scope : All terminal patients in	Revision date: 27/2/2013
Applied to :physicians, ethical committee, social worker	
Written by :	Page No : (1/6)
Approved by: Date: 28 /2/	Title: Nursing Director Sig:
Approved by: Date: 3 /3/2	Title : Director Quality Office Sig:
Approved by: Pr Date: 3 /3/ 20	Title: General Director Sig:........

Policy:

It is the policy of Jordan university hospital to insure that the hospital staff probably utilizes the procedure of "No CPR" or "Don't resuscitate" order according to the National legal and Ethical principles

Purposes:

1- To identify the circumstances in which the attending physician in JUH could hold the resuscitated measures.
2- To disseminate to family members the situation of seriously deteriorating health condition.

Definition:

1. **"NO CPR"** means NO chest compression's, No defibrillation , No assisted ventilation, No basic air way adjuncts, No advanced air way adjuncts (Endotracheal and suction tube),No cardiac medications or other medications, or means intended to initiated heart beat or treat non perusing rhythm

2. **"Futile"** refers to known terminal or untreatable chronic disease with low chance of survival, or when the patient's quality of life before cardio-pulmonary arrest had proven to be very poor. The following are examples of futile health condition: advanced late stage cancer, irreversible multi-organ failure, severe brain damage, inoperable malformations that are incompatible with life, fatal chromosome anomalies, irreversible or untreatable fatal neuro-muscular disease, etc.

Procedures:

PROCEDURE	RESPONSIBILITY
1-The attending physician shall identify the patient in whom resuscitation is inappropriate. In some instances however, others having to do with the care of the patient may prompt the attending physician to consider "NO CPR"	Attending Physician
2-The attending physician solicits the opinion of two (2) other physicians (consultant or associate consultant) concerning the "NO CPR" of the patient 2.1. The discussion concerning the "NO CPR" order shall be documented in the Progress Notes and co-signed by all three (3) doctors: Attending physician; and two others involved in the discussion within 48 hours. 2.2. In special situation, Attending Physician solicits verbal confirmation from other specialist or physician the "NO CPR" order shall be documented in the patient's chart. Document the verbal confirmation in writing by other member of the staff present in the discussion. 2.2.3. Upon reaching an agreement, a doctor's order shall be hand-written on the Doctor's Order Sheet with the "NO CPR" order and identifying the patient as "NO CPR".	Attending Physician

258

3- A progress note entered in the patient's chart shall describe:	
3.1. Patient's condition and emphasize the natural history of the disease as treatable or untreatable. 3.2. Quality of life, if the patient undergoes CPR. 3.3. Lack of therapy that can improve the patient's survival with improved quality of life.	Attending Physician
4-Patient (if conscious) and family involvement:	
4.1. In all situations of patient deterioration, the patient and family should receive ongoing information regarding the patient's status. 4.2. Inform the patient or immediate family members concerning the patient's condition and the decision for "NO CPR". 4.3. Do not leave the burden to the family members on making the decision not to resuscitate since it is a medical decision requiring good medical knowledge about the disease and judgment on the patient's deteriorating condition. 4.4. The Social Worker shall support the attending physician, after consultation with other healthcare team members, whenever possible in explaining to the family members to understand the futility of medical intervention in the patient's case and why the "NO CPR" status would be reasonable in that condition. Document such discussions in the Progress Notes and patient family education form.	Social Worker
5-If there is an unresolved conflict between the patient or family and the treating physician, the following guidelines shall apply:	
5.1. Involve another consultant of the same specialty to evaluate and confirm the "No CPR" decision. In the best interest of both the patient and JUH organization including treating physician, re-evaluation must be consistent. 5.2. Unachieved resolution shall involve more healthcare members either the Chief of the concerned specialty or the deputy medical director or both. 5.3. If still unachieved, refer the case to the Ethical Committee. If still unresolved, inform the family of the option to transfer the patient to another facility or to seek a second	Attending Physician

opinion **6-Validity of "NO CPR" Decision:** 6.1. Review the "NO CPR" order at intervals as appropriate to the patient's condition. In case of rapidly deteriorating condition, review every 7 days; and in case of a chronically ill long-term care patient, review every 6 months at least or more frequently as appropriate. 6.2 For readmitted patient to the hospital, revise the "NO CPR" status with a new order entered by the Admitting Physician in the Doctor's Order Sheet and Progress Notes	Attending Physician

GENERAL RULES:

- In case of an emergency management in which the family objected to the "NO CPR" of the patient, resuscitate the patient appropriately , and this should be documented in the medical record by physician who performing CPR

References:

Islamic View of Treating Terminal Illness (withholding and withdrawing)

- There are many Fatwas (legal Islamic Decisions) allowing withdrawal of all resuscitative measures when brain-death is diagnosed. The respirator could be switched off and any drugs being administered, discontinued. The decision of diagnosing brain-death is always a medical one and the ensuing ending of resuscitative measures should not be left to the family. It has to remain a medical decision.

- Similarly, if the treating physicians find a certain modality of treatment useless or going to increase the suffering of the patient, that modality of treatment should not be enforced from the start. Simply put, that means withholding certain useless or harmful modes of treatment. The Prophet Mohammed (PBUH) says "above all do non harm" and this rule of non-maleficence is the corner stone of all medical ethics.

قال صلى الله عليه وسلم:(لا ضرر ولا ضرر).

260

- Stopping a useless type of medication/ treatment or certain measures that support life will come under the same rule, but the lifting of life support should be decided by a committee involving the treating physicians, ethicist and a community member. It should also be discussed with the family.

The first Fatwa to stop the life support machine in cases of brain-death was that of Riyadh 1983: The Permanent Committee for Research and Fatwa, Fatwa No 6619 on 15/2/1404 (1983) Riyadh.

Q. If a person is on life support measures, but it was proved that his brain has stopped functioning irreversibly, is it permissible to remove the life supporting machines?

A. In such a case, it is permissible to stop the life support machines, as he is considered dead. The movement of the heart and respiration are only through the machines working on a person with no life. But it is imperative to ascertain his death after lifting the life support machines and before declaring death i.e. when circulation and respiration stops irreversibly.

The second Fatwa (included in the Tissue Transplantation Act. Of 1977 and its amendments).

According to Shariah, a person is considered dead and all the Shariah rules regarding death become effective if he/she shows one of the following two signs:

- Complete irreversible cardio-respiratory arrest and confirmed by medical report signed by a physician.
- Cessation of the brain activity and confirmation by physicians that such cessation is irreversible and that the brain has entered the state of decomposition.
- DIAGNOSIS OF Brain Death must be confirmed by three consultants, including a neurosurgeon , neurologist and an anesthesiologist.

Under these circumstances, the intensive care equipment supporting him can be stopped, even though some organs of his body, like his heart, continues to function with the help of the support equipment.

The third Fatwa is that of Islamic Jurisprudence Council of Makkah Al Mukkaramah, 10th Session (Oct. 17-21, 1987), Resolution No. 2. The life supporting equipment could be lifted from the patient whose brain functions have completely and irreversibly stopped and has been decided by three specialist physicians, even though the heart and respiration are still functioning (with the help of machines).

- However, such a person will not be considered legally dead until his respiration and circulation stops irreversibly after lifting the life support machines.

This Fatwa, although looks similar to the Fatwa of Amman in allowing the removal of supporting equipment from brain-dead persons, does not allow procuring organs from heart beating cadavers. It indicated that the heart and circulation should stop irreversibly before allowing harvesting of vital organs.

Revised by:

- Head of ethical committee

- Hospital legal consultation

APPENDIX J: Survey Results

Table 1: The mean scores for obstacle intensity perceived by nurses

Obstacles	Intensity mean
Family members not understanding what "life-saving measures" really mean, i.e., that multiple needle sticks cause pain and bruising, that an endotracheal tube won't allow the patient to talk etc.	4.12
Poor design of units which do not allow for privacy of dying patients or grieving family members.	3.89
Not enough time to provide quality end-of-life care because the clinicians focus is on activities that are trying to save the patient's life.	3.86
Lack of clinician's education and training regarding family grieving and quality end-of-life care.	3.84
Clinicians who are evasive and avoid having conversations with family members.	3.71
Clinicians' having to deal with angry family members.	3.68
Families not accepting what the clinicians are telling them about the patient's poor prognosis.	3.59
Multiple clinicians, involved with one patient, who differ in opinion about the direction of care.	3.59
The unavailability of an ethics board or committee to review difficult patient cases.	3.57
No available support person for the family such as a social worker or religious leader.	3.49
The clinician not knowing the patient's wishes regarding continuing with treatments and tests due to the patient's inability to communicate.	3.49
Dealing with the cultural differences that families employ in grieving for their dying family member.	3.45
Continuing treatments for a dying patient even though the treatments cause the patient pain or discomfort.	3.45
Unit visiting hours those are too liberal.	3.43
Continuing to provide advanced treatments to dying patients because of financial benefits to the hospital.	3.36
The patient having pain that is difficult to control or alleviate.	3.33

Table1 (Continued)

Obstacles	Intensity mean
Being called away from the patient and family because of the need to deal with a new admission or consultation.	3.29
Continuing intensive care for a patient with a poor prognosis because of the real or imagined threat of future legal action by the patient's family.	3.26
Clinicians having to deal with distraught family members while still providing care for the patient.	3.17
Pressure to limit family grieving after the patient's death to accommodate a new admission to that room.	3.17
Family and friends who continually call the clinician wanting an update on the patient's condition rather than calling the designated family member for information.	3.12
Intra-family fighting about whether to continue or stop life support.	3.04
Clinicians who won't allow the patient to die.	2.99
Employing life sustaining measures at the families' request even though the patient had signed advanced directives requesting no such care.	2.93
Opinions of other critical care staff about the direction of patient care not being requested, valued, or considered.	2.93
Clinicians who are overly optimistic to the family about the patient surviving.	2.91
The family, not being with the patient when he or she is dying.	2.86
Unit visiting hours that is too restrictive.	2.47
Clinicians' knowing about the patient's poor prognosis before the family is informed.	2.21

Table 2: The mean scores for obstacle frequency perceived by nurses

Obstacles	Frequency mean
Poor design of units which do not allow for privacy of dying patients or grieving family members.	4
Family members not understanding what "life-saving measures" really mean, i.e., that multiple needle sticks cause pain and bruising, that an endotracheal tube won't allow the patient to talk etc.	3.89
Clinicians' having to deal with angry family members.	3.76
Not enough time to provide quality end-of-life care because the clinicians focus is on activities that are trying to save the patient's life.	3.75
Families not accepting what the clinicians are telling them about the patient's poor prognosis.	3.5
Family and friends who continually call the clinician wanting an update on the patient's condition rather than calling the designated family member for information.	3.42
Lack of clinician's education and training regarding family grieving and quality end-of-life care.	3.38
Clinicians' knowing about the patient's poor prognosis before the family is informed.	3.38
The clinician not knowing the patient's wishes regarding continuing with treatments and tests due to the patient's inability to communicate.	3.37
Continuing treatments for a dying patient even though the treatments cause the patient pain or discomfort.	3.33
Clinicians having to deal with distraught family members while still providing care for the patient.	3.32
No available support person for the family such as a social worker or religious leader.	3.3
Being called away from the patient and family because of the need to deal with a new admission or consultation.	3.3
Continuing intensive care for a patient with a poor prognosis because of the real or imagined threat of future legal action by the patient's family.	3.25
Unit visiting hours those are too liberal.	3.14

Table2 (Continued)

Obstacles	Frequency mean
The unavailability of an ethics board or committee to review difficult patient cases.	3.11
Pressure to limit family grieving after the patient's death to accommodate a new admission to that room.	2.88
The family, not being with the patient when he or she is dying.	2.88
Clinicians who are evasive and avoid having conversations with family members.	2.78
Multiple clinicians, involved with one patient, who differ in opinion about the direction of care.	2.78
Unit visiting hours that is too restrictive.	2.74
Dealing with the cultural differences that families employ in grieving for their dying family member.	2.72
Continuing to provide advanced treatments to dying patients because of financial benefits to the hospital.	2.61
The patient having pain that is difficult to control or alleviate.	2.59
Clinicians who are overly optimistic to the family about the patient surviving.	2.54
Opinions of other critical care staff about the direction of patient care not being requested, valued, or considered.	2.47
Intra-family fighting about whether to continue or stop life support.	2.37
Clinicians who won't allow the patient to die.	2.37
Employing life sustaining measures at the families' request even though the patient had signed advanced directives requesting no such care.	1.78

Table 3: The perceived intensity scores for critical care nurses

Obstacles	PISs
Family members not understanding what "life-saving measures" really mean, i.e., that multiple needle sticks cause pain and bruising, that an endotracheal tube won't allow the patient to talk etc.	16.02
Poor design of units which do not allow for privacy of dying patients or grieving family members.	15.56
Not enough time to provide quality end-of-life care because the clinicians focus is on activities that are trying to save the patient's life.	14.47
Clinicians' having to deal with angry family members.	13.83
Lack of clinician's education and training regarding family grieving and quality end-of-life care.	12.97
Families not accepting what the clinicians are telling them about the patient's poor prognosis.	12.56
The clinician not knowing the patient's wishes regarding continuing with treatments and tests due to the patient's inability to communicate.	11.76
No available support person for the family such as a social worker or religious leader.	11.51
Continuing treatments for a dying patient even though the treatments cause the patient pain or discomfort.	11.48
The unavailability of an ethics board or committee to review difficult patient cases.	11.10
Being called away from the patient and family because of the need to deal with a new admission or consultation.	10.85
Unit visiting hours those are too liberal.	10.77
Family and friends who continually call the clinician wanting an update on the patient's condition rather than calling the designated family member for information.	10.67
Continuing intensive care for a patient with a poor prognosis because of the real or imagined threat of future legal action by the patient's family.	10.59
Clinicians having to deal with distraught family members while still providing care for the patient.	10.52
Clinicians who are evasive and avoid having conversations with family members.	10.31

Table3 (Continued)

Obstacles	PISs
Multiple clinicians, involved with one patient, who differ in opinion about the direction of care.	9.98
Dealing with the cultural differences that families employ in grieving for their dying family member.	9.38
Pressure to limit family grieving after the patient's death to accommodate a new admission to that room.	9.12
Continuing to provide advanced treatments to dying patients because of financial benefits to the hospital.	8.76
The patient having pain that is difficult to control or alleviate.	8.62
The family, not being with the patient when he or she is dying.	8.23
Clinicians' knowing about the patient's poor prognosis before the family is informed.	7.46
Clinicians who are overly optimistic to the family about the patient surviving.	7.39
Opinions of other critical care staff about the direction of patient care not being requested, valued, or considered.	7.23
Intra-family fighting about whether to continue or stop life support.	7.20
Clinicians who won't allow the patient to die.	7.08
Unit visiting hours that is too restrictive.	6.76
Employing life sustaining measures at the families' request even though the patient had signed advanced directives requesting no such care.	5.21

Table 4: The mean scores for obstacle intensity perceived by doctors

Obstacles	Intensity mean
Family members not understanding what "life-saving measures" really mean, i.e., that multiple needle sticks cause pain and bruising, that an endotracheal tube won't allow the patient to talk, or that ribs may be broken during chest compressions.	3.92
Continuing treatments for a dying patient even though the treatments cause the patient pain or discomfort.	3.85
Clinicians' having to deal with angry family members.	3.77
Family and friends who continually call the clinician wanting an update on the patient's condition rather than calling the designated family member for information.	3.65
Poor design of units which do not allow for privacy of dying patients or grieving family members.	3.65
The unavailability of an ethics board or committee to review difficult patient cases.	3.5
Continuing intensive care for a patient with a poor prognosis because of the real or imagined threat of future legal action by the patient's family.	3.46
Clinicians who are evasive and avoid having conversations with family members.	3.46
The clinician not knowing the patient's wishes regarding continuing with treatments and tests due to the patient's inability to communicate.	3.42
Lack of clinician's education and training regarding family grieving and quality end-of-life care.	3.42
Being called away from the patient and family because of the need to deal with a new admission or consultation.	3.38
Families' not accepting what the clinician is telling them about the patient's poor prognosis.	3.35
Unit visiting hours those are too liberal.	3.27
Pressure to limit family grieving after the patient's death to accommodate a new admission to that room.	3.15
Clinicians who are overly optimistic to the family about the patient surviving.	3.08

Table4 (Continued)

Obstacles	Intensity mean
No available support person for the family such as a social worker or religious leader.	3.04
Clinicians having to deal with distraught family members while still providing care for the patient.	3.04
The patient having pain that is difficult to control or alleviate.	3.04
Clinicians who won't allow the patient to die.	3.00
Multiple clinicians, involved with one patient, who differ in opinion about the direction of care.	2.92
The family, not being with the patient when he or she is dying.	2.62
Intra-family fighting about whether to continue or stop life support.	2.62
Dealing with the cultural differences that families employ in grieving for their dying family member.	2.58
Employing life sustaining measures at the families' request even though the patient had signed advanced directives requesting no such care.	2.58
Continuing to provide advanced treatments to dying patients because of financial benefits to the hospital.	2.35
Unit visiting hours that is too restrictive.	2.19
Opinions of other critical care staff about the direction of patient care not being requested, valued, or considered.	2.15
Clinicians' knowing about the patient's poor prognosis before the family is informed.	1.85

Table 5: The mean scores for obstacle frequency perceived by doctors

Obstacles	Frequency mean
Family members not understanding what "life-saving measures" really mean, i.e., that multiple needle sticks cause pain and bruising, that an endotracheal tube won't allow the patient to talk, or that ribs may be broken during chest compressions.	3.85
Poor design of units which do not allow for privacy of dying patients or grieving family members.	3.77
Family and friends who continually call the clinician wanting an update on the patient's condition rather than calling the designated family member for information.	3.69
Continuing treatments for a dying patient even though the treatments cause the patient pain or discomfort.	3.5
Continuing intensive care for a patient with a poor prognosis because of the real or imagined threat of future legal action by the patient's family.	3.46
No available support person for the family such as a social worker or religious leader.	3.42
Clinicians having to deal with distraught family members while still providing care for the patient.	3.42
The clinician not knowing the patient's wishes regarding continuing with treatments and tests due to the patient's inability to communicate.	3.31
Being called away from the patient and family because of the need to deal with a new admission or consultation.	3.27
Lack of clinician's education and training regarding family grieving and quality end-of-life care.	3.23
Not enough time to provide quality end-of-life care because the clinicians focus is on activities that are trying to save the patient's life	3.23
Clinicians' having to deal with angry family members.	3.15
The unavailability of an ethics board or committee to review difficult patient cases.	3.12
Clinicians' knowing about the patient's poor prognosis before the family is informed.	3.08
Families' not accepting what the clinician is telling them about the patient's poor prognosis.	2.96

Table5 (Continued)

Obstacles	Frequency mean
The patient having pain that is difficult to control or alleviate.	2.85
The family, not being with the patient when he or she is dying.	2.81
Clinicians who are evasive and avoid having conversations with family members.	2.77
Multiple clinicians, involved with one patient, who differ in opinion about the direction of care.	2.5
Pressure to limit family grieving after the patient's death to accommodate a new admission to that room.	2.5
Clinicians who are overly optimistic to the family about the patient surviving.	2.46
Dealing with the cultural differences that families employ in grieving for their dying family member.	2.42
Clinicians who won't allow the patient to die.	2.38
Intra-family fighting about whether to continue or stop life support.	2.38
Unit visiting hours that is too restrictive.	2.19
Opinions of other critical care staff about the direction of patient care not being requested, valued, or considered.	2.15
Continuing to provide advanced treatments to dying patients because of financial benefits to the hospital.	1.69
Employing life sustaining measures at the families' request even though the patient had signed advanced directives requesting no such care.	1.23

Table 6: The perceived intensity scores for obstacles intensity and frequency for doctors

Obstacles	PISs
Family members not understanding what "life-saving measures" really mean, i.e., that multiple needle sticks cause pain and bruising, that an endotracheal tube won't allow the patient to talk, or that ribs may be broken during chest compressions.	15.09
Poor design of units which do not allow for privacy of dying patients or grieving family members.	13.76
Continuing treatments for a dying patient even though the treatments cause the patient pain or discomfort.	13.47
Family and friends who continually call the clinician wanting an update on the patient's condition rather than calling the designated family member for information.	13.46
Continuing intensive care for a patient with a poor prognosis because of the real or imagined threat of future legal action by the patient's family.	11.97
Clinicians' having to deal with angry family members.	11.87
The clinician not knowing the patient's wishes regarding continuing with treatments and tests due to the patient's inability to communicate.	11.32
Being called away from the patient and family because of the need to deal with a new admission or consultation.	11.05
Lack of clinician's education and training regarding family grieving and quality end-of-life care.	11.04
The unavailability of an ethics board or committee to review difficult patient cases.	10.92
Clinicians having to deal with distraught family members while still providing care for the patient.	10.39
No available support person for the family such as a social worker or religious leader.	10.39
Families' not accepting what the clinician is telling them about the patient's poor prognosis.	9.91
Not enough time to provide quality end-of-life care because the clinicians focus is on activities that are trying to save the patient's life	9.81
Clinicians who are evasive and avoid having conversations with family members.	9.58

Table6 (Continued)

Obstacles	PISs
The patient having pain that is difficult to control or alleviate.	8.66
Pressure to limit family grieving after the patient's death to accommodate a new admission to that room.	7.87
Clinicians who are overly optimistic to the family about the patient surviving.	7.57
The family, not being with the patient when he or she is dying.	7.36
Multiple clinicians, involved with one patient, who differ in opinion about the direction of care.	7.3
Clinicians who won't allow the patient to die.	7.14
Dealing with the cultural differences that families employ in grieving for their dying family member.	6.24
Intra-family fighting about whether to continue or stop life support.	6.23
Clinicians' knowing about the patient's poor prognosis before the family is informed.	5.69
Unit visiting hours that is too restrictive.	4.79
Opinions of other critical care staff about the direction of patient care not being requested, valued, or considered.	4.62
Continuing to provide advanced treatments to dying patients because of financial benefits to the hospital.	3.97
Employing life sustaining measures at the families' request even though the patient had signed advanced directives requesting no such care.	3.17

Table 7: The mean scores for supportive behaviours intensity

Supportive Behaviours	intensity mean
Having family members accept that the patient is dying.	4.12
Having enough time to prepare the family for the expected death of the patient.	3.91
Allowing family members adequate time to be alone with the patient after he or she has died.	3.83
Having the physician meet in person with the family after the patient's death to offer support and validate that all possible care was done.	3.75
Having family members thank you or in some other way show appreciation for your care of the patient who has died.	3.75
Having one family member be the designated contact person for all other family members regarding patient information.	3.67
Having a fellow nurse tell you that, "you did all you could for the patients," or some other word of support.	3.63
Having the physicians involved in the patient's care agree about the direction care should go.	3.59
Providing a peaceful, dignified bedside scene for family members once the patient has died.	3.53
A unit designed so that the family has a place to go to grieve in private.	3.51
Having fellow nurses take care of your other patient(s) while you get away from the unit for a few moments after the death of your patient.	3.47
Letting the social worker or religious leader take primary care of the grieving family.	3.46
Having an ethics committee member routinely attend unit rounds so they are involved from the beginning should an ethical situation with a patient arise later.	3.36
The nurse drawing on his/her own previous experience with the critical illness or death of a family member.	3.28
Having a fellow nurse put his or her arm around you, hugs you, pat you on the back or give some other kind of brief physical support after the death of your patient. Help	3.18
Teaching families how to act around the dying patient such as saying to them, "She can still hear...it is OK to talk to her."	3.17

Table7 (Continued)

Supportive Behaviours	intensity mean
Having a support person outside of the work setting who will listen to you after the death of your patient.47Help	3.16
After the patient's death, having support staff compile all the necessary paper work for you which must be signed by the family before they leave the unit.	3.12
Talking with the patient about his or her feelings and thoughts about dying.	3.01
Having a unit schedule that allows for continuity of care for the dying patient by the same nurses.	3.01
Physicians who put hope in real tangible terms by saying to the family that, for example, only 1 out of 100 patients in this patient's condition will completely recover.	2.91
Having the family physically help care for the dying patient.	2.8
Having un-licensed personnel available to help care for dying patients.	2.5
Allowing families unlimited access to the dying patient even if it conflicts with nursing care at times.	2.47

Table 8: The mean scores for supportive behaviours frequency

Supportive Behaviour	Frequency mean
Allowing family members adequate time to be alone with the patient after he or she has died.	3.03
Having family members accept that the patient is dying.	2.82
The nurse drawing on his/her own previous experience with the critical illness or death of a family member.	2.78
Having the physicians involved in the patient's care agree about the direction care should go.	2.71
Having family members thank you or in some other way show appreciation for your care of the patient who has died.	2.54
Providing a peaceful, dignified bedside scene for family members once the patient has died.	2.49
Having a fellow nurse tell you that, "you did all you could for the patients," or some other word of support.	2.41
After the patient's death, having support staff compile all the necessary paper work for you which must be signed by the family before they leave the unit.	2.38
Having enough time to prepare the family for the expected death of the patient.	2.36
Allowing families unlimited access to the dying patient even if it conflicts with nursing care at times.	2.32
Having the physician meet in person with the family after the patient's death to offer support and validate that all possible care was done.	2.24
Teaching families how to act around the dying patient such as saying to them, "She can still hear...it is OK to talk to her."	2.22
Physicians who put hope in real tangible terms by saying to the family that, for example, only 1 out of 100 patients in this patient's condition will completely recover.	2.17
Having fellow nurses take care of your other patient(s) while you get away from the unit for a few moments after the death of your patient.	2.11
Having one family member be the designated contact person for all other family members regarding patient information.	2.11
Having the family physically help care for the dying patient.	1.95

Table8 (Continued)

Supportive Behaviours	Frequency mean
Having a support person outside of the work setting who will listen to you after the death of your patient.	1.82
Having a fellow nurse put his or her arm around you, hugs you, pat you on the back or give some other kind of brief physical support after the death of your patient. Help	1.67
Talking with the patient about his or her feelings and thoughts about dying.	1.47
Having a unit schedule that allows for continuity of care for the dying patient by the same nurses.	1.41
A unit designed so that the family has a place to go to grieve in private.	1.33
Letting the social worker or religious leader take primary care of the grieving family.	1.12
Having an ethics committee member routinely attend unit rounds so they are involved from the beginning should an ethical situation with a patient arise later.	1.08
Having un-licensed personnel available to help care for dying patients.	1

Table 9: the perceived intensity scores for supportive behaviours

Supportive Behaviours	PSBSs
Having family members accept that the patient is dying.	11.61
Allowing family members adequate time to be alone with the patient after he or she has died.	11.60
Having the physicians involved in the patient's care agree about the direction care should go.	9.72
Having family members thank you or in some other way show appreciation for your care of the patient who has died.	9.52
Having enough time to prepare the family for the expected death of the patient.	9.22
The nurse drawing on his/her own previous experience with the critical illness or death of a family member.	9.11
Providing a peaceful, dignified bedside scene for family members once the patient has died.	8.78
Having a fellow nurse tell you that, "you did all you could for the patients," or some other word of support.	8.74
Having the physician meet in person with the family after the patient's death to offer support and validate that all possible care was done.	8.40
Having one family member be the designated contact person for all other family members regarding patient information.	7.74
After the patient's death, having support staff compile all the necessary paper work for you which must be signed by the family before they leave the unit.	7.42
Having fellow nurses take care of your other patient(s) while you get away from the unit for a few moments after the death of your patient.	7.32
Teaching families how to act around the dying patient such as saying to them, "She can still hear...it is OK to talk to her."	7.03
Physicians who put hope in real tangible terms by saying to the family that, for example, only 1 out of 100 patients in this patient's condition will completely recover.	6.31
Having a support person outside of the work setting who will listen to you after the death of your patient.	5.75
Allowing families unlimited access to the dying patient even if it conflicts with nursing care at times.	5.73

Table 9 (Continued)

Supportive Behaviours	PSBSs
Having the family physically help care for the dying patient.	5.46
Having a fellow nurse put his or her arm around you, hugs you, pat you on the back or give some other kind of brief physical support after the death of your patient. Help	5.31
A unit designed so that the family has a place to go to grieve in private.	4.66
Talking with the patient about his or her feelings and thoughts about dying.	4.42
Having a unit schedule that allows for continuity of care for the dying patient by the same nurses.	4.24
Letting the social worker or religious leader take primary care of the grieving family.	3.87
Having an ethics committee member routinely attend unit rounds so they are involved from the beginning should an ethical situation with a patient arise later.	3.62
Having un-licensed personnel available to help care for dying patients.	2.5

Appendix K- Example of the Process Undertaken to Develop the Themes, Sub-Themes 'staff-families trust relationship' from the Codes.

Codes	Sub-themes	Theme
• I believe that lacking of trust is the whole problem. • Mistrust that families have is why we provide futile care. • Losing trust between staff and patients' families provoke accountability worries for staff. • Without trust, families hold the perception that there has been a mistake and negligence has took place. • We would have a strong relationship with families if we trust each other. • Losing trust limit our communication and interaction with families. • Mistrust increase the chance for staff-family conflict. • Blaming staff for the deterioration of patient's condition is common because simply the families don't trust us. • Families' lack of appropriate knowledge is the key driver behind mistrust. • Lacking trust result in clinicians' avoidance of families. • If families trust us, they become involved with us and accept us. • The family always convince themselves that there is a medical negligence behind their patient's deterioration; they don't trust us.	Trust and lacking of trust	Staff-families trust relationship
• Time constraints is very crucial reason in interrupting the development of trust. • Long critical unit stay increase the chance for building trust. • No prior relationship between staff and families makes establishing trust difficult. • How I could talk with and support families if I couldn't have a time to do my clinical job?	Time and trust	

• We need to become familiar with the families with whom we will work during the patients' stay in the critical care unit. • We do some sort of informal assessment about the patient and the family members. • This assessment allow us to work effectively with families. • I did this assessment once I realised that the patient was going to die. • As I talked about other issues, I also examined family emotional status and what type of family they are, namely, whether they were educated and understandable or not and such these things. • This was to build a rapport and provide an appropriate support for them by putting myself in their position. • We try to assess family's acceptance of their patient's condition.	Knowing patients families	
• Detailed, honest and understandable communications with patients' families is a vital strategy to attain their trust. • In intensive care units basically you are providing care for families; not patients. Families is important for us, you see? • There are 'simple things' we can do for families. So to speak, there is a little. • Being not strict about visiting; being humanistic so they can accept you. • I may give the family our meeting room; I may set with them a little; I feel they quite like this. • I allow visitors to stay with patient and I allow them to read "Quran" (Muslim Book); this make them feel comfortable. • Explaining to families about their patient's prognosis day by day and give them a follow up even it's a simple follow up. • We may allow families to participate in providing care for their dying patients so they realise the effort we do. • I allow the families of the dying patients to stay with their patient too much; they appreciate this for us.	Trust optimising behaviours	