



The involvement of relatives in the care of patients in medical settings in Australia and  
Saudi Arabia - an ethnographic study

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## **Declaration**

I certify that this work contains no material which has been accepted for the award of any other degree or diploma in my name, in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. In addition, I certify that no part of this work will, in the future, be used in a submission in my name, for any other degree or diploma in any university or other tertiary institution without the prior approval of the University of Adelaide and where applicable, any partner institution responsible for the joint award of this degree.

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بِسْمِ اللَّهِ الرَّحْمَنِ الرَّحِيمِ  
وَأَجْرُكُمْ فِي مَا كُنْتُمْ  
تَعْمَلُونَ



## **Abstract**

Relatives play an essential role in looking after patients in hospitals and help to improve quality of care in many ways. Currently, hospital policies acknowledge the role relatives play as partners in the healthcare sector; their role is also encouraged through the 'family and patient centred care' model. The role of relatives as advocates is a key element in critical health settings, where patients need help from family members to make decisions regarding their treatment. However, some healthcare professionals see a relative's presence in hospital as a threat to a patient's autonomy. Additionally, there is little known about how nurses and relatives respond to the involvement of relatives in patient care in a healthcare context, and the impact of their participation on quality of care and the fundamentals of care. The aim of this study was to explore the role relatives play in the care of patients in medical settings in Australia and Saudi Arabia and to understand the nature of this involvement. This is an ethnographic study based on an interpretive paradigm. The study was conducted in acute hospital medical wards, one in Australia and another in Saudi Arabia. Data collection was carried out over a six month period, three months spent in each setting. The Spradley data analysis framework was adopted to analyse the results of this ethnographic inquiry (Spradley, 1979, 1980). These indicated that there was no shared understanding of the role of relatives. In both fields nurses and relatives faced ongoing ambiguity about the role relatives should play in the hospital environment and nurses were challenged by the unpredictability of relatives' participation in patient care. The fear of taking responsibility and uncertainty about their responsibility towards relatives led nurses to take a varied and individualised approach to the involvement in patient care. Relatives were unclear about how to behave in the role, what the needs of patients were, and whether they were contributing to care and this increased their frustration. Lack of guidelines around the role relatives play in patient care affected the interaction between relatives and nurses and their ability to work in partnership.

# **Chapter one**

## **Chapter 1: Introduction**

This introductory chapter focuses on describing the context of the study; the statement of the research problem; purpose of the study; research question and aims; theoretical framework; significance of the study; assumptions; definition of terms and finally, structure of the thesis. However, the introduction will begin with a personal reflection, which also sets the scene for this study.

### **A personal reflection and setting the scene**

Prior to commencing this study the researcher worked as a registered nurse (RN) in Saudi Arabia and understood that families were always part of a hospital environment; their presence in hospitals was customary. Finding oneself in hospital giving support and care to a family member can be challenging. A few years ago the researcher's mother fell sick and was admitted to a hospital for two weeks. The researcher was companion to her mother for this period of time. During this time she helped her mother in basic care, assisting in feeding, toileting and walking. She was also involved in health team discussions.

Being an experienced nurse did not lessen the stress she felt in being a caregiver in the hospital. One of the main issues the researcher experienced was that she had never worked in the hospital to which her mother had been admitted and was unfamiliar with the environment and nursing care routines. The interaction with nurses on the unit occurred rarely and was not always as informative as expected. Many times the researcher was concerned about whether the assistance she provided to her mother was sufficient and asked nurses questions to help her to understand what they expected of her in her role as a 'relative carer'. There were high levels of physical and psychological exhaustion at the time. Being a registered nurse made this experience very difficult, especially from a safety viewpoint because she saw other relatives assisting patients in basic care with no guidance from nurses.

After this experience the researcher's views about the impact relatives have on quality of care and safety changed completely. There was a realisation that nurses have an important role to play in making relatives' and patients' experiences in hospital positive, through interaction, guidance and support. Most importantly, it reinforced the researcher's view that nurses have a duty of care to both patients and relatives, which should not be affected by a relative's presence in the hospital setting, but should be strengthened by it.

In some Middle Eastern countries (Mobeireek et al., 2008) and those of Asia (Ito, Tanida & Turale, 2010), the presence of relatives in hospitals is considered common practice and their contribution to care and decision-making is customary. In addition, relatives in these countries often provide basic care to the patient (Khosravan et al., 2014). Whereas, in Western countries the presence of relatives in hospitals may be limited (Cooper et al., 2008), depending on the patient's age and needs (Clayman et al., 2005). In recent years and with the increased attention to the principle of 'patient and family-centred care' (Greene, Tuzzio & Cherkin, 2012), the involvement of relatives is recognised as a requirement of providing good quality healthcare and improving healthcare services (Australian Commission on Safety and Quality in Health Care, 2011a). From this perspective comes the concept of a partnership between the health team, patients and their loved ones. This partnership also promotes a patient and family centred care approach to healthcare. Therefore, many healthcare systems around the world are developing healthcare policies and also hospitals designed to adapt to the new era of relatives' involvement (Choi & Bosch, 2013). In addition, in response to this development, the literature also discusses and evaluates the architectural layout of hospitals and how this affects the inclusion of relatives in the support of patient centred care principles, such as in a study by Rippin et al., (2015). The study results present suggestions about how to improve hospital layout so that relatives can be included (Rippin et al., 2015).

The relatives' involvement in patient care is addressed through patient centred care or partnership with relatives (Australian Commission on Safety and Quality in Health Care 2011). However, there is less emphasis and detail in the literature on the role they play in hospitals and how nurses and relatives manage this involvement. The involvement of relatives in hospitals as partners has long been discussed and is associated with certain settings or patient conditions such as mental health, paediatrics or intensive care; in particular, it is common in settings where assistance by relatives in decision-making is needed (McConnell & Moroney, 2015; Linton, Grant & Pellegrini, 2008). Nowadays, partnerships between nurses, patients and their relatives are considered to be a component of standard care in hospitals, yet it is not clear how this has been implemented (Kuo et al., 2012). There are emerging concerns about the involvement of relatives that are discussed widely in the literature, such as safety concerns, interaction difficulties (Agård, 2005 cited in Agård & Maindal, 2009) and impediments to patient care (Bramstedt et al., 2005). The potential for harm to patients is another issue that has been highlighted in research (Stayt, 2007). Finally, although there is a wealth of literature investigating relatives role in particular settings such as critical settings (Tallon, Kendall & Snider, 2015; Rainey et al., 2015), the role of relatives generally and their impact on the quality of care remains inadequately investigated.

## **Context of the study**

This study was conducted in large metropolitan hospitals in two medical settings, one in Australia and the other in Saudi Arabia. The Australian hospital is the largest hospital in the state (South Australia) and is located in the metropolitan area. This hospital provides tertiary health care services, rehabilitation and referral services. It has 680 beds and the medical care unit where the study took place had 27 beds. The Saudi hospital is operated by the Ministry of Health, (South Province) and is considered to be the largest in the area; it has 300 beds with 30 beds allocated for the female medical unit. This hospital provides tertiary and referral services.

The medical care unit in both settings was selected because it was believed that patients would stay in these units for long periods of time and relatives would be present in the settings to provide help and support to patients. The participants for the study included patients, their relatives and the nurses directly providing care. Since there were religious and cultural barriers for a female researcher to perform observations in Saudi male medical units, it was decided to keep the sample consistent between both research settings: therefore only female patients were selected. However, the patients' relatives who participated in the study were both male and female, with a close or distant relationship with patients. The nursing participants were those assigned to care for the selected patients. The participants were those who spoke English or Arabic, these being the two languages in which the researcher is fluent.

## **Statement of the research problem**

There is a lack of research investigating the role relatives play in patient care in acute medical settings. Additionally, the researcher could not locate any studies that compared two countries (Australia and Saudi Arabia) in terms of the involvement of relatives in patient care. Therefore, this study was conducted to understand this from a qualitative and descriptive point of view. Understanding the role and involvement of relatives in patient care should contribute to an increase in positive interactions between patients, relatives and nurses and also enhance safety in hospital environments.

## **Purpose of the study**

In hospitals where relatives work in partnership with health teams to provide care for patients, the literature documents positive outcomes for patients, both in healthcare and quality of life (Rantz & Zwygart-Stauffacher, 2004; Ewart, et al., 2014). The purpose of this study was to understand the role

relatives play in patient care and nurses' roles in relation to the involvement of relatives in medical settings in two different countries, from a cultural perspective. How involved a relative is in patient care and their behaviour and interaction with nurses is usually connected with the cultural setting. Additionally, to study the impact of relatives involvement on quality patient care in both medical settings.

## **Research question**

The research question for this study was:

What are the roles relatives play in the care of patients in medical settings in Australia and Saudi Arabia, and what are the perceptions, attitudes of nurses, patients, and relatives themselves about the involvement?

## **Aims of study**

The aims of this project were to:

- Describe the nature of relatives' involvement in the care of patients in acute medical settings in two different cultural contexts.
- Explore the nursing care activities delegated by nurses to relatives.
- Explore relatives' perceptions of their involvement in patient care.
- Explore nurses' perceptions of relatives' inclusion in patient care
- Explore patients' perceptions of relatives' involvement in their care.
- Investigate the impact of relatives' involvement in the care of patients on the fundamentals of care.
- Explore the differences between participants' attitudes in Australia and Saudi Arabia.

## **Theoretical framework**

The theoretical framework of the research defined the choice of data collection and analysis techniques. The methodological framework, which underpins this study is ethnographic, based on an interpretive paradigm (Bowen, 2005). The data collection methods involved observation, interviews and finding public documents. The observations were shaped by the fundamentals of care framework and also a growing understanding of the importance of addressing patients' fundamental care needs in a holistic and integrated way. Data analysis was undertaken utilising Spradley's methods of analysis in ethnographic inquiry (Spradley, 1979, 1980). The choice of ethnography for this study allowed the

collection of extensive and holistic information about the relatives' role and involvement in patient care. Ethnography enabled the researcher to explore the experiences of people involved in this study and to understand their interactions with one another.

### **Significance of the study**

This study is significant because it discloses what it is like to be a relative caring for a loved one in a hospital setting. It provides insight for the first time into the experience of relatives caring for a family member in acute medical settings and Saudi Arabia. In addition, the findings of this study should help healthcare professionals to understand relatives and nurses' roles, rights and responsibilities under the term 'partnership' and should also enhance cooperation and interaction. Additionally, this research can improve nursing practice by providing information that assists nurses to negotiate nursing care in a variety of situations, preventing disruption or challenges to their nursing role. The findings should also contribute to the body of knowledge around relatives' involvement in the care of patients in acute hospitals and provide cross-cultural comparisons promoting shared understanding and mutual learning.

This study is also important as it may assist in the development of hospital policies regarding relatives' involvement in the care of patients. Policy makers may also benefit from evidence, which indicates the importance of maintaining a sustainable nursing workforce in settings similar to the field settings. Importantly it also provides knowledge about patient integrity, safety, and wellbeing. Finally, the study highlights the perspectives of patients in relation to their own care outcomes.

### **Assumptions**

In undertaking any ethnographic study it is important to be explicit about the assumptions held by the person who perform a research. In this study, the researcher has already shared her personal experiences of caring for her mother in an acute hospital setting in Saudi Arabia. The ethnographic approach was preferred because the researcher held several assumptions, which have been developed by working in clinical settings and from her own personal experiences. The researcher assumed that the involvement of the relatives in the care of patients would be more apparent in Saudi Arabian hospitals than the Australian hospital setting. It is assumed that socio-cultural notions influence the concept of having relatives accompanying patients in Saudi Arabian hospitals.

Further assumptions were that, when performing this study in two different countries there would be significant variation of cultural practices in the settings. In several research articles it was clear that

there is a limited understanding of how patients, relatives and nurses perceive their role in hospitals. It was anticipated that the research design chosen should help to explore the interaction between patients, relatives and nurses and their roles in clinical settings and also develop an understanding of how they function in everyday clinical settings. Raising awareness of the culture and practices in each setting and also perceptions of the population under study may help in addressing issues within the cultural environment. Additionally, the understanding of relatives' roles may provide an insight for the multi-professional team of the extent and nature of relatives' involvement.

## **Definitions of terms**

### ***Relatives***

The Oxford Dictionaries, (2016) defines the word relatives as a member of the family who is in a relationship with or connected to someone by blood or marriage. The term 'relatives' in this research is broader and used to indicate the loved ones, family members, spouse, parents, or any person providing support and care to the patient during their illness and not necessarily having a blood relationship with the patient.

### ***Role***

The term 'role' is defined as the obligations, responsibilities, position and expected behaviour patterns associated with a particular social status (Dictionary, 2016). In this research, the term 'role' is used to describe the range of activities undertaken by relatives in caring for patients in the hospital setting. In relation to nurses, the term describes the activities undertaken by nurses to manage the involvement of relatives in the hospital environment.

### ***Partnership***

The term partnership varies in definition and differs according to the context and the people involved. In this study it refers to nurse/ relative partnerships. Gallant, Beaulieu and Carnevale (2002) present the term partnership as an actual process of relationship- building, between the health care provider and the client. The authors suggested that the key elements in this process are 'interactions, sharing of power and negotiations' (Gallant, Beaulieu & Carnevale, 2002, p.153-154).



### ***Patient centred care***

Patient centred care means 'improving the outcomes of the patient and quality care through involving the patient in decision making, increasing understanding between the patient and health care provider and involvement of the family as part of the caring team' (Bechel, Myers & Smith, 2000 in Rathert et al., 2015, p. 200).

### ***Family centred care***

Family centred care is an approach to care giving collaboration, planning and decision making that is managed by the partnership between the health care provider and the family (Institute for Patient and Family Centred Care, 2016).

### ***Fundamentals of care***

The definition of fundamentals of care varies from one healthcare service to another. However, in this research it is referred to as caring activities that are essential and required by individuals regardless of their health conditions or care settings (Kitson et al., 2010). The word 'fundamental' means centric to the caring activities for the purpose of preventing harmful incidents and promoting the delivery of quality care (Kitson et al., 2013).

### ***Quality of care***

Quality of care was defined by the Institute of Medicine in 1990 as the degree to which the individual healthcare services increase health outcomes (Donaldson, 1999).

### ***Cultural competence***

Cultural competence means 'the ability of healthcare providers and healthcare organisations to understand and effectively respond to the cultural and linguistic needs brought by clients to the healthcare encounter' (Andrews, Boyle & Carr, 2003, p.16).

### ***Cultural safety***

Cultural safety is defined as 'ensuring that patients from different backgrounds feel safe in their clinical encounters' (Smith, Fitzpatrick, & Carpenter, 2015, p. 93).

### ***Medical ward***

A medical ward is a hospital ward that provides preventive, diagnostic and treatment services or measures to patients, rather than surgical interventions (US Legal definitions, 2016).

### ***Culture***

Culture can be defined as 'ideas, beliefs and knowledge' that distinguish a particular group of people (Strauss & Quinn, 1997, p. 5).

### ***Islam***

Islam is 'the complete submission to Allah and a way of life used to deal with all aspects of life, whether they be physical, social, moral, spiritual, economic and political' (Nabolsi & Carson, 2011, p. 716).

### **Structure of thesis**

Firstly, chapter one provides a brief description of the study background, purpose, research question and aims, theoretical framework, significance and overview of the thesis. Then, the literature review chapter presents a review of the literature relevant to this study and also includes a critical evaluation. The methodology presents the ethnographic background and the philosophical principles underlining the study's approach. Next, the methods chapter presents the approach used for data collection and explains in detail the strategies used for systematic data analysis. Subsequently, the findings chapter is divided into two sections; one is titled 'the cultural scene' and this involves detailed cultural descriptions of the Australian and Saudi settings. Section two is called 'the cultural domains', which provide an ethnographic framework for presenting the outcomes of the study. Following this, the discussion chapter integrates the findings of the study with their wider implications and provides a detailed discussion of the outcomes and their impact on practice. Finally, the conclusion summarises the major findings and their significance, presents the strengths and limitations and offers recommendations.

The next chapter will review the relevant literature and will evaluate current knowledge about the roles and involvement of relatives in patient care. It will then identify the gaps in knowledge relevant to the inquiry associated with this matter.

## **Chapter two**

## **Chapter 2: Literature review**

### **Introduction**

This chapter provides a review of the literature regarding the role relatives play in taking care of patients in hospitals from the perspectives of relatives, patients and nurses. It will initially focus on the relatives themselves and will consider the following points: relatives' role in taking care of patients and its benefits; the drawbacks of involving relatives in patient care; the stress relatives may experience from being involved in patient care; and factors relating to the impact of relatives' involvement on patients' autonomy and integrity during hospitalisation. In addition, nurses' role and perceptions of relatives' involvement in the care of patients will be described. Next, the review highlights the essential aspects of relatives' involvement in patients' care in Australian and Saudi Arabian hospitals. Lastly, the following principles and concepts will be discussed, as well as their effect on patient care; fundamentals of care, patient and family centred care, cultural diversity and culturally competent care.

### **Search strategy**

The search for literature was conducted using Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medline, Google scholar and Scopus. The search terms used were 'family', 'relatives', 'parents', 'next of kin', 'partner', 'loved ones', 'informal carers', 'involvement', 'relatives and family role', 'patient care', 'hospitals', 'acute settings', 'medical', 'adult', 'family centred care', 'patient centred care', 'Saudi' and 'Australia'. The keywords were chosen because they are the terms in the research question and were used in literature that had been found in initial searches. Additionally, the search terms were recorded during the progress of the study and subject keywords and abstracts of retrieved articles helped to make decisions regarding these. The MeSH Database was also used in the search to decide the search terms.

At the beginning of the literature search the researcher sought help of a Librarian to create a logic grid for the search. Furthermore, the search was limited to English language and peer reviewed articles but not limited to Australia and Saudi Arabia. The search aimed to locate studies focused on relatives and their experiences of patient care in hospitals and published from 1984 to 2016. During the initial search for articles that discussed the role relatives play in patient care, it appeared that there were a limited number of studies conducted in the past fifteen years; therefore, there was a need to extend the search years to find more articles. The search for literature was conducted from mid-2012 to mid-2016.

## **Relatives' involvement in the care of patients**

Relatives have long played a role in providing care for family members with chronic health conditions or disabilities (Australian Institute of Health and Welfare, 2009). Some relatives spend considerable time looking after ill members of their families; for example, this can include caregiving for up to five years of their lives (Donelan et al., 2002). Relatives commonly provide support and help to their loved ones or patients throughout hospitalisation. The pre-existing relationships between relatives may enhance a patient's feeling of security and safety. When a person feels ill they may need their relatives around for help and support. Traditionally, caring for a sick person was performed by families within the households (Australian Institute of Health and Welfare, 2009). Nowadays, with the advent of modern nursing and medicine, hospitals provide healthcare to patients in acute situations and the involvement of relatives in patient care is part of a patients' support system (Hughes, 2008).

Research has cited some benefits of involving family members in the care of patients in settings such as critical care (Leon & Knapp, 2008), which include overcoming patients' fear, anxiety, stress, and depression. Furthermore, literature has reported different types of involvement in care, with an emphasis on its contribution to a patient's wellbeing and welfare (Hopkinson et al., 2012; Leon & Knapp, 2008). For example, providing patients with basic healthcare, emotional support (Hopkinson et al., 2012) assist them in making decisions (Lindhardt, Nyberg & Hallberg, 2008), and being the patient's advocate (Mangurten et al., 2006). Although some positive patient outcomes, stemming from family involvement, have been identified in the literature (Leon & Knapp, 2008), some research has highlighted drawbacks, specifically from the viewpoint of nurses and the health team in general. One concern that has been highlighted by Engström, Uusitalo and Engström (2011) is the threat to a patient's autonomy and privacy when relatives administer care, and relatives being overprotective, which may obstruct nursing care procedures. Additionally, relatives may make decisions for the patient, which may be seen as taking control.

Relatives may take a part or contribute to the basic care of the hospitalised patient. This basic care usually involves activities of nursing care, such as oral and facial care, feeding, giving oral medication, providing a bedpan or even monitoring the flow of intravenous fluids (Sapountzi-Krepia et al., 2008). Relatives may not necessarily be trained to take responsibility for these caring activities. More often, those relatives feel unprepared and lacked knowledge about how to look after patients (Bucher et al., 2001). In addition, few relatives receive support and caregiving guidance by health care professionals during their presence in hospitals (Reinhard et al., 2008). Allen (2000) highlighted the frustration

relatives felt because they had no control over the caring process, and had limited involvement on the ward and referred to the lack of guidance they received from the nursing team. Many healthcare professionals find it difficult to provide constant guidance and information about caregiving because of issues such as, fear of losing authority (Allen, 2000); time constrains (Paliadelis et al., 2005), lack knowledge and structured guidelines on how to provide information (Paliadelis et al., 2005).

In some cases the frustration experienced by relatives has an effect on their ability or willingness to provide caregiving to their loved ones. For example, relatives sometimes fear the hospital environment because of the complicated equipment or technical devices; this can prevent them from spending time with patients in hospitals, especially in cases where patients depend on machinery for their treatment (Stayt, 2007). A study by Engström and colleagues (2011) described nurses' experiences of the role relatives play in the nursing care of patients in the intensive care unit (ICU). The authors highlighted that relatives who were reluctant to involve themselves in caregiving felt unfamiliar with the equipment used in the hospital (Engström, Uusitalo & Engström, 2011). Furthermore, in a study by Kirk, Glendinning and Callery (2005), relatives felt worried they may cause inconvenience to the nursing team or may negatively impact the patient's wellbeing.

However, some researchers argue that relatives need to understand how to care for patients using hospital equipment (Kirk, Glendinning & Callery, 2005), especially when relatives care for patients who have chronic physical problems and rely on hospital equipment but then have to be transferred home for care. Löf and colleagues (2010) described relatives' experiences of unfamiliarity and uncertainty regarding the condition of patients using hospital equipment in the ICU. The authors emphasise the importance of providing information to relatives and revealed that relatives who obtained knowledge of hospital equipment understood the importance of this life-sustaining equipment to patients (Löf, Sandström & Engström 2010). Giving relatives information about hospital equipment would be important step towards helping carers to support patients appropriately and also in reducing the stress experienced by relatives.

The notion of helping relatives to be more comfortable in the hospital environment may encourage relatives to spend more time with the patient providing additional support to the health team. In addition, assessment of relatives' knowledge and ability to carry out some basic care or to be involved in the care generally, has been highlighted in research as a method of maintaining a patient's safety (Kirk, Glendinning & Callery, 2005). Furthermore, research conducted in England and Denmark indicated that

family members preferred to be asked if they would like to be involved in caring for their loved one, and the extent to which they wanted to be involved (Kirk, Glendinning & Callery 2005; Agård & Harder, 2007). It appears that relatives want to feel comfortable assisting patients with some basic care, but do not necessarily want to feel obligated to carry out this care. In a study by Kirk, Glendinning and Callery (2005) parents of a sick child wanted their role to be identified and distinguished from the role of nurses, because they believed their knowledge and expertise differed from the nurses'. These relatives wanted to be recognised by the health care team as family members not caregivers in the hospital setting. Additionally, the parents in this study identified their limitations and recognised the expertise of nurses.

Some authors highlighted the obligations relatives may feel about participating in patient care (Lindhardt, Nyberg & Hallberg, 2008). Relatives may consider their involvement in patient care as a part of their family role, duty, or responsibility. Therefore, they can find themselves participating in the basic healthcare of patients, simply because they are present when nursing care is delivered. However, it is necessary to determine whether patients perceive their relatives' involvement in their care positively. From the perspective of respect for patient autonomy, patients should be able to decide the extent to which they want their relatives to be involved in their care (Beauchamp & Childress, 2001). This may also raise concerns for health care professionals, particularly when relatives are present during the nursing care or giving information to patients. Some studies addressed the ethical issues that health professionals experienced and indicated that nurses believed they violated a patient's autonomy by including families in decision making for independent patients (Ito, Tanida & Turale, 2010).

A study by Ito and colleagues (2010) in Japan argued that ethical principles and definitions in Western countries regarding patient autonomy can be culturally inappropriate for people living in countries located in the Middle East and Asia; for example in Japan families are considered to contribute to a patient's decision making even if patients were competent to make their own decisions (Konishi, & Davis, 1999; Mobeireek et al., 2008). With increased universal attention to patient's rights, many ethical principles are adopted without adequate thought about their appropriateness for certain cultures (Rassool, 2000) or settings, such as whether information should be disclosed to patients' families (Konishi, & Davis, 1999). The non-disclosure of information and non-consultation with families in which occurs in some cultures, could create difficulties for healthcare professionals in other settings and also confuse patients and their families.

There is research which has investigated the impact of relatives' presence and contribution to patients' autonomy and integrity during hospitalisation (Clayman et al., 2005). The results of a study by Clayman and colleagues (2005) showed that relatives enhanced elderly patients' ability to make decisions regarding their treatment and communication with the health team. Additionally, the results of a study by Engström & Söderberg (2007b) revealed that relatives' presence and their positive encouragement increased patients' understanding, safety and wellbeing. Clayman and colleagues (2005) also indicated that autonomy detracting behaviours of relatives such as taking control of patients were trivial and did not hinder patients' autonomy and integrity. Furthermore, relatives may help to clarify issues physicians have discussed with a patient, or may assist in a patient's understanding of certain information (Clayman et al., 2005). Relatives may also contribute important information simply by answering health team questions about the patient's condition.

### **Nurses' role and opinions of relatives' involvement in patient care**

Nurses may face challenges in their professional role when they are trying to balance patient care and the emotional demands of a patient's family. In a study by Stayt (2007) the author highlighted that intensive care unit nurses understand that establishing a good relationship with patients' relatives is essential in delivering quality nursing care. However, nurses in this study found it difficult to balance the needs of critically ill patients who are dependent on machines for their survival, with care of patients' families who require emotional support (Stayt, 2007). This suggests that nurses thought that offering emotional support to relatives needed dedicated time and effort. Stayt (2007) highlighted nurses' feelings of conflict because they believed in the importance of communicating with relatives but the actual level of communication they presented in the field was lacking. From this perspective nurses may spend many hours caring for critically ill patients, but not consciously consider their role in relation to patient families or carers.

Communication has been seen as key to improving outcomes for patients but nurses also express concern about prioritising communication with relatives (Stayt, 2007). Mutual communication between nurses and relatives can mean that both parties remain satisfied with the patient information made available to each of them (Engström & Söderberg, 2007a; Omari, 2009). Health professionals may also view good relationships between the health team and patients' relatives as a way of better understanding the patient's condition. Engström (2008) (cited in Engström, Uusitalo, & Engström, 2011) indicated that relatives were reliant on the nursing team to permit their access to patients and to involve them in the information sharing process. However, nurses also need to communicate with relatives in



order to understand their needs from the care giving process. Nurses also perceive that a good relationship with patients' relatives is a way of maintaining a caring relationship (Engström & Söderberg, 2007a). On the other hand, nurses also feel worried that their relationships with relatives will have a negative impact on their nursing role. For example, some nurses were concerned that their emotional involvement with patients and their relatives could affect their clinical judgment (Stayt, 2007). Söderström, Benzein and Saveman (2003) emphasise that creating a good relationship with the family members can be demanding for nurses, emotionally and professionally. As a result, nurses may prefer to maintain a distance from relatives and keep the relationship and communication focused on the patient.

The presence of relatives with patients in hospitals can cause stress to nursing staff in cases where they interfere with nursing practice or performance, but relatives also alleviate nursing stress by assisting nurses in patient care. Some studies suggest that nurses find the presence of relatives stressful, because some relatives interfere in nursing care. Macy and colleagues (2006) observed that a relative's presence during procedures such as resuscitation might be stressful to the health team, and negatively impact their performance. However, this may be due to the fact that the resuscitation procedure is performed in a life-threatening situation. While the involvement of relatives can be stressful to a health team, relatives are also utilised to reduce staff stress and workload. Generally, hospital policies do not allow nurses to delegate nursing care to unregulated care providers and this includes family carers because they do not have mandatory education or practice standards (College of Registered Nurses of British Columbia, 2002). However, nurses may feel that asking relatives to perform some basic care, such as oral care and personal hygiene saves them the time, allowing them to do more complicated nursing care. Aein and colleagues (2009) performed a study in two paediatric hospitals in Iran; the authors indicated that nurses delegated some of the children's basic nursing care to parents. Nurses handed over care such as oral temperature to relatives to overcome the workload and shortage of nurses. Nurses in this study explained that they provided relatives with sufficient guidance before delegating the care (Aein et al., 2009). Generally, nurses understand that they should perform the care that requires skill and expertise. Garrouste-Orgeas and associates (2010) highlighted that the ICU team allowed relatives to participate in care, which they thought would not harm the patient's life. Wiping patients' eyes, moisturising lips, and cleaning the nose were some of the activities delegated to family members in the ICU. These activities may be considered basic care if they do not negatively impact the patient's wellbeing. However, there was no discussion on whether the nursing team prepared the family members to perform these basic tasks.

## The Australian context

Relatives in Australia play a significant role in caring for their families and providing support when needed (Carers Australia, 2012b). Relatives, family members, and paid carers who provide care for patients at home or in hospitals are termed 'carers' in community care (Australian Institute of Health and Welfare, 2011). Australia's population is diverse in language and cultural background (Australian Bureau of Statistics, 2012) and the meaning of family has been shaped by this diversity. This diversity has been highlighted in research (Cioffi, 2006) and has resulted in the delivery of ethnic specific health services (Allotey, Manderson, & Reidpath, 2002). Additionally, Australian society has evolved and social changes have impacted the family structure in many different ways; these changes may affect the bonds of family relationships. For instance, there has been an increase in the population of people living alone, or as single parents, high rates of divorce and childlessness (Australian Institute of Health and Welfare, AIHW, 2011). This may mean the chances of relatives being available when care is needed are low. Traditionally, females in the family structure are the ones who provide the care for other family members when required (AIHW, 2009). However, in recent years women have become more educated and their participation in the workforce has been increased (Gilfillan & Andrews, 2010). Therefore, their caring responsibilities for family members will be limited by their employment responsibilities.

In Australia the role relatives' play in providing care to family members has been recognised as a community service (AIHW, 2011). In all Australian States and Territories caregiving has been accepted as a community responsibility and recognised in the *National Carer Recognition Act 2010* (Commonwealth of Australia, 2011). This Act acknowledges the role of carers in Australia and the support their caring role provides in the community. Carers are people who 'provide care and support for their parent, partners, child or friend who has a disability, is frail aged or who has a chronic mental or physical illness' (Carers South Australia, 2011, p. 4). The recognition of carers' responsibilities in Australia has helped to provide carers with information, access to services, education, training, and financial support (AIHW, 2011). Additionally, the recognition of carers' roles has helped to consolidate and clarify relationships with other care providers (Carers South Australia, 2011). This relationship means carers are accepted as partners with health professionals in the provision of care (Commonwealth of Australia, 2011).

In the hospital setting, the roles of family carers need to be adequately identified to achieve partnership in the delivery of health care. In a discussion paper named 'Responding to the Independent Hospital

Pricing Authority about funding Australian public hospitals', Carer's Australia (2012a, p.2) has declared that clinical care activities need to be 'described' and 'classified' to clarify carers' roles in the delivery of patient care. In Australian hospitals there are consumer support programs that claim to be family centric which also support family and carers' rights. However, their focus tends to be on the patient alone rather than the patient and their relative/carer (Carers Australia, 2012b). There are difficulties in maintaining the partnership between relatives and healthcare professionals in hospitals because there are no processes or follow up actions to maintain this partnership (Carers Australia, 2012b). As a result, the inclusion of relatives in clinical health activities may be limited due to the absence of policies that identify carers' roles in hospital settings (Carers Australia, 2012a). This may mean that the inclusion of relatives in caring activities are dependent upon the health team, or may be a matter of a family preference.

In recent years Australian hospitals became increasingly interested in patient centred care and family centred care (Australian Commission on Safety and Quality in Health Care, 2010). Patient centred care is the approach used to describe the health team's relationship with patients in planning and delivering care and family centred care means working with families collaboratively in the caring process, and decision-making (Australian Commission on Safety and Quality in Health Care, 2010). In addition, there are several papers, which highlight the importance of involving patients and their families in the process of caring in Australian hospitals to support the patient centred care or family centred care models (Mitchell & Chaboyer, 2010; Wong et al., 2015; McConnell & Moroney, 2015; Rennick et al., 2011). However, some of these studies focused on nurses' perspectives of relatives' involvement in care (Linton, Grant & Pellegrini, 2008), and were conducted in a critical care setting (Mitchell & Chaboyer, 2010; Wong et al., 2015; McConnell & Moroney, 2015) or paediatric setting (Rennick et al., 2011; Linton, Grant & Pellegrini, 2008). This suggests that the role relatives play in the Australian and health care context is preferred by healthcare professionals in cases where they need relatives' assistance in care planning and decision making. Even though care in hospitals is meant to be centric to patients and their families, there is a lack of discussion about how to apply and assess patient centred care and family centred care in the Australian healthcare context.

### **The Saudi Arabian context**

The family in Saudi Arabia is considered the primary unit in society (Brown, 2005). In Saudi Arabia the norm is to maintain family connections; therefore, losing contact with family members is not acceptable. Additionally, Saudi nationals are Muslims and they follow Islamic rules, which focus on the importance

of keeping strong family bonds. The relationships are guided by Islamic beliefs and cultural expectations (Said & Funk, 2002). Severing the relationship with any family member in Islam is considered a sin. Traditionally, in Saudi Arabia when a family member is hospitalised all family members will attend the hospital. The attitudes of patients and their families are influenced by Islamic beliefs. The families in Saudi hospitals are expected to provide care to hospitalised patients and this is considered a part of keeping the patient safe and supported. There have been several studies conducted in Saudi Arabia and these highlighted the importance of a relative's role in patient care (Al Mutair and colleagues 2012; 2014a; 2014b; 2014c; de Beer & Moleki, 2012; and Halligan, 2006). However, they were either focused on nurses' perspectives about the participation of relatives in patient care or conducted in the ICU.

In Saudi Arabia, nurses' roles are tied to Islam in all aspects of patient care (Halligan, 2006). This may change the role and priorities nurses have when delivering patient care. Nurses in Saudi Arabia face difficulties and challenges when delivering care because relatives usually dictate the nurse's role and very often the extent of the care given (Halligan, 2006). As a consequence, nurses may not deliver the care or perform a procedure as they consider it should be done (Halligan, 2006). Nurses may feel their nursing role in Saudi hospitals is diminished because no matter what they do to help the patient, it is Allah's (God) will that has helped the patient not the caregiver. In a study by Halligan (2006) the author stated that foreign nurses in Saudi Arabia felt stressed and powerless when delivering nursing care. In addition, Alosaimi and colleagues (2013) highlighted the stress non-Saudi nurses felt in dealing with Saudi patients and their families because they felt they were only a hired helper. Nurses also believed their professionalism was threatened and they were less respected because of their cultural differences (Alosaimi, Dyson & Anthony, 2013). However this point of view reflects the concerns of foreign nurses but not necessarily local or Muslim nurses.

Halligan (2006) also highlighted that ethical decision-making concerning the patient's life is discussed between physicians and relatives in Saudi Arabia with less involvement of patients. This perspective suggests that family members in Saudi Arabia are empowered to make decisions concerning patients' health on behalf of patients. For example, a male member of a family such as father, brother, or husband needs to sign and approve a consent form for surgery. In a study by Wåhlin, EK and Idvall (2009) the authors emphasised that patients seemed to believe that next of kin should be involved in decision-making matters. Therefore, in this context, health teams may favour communication with relatives in relation to treatment decisions and neglect patient decision-making. Halligan (2006) found that nurses felt that the presence of relatives in the critical care setting in Saudi Arabia, obstructed

patients' contribution to their own care. Some nurses were also reluctant to provide care in some instances, such as comforting patients, because they did not want to be rejected by the patient's relatives. They also lacked understanding about how to provide comfort according to religious and cultural beliefs (Halligan, 2006).

Nurses from other nationalities (non-Saudi) or from non-Muslim countries may not have a comprehensive understanding of the religion and culture of Saudi Arabia. This can affect the role of a nurse, because the patient and his or her relatives expect the nurse to deliver care in a certain way. For instance, patient and relatives expect nurses who take a blood specimen to say a specific word in Arabic (*Bismillah*), which means 'in the name of Allah'. This word in Islam is used for protection and is also used at the beginning of any task (Rassool, 2000). If the nurse does not know this word or forgets to say it before performing the procedure, she or he might alienate the patient and the relatives. In a study by Rafii, Hajinezhad and Haghani (2008) the authors studied nursing care in Iran and its relationship with the patient satisfaction. The authors highlighted cultural practices and beliefs that may challenge many nurses in Iran (Rafii, Hajinezhad & Haghani, 2008). For instance, female nurses should not spend time with a male patient unless performing a procedure. In the study authors explained that Persian culture and Islamic beliefs prohibits females talking with males who are not family members (Rafii, Hajinezhad & Haghani 2008). Consequently, a female nurse may not want to deal with male patients and interact with their relatives because she may experience rejection. Rafii, Hajinezhad and Haghani (2008) indicated that these religious or cultural obstacles might in fact affect nurses' interventions and interactions with the patients. This example shows that some cultural beliefs can impact on the interaction between female nurses and male relatives and could be an obstacle to giving patient care.

### **Fundamentals of care and relatives' involvement**

The fundamentals of care have been highlighted in research as daily life activities, which are essential for survival irrespective of a person's health condition or care setting (Kitson et al., 2010). These fundamental activities are practices people perform every day and spontaneously to maintain their health and wellbeing, such as eating, drinking, toileting, and sleeping. It is common sense that a healthy person can perform these activities independently; however, when a person has health difficulties, he or she may need someone to assist them. In this context, basic life activities can become critical issues affecting someone's quality of life if not fulfilled. In hospitals, health teams, especially nurses can articulate whether a patient needs assistance to perform these activities (Dijkstra et al.,

2012). This means that the health care team needs to assess the patient's ability to perform the activities dependently or independently and from there the health care team can negotiate assistance for the patient.

Providing patients with quality basic care activities has been linked to better quality of life (Kassean & Vythilingum, 2005; Rantz & Zwygart-Stauffacher, 2004). Fundamentals of care aim to improve quality of care given to patients and can result in patient harm if delivered incorrectly. For example, a patient with swallowing difficulties may need to be fed via a nasogastric tube instead of being spoon-fed. Therefore, fundamentals of care are skills in nursing, which are linked to evidence-based practices to reduce or prevent negative outcomes (Vollman, 2009). Nurses have the education and the expertise to deliver fundamentals of care to patients properly. On the other hand, relatives of patients may not have sufficient education about how to deliver the basics of care safely; this may endanger patients' lives or medical condition. In a study by Garrouste-Orgeas and colleagues (2010) the authors cited that nurses delegated basic care activities to relatives on the grounds that this would not harm patients. However, basic care may impact upon patients' wellbeing in a negative manner if delivered incorrectly. Fundamentals of care are essential because patients in hospitals are vulnerable and dependent on the care delivered to them. Therefore, the involvement of relatives in patient care can impact upon the quality of care provided to patients.

### **Patient and family centred care**

Patient and family centred care is a model of care which recognises the role patients and their families play in health care management, planning and the decision making process; this term also refers to the recognition of patients and their families as partners with health professionals (Australian institute, Patients and Family Centred Care, 2016). Significantly, patient and family centred care enables patients to provide a definition of whom they consider family and the extent of their involvement (Ciufu, Hader & Holly, 2011). Some authors indicate that there is a lack of understanding of patient and family centred care in many health organisations and this is because of the confusion over its meaning (Frampton et al., 2008). Furthermore, the authors of a systematic review, Ciufu, Hader and Holly (2011), suggested that a framework be used to test the implementation of patient and family centred care in the field, which would include elements such as dignity and respect, information sharing, participation and collaboration. This was proposed in order to emphasise the valuable collaborative relationships between patients, families and nurses.

Family involvement in patient care has been shown to increase patients' safety and the quality of care provided to them (Spruce, L, 2015; Ewart, et al., 2014). One way of providing patient and family centred care is by involving families in direct care as in paediatric settings where parents have the choice to assist nurses in care giving tasks. The patient and family care approach was prevalent in child health care more than adult care, and predominantly in paediatric settings. There are many studies that have explored patient and family care in paediatrics settings; most notably these studies indicated that this model is well implemented in many hospital settings (Mikkelsen & Frederiksen, 2011; Mortensen et al., 2015; Tallon, Kendall, & Snider, 2015). There is evidence to show that involving parents in their children's care in hospitals was desirable for both parents and nurses (de Melo et al., 2014; Soury-Lavergne et al., 2012). Perhaps this was because nurses needed to keep in constant communication with parents for decision-making purposes and parents needed to be close and involved in their children's care.

Patient and family centred care is being increasingly adopted in adult care such as in critical care settings (Kean & Mitchell, 2014). Several publications have explored the model in acute care settings (Peek et al., 2007; Ross, Tod & Clarke, 2015) and many nurses value families' involvement in the care of critically ill patients (Engström & Söderberg, 2010). This model has also been discussed in some studies involving the elderly population (Nagae et al., 2013; Cott et al., 2008). However, many of these studies focused on people with dementia or on patients discharged from hospitals. There are a lack of studies discussing patient and family centred care in adult care such as in general medical settings. There is no doubt that patient and family centred care could improve the quality of care given to patients if implemented adequately; however the continuity of this model of care can be challenging and complex (Bergbom, 2008) and will not continue to be implemented without leadership, support and participation (Shaller, 2007).

The authors of a paper, which compared the views of ICU nurses from the United Kingdom and Australia, indicated that nurses encouraged their partnership with patients' families and considered it daily practice in intensive care units (Kean & Mitchell, 2014). However, the implementation of patient and family centred care in the ICU could be problematic. One aspect of patient and family centred care interventions in the ICU, which is discussed repeatedly in research, is extended visiting hours or open visits for families. Studies highlight issues associated with extended visit hours, such as nurses being overworked and delays caused to patient care activities (Ross, Tod & Clarke, 2015; Ciufu, Hader & Holly, 2011). Researchers suggested a need for nurses and families to become educated about the nature of their partnership (Ciufu, Hader & Holly, 2011). This will only be achieved through the

considerable commitment of organisations to this partnership, by addressing variances across practices, and by tackling the limitations associated with implementing this model.

## **Cultural diversity and culturally competent care**

With globalisation there has been an increased focus on recognising the impact of multiculturalism and diversity in healthcare services. This focus is not to emphasise the differences (McMillan & Larson, 2003) but to create culturally competent care. For instance, the Australian Bureau of Statistics (2015) showed that since 1973 and with the broadening of Australian immigration policies, many people from Asia, Italy, Germany, India and Greece immigrated to Australia and have contributed to its cultural diversity and to population growth. Similarly, the Saudi community has lived with multicultural diversity for many years, as most of its workforce comes from various racial and cultural backgrounds (AlYateem, AlYateem, Rossiter, 2015). Therefore, with an increasingly diverse population there has been a need for healthcare systems to provide transcultural care. There are healthcare systems that have responded to this diversity at management levels and which have ensured access to healthcare services, such as translating hospital information into different languages and providing competent translators and interpreters. However, providing translated information such as printed materials into different languages has not always been efficient as many people lack health literacy knowledge (Oliva, 2008). However, translation services can be a step towards breaking down language barriers and enhancing interactions between patients, their families and nurses. The results of a study by Si et al (2006) showed that the use of male Indigenous workers in seven diabetic clinics in the Australian Northern Territory helped the Indigenous diabetic patients adhere to their diabetic guidelines. However, some authors argued that translation services are not always immediate or accessible, even if this service is provided by hospitals (Almutairi, McCarthy & Gardner, 2015). For example, a study by Almutairi and associates (2015) was conducted in Saudi Arabia to explore how cultural diversity can be managed in a multicultural environment. The results of this study showed that non-Saudi nurses tended to use sign language or body gestures to communicate with patients and their families since translation services were time consuming and caused work delays. This way of communication is problematic because a sign in one culture can have a different meaning in another and can create more misunderstanding.

Research indicates that there are negative consequences for patients and their families when healthcare services do not cater to the needs of diverse populations. Diversity may put healthcare providers, patients and their families under pressure, not only because of language barriers, but also



due to a lack knowledge and understanding of cultural and religious beliefs, which can have a negative impact on care quality and delivery (Al -Yateem, AlYateem, Rossiter, 2015). There is also evidence that social and ethnic background contributes to disparities in healthcare in terms of access and delivery systems (Betancourt et al., 2003; Henderson, Kendall & See, 2011). This is why healthcare providers' awareness of ethnic and racial disparities promotes cultural competence, safety and appropriate interventions (Brach & Fraser, 2000). Wehbe-Alamah (2008) proposed the need for healthcare services to be culturally specific. This concept was supported by Bainbridge and colleagues (2015) in a paper presented to the Australian Institute of Health and Welfare. This paper concerned the Australian indigenous population, with the authors endorsing cultural competence practices through partnership and interaction with patients and their relatives, to better understand cultural differences and to minimise personal judgment and negative interventions by care providers.

The literature suggests that nurses often lack knowledge about how to work with culturally diverse populations and that inter-cultural education may ameliorate this problem. A feeling of uncertainty was an issue that arose when healthcare providers dealt with people from various cultural backgrounds (Høye & Severinsson, 2010); this affected the ability of nurses to implement their own health care values. Furthermore, Høye and Severinsson (2008) explored nurses' perceptions of their encounters with multicultural families in intensive care units in Norwegian hospitals; the results showed that some nurses faced challenges interacting with different ethnic families and this made the working environment stressful. Another study by Sidumo, Ehlers and Hattingh (2010) presented views of 50 non-Muslim nurses who worked in gynaecological settings in Saudi Arabia. The results showed that nurses lacked knowledge of the cultural practices of patients and their families in relation to food taboos, visits, illness, modesty and medicines. Nurses experienced stress as a result and this affected care delivery. To manage these challenges Boi (2000) suggested post registration and continuous education for nurses to increase their cultural knowledge and improve confidence. Moreover, Høye and Severinsson (2010) emphasised the responsibility of nurses to create cultural safety in hospitals. As nurses manage and direct a large part of patient care, they also have the responsibility to provide culturally competent care. The health system's acknowledgement of cultural diversity could have an impact upon how nurses and relatives interact and communicate.

## **Summary**

The literature review focused on finding papers that discussed the role of relatives in patient care in hospitals as well as its prevalence, advantages and disadvantages. In addition, the search highlighted

the gaps in knowledge in relation to relatives' involvement in patient care. There are studies that discussed relatives' involvement in hospitals; however, these studies primarily focused on nurses' perspectives. Many of these studies have also been conducted in ICU or paediatric settings where relatives' involvement is necessary because of patient age or type of patient condition. There are a lack of studies focusing on the cultural aspects of relatives' involvement and role in the hospital environment or conducted with an ethnographic approach. Significantly, there is limited understanding of relatives' role in hospitals as partners in care. The available literature showed that partnership could be a challenging task, especially for nurses, and the continuity of it cannot be guaranteed. Even though it is more culturally acceptable for relatives to stay with patients in Saudi settings, the research still found the same problems in both Saudi and other settings.

Furthermore, there are limited studies which explore the impact of relatives' involvement in fundamentals of care and the quality of care given to patients. Few studies highlighted the discrepancies between the perspectives of relatives and nurses in terms of what could be achieved from the involvement. Patient and family centred care is a term connected with settings where relatives' role as advocates is most needed by health team professionals. Finally, literature indicates that cultural competence is a fundamental skill for nurses.

## **Chapter three**

## **Chapter 3: Methodology**

### **Introduction**

In this study, the researcher explored the role relatives play in the care of patients in medical settings in hospitals in both Australia and Saudi Arabia. The researcher adopted an interpretive ethnographic approach because it helped in gaining a focused and deep understanding of social aspects of relatives' involvement in patient care. This approach was appropriate to enable this researcher to gain an understanding of the naturalistic and holistic cultural aspects of relatives' involvement in the field. Applying this approach helped the researcher to investigate the diversity of field settings and practices.

This chapter discusses the following aspects of the research: choice of design; the definition of ethnography; a discussion of the history of ethnography; ethnography in health research; and a description of ethnographic paradigms. Subsequently, it provides a detailed explanation of the interpretive paradigm and finally the data analysis.

### **Design choice**

The research adopted an ethnographic design. It was believed that ethnography would provide a broad and holistic view of the role relatives play in medical fields. The use of this design strengthened and validated the results because it explored the issues through various data sources. It also facilitated the interpretive and inductive nature of the inquiry, as Hammersley & Atkinson indicate,

Ethnography usually involves the ethnographer participating, overtly or covertly, in people's daily lives for an extended period of time, watching what happens, listening to what is said, and/or asking questions through informal and formal interviews, collecting documents and artefacts, in fact, gathering whatever data are available to throw light on the issues that are the emerging focus of inquiry. (Hammersley & Atkinson, 2007, p. 3).

The choice of this design was guided by the question and aims of the study. In addition, the role relatives play in hospital settings has been explored to some extent in research literature, with relatives being involved in decision making where required, or present in some units because of the nature of a patient's condition, such as where a patient is critically ill in an intensive care unit, in mental health care or paediatric care. However, there are a lack of studies that explore the role of relatives in general departments such as medical units and there are also a shortage of reports about the role relatives play in hospitals as partners in care. Therefore, ethnography was believed to be appropriate to provide an

extensive report about the role of relatives in hospitals and to address the shortcomings in the literature.

## **Defining ethnography**

Although there is much debate and a lack of consensus over the definition of ethnography, it can be defined as 'the work of describing a culture' (Spradley, 1980, p. 3). Hammersley and Atkinson (2007) state that ethnography has no standard definition and it has been reconceptualised in different ways in order to shape different disciplinary contexts. Ethnography is a way of studying people's social lives and culture for extended periods of time (Hammersley & Atkinson, 2007). Culture can be defined as a 'set of rules and guidelines that people inherit from being a member of a particular society' (Baldwin, et al. 2006, p. 8). Additionally, Spradley the author of seminal text in ethnography 'participant observation' (1980, p. 5), defined culture as dealing with 'three fundamental aspects of human experiences: what people do, what people know and the things people make and use'. Data in this type of research can be collected through various sources to help understand the meaning of human actions and practices (Lambert, Glacken & McCarron, 2011; Hammersley & Atkinson, 2007). Thus, regardless of the definition used, ethnographic research is always concerned with investigating culture (Wolcott, 2008).

The ethnographic approach focuses on the natural settings of the phenomenon under study. In other words, it differs from experimental studies in that the setting for the research is the field itself and thus it has not been organised for research purposes (Hammersley & Atkinson, 2007). Furthermore, the data is collected in an exploratory manner using a variety of methods, to provide a comprehensive understanding of what is happening. Ethnography has been adopted in health research for many years (Goodson & Vassar, 2011), since health organisations may benefit from the in-depth investigation of health care issues and practices. Goodson and Vassar (2011) stated that hospitals may appear the same externally, but patient care and policies differ widely. Thus, applying this approach has helped the researcher to investigate the diversity of field setting practices in Australia and Saudi Arabia.

## **A brief history of ethnography**

Ethnography was originally developed within the discipline of anthropology (Murchison, 2010). There were many anthropologists who represented classical or traditional ethnography such as Bronislaw Malinowski, Evans Pritchard, Ruth Benedict and Margaret Mead (Moore, 2000). These anthropologists studied the history of people's lifestyles and societies such as the Nuer tribe in Africa, and communities in Japan. Anthropology and ethnography developed in the late stages of the nineteenth century and

were connected to travellers and missionaries and often involved 'white men' exploring other cultures. The anthropologists had a long history of revealing systems of power and domination (Murchison, 2010). The ethnographic approach was connected to the politics of the time such as colonialism. For example, the anthropologist Pritchard lived in and studied the Nuer colony in South Sudan, which was under the control of the British Empire (Pritchard, 1940).

Ethnography was influential in sociology (Angrosino, 2007). Between the 1920s and the 1950s the School of Sociology at the University of Chicago adopted ethnography to study American communities (Hammersley & Atkinson, 2007). In the beginning, most projects were performed in the School's labs before researchers moved on to study populations in the city of Chicago itself. This move allowed the ethnographers of the Chicago School to study a wide variety of cultural processes and human behaviours (Scott-Jones & Watt, 2010). The sociology of the homeless man (Anderson, 1923) is one example of an ethnographic study performed by the Chicago School. This move in ethnography by anthropologists and sociologists created more and more questions around the strategic methods associated with ethnography; an example of critiquing these methods was shown in the ethnographer Freeman's work in (1983). Freeman critiqued Margaret Mead's research strategy in Samoa and explained how she was misled by the informants and therefore presented inconsistent information. Later Freeman also performed a study in Samoa, speaking to some of Mead's informants and presented an entirely different account of the information which emerged from the data. The work of Freeman showed how views of people and researchers could change from one another over time. It is important to point out that the critique of classical ethnography helped to shape ethnography in non-classical or contemporary practices.

Contemporary ethnography emerged in the 1980s and was adopted by many disciplines. The contemporary approach is known for its epistemological foundation such as the use of various methods, which continues throughout ethnographic research (Savage 2000). Contemporary ethnographers challenged the assumptions of the classical ethnographic approach such as objectivity and focused more on the participants and their subjectivity and how people explain their lives in their own words. Contemporary ethnographers spend shorter periods of time in the field but do extensive work in data analysis, which is opposite to the classical way of doing ethnography (Roper & Shapira, 1999). Contemporary researchers spend some time developing a detailed structure of research processes before they start collecting data. In addition, their focus has moved away from studying others or distant groups to locals. Contemporary ethnographers have also adopted the role of an insider rather than the outsider (Draper, 2015). In addition, contemporary ethnographers ensure that

participants understand and accept being part of researchers' investigations, and promote participants' rights to voluntary participation and withdrawal, which was not so important for classical ethnographers (Cudmore & Sondermeyer, 2007). Contemporary ethnographers also adopt a variety of methods to collect data, with structural and systematic strategies. Furthermore, contemporary ethnography can be completed through quantitative data such as surveys. Finally, contemporary ethnography focuses on studying the culture as well as the process of performing ethnography.

## **Ethnography in health care research**

In 1950 Leininger first introduced ethnography to the discipline of Nursing (Leininger, 1970). Her notions of ethnographic design and its value for nursing challenged the positivist research paradigm of the time (Bruni, 1995). Traditionally, quantitative approaches were accepted more widely than qualitative research, especially in health contexts. In spite of this, ethnography continued to gain acceptance among nursing researchers and was applied to inquiry about health and illness and this has continued. Additionally, ethnography has helped health researchers understand many complex issues in health care and practices since it highlights the relationship between assessment and intervention (Savage, 2006). The common approaches to ethnography used in recent nursing studies focus on specific inquiry or study of small groups of people; these are variously called focused, mini or micro ethnographies (Roper & Shapira, 1999). The intent of using focused or mini ethnography is to study specific groups, which are socially and culturally unique.

Nursing is undertaken in many fields, contexts and cultural settings. Therefore, the diversity of ethnographic methods and analysis can offer deep insights into the particular culture of a healthcare setting. The insights gained from ethnographic studies in nursing have helped to implement change and improvement to patient care (Allen, 1998; Admodt, 1972 cited in Beck, 2013). There are many nursing researchers who have explored specific health practices among different cultural groups and settings. These researchers have provided rich details on a variety of topics and offer solutions or recommendations to improve care practices. The use of ethnography in studying hospitals provides unique data about every division or specialty (Goodson & Vassar, 2011). Such an understanding of practices and cultures may facilitate regular change in practice and help in decision making for future care. The scope of the resulting evidence which emerges from ethnography is comprehensive, which leads to better solutions, as it can suggest the most appropriate action based on a particular situation. In a comparative study by Murphy, Griffiths and Merrell (2014), the authors compared three studies to confirm if ethnography could help in the understanding of nursing work at hospitals. The authors stated

that the analysis of those three ethnographic studies (Philpin, 2007, Murphy & Merrell, 2009 and Griffiths, 2011) showed that prolonged observation, interviews and document reviews helped them to understand the complexities of nursing work. The extensive analysis of observations and field notes revealed the similarities and differences associated with nursing practices in the fields where the studies were performed. The insight gained from applying ethnographic methods and analysis in these three studies showed that culture was individual to every nurse and setting (Murphy, Griffiths & Merrell, 2014).

The debates concerning ethnography shed light on the challenges that can face ethnographers in conducting research, such as issues with accessing information, variation of cultural experiences among researchers, and ethical issues relating to prolonged periods of time spent in the field (Murphy, Griffiths & Merrell, 2014; Goodson & Vassar, 2011). One main issue with ethnographic research is that the results cannot automatically be applied to settings beyond where the studies were conducted (Goodson & Vassar, 2011); for example, outcomes of a study performed in an intensive care unit may not be applied to other departments in the hospital or in another city. Furthermore, gaining acceptance from participants and maintaining this can be very challenging. Apart from the challenges, ethnography is an excellent tool for investigating concealed cultures and is appropriate for investigating nursing and health issues. Immersion in the field provides valuable information which can improve nursing practices and decision-making. In addition, for many years nurse ethnographers have helped health professionals to understand behaviour that might have an impact on their practices, of which they were not aware (Savage, 2000).

## **Types of ethnographic research**

The following section discusses the different paradigms used in ethnographic research. These are the positivist/ realist, critical/ emancipatory, feminist/ post structural and interpretive/ constructive paradigms.

### ***Positivist / realist***

The philosophical assumption guiding the positivist approach is an objective view of reality (Belk, 2007). This approach came into existence in the mid twentieth century after anthropologists criticised the subjective ethnographic approach, as this created an issue with scientific rigour (Hammersley & Atkinson, 2007). Emile Durkheim introduced the term positivism to ethnography in 1858-1917. Durkheim's theory focused on treating social facts as real; he believed that things exist before an



individual participates in them (de Laine, 1997, p. 25). Durkheim presented this theory in 1951 in a study called 'Suicide', where he showed that social facts relate to each other and enable a discussion of the causes of physical sciences (de Laine, 1997). Furthermore, positivist researchers tended to generalise the results of their studies across different populations and sites. The data collection methods used in this approach are usually quantitative. Surveys and qualitative methods such as structured interviews are used to support or clarify the quantitative results. This approach is built on deductive reasoning, which means the researcher has a hypothesis and needs to prove its truth or falsity. The researchers using this approach remain detached from the participants to keep their judgments unbiased.

### ***Critical / emancipatory***

Critical ethnography is concerned with issues of justice, domination and power in relation to economy, race, gender, religion, education, and ideologies (Zou & Trueba, 2002). Critical theory was developed by the theorists of the Frankfurt School such as, Horkheimer, Adorno, and Marcuse (Held, 2013). Their initial interest was studying the devastation people experienced after World War1 (WW1) (Corradetti, 2011). Some of the issues they studied were increased unemployment rates, and the failed protests of unemployed people in Germany and central Europe at that time. A decade after WW1, the theorists fled Germany to the United States after the Nazis took control of Germany. The School's members feared that their Jewish backgrounds and their School's relationship with Marxist orthodoxy could put them in danger (Zou & Trueba, 2002). After they settled in California they started their Social School of Critical Theory. The approach focused on the productive components of power and its ability to create independent spaces where people could engage in their social roles (Giroux, 1997). The researchers of this approach were interested in the construction of reality and the tacit rules that control it. In addition, they aimed to expose the cultural pedagogy behind issues of power or domination. Many critical researchers consider their work a first step towards social change. This approach has no specific methods of collecting data; however the data is mainly qualitative. Critical researchers also begin their research holding assumptions (Zou & Trueba, 2002). They believe that by clarifying assumptions researchers avoid bringing any confusion to the research. However, they also recognise that as their investigation progresses, assumptions can change. Their emancipatory goals are presented through their work and approach and its impact is measured by the ability of these researchers to expose issues of inequality or injustice.

### ***Feminist / post structural***

The feminist approach is linked with the socio-political movement for women's rights throughout history; this approach is also characterised by analysis of women's social position, which is shaped by social conditions they do not control (Angrosino, 2007). Feminist theory developed in the early twentieth century with famous individuals such as Virginia Woolf and Charlotte Perkins Gilman. Feminists were also motivated by the work of activists in 'gay' and 'black' rights at the time. Many feminist supporters were students, academics and researchers and their views were transferred to their work and this helped in creating political change. Angrosino (2007) discusses some characteristics of feminism which arise in different social contexts and believes they underpin feminism. First, feminists assume that gender defines a person's position in a social hierarchy. Secondly, feminists suggest that a female's fundamental nature is connected to caring and nurturance. Next, gender is considered to be socially learned rather than biologically inherited, meaning the differences between genders are socio cultural. Finally, universal sexual asymmetries, for example some females or males partners are treated unequally in society. The researchers of this approach are usually involved in detailed dialogue with their participants and present their data in a qualitative and subjective manner to present the exact perspective of women, with less interference from the researcher.

### ***Interpretive / constructive***

The ontology of the interpretive paradigm is relativistic, meaning there is no absolute law or absolute truth and that reality is socially constructed (Mertens, 2005). This approach generates meaning inductively throughout the research (Creswell, 2003). Researchers who adopt an interpretive paradigm 'usually assume the world is produced and reproduced by acting units or human beings, reality is considered an inter subjective world of cultural objects, meanings and social institutions derived as a consequence of social interaction' (de Laine, 1997, p. 35). Furthermore, the epistemology of this paradigm is subjectivism; the meaning of culture is constructed through interactions between consciousness and the world (Heron & Reason, 1997). Therefore, reality can be understood from the point view of participants. Interpretive methods yield insight and understanding of behaviour, actions and reactions of participants.

An interpretive constructive paradigm was chosen for this study because there was no intention to focus on the rights of women or groups experiencing discrimination and the researcher believed insight into the culture being studied would be best achieved using qualitative data. The choice of paradigm

guides a researcher in the development of the overall structure of the research. The theoretical orientation of the research also has implications for decisions made regarding the process of research, including the choice of data collection and analysis methods (Mertens, 2005). The researcher may combine methods in data collection, which align with the paradigm (Wiersma, 2000). Additionally, the use of mixed methods in any research strengthens the results and lessens useful or potential information waste (Gorard, 2004). This paradigm predominantly aligns with the use of qualitative methods (Silverman, 2000, Wiersma, 2000, Mertens, 2005) and it assisted the researcher in the exploration of issues of influence, the outcomes associated with the role relatives play in patient' care and their involvement in general. Additionally, it assisted in understanding field contexts.

The interpretive process aims to provide cultural interpretations and usually relies on a variety of data collection methods. The techniques used in data analysis reflect holistic views, contextualisation and emic (insider), etic (outsider), and unprejudiced reflections and perceptions of reality (Fetterman, 2010). The holistic view, for example, creates demands on the researcher to spend extended periods of time in the field to collect a comprehensive picture and detailed information of the site and participants. Observation and in-depth interviews are important aspects of the interpretive approach as they assist in finding meaning and relationships inside the culture (Fetterman, 2010). For example, the process of finding themes, which reflect the participants' thoughts and experiences help the researcher to answer research questions.

The researcher who adopts this paradigm focuses on the participant's subjective point of view; this paradigm also involves the researcher's insight into understanding the behaviour of participants to create meaning in relation to the social site culture. Researchers usually integrate both of these aspects into the process of creating meaning. Additionally, the perspectives gained from participants' views are usually referred to as an emic perspective and reflect the insider's perception and understanding of reality (Fetterman, 2010). Therefore, different participants' perceptions usually help a researcher to understand people's beliefs and why they act the way they do, since each perception shows a different reality. Alternatively, the etic perspective provides scientific meaning of reality (Fetterman, 2010) and this comes into use when the emic point of view is unable to answer questions. The etic perspective happens during the thematic analysis when the researcher uses his or her intuitive and interpretive sensibility to turn transcribed texts or passages into simple words to give them meaning.

The interpretive paradigm may put researchers under pressure because their interpretation of meaning may be simple or superficial. Therefore it is useful for researchers who adopt this approach to have

another researcher to assist in a project, in order to offer other views and interpretations (Grubs & Piantanida, 2010). In addition, the purpose of qualitative research is not to generalise the outcome over different settings or population. The interpretive paradigm has long been criticised because of its subjectivism, as the paradigm holds that there is no objective truth. Reaching a consensus in relation to cultural meaning in an interpretive paradigm may be problematic (Scotland, 2012); however, the credibility of the process and results may be achieved without claiming certainty or fact. Rolfe (2006) indicated that, if reality is gained in a subjective manner then it is anticipated that the participants may not have the same interpretations as the researcher. However, to add confirmation to the findings of this study and apply different perspectives, the researcher used different methods and triangulation to add breadth and validation to the information of interest. Since the use of triangulation of methods adds confirmation and different perspectives to the findings (Denzin, 1978), more discussion of triangulation and methods of combining data are given in the methods chapter.

### **Data analysis in ethnographic research**

Analysis in ethnographic research aims to narrow extensive data to readable and concise knowledge. Patton (1990) said that analysis occurs in three steps; step one brings order to the accumulated data; step two turns the large load of data into summarised information and lastly, step three assists the ethnographer to discover codes and themes and link them with other patterns. It is when reading, and rereading the data collected from the interviews, field notes and other sources, that the researcher starts to interpret the data and make sense of them. This step assists in creating categories and giving these titles or names. The interpretation of data involves finding meaning and also involves attaching significance to patterns and explaining why they exist (LeCompte & Schensul, 1999). This process incorporates several stages that make large clusters of data understandable to an outsider.

The ethnographer integrates data collection and data analysis at the same time, to refine knowledge, and create understandable categories. After this process the researcher decides if they need to focus on or elaborate on specific inquires in the future. According to LeCompte and Schensul (1999), analysis of ethnographic data requires transcribing the ethnographic notes, tidying up the data after the fieldwork, then managing data into categories, subsequently deciding the next step. The distinctive characteristics of ethnographic analysis are the use of reflexivity and the interactive nature of the researcher throughout the process. The ethnographic researcher stays central to the information under study, and uses their reflexivity in the process to help make judgments as to whether the information should be included or left out (LeCompte & Schensul, 1999). This means that analysis of ethnographic

data requires cognitive processes and concentration to provide the researcher with a sense of the data. Additionally, the analysis of ethnographic data is systematic in nature and its progress. The researcher follows links between the information; this is achieved by looking at similarities and differences between the data to find associations. The analysis puts the researcher in a constant discovery mode and requires them to constantly compare the data.

Data analysis in ethnographic studies usually follows a systematic examination of aspects of certain phenomena and the relationship between these parts. Data analysis can be accomplished through different methods, but the aim is to discover tacit knowledge, as indicated in Spradley's book 'The ethnographic interview' (1979): 'the ethnographer's goal is to employ methods of analysing that lead to discovering the organisation of cultural knowledge' (Spradley, 1979, p. 93).

The researcher adopted Spradley's method of data analysis; more detail of his techniques is given in the methods chapter.

## **Summary**

Ethnography provides a deep understanding of the world around us through involvement and immersion in different social contexts. It has no exact definition as it is used in diverse ways across a wide range of disciplines but always relates to the investigation of culture. This approach can be applied through a number of methods to provide systematic and rigorous evidence. Ethnography has long been used in health contexts and its use has increased rapidly in recent years, as the approach is well suited to providing an understanding of complex issues around patient care. In addition, ethnography is informed by a variety of different paradigms and researchers select the one which aligns with the chosen research questions and the aims of the research. For this research, ethnography, based on the interpretive paradigm, was considered most appropriate for exploring the role relatives play in patient care in medical settings. This chapter has explained the ethnographic approach used in this research and the reasons for this choice.

## **Chapter four**

## **Chapter 4: Methods**

### **Introduction**

The purpose of this chapter is to present the research methods used in the study. These facilitated a detailed and deep exploration of the culture associated with relatives' role in looking after patients in the two geographical and culturally diverse settings. The methods used in this research required considerable time and effort to yield insight into fields that cannot be obtained by other means: The time spent in the organisation allows the ethnographer to move back and forth over previous observations and to assess what is going on (Neyland, 2008). This research was performed in two countries to allow in-depth study of participants' social behaviour and attitudes and to compare different cultures. This enabled the researcher to gain a variety of insights into participants' views and interactions in both countries. This chapter is divided into four parts; section one describes the research settings, the participants, inclusion and exclusion criteria, recruitment procedure, gaining access, and ethical considerations. Section two presents the data collection methods. Section three discusses data analysis techniques and integration and the final section explains the process used to ensure the rigour of the study.

### **Section one: Description of the study**

#### ***Research settings***

This study took place in a medical unit in both Saudi and Australia; it was conducted in two major hospitals. The hospitals were chosen because they were large, with a broad spectrum of patients and had many specialities.

The Saudi hospital is operated by the Ministry of Health and is considered to be the largest hospital in the region and located in a metropolitan area. It is a government hospital, less than ten years old and has 300 beds. It provides tertiary and referral services.

The Australian hospital is the largest hospital in the state and located in a metropolitan area. It is located in the city centre and provides tertiary health care services, rehabilitation and referral services. It has 680 beds, was founded in 1840 and is also a government hospital (termed a public hospital).

More detail about the settings will be discussed in the section titled 'cultural scene' in the findings chapter.

## ***Participants***

There were three sets of participants: women who were patients on the medical ward, their relatives and nurses who were employed on the medical ward, and they were recruited in two medical settings (one medical unit within each of the hospitals, one in Saudi Arabia and one in Australia).

## **Number**

The sample size for all three sets of participants was determined by the data generated from the observations and the interviews, meaning that the researcher continued the recruitment until no further new information was gained for the research inquiry. This process followed the principle of 'data saturation' which means making a decision to stop collecting data if there are no more new ideas emerging from the information that has been gathered from the field (Wray, Markovic & Manderson 2007).

## **Age range**

The sample group comprised of adult women who were patients, aged 18 years and above, who needed assistance to meet their daily needs. The relatives and nurses who cared for these patients were from diverse age groups.

## ***Inclusion and exclusion criteria***

The following details explain the inclusion and exclusion criteria:

### **Inclusion criteria**

The patients included in this study were female adults, aged 18 years and above, who had been admitted to the medical ward for more than 12 hours and required bed rest. The patients' relatives were from any age group, male or female, with any level of education and any type of relationship with the patient. As previously discussed the term relatives is used in this study to indicate the loved ones, family members, spouse, parents, or any person providing support and care to the patient during their illness and not necessarily having a blood relationship with the patient. These relatives were caring for, accompanying or visiting patients. The nursing participants were those assigned to care for the selected patients and included registered nurses, enrolled nurses, agency nurses, with any level of



education and experience and from any age group or background. Participants who spoke either Arabic or English were included in both countries.

### **Exclusion criteria**

The patients who did not match the inclusion criteria were excluded from this study; mentally ill patients were excluded because of their special needs as a vulnerable group and they could be put under pressure especially by the chosen methodology, which was prolonged observation. Patients who were admitted to medical wards for less than 12 hours were excluded because it was thought this would not provide enough time for relatives to be involved in the care when observations were conducted. Nurse managers were excluded from this study because they do not work directly with patients and were not involved in the patients' care in those chosen settings. Participants who could not speak Arabic or English language were excluded from this study. Further clarifications for the inclusion and the exclusion criteria are provided in the inclusion process section.

### **Inclusion process**

Medical patients, their relatives and ward nurses were recruited in the medical settings of large metropolitan hospitals in both Saudi Arabia and Australia. In the Saudi setting, the head nurse and medical nurses were asked to recruit patients and their relatives for the researcher, following the recruitment criteria of this study. In the Australian setting, the shift coordinator and nurses were asked to do likewise. Patients were recruited if they needed assistance to meet their daily needs, since this research was intended to explore relatives' involvement in the care of patients and focused on delivering care in hospitals.

Participants were recruited in medical settings because it was anticipated patients in these settings would have illnesses, which required them to spend extended time resting in bed, which would allow relatives to provide more support than those in surgical wards. Additionally, anecdotal evidence suggests relatives spent more time with patients in these settings; this creates a space for relatives to interact with nurses, which could be observed by the researcher. In addition, these settings also helped the researcher to identify the extent of relatives' participation in the care of patients. Only female patients were included as in Saudi hospitals as the researcher, being female, was only allowed to observe female patients because of the difficulties the researcher may face of conducting observations in male units. For this reason it was logical to recruit female patients in Saudi Arabia and Australia. However, male relatives caring for or visiting female patients were included in this study.

Patients and relatives who could not speak Arabic or English language were excluded from this study. The researcher is only fluent in these languages; thus if the participants spoke another language then difficulty may arise from miscommunication. The nurses employed or assisting in medical settings who were responsible for the direct care of patients with relatives were recruited into this study. Nurses from different backgrounds and from a variety of levels of experience were included. Nurses were excluded if they did not want to participate or continue to participate in this study. When overlapping of relatives and nurses happened during the shifts, this did not interrupt the consistency of observations. Furthermore, the time frame for data collection was planned to be equivalent in Saudi Arabia and Australia, which was three months spent in each hospital; this was decided based on the process of reflexivity, for example, keeping track of the progress of data analysis and making a judgement about whether the findings were sufficient to answer the research question. After this three months period there were no new findings (data saturation). During this period of time the researcher observed participants and collected field notes and involvement related guidelines. Interviews with participants were conducted in formal and informal ways.

### ***Recruitment procedure***

A letter was sent to the nursing manager informing them of the study. Nursing directors in Saudi Arabia and Australia were contacted and asked to provide letters of support for the research to be conducted in their departments. Additionally, consent had to be gained from the manager of the Saudi hospital to facilitate the process, along with the chief nurse. The clinical nurse coordinator of the medical ward in the Australian setting was also asked to provide consent. In the Saudi setting the researcher gave a short presentation about the study to nurses and in the Australian setting the shift coordinator introduced the researcher to the nurses and distributed information about the study. In addition the researcher wrote a short note in a communication book for the nurses from different shifts to read. Each day the researcher approached the nurses in charge to ascertain the patients who met the inclusion criteria. The nurses were recruited after patients had agreed to participate. The researcher requested the participation of patients' relatives, introduced the research, gave them the information sheet, and offered to answer their questions about the research. It is important to state that usually the patients led to the participation of relatives and nurses, so there was a 'nested' approach to recruitment. All participants were informed that they were entitled to opt out at any point of the study up until publication of the study findings.

### ***Gaining access***

Gaining access to the fields was not problematic; however the researcher spent a considerable amount of the time getting to know the nurses. It is very important that researchers gain the trust of participants and have social skills like the ability to interact, listen and convey one's thoughts and ideas, to access the required information (Wasserman & Jeffrey, 2007). Spending long hours in the fields allowed the researcher to help the participants feel comfortable with her and for them to speak freely. Additionally, this assisted the researcher to gain some confidence in approaching people and to become familiar with the units, nurses, people and routines. The researcher also introduced herself to people who entered the area being observed and gave them information to ensure a continuing relationship with people in the field. With the progress of data collection, many nurses, patients and relatives introduced the researcher to new visitors in the observed area, and this made the process of giving information and collecting data more manageable.

There is no doubt that being clear about the objectives of the research facilitated acceptance in the fields. Giving participants the information sheet, showing them the identification card and also allowing them to ask questions created a space for mutual discussions. Buchanan, Boddy and McCalman (1988) stated four objectives of gaining access to the field: getting in, getting on, getting out, and getting back. The researchers said that getting in the field is the stage where the researcher needs to be clear about the objectives of the research and time and resources involved, as this facilitates access to information. After that the individual's ability to maintain the relationship until the end of the inquiry is important (Buchanan, Boddy & McCalman 1988).

When beginning to collect data it was helpful to be introduced to nurses, patients and relatives by the head nurse (Saudi), shift coordinator (Australia), or nurses who were already familiar with the researcher in each field, because this helped to build trust with others. Additionally, it gave the impression to participants that nurses acknowledged the presence of the researcher. However, being introduced to others by nurses was not always offered at hectic times or when nurses were busy. In saying this, the process became smoother with time and the progress of research. The researcher felt that greeting nurses, patients and their relatives was helpful to create a friendly atmosphere and was a way to inform them of the presence of the researcher and about the observations. The greeting gave participants opportunities to open discussions with other participants, because some were new to the field or had not experienced being observed or interviewed.

When data collection started in the Australian field, it was necessary for the researcher to be introduced to nurses by the shift coordinator. To begin with there appeared to be a lack of interest from nurses, patients and relatives in the Australian setting. The researcher thought their lack of interest could be because she was an outsider or from a different country. In the Australian setting it was clear that nurses interacted better with the researcher when she had been introduced to them by the shift coordinator. Once this introduction ceased, nurses became reluctant to interact with the researcher. Some nurses apologised to the researcher for not being able to find time to speak with her. There were suggestions that this was because they thought they could not help, or lacked information about the research. Therefore, the researcher believed there was a need to give further information to nurses to reassure them about the purpose of the study. This is where the researcher put effort into building a relationship with the nursing team to sustain this relationship for easy access to information. This was by introducing herself to unfamiliar faces, greeting nurses, writing nurses' letters in the ward's communication book, and then distributing information sheets to nurses by placing them in their pigeonholes. With the progress of time nurses became more comfortable in their interactions with the researcher.

### ***Ethical considerations***

Ethical approval was gained from the University of Adelaide's Ethics Committee (Appendix: 1) and from the Australian Hospital (Appendix: 2); correspondingly, the researcher obtained permission from the management of the Australian hospital and the consent of the clinical coordinator of the hospital's medical ward. The researcher also gained approval for a low and negligible risk study from the South Australian Health site through its Specific Assessment Review (Appendix: 3) to perform the study in an Australian hospital. Ethical approval was obtained from Saudi Arabia's Institutional Review Board (Appendix: 4); Ministry of Health (Appendix: 5); and confirmation letters were also provided by South Region Health Research Board, and from the hospital itself. Completing the ethical approval process enabled the researcher to gain verbal consent from the participants for the observation phase. Signed consent was required for the interview phase. This was a non-intervention study, meaning there was no interference from the researcher, and the observations were around normal care. Additionally, no physical harm had been identified and there was no possible risk to the participants except the threat to privacy. Therefore, personal activities such as showering and toileting were not observed. Furthermore, the researcher did not intrude upon participants' privacy and if the participant was uncomfortable with the observations at any point the observations discontinued. The researcher and supervisors agreed

that the researcher should report any potential for harm associated with the research to the assigned nurse, without interfering.

The participants were asked to read the information sheet and then decide whether they would like to be part of this study (Appendix 6, 7, 8: Information sheet). They were encouraged to ask questions about the research observations; there was no pressure on them to participate. The researcher took responsibility for describing and clarifying the points of concern participants had. The researcher also read and explained any information to participants who could not read or write. No individuals were identified and the participants remain anonymous. No names or descriptions that may identify the participants were documented. The study was voluntary and the participants had the freedom to contribute or withdraw at any stage except after publication. If the patient and one or more relatives agreed to participate they were included in observations. If one or more relatives didn't agree to participate, then no observations were conducted while they were present. If the visitor of the patient was a friend or a neighbour of the participant and intended to help or assist the patient in the care during visit hours, then the visitor was given a short description of the study and information sheet; if they agreed verbally to be observed then the observation continued. If they did not agree then the observation discontinued until they left.

Participants, nurses, patients and their relatives were asked to provide written consent to participate in the interviews (Appendix 9,10: Consent form). This happened after conducting the observation and the participants who had been observed were asked to participate in interviews. All participants were given a complaint sheet to express their opinions or concerns (Appendix 11: Complaint form). The collected data were titled and stored in password protected computer files. Pseudonyms were used and data were coded from recorded interviews and transcribed into written texts. No one had access to the data except the researcher and her supervisors. Data will be stored for a period of five years in an electronic password-protected file on the School of Nursing shared file at the University of Adelaide.

The participants were provided with the contact details of the researcher, her supervisors and her University in case they wanted to ask about the results of the research. The research findings were disseminated regularly to the participants. Additionally, results of this study were disseminated via audio-visual presentations at the University of Adelaide Nursing School and hard copies will be provided to health and educational organisations in both countries. The study results will be published in a journal at a later stage.

## **Consent**

Verbal consent was required before commencing the observations. Before the start of the observation the researcher introduced herself to potential participants and an information sheet was provided to them. Some participants preferred verbal information before they read the information sheet. A few patients and relatives in both settings could not read because they could not see clearly, or because they were unable to read; therefore, the researcher read the information sheet and answered all relevant questions. The participants were encouraged to ask further questions. Verbal consent was gained from all the nurses who were observed. No nurse throughout the observation phase in either setting refused to be observed.

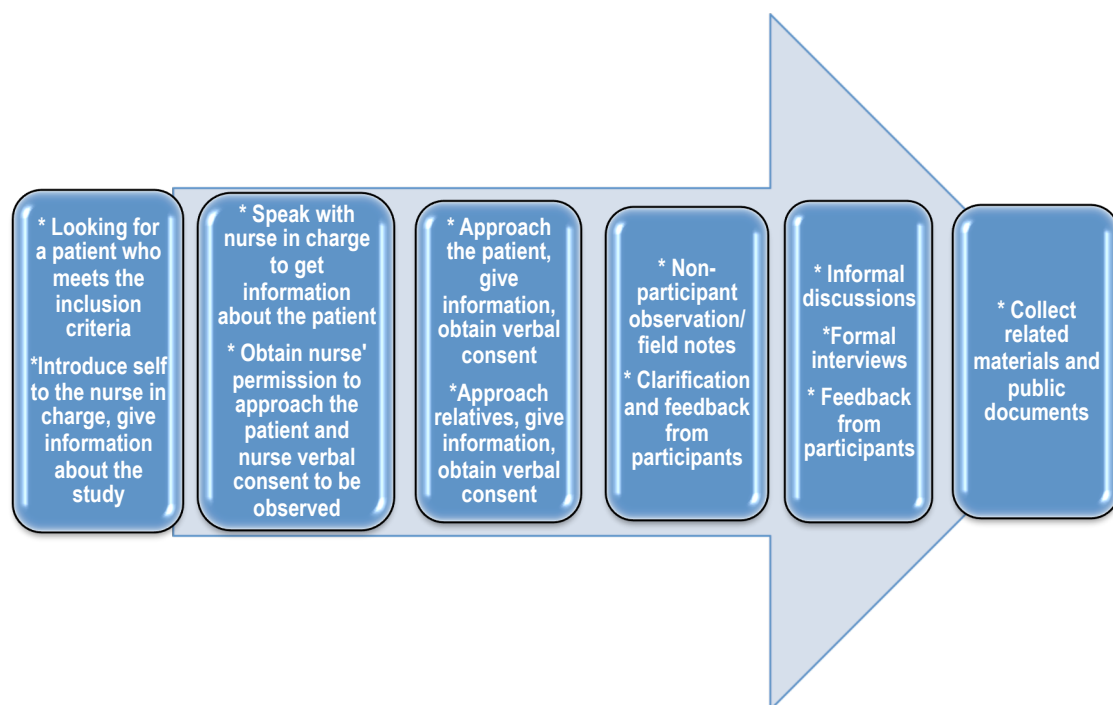
One may argue that when people are informed about observations this can interfere with the natural state of the settings or participants attitudes. However, in this study it was a requirement to ensure participants were aware of the observation. Furthermore, if the researcher did not obtain verbal or written consent from participants then the purpose of the long hours spent in the bay would be hard to explain to participants. It also could make participants feel uncomfortable in being watched or acting naturally. The researcher was aware of the possible impact of the '*Hawthorne effect*'. This is when participants change their behaviours because they are being watched (Parsons, 1974). However, the prolonged time spent in the field and by providing clear information about the aim of the observation to participants, it was anticipated that this effect would diminish with time. As time went by it appeared to the researcher that the staff and patients did not seem to notice her presence.

Written consent was discussed with all potential participants. The observed participants were informed that they would also be interviewed. It was necessary in this research that all observed participants were interviewed to complete the subjective picture of the data. The participants were informed of the interviews before the observations. In this study all observed participants agreed to be interviewed. The participants agreed to participate in the interviews at a certain time; therefore they had time to think before signing the consent form.

## **Section two: Data collection methods**

The study was guided by the ethnographic approach and data were collected by observations and interviews of participants in formal and informal ways. The observations and interviews were planned and organised with nurses on the medical wards in both hospitals. Additionally, the time for the

interviews was arranged between the researcher and participants after gaining their consent. In this research, the data collection tools were tested to confirm whether they are valid and yielded information relevant to the research inquiry. The observational criteria and the formal interview questions were test piloted to ensure their validity to answer the research question. The opinion of the supervisors were also sought to validate the content of the tools. Additionally, the validity of the observational tool and the interview questions were reviewed to attain ethnographic information. Then changes were made according to the evaluation. Next, the tools were test piloted after the changes had been added. The diagram below shows the full process of recruitment and data collection:



**Figure 1: The process of participant recruitment and data collection**

### **Observations**

The field notes were collected through non-participant observations. The researcher observed everyday activities of the participants to ensure a comprehensive picture was captured. Vandenberg and Hall (2011) stated that observation as a data collection method contributes in creating in-depth descriptions of the 'social site'. The observation tool was developed based on information provided from three main sources: nursing textbooks (Taylor et al., 2012), fundamentals of care framework (Kitson et al., 2013), and the researcher's experience in hospital settings (Appendix 12: Observation tool). The observation tool contains observation descriptions, care activities, observation protocol, and information sheets to patients, relatives and nurses. Before the commencement of the research observation, the researcher

practised the observation techniques with one of her supervisors and had discussions regarding the findings. Roberts (2009) indicated that one advantage of non-participant observation is that the researcher can follow a plan for the observation. It may also allow the researcher to describe the events naturally as they occur.

At the beginning, the researcher started a descriptive observation of the routines in each medical setting. This observation was unstructured; the aim of this observation was to get familiar with the people and understand the norms, values and environment of the field settings. Then the researcher commenced structured observation of the interactions that occurred between participants, following the observation guidelines. This process was important to gain valid answers to the inquiry. As the study progressed, the researcher scheduled a more focused observation of the culture of settings and practices of involving patients' relatives in the care of patients. The researcher planned to have a schedule of observations to capture the critical times when care is delivered to patients.

The first plan of the observations was for the researcher to conduct observations to a group of participants (patients, relatives, and nurses caring for them); the group consisted of two patients and they were observed over a total period of 48 hours. The researcher believed this timeframe would be sufficient to capture a comprehensive picture of the culture of the setting. The plan was to conduct six hours of observations on one family/ group over a 48 hour period. Two families/ groups were to be observed at the same time if they happened to be in the same room, followed by interviews and then the researcher would transfer to another group for more observation and interviews. However, this approach could not always be implemented in the Australian setting. One reason was that the researcher could not find two patients in the same room who fitted the inclusion criteria during the data collection period. Secondly, the researcher was not able to conduct six-hour observations of relatives in the field because relatives did not spend six hours in the field. The third reason was that observations could not be implemented for 48 hours because many patients left the unit the day after the first observation. Therefore another approach was implemented to suit the observations in the Australian setting.

In the Australian setting the observations focused on the visits where relatives were present. The researcher usually asked potential patients if they were expecting any visitors; when visitors came the observations then took place. If the visitors were already there when the researcher arrived then the observations started immediately. Sometimes potential patients were in different rooms. Usually the researcher focused on one patient, the relatives and the assigned nurse at a time, then moved to the



other group of participants if relatives were still present. In cases where the relatives had left, the researcher observed the care and interaction between the nurse and the patient without relatives. On many occasions the researcher was not able to anticipate the arrival of relatives, therefore spent long hours in the field to ensure she did not miss them when they arrived. The process of finding patients who met the inclusion criteria was slow, which was a contributing factor in impeding the progress of observations.

The observations in the Saudi setting followed the planned process, which was observing two groups of participants for six hours over a 48 hour period unless situations changed, such as patients being transferred to another room or discharged; then the researcher would change the plan to suit the progress of the observation. In this unit relatives were already accompanying patients so the process of collecting data progressed faster in this setting. The researcher did not necessarily target the visits in order to do the observations, such as in the Australian field, yet visits were part of the observations.

When the observations of the Australian setting started the researcher discovered that the observation tool that had been developed prior to the observations would not capture all events in the field. However, after doing a sample analysis of the data collected at the first observations, it was discovered that the researcher had not noted some of the required data to answer the research question. Therefore, the researcher wrote extra points that were needed to focus on during coming observations, such as nurses' attitudes, interaction and environmental aspects; the observation guidelines included all required information after these modifications (Appendix 13: Observation guidelines). In this study the observations were written in notebooks during the time of observation. After these were completed, the researcher typed them in Microsoft Word and saved them in an electronic file. Extra notes were kept aside as a reminder for the researcher to remark on the focus and progress of the observations. Additionally, the researcher also documented her feelings about the events occurred during the observation and would come back to these notes in the process of reflexivity. Thomson (2011) stated that field notes consist of local descriptions of events, interactions between groups and further plans. This indicates that field notes may be considered as a technique to structure data collection in a systematic manner.

The researcher usually sat in the bay where she could see and hear the participants. She ensured that the place where she sat would not interrupt workflow in the bay. The researcher engaged in informal discussions with participants to gain feedback, or clarify information; this usually happened after observations were conducted. The researcher did not want to ask many questions during the

observations because this could distract the participants or interfere with the nature of observations. Additionally, being in patients' rooms for long hours created a space for participants to ask the researcher personal questions; the researcher kept herself away from engaging in personal conversation to avoid any distraction from the purpose of the observations. There were times when relatives asked the researcher to help them in the care of their loved ones and some patients also asked for assistance and in these situations the researcher informed participants that she was a research student and could not help. There were two incidents where the researcher experienced role conflict for herself, being both a nurse and a researcher. For example, the researcher had to assist one patient in the Australian setting where she tried to leave the bed and was about to fall. The assigned nurse was not around to prevent the patient from being harmed, therefore the researcher helped at that critical point. Furthermore, the researcher also had to call the assigned nurse in the Saudi setting to assist one patient because the relative of the patient was changing the patient's soiled sheets with no idea what she was doing and the patient was in tears and pain. It is essential to state that prior to the commencement of observations a plan was discussed with the supervisors to deal with these types of situations.

### **Duration of the observation**

The time frame planned for the observations was three months in each field. This time period was considered sufficient for data completion. The researcher was able to confirm this time period after data analysis were finalised in each hospital. The researcher spent a total of seven months in the field, three months in the Saudi setting, and four months in the Australian setting. After data collection in the Australian setting the researcher travelled to Saudi Arabia for data collection. However the researcher then needed to return to the Australian setting to confirm some data revealed in the Saudi setting. Thus another month was required to clarify the data from the Australian setting from a comparative point of view. In both settings, the researcher spent a maximum of eight hours at the start of the observations, then spent an average of five hours, five days a week. For each day of observation the minimum hours spent in either field was three hours.

The time spent in the field was influenced by factors such as patient care activities, presence of relatives, and sometimes the convenience of the researcher. At the start of the observations the researcher wanted to spend some time in the field to become familiar with the hospital units and people and vice versa, and to validate data collection tools. Additionally, the researcher thought if she spent two hours every day conducting observations throughout the whole process, this would cause a delay

in the timeframe proposed for data collection which was three months in each field; therefore extending observation hours at the start was convenient. The duration of the observations was extended when relatives were assisting patients in day care or activities for daily living, during interactions between nurses and relatives, on hectic or busy days. In the Australian setting the visiting hours and the presence of relatives was the starting point of the observation; this is where the assistance and interactions between participants was expected to occur. However, the observations were not restricted to when relatives were present but were also conducted in between visiting hours because the researcher wanted to observe the interactions between patients and nurses in the absence of patients' relatives.

### **Types of observation**

The researcher followed Spradley (1980) method of observation; this method has three different stages and they are descriptive, focused and selective. The descriptive stage is when the researcher starts the fieldwork observations. Descriptive observation means recording as much information as possible; this is where the researcher does not focus on particular aspects of the observation. This stage of observation is important as at the beginning of the field work the researcher does not know what to focus on and the data collected at this stage directs future observations. According to Spradley at this stage the researcher should be 'approaching the activity in process without any particular orientation in mind, but only the general question, what is going on here?' (Spradley, 1980, p. 73). The second stage of observation is called 'focused' observation and this where the researcher focuses on certain events to answer specific questions. This stage is also applied as a part of data analysis. This type of observation also helped the researcher ask herself questions to guide the observation. The third stage is 'selective observation', and this is where the researcher asks questions to find similarities and differences. This stage helped the researcher to refine the results of the data and validate the final answers. Further explanations and examples of the observations will be provided in the data analysis section.

### **Interviews**

The patients, relatives and nurses were interviewed in formal and informal ways. The formal interviews were prepared in the English and Arabic languages. The planned timeframe to complete these interviews was 30 minutes and the location of the interviews was arranged between the researcher and each participant. In both settings the nurses were interviewed in the nursing meeting room, the patients and relatives were interviewed at the patients' bedside. For interviews with patients and relatives, the

assigned nurses were informed before the interviews and the interview time was decided upon the convenience of participants. These interviews fell at times when patient care was less expected and to avoid interruptions, privacy was maintained by closing curtains. The researcher always checked with participants to ensure they were not concerned about being overheard. The researcher always spoke quietly and sat close to the participant. None were concerned about the probability of being heard. In addition, the researcher negotiated additional interview time with participants if more time was needed to complete the interviews.

The researcher performed the formal interviews before patients were discharged from hospital. Relatives were asked to be interviewed if they were visiting patients and intended to stay for some time or assist in their care. If relatives were visiting for a short time and could not be interviewed the same day of their visit, they were asked if they could be interviewed at another time before the discharge of the patient. If they agreed, they were asked to provide written consent before the interviews. These interviews assisted in gaining an 'emic' perception of the phenomenon under study. The 'emic' perspective is the participants' perceptions of their lived experiences (Deitrick, et al. 2006). The interviews assisted in constructing more insight into participants' attitudes and interactions. The researcher organised formal interviews for patients, relatives and nurses. The items consisted of open-ended questions to allow participants to express their opinions (Appendix 14, 15, 16,17, 18, 19: Interviews questions). The main aim of the questions was to reveal information related to relatives' involvement in patient care; the questions also aimed to expose all sides of the inquiry. The patients and relatives' interview questions focused on assisting them to discuss their opinions about their involvement in patient care, experiences, needs, and interaction with nurses. The nurses' interviews aimed to answer questions related to their perceptions about relatives' involvement, interaction, and support in patient care. There were two parts to the questions; one was demographic and the second comprised of open-ended questions. The open-ended questions also targeted safety and communication-related issues. In this research the researcher used semi-structured interviews to allow her to ask questions related to a participants' involvement and to incorporate events and experiences which had occurred to participants.

The demographic based interview questions involved asking participants about topics such as social status, education, and background. Usually the researcher collected the socio-demographic characteristics of participants prior to interviews. The open-ended questions were used as an interview guide to allow the researcher to gather a variety of information and elaborate on the inquiry. All participants were asked the same questions, but the direction of the conversation changed depending

on the information provided at the time. Galletta, (2013) indicates that semi and unstructured interviews have unique flexibility, and are sufficiently structured to address several dimensions of research inquiry; it creates space for narrative information to unfold. The researcher used interview techniques adopted from Spradley (1979) and these techniques were used to confirm and verify data. A description of the techniques will be provided in the analysis section. In this research, nurses in both settings were interviewed after completing the observations; however, sometimes the interviews were delayed for a few days because nurses were unable to keep to the scheduled interview time. All scheduled interviews with participant patients and relatives took place at the designated time.

As data collection progressed, the researcher gained additional information that required further clarification. Therefore, there was a need to go backwards and forwards to the participants with questions for further exploration. This is where the informal conversations between participants and the researcher occurred. These helped the researcher to elaborate on events or reactions at a convenient time or a short time after they happened. The informality of these discussions made them easy to conduct because they did not contain any prearranged questions; they followed the flow of events. Fetterman (2010) stated that informal interviews are a form of conversation with embedded questions, where the researcher may have many questions to ask participants and wait for the most appropriate time to ask them during the conversation.

The participants in Saudi Arabia were asked to choose their language preference; in Australia the interviews were performed in English. The Arabic version of questions used in the interviews were revised by an Arabic speaking tutor who had a university degree in English, and her comments were taken into account. At the time of interviews in Saudi Arabia relatives and patients were interviewed in Arabic because the majority were Saudis. The nurses in Saudi Arabia were also asked if they preferred to be interviewed in English or Arabic. Many of the Saudi nurses preferred to be interviewed in Arabic, and other nationalities chose English for their interviews. The interviews were transcribed into written documents and given to the supervisors to discuss, and their comments regarding the translation were incorporated. The researcher reviewed the translations several times to ensure the translation reflected the actual meaning of words and to avoid misinterpretation.

### ***Written artefacts***

The researcher collected any written documents relating to the inclusion of relatives in patient care from the field settings. Written artefacts did not include patients' files, nursing notes or medical records.

Hospital policies were obtained because these could explain the rules about how nurses managed the involvement of relatives. Policies could also provide information sources to guide relatives and assist them in understanding hospital rules. The researcher requested all available reports or documents from the health team around the topic of this study. Document collection was aimed at constructing meaning out of the routines and rules in each field settings. The researcher also collected any written educational information which disclosed information about the involvement of relatives in patient care or was provided to relatives. The head nurse in the Saudi setting and the clinical coordinator in the Australian setting were asked to provide the researcher with all available policy documents concerning care provided by relatives. The artefacts also included any public documents available concerning this topic, for example, visitor information. This information was believed to identify whether relatives had been educated or instructed about their involvement or caring for patients.

### **Section three: Data analysis**

The transcribed texts were analysed throughout the data collection phase. During data analysis the researcher used facilitating software and this was MAXQDA. MAXQDA is software used to analyse qualitative data. This software helped the researcher to review the participants' interviews and notes and it helped in visualising, sorting and classifying data. In the analysis process the data generated were classified and represented as themes. The analysis followed many steps, which included 'finding terms, covering terms, domains and relationships' (Spradley; 1979,1980). All steps of the analysis were supervised and revised and the experts' comments were considered throughout the process. Furthermore, the researcher generated the codes from narrative texts, and then the supervisors reviewed texts, codes and themes.

This section will include the process of data integration and analysis that was followed in this study. The following segment presents the framework of data analysis for this study:

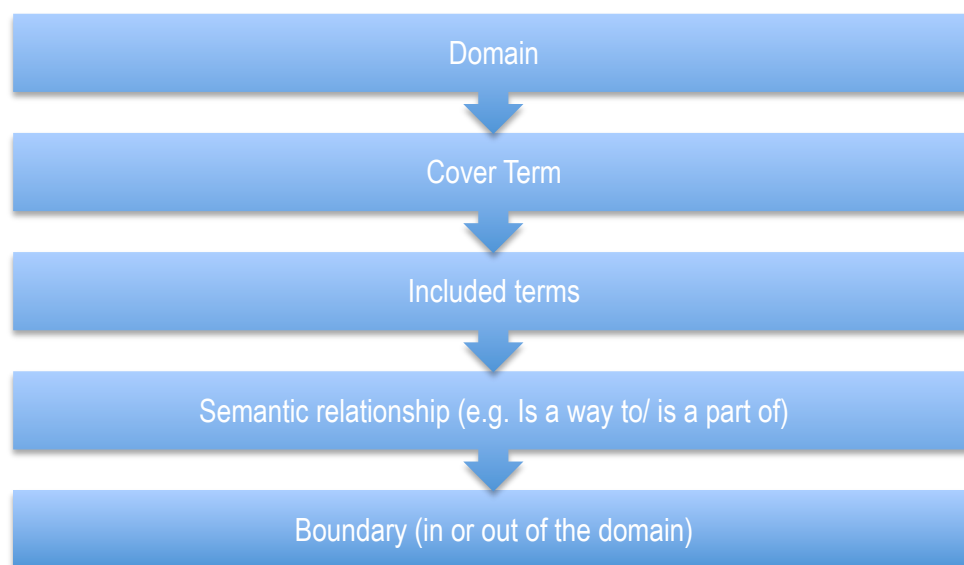
#### ***Data analysis framework***

Data analysis integrated qualitative data from field notes and formal and informal interviews. The overall structure of analysis was based on Spradley's criteria (1979, 1980). The researcher used this method because it was detailed and also presented concrete and structured steps. The analysis process also utilised Spradley's perspective on interviewing (1979) and observation (1980); the researcher merged both techniques to avoid repetition of information. Most social ethnographic research follows sequence data analysis, finding similar words, putting them into categories, and finding a link between these

categories. In Spradley (1979, 1980), the author used a four step data analysing style. The first step is called domain analysis; domain analysis consists of larger categories that mainly find similarities between selected terms or similar characteristics. Taxonomic analysis is the second step; this focuses on finding the internal category and identifying contrast sets. Componential analysis is the third step and it involves searching for attributes to find differences among samples, and lastly theme analysis involves the search for relationships between the categories and trying to find the links of targeted inquiry. More details are provided in the next section.

### **Stage 1: Domain analysis**

Domain analysis is performed to identify large categories that contain smaller categories of cultural meaning. The smaller categories are defined by a 'cover term' which is the name or title for the cultural domain. Included terms are then added to this category; these included terms are all names that are inside a domain. These terms usually have something in common such as being a form of person or behaviour. The semantic relationship is the link between the cover term and included terms. Examples of the meaning of the terms will be discussed further in this section. The diagram below shows the systematic process.



(Adopted from Spradley, 1979; Basic elements in a domain)

***Figure 2: The systematic process of domain analysis***

The following are steps in undertaking domain analysis:

Once the researcher discovered the term she was looking for, (these terms could be names, characters, behaviours, and objects) she followed the next steps. All steps are adopted from Spradley's method of domain analysis.

Step 1: Selecting a sample from the researcher's field notes or interviews to find domains

Step 2: Looking for names or characters in the selected sections of the researcher's field notes or interviews. The following example comes from field notes taken on the Australian setting, on 15 August 2013 at 10.30 AM; the terms are underlined and named.

The patient wanted to sit up to speak to her sister in law. The relative was looking for the bed's lifting button, and the patient told the relative, '*Maybe the handle is on the left side*'. The relative found the button and started to press it up and down till she finally adjusted it (**assisting/ learning**). The relative said, '*You have beautiful kids and a life out there, get well*' (**reminding/ encouraging, supporting**). The relative said '*You are a strong lady*' and '*You need to eat well*' (**encouraging, showing care**) and '*Do something, go for a walk*' (**instructing, educating**) '*...so you could go back to your normal life*' (**reminding**). The assigned nurse came to the bay holding a medication tray. The nurse administered meds (**giving medication**), she looked around, looked at the relative and said, '*Oh hi there, how are you and the kids?*' (**greeting, asking**) and checked on other patients. She told one patient, '*Drink plenty of water after taking the tablets*'. (**observing, checking patients' needs, prioritising, instructing, directing**) and she measured the patient's blood pressure (**monitoring vital signs**).



Step 3: Identifying cover terms and included terms from the sample

| Included terms   | Semantic relationships | Cover terms/ names  |
|--|------------------------|---|
| Encouraging<br>Instructing<br>Educating<br>Reminding<br>Supporting<br>Showing care<br>Assisting  | Was a part of          | The role relatives played when visiting the patient in hospital |
| Hi<br>How are you<br>Asked about the relative's kids   | Was a way of           | The nurse initiating communication                              |
| Asking the patient<br>Monitoring vital signs<br>Directing<br>Prioritising<br>Instructing<br>Giving medication<br>Checking on the patient | Is a part of           | The role demonstrated by the nurse                              |

**Table 1: Cover terms**

Step 4: Listing the domains identified in the first observation:

- A part of the role relatives undertook when visiting the patient in hospital
- Ways the nurses initiated communication
- A part of the role demonstrated by the nurse

Step 5: Repeating the steps above for all field notes and interviews.

### Step 6: Asking verification questions

These were questions asked to verify the domains, cover terms, included terms, and semantic relationships. The verifications at this stage were implemented to include or exclude terms. The researcher used this step at the time of the interviews to confirm the answers. For example, during a conversation with a relative, the researcher said, *'During our talk you told me different types of activities you do when you are around the patient. I would like to go over the ones you told me, just to quickly see if I have them correct. You said that you take the patient for a walk? You feed her? You assisted her in her showers?'* This is where the participants agree or disagree with the statement and this confirms if the term belongs in the domain. Another example of verification questions about included terms was, *'Is assisting the patient in her showers part of your role?'* These techniques helped verifying the domains and terms during data analysis.

### **Stage 2: Taxonomic analysis**

With taxonomical analysis the focus moves from finding the domain to the internal structure of the domain. This process focuses on finding relationships among the terms and their relationship to the whole domain. For example, the researcher found the parts that describe the role relatives play in patient care and found relationships between these parts. This process can be merged with domain analysis. As stated by Spradley (1979) an expert ethnographer can combine the process of finding the domains and searching for taxonomic figures in one process. However, because the researcher was a novice in the field of ethnography, it was sensible to treat these as two distinct processes. During taxonomic analysis, additional terms should be identified; these terms can be connected to the previously selected domain, or the researcher can identify new domains that need to be investigated. For taxonomic analysis the first step is to choose a domain that may represent or include most information. In this step, the researcher chose the following domain: *a part of the role relatives undertook when visiting the patient in hospital.* From analysing the observation there were some terms which emerged that could be a part of the role relative's undertook in visiting the patient in hospital. The researcher continued to look at her general and focused observations and interviews to find additional roles played by relatives in the hospital environment.

Step 1: Selecting one domain. This step helped to find additional terms, which related to the role relatives carried out in the hospital. In order to add additional terms it was necessary for the researcher to ask herself a structured question to determine whether the term should be included (Spradley, 1979, 1980). The question was, *what were the different parts of the role undertaken by relatives when they visited patients?* Some of the relatives' roles discovered are shown in the list below:

|   |  |
|---|--|
| <ul style="list-style-type: none"> <li>• Visiting</li> <li>• Supporting</li> <li>• Showing care</li> <li>• Helping understand</li> <li>• Offering help</li> <li>• Giving information</li> <li>• Asking questions</li> <li>• Interpreting</li> <li>• Translating</li> <li>• Speaking on the patient's behalf</li> <li>• Educating</li> <li>• Giving information</li> <li>• Directing patients</li> <li>• Giving patient history</li> <li>• Reminding</li> <li>• Observing</li> </ul> | <ul style="list-style-type: none"> <li>• Assisting in feeding/ drinking</li> <li>• Showering</li> <li>• Combing hair</li> <li>• Brushing teeth</li> <li>• Wiping mouth</li> <li>• Assisting in movement</li> <li>• Assisting in transferring the patient</li> <li>• Assisting the patient to walk</li> <li>• Changing patient's clothes</li> <li>• Massaging the patient's hands/ feet</li> <li>• Applying ointment</li> <li>• Assisting to exercise</li> <li>• Assisting in toileting</li> <li>• Maintaining privacy</li> </ul> |
|---|--|

***Table 2: Relatives' roles in the hospital setting***

Step 2: Looking for similarities based on relationship between the categories. The researcher combined roles that were similar in nature. Examples are shown in the list below (please note that terms may be considered under more than one category).

|  |  |  |
|--|--|--|
| <ul style="list-style-type: none"> <li>• Assisted in feeding/ drinking</li> <li>• Showering</li> <li>• Combing hair</li> <li>• Brushing teeth</li> <li>• Wiping mouth</li> <li>• Assisting in movement</li> <li>• Transferring the patient</li> <li>• Helping the patient to walk</li> <li>• Changing patient's clothes</li> <li>• Massaging patient's hands/ feet</li> <li>• Applying ointment</li> <li>• Assisting to exercise</li> <li>• Assisting in toileting</li> <li>• Maintaining privacy</li> </ul> | <ul style="list-style-type: none"> <li>• Visiting</li> <li>• Educating</li> <li>• Giving information</li> <li>• Directing patients</li> <li>• Giving patient history</li> <li>• Reminding</li> <li>• Helping understand</li> <li>• Interpreting</li> <li>• Translating</li> <li>• Speaking on the patient's behalf</li> <li>• Observing</li> <li>• Seeking medical attention for patient</li> <li>• Clarifying information for the patient</li> <li>• Repeating information provided by the health team</li> <li>• Calling doctor, nurses</li> </ul> | <ul style="list-style-type: none"> <li>• Visiting</li> <li>• Emotional support</li> <li>• Praying for the patient</li> <li>• Reading for the patient</li> <li>• Showing care</li> <li>• Showing love</li> <li>• Offering help</li> <li>• Protecting patient's privacy</li> <li>• Giving protection</li> <li>• Reminding</li> <li>• Checking needs</li> <li>• Kissing</li> <li>• Cuddling</li> <li>• Phone calls</li> </ul> |
|--|--|--|

**Table 3: Relatives' roles that were similar in nature**

Step 3: Searching for possible subsets among the included terms. This step allowed the researcher to identify whether the terms fit under the allocated headings. This step could be repeated whenever necessary to find new terms or categories.

For example:

The researcher devised headings for the three categories which were represented above in Table 3:

- The first category is physical involvement; relatives helping the patients physically to meet their daily/fundamental care needs.

- The second category is psychosocial involvement; relatives help sustain patients' psychological and social needs such as support, providing or transferring information.
- The third category are activities or what relatives do to lift the spirit of patients.

| <b>A part of the role relatives undertook when visiting patients in hospital</b> |  |   |
|--|--|---|
| <b>Physical involvement</b>  | <b>Psychosocial involvement</b>                                    | <b>Lifting the spirit and spiritual involvement</b>                         |
| <ul style="list-style-type: none"> <li>• Assisted in feeding, etc.</li> </ul>    | <ul style="list-style-type: none"> <li>• Visiting, etc.</li> </ul> | <ul style="list-style-type: none"> <li>• Emotional support, etc.</li> </ul> |

**Table 4: Relatives' roles in patient care**

Step 4: Searching for more inclusive domains that may include as subsets; this step could be followed by starting a larger search from field notes, interviews, observation, participants' feedback or researcher's self-reflection. The advantage of this step is to ensure that the researcher did not leave any undiscovered terms which could fit under the three headings, and also would help in creating new domains. In addition, the participants were asked descriptive questions to encourage them to speak about their roles in hospital when they were present with patients such as, 'Can you tell me what you do to help the patient during your presence?' This question encourages relatives to talk about other roles in patient care.

Step 5: Constructing classification from outlines, tables or diagrams. This step provided a clear picture of the semantic relationship between terms, such as the following:

1. A part of the role relatives undertook when visiting the patient in hospital

- Visiting to show care, support, check needs
- Showing care, to raise confidence and to be there for the patient
- Supporting, speaking on the patient's behalf.

All semantic relationship will be shown at the end of this process in relation to each of the cover terms. This step also includes focused observations to check the analysis. Taxonomic analysis leads to focus observations (Spradley, 1980).

Step 6: Formulating more structured questions to study the relationship between the subsets in a more comprehensive way to discover new terms. For example:

- What are the different roles relatives undertake in caring for the patient in hospital?
- Is feeding the patient a part of a relative's role? Is support/ mobilising patients part of their role? etc.
- What do relatives do to assist patients when they visit?
- Are there any other kinds of support or assistance provided to patients by their relatives?

Step 7: Constructing more structured interviews to confirm the taxonomic analysis; more questions could emerge from the interviews themselves. This step helped the researcher to perform *focused observations* to find any information that may help in identifying more terms, until no further information could come from the search.

Step 8: Developing a more complete taxonomic analysis. After the search for meaning was complete, there was a need to stop analysing the data. Componential analysis could continue where any new information was discovered.

Step 9: Asking contrast questions. The researcher considered this step as a verification step before moving onto the last analytical step. The last few steps helped to find similarities between the new discovered terms. When looking for similarities in the taxonomical analysis the similarities always suggest contrast (Spradley, 1980). The cultural symbols discovered could be different, and it was important to know how they differed from each other (Spradley, 1979, 1980). For example, in the Australian setting relatives might visit patients at visiting hours; however, some relatives came outside these times. The aim was to know factors which facilitated or hindered the involvement of relatives in the Australian setting. The contrast could be minimal but as Spradley (1979) indicated, the trivial contrast supports an interpretation of the culture.

Contrast questions were put in an analysis sheet. This process helped to verify the differences in meaning present in the data. Reviewing the interviews and the field notes also revealed some questions that needed to be answered to find new information. For example, '*How did relatives differ from each other and how did these differences influence what they did?*' This allowed the researcher to then devise new questions; the intention was to understand the differences between the relatives and the factors that may contribute to any variance.

When the researcher revised the different parts of the roles undertaken by relatives, and then asked herself a question such as, *'What are the differences between relatives?'* the other question she asked in order to verify the data analysis was, *'Did all the relatives assist patients in showering/walking /supporting etc.?'* It was apparent that not all relatives did this when they visited patients. Therefore the researcher asked the question *'What were the reasons some visitors showered patients or assisted patients in walking while others did not assist in showers or walking?'* The questions revealed the reasoning behind relatives either being or not being involved in patient care.

When the focus was on relatives' visits, then the question was *'Did all relatives come to the hospital to visit patients during visiting hours?'* For relatives who visited at other times, the next question was, *'Why didn't these relatives come to visit patients during visiting hours?'* Examples of contrast questions are below:

| Suggested areas to contrast              | Contrast question   | Answer | Notes  |
|--|---|--------|--|
| The time relatives' visited the hospital | <p>Did all relatives come to visit patients in the visiting hours?</p> <p>Why did some relatives come to visit patients outside the visiting hours?</p> <p>What are differences between the relatives who came at visits hours and those who did not?</p> | No     | <p>Some relatives came to visit at the visit times. Some also came outside visiting hours.</p> <p>Convenience; other responsibilities, family commitments; were working; were sick; lived far from the hospital; visited during their work break; traffic, availability of car parking; dislike of a busy environment, noises; patient being in a critical condition; patients being unable to speak English therefore needing help; patients' constant need for relative's support; came to bring clothes or bring food or to speak to health team; promised patients they would visit; patients were shy, stressed or lonely; came because patient was being discharged.</p> <p>Usually the visiting hours were convenient; had no work commitments or on leave from work; patients wanted to rest or sleep outside the visits; patients had no specific needs; patients were in a stable medical condition.</p> |

**Table 5: Example of contrast questions**



The differences discovered at this stage were called 'dimensions of contrast' and were an important step towards identifying aspects of cultural meaning.

The contrast questions step also includes asking questions to show the differences between categories; for example, were 'having work commitments', 'the dislike of noises' and 'the dislike of a busy environment' alike?

In answer to this question, the researcher was able to determine that a dislike of noises and the dislike of a busy environment are alike, being reasons related to the hospital environment, but not attending at visit times due to work commitments was unrelated to the hospital environment, and so on. During this process of verification the researcher chose two or three items and contrasted them.

After this stage it was necessary to construct more selective observations on the basis of a specific or single inquiry.

### Stage 3: Componential analysis

Componential analysis is 'systematic search for the attributes (components of meanings) associated with cultural symbols' (Spradley 1979, p. 174). This process helped to find the attributes that appeared regularly with the same symbol or domain. If the researcher could not find a semantic relationship during a taxonomic search, the process of componential analysis led to finding extra information. The process is described below.

Step 1: Choosing a contrast set for analysis.

In this step the researcher chose one domain. The example below is a partial taxonomy that shows characteristics particular to some relatives that impacted upon their involvement in patient care.

| Relationship     | Education         | Work      | Responsibilities | Gender | Nationality |
|------------------|-------------------|-----------|------------------|--------|-------------|
| Close relative   | Not educated      | No job    | With Family      | Male   | Asian       |
| Distant relative | Primary           | Housewife | Kids             | Female | Indian      |
| Friend           | School            | Teacher   | Pets             |        | Hispanic    |
|                  | Secondary         | Nurse     |                  |        | Italian     |
|                  | School            |           |                  |        |             |
|                  | University degree |           |                  |        |             |
|                  | TAFE diploma      |           |                  |        |             |

**Table 6: Characteristics of some relatives**

Step 2: Finding contrasts either from asking questions during interviews or by focusing on collecting contrasting data from field notes. Any statement from the contrast data could be used. The researcher pulled out a few statements, which showed some contrasting attributes which relatives had and how this impacted upon their involvement. For example:

- The young adults and middle aged relatives ‘*assisted patients physically*’ when they visited ‘*during care-giving time*’.
- Elderly relatives apologised to relatives for ‘*not being able to assist them*’; however they ‘*offered*’ to call the nurse.
- Young adults and middle aged relatives who visited patients ‘*with a high risk of falls*’ did not assist patients in toileting, walking and showering.
- Young adults and middle aged relatives stayed ‘*more than one hour*’ and assisted in physical care.

Step 3: After finding the contrasting information, it was then time to develop a worksheet; this work sheet helped the researcher to show the contrasting attributes. The dimension of contrasts discovered were used for all sets of relatives’ characteristics.

Step 4: The researcher identified the dimensions of contrast that had binary or two values. A dimension of contrast is ‘an idea or concept that has at least two parts’ (Spradley, 1979, p. 180). For example, ‘*Did all relatives visit patients during visits?*’ The answer was no, as sometimes relatives visited outside visit times, such as between visiting hours or after visiting hours. These were the dimensions of contrast. At this stage the researcher was using yes and no answers because she was still in the process of collecting data for every individual participant; an example is below:

| Dimensions of contrast |   |                          |                          |                                   |                        |                                |                                |                               |                                 |
|------------------------|---|--------------------------|--------------------------|-----------------------------------|------------------------|--------------------------------|--------------------------------|-------------------------------|---------------------------------|
| Contrast set           | Visited in between visits or after visits | Visited during care time | Visited critical patient | Visited relatively stable patient | Visited stable patient | Visited for less than one hour | Visited for more than one hour | Assisted patient when visited | Offered assistance when visited |
| The relative           | No  | Yes                      | No                       | Yes                               | No                     | Yes                            | No                             | Yes                           | Yes                             |

**Table 7: Dimensions of contrast in relation to relatives’ visits**

Step 5: Combining related dimensions of contrast to those with multiple values, dimensions of contrast here could be a person names, gender, education or age. Some contrasts were combined under one category together if they were closely related. Sometimes there was no space for all attributes so they were recorded in extended tables. The example below shows the characteristics of some relatives, retrieved from the field notes and interviews. They were numbered for easy registration inside the tables.

|                   |                     |
|-------------------|---------------------|
| Close relatives 1 | Distant relatives 2 |
| Friend 3          | Carer 4             |
| Other 5           | Male 6              |
| Female 7          |                     |
| Not educated 8    | Intermediate 10     |
| Primary 9         | TAFE 12             |
| Secondary 11      | Other 14            |
| University13      |                     |
| Australian15      | Asian16             |
| Indian17          | Hispanic18          |

Step 6: Preparing more contrast questions to elicit missing attributes, which helped the researcher to add more attributes to the worksheet, such as the kind of responsibilities relatives have outside the hospital, as these were seen as a highlighting relatives' readiness to stay and assist in patient care.

Step 7: Preparing a complete paradigm. This process was completed after analysing each contrast list. The researcher completed as many componential analyses for each domain as was possible to describe a detailed cultural scene and to understand previously hidden information. At this point selective observations were organised to fill in any missing information. However, Spradley (1980, p. 137) stated 'there is nothing wrong with blank spaces in the paradigm'. The researcher added into the table the word 'other' to represent missing content, which needs to be completed at a later stage of data analysis. The numbers inside the table below represents the relatives' characteristics which were outlined in Step 5.

| Contrast set | Dimensions of contrast |                                   |        |           |             |            |                  |               |                           |                    |                 |                    |
|--------------|------------------------|-----------------------------------|--------|-----------|-------------|------------|------------------|---------------|---------------------------|--------------------|-----------------|--------------------|
|              | Age                    | Type of relationship with patient | Gender | Education | Nationality | Occupation | Responsibilities | Time of visit | Type of patient condition | Type of assistance | Length of visit | Remarks            |
| The relative | 43                     | 3                                 | 7      | 13        | 15          | Other      | 28               | 30            | 34                        | 39                 | 40              | Occupation missing |

**Table 8: Dimensions of contrast as a complete paradigm**

Step 8: Presenting the complete paradigm, as shown in Table 8. It is essential to point out that the worksheet can be used to collect data for relatives who were both visitors and companions; however, the researcher highlighted the main role of relatives as either 'visitor' or 'companion' on the working sheet.

### ***Discovering cultural themes***

Following identification of cultural domains, it is important to identify cultural themes and integrate the data in order to understand the culture of the settings. Finally, the researcher takes a broad overview of the domains and their connections to each other to convey a sense of the whole culture. Spradley (1979, p. 186) defined the cultural theme as 'any cognitive principle, tacit or explicit, recurrent in a number of domains, and serving a relationship among subsystems of cultural meaning'. Spradley indicated (1980) that a cultural inventory to identify domains is not enough to understand the culture; instead ethnographers need to go beyond the inventory approach to cultural themes in order to investigate the connections between the explored domains and to get a holistic view of the culture. Additionally, themes emerge from general ideas or concepts that are common in the culture under study; for example, relatives assisted patients in their physical needs and this was common in both settings. The following steps were part of the process of finding cultural themes.

### ***Cognitive principle***

The cognitive principle is achieved through finding people's views about their own culture, and what they believe and accept as their reality (Spradley, 1980). It emerges from assertions made by people in different situations. For example, visitors stated many times that it was hard to speak to nurses in the visiting hours. When the assertion applies in many situations and is repeated across domains then it is

considered to be a cultural theme. Assertions can be examined throughout the process of finding domains. In addition, cultural themes do not need to be discovered across all domains. Some assertions can be discovered in one or two domains, meaning they can be either themes or subthemes connected to cultural knowledge.

### ***Tacit or explicit***

Cultural themes usually emerge from two kinds of knowledge, tacit or explicit. They can be gained from participants during discussions, but the researcher is not to treat the information as complete. This is because, discussions with participants may hold a key to understanding culture but this requires further investigation. For example, when a nurse stated that her interaction with patients' relatives should contribute to *'patient centred care'*, this information is known as 'explicit knowledge'. Explicit knowledge helps a researcher to understand some of the facts which emerge from interactions between nurses and relatives; however, this explicit knowledge is treated as incomplete because it holds some but not all facts about the interactions. Spradley (1980, p.143) stated 'most cultural themes remain at a tacit level of knowledge'. For example, when participants expressed their thoughts, their language was sometimes vague or held other, undisclosed meanings; therefore there was a need for more investigation. Information given by participants can also be tacit because often people are simply not aware of their behaviour or feelings.

### ***Themes as relationships***

Themes emerge when the relationship between the domains and the culture are discovered. Finding the relationship between terms and cover terms helps in the development of the search and analysis process. Spradley (1980, p. 144) explained this process as searching parts of a culture, then the relationship among the parts and the relationship of the parts to the whole. A strategy of finding the relationship between the domains and the culture is by immersing oneself in the field notes and transcribed texts, in an intensive way to reveal the relationships.

## **Section four: Data rigour**

This section includes the process followed to maintain the rigour of the study. The aim of qualitative research is to provide descriptions of information but not to generalise ideas across the groups; this way of evaluation is called external validity (Schensul, Schensul & LeCompte, 1999). Therefore, the researcher does not claim that findings of this study can be generalised to all situations or populations. From this perspective, only internal validity will be discussed since it reflects the study's approach.

Internal validity can be defined as the extent to which results represent reality. In general internal validity is concerned with the dependability of instruments and observation (Schensul & LeCompte, 2012). Internal validity or credibility in ethnographic research can be maintained through different techniques such as triangulation (Schensul, Schensul & LeCompte, 1999). Schensul, Schensul and LeCompte (1999) proposed that validity is a major strength of ethnographic research. However, there are threats to validity and reliability in ethnographic research such as prolonged observation and its impact on the nature of participants' behaviour, known as the '*Hawthorne effect*'. Many commentators do not see prolonged observation as threat to validity. For example, Lincoln and Guba (1985) suggested that credibility and validity in naturalistic enquiry such as ethnographic research could be addressed through extended observation and engagement in the field. The researcher believed that prolonged observation helped participants become accustomed to her presence so that over time she had less of an impact upon their behaviour.

The following section includes the process of maintaining internal validity and some issues addressed during data collection and analysis:

### ***Internal validity or credibility***

Denzin (1978) and Schensul, Schensul and LeCompte, (1999) state that internal validity in ethnographic research is derived from the nature of data collection and multiple data collection methods, the researcher's prolonged involvement in the field, and data analysis. In this study the validity of the results was maintained through aspects such as prolonged observation, interviews, reflexivity and triangulation.

### **Observation**

The time spent in the field allowed the researcher to observe participants in their natural setting and understand the language and behaviour patterns of participants. Extended periods of time spent in data collection and analysis helped the researcher to identify the relationship between scientific information and each participant's reality and views. The main issue associated with prolonged observation is that observed participants might change their behaviour (Lincoln & Guba, 1985). However, with the constant presence of the researcher in the field participants became less sensitive to the observation, and indeed, a few nurses in both settings commented that the researcher had become one of the staff.

In addition, the field notes taken during observations provided extensive descriptions of the nature of the culture and interactions within this culture. Common debates in reporting and writing about events in social contexts indicate that the accuracy of reporting can be jeopardised or biased and can be shaped by the researcher's views and use of words (Smith, 2014). The researcher was aware that such issue may happen; therefore, she recorded systematic and concrete descriptions of what was seen and heard in the field; typed the notes a short time after the field observation was finished to avoid missing details and feelings attached to the events; denoted verbatim remarks in transcribed texts; and had multiple and separated notes on topics such as main field notes, notes of self-reflection and participants' feedback.

### **The interviews**

Maintaining internal validity was achieved through a number of interview strategies; these included refining and confirming information, using unstructured interviews; and avoiding the use of questions, comments or actions which would lead a participant in a particular direction during the interview process. Usually the ethnographic information gained from participants should be treated as valid, although incomplete (Schensul & LeCompte, 2012). For example, the answers to interview questions could vary between participants, but this did not compromise the results. The variance of information is not an issue as it could be refined and clarified with the progress of the research. Refining information in this study was completed through verbal verbatim (using the exact words used by participants) and self-reflection. This process assisted the researcher to be focused and to ensure that the interview data was central to interview analysis. One great benefit of the interviews was that participants' answers could be presented as they were (verbatim), to provide evidence for the researcher's interpretations. In addition, the process of getting participants to confirm the information gained from them was a great source of validation, refuting the researcher's personal interpretation of their feelings.

An issue with formal and structured interviews in qualitative research is said to be the reactivity of the researcher during the interview, which can direct and limit the interviewee's answers (Goetz & LeCompte, 1984). However, reactivity was not an issue during the interviews because the researcher did not conduct interviews with structured questions, which could limit participants' answers. Furthermore, participants were not asked to verify perceived or held notions of other participants, which could limit the possibility of obtaining correct information. Interruptions during the interviews were avoided as much as possible, and the researcher made a nodding gesture to provide support and avoided verbalising supporting words, which could change the directions of participants' answers.

Restating what has been said by participants is a helpful technique to validate answers (Partington, 2001). The researcher followed this technique to avoid misinterpreting what had been said and to confirm that the researcher understood the participant's words correctly.

## **Reflexivity**

Reflexivity is a method used in ethnography to establish the validity of the topic under study; this is when researchers refer to their own ideas to interpret events and interactions that occur in social sites during data collection (Cruz & Higginbottom, 2013). The researcher should incorporate reflexivity into their data analysis through personal, interpersonal, emotional, pragmatic, epistemological, ontological and social accounts (Mauthner & Doucet, 2003), the aim being to bridge gaps in the information.

The researcher also used reflexivity to decide whether to continue collecting data and when to stop, based on the progress of data analysis. Additionally, reflexivity contributed to developing more questions and deciding on the structure of potential observation. It assisted the researcher to stay introspective during the process of data analysis. This process requires critical intuition and documentation as the researcher makes judgments about how the data is interpreted, conveyed and presented. Different techniques helped to provide the researcher with a reflexive account of this study. Techniques included the researcher documenting her decisions, feelings and preconceived ideas about participants and the study's two settings. The researcher also documented participants' feedback, their feelings and their clarification of the interview data; this helped the researcher to understand the culture.

When the researcher conducted data analysis she went beyond the words to attempt to understand the cultural significance of the fields. It is important to mention that the paradigm of the study shaped the reflexive process. The cognitive principle used throughout data analysis enhanced the researcher's reflexivity as it helped her to distinguish the relationship between themes and codes and to exclude of irrelevant information. For example, the cognitive principle in data analysis is what people accept as their real and valid world (Spradley, 1980); the reflexive role is to find universal experiences or general assertions to help in the interpretation process. Denzin (1994) criticizes the process of reflexivity, as he believes that the researcher's thoughts integrate with the social world and may not actually represent the given culture. However, the validity of a researcher's interpretations can be validated through demonstrating how they were reached (Boulton & Hammersley, 1996). To avoid



misinterpretation of information the researcher recorded field notes and her thoughts separately and the interpretations were confirmed by the field observation and the feedback of participants.

## **Triangulation**

Triangulation involves using multiple data sources for verification of results and to address the research question from different perspectives. There are four types of triangulation: method, theory, investigator, and data triangulation (Denzin, 1989). In this research three types of triangulation were used, excluding theory triangulation. Firstly, investigator triangulation refers to using two or more researchers to collect, code, and make decisions in relation to data analysis. In this study the supervisors assisted the researcher in the coding and analytical process and in making decisions in terms of confirming true and irrelevant information. The researcher performed visual presentations using a whiteboard for the supervisors to confirm the terms, cover terms, domains, themes and subthemes and also the relationships between the resulting categories. There were meetings held with the supervisors to specifically interpret the data and evaluate the outcomes. The feedback of the supervisors was incorporated in the data and thematic analysis.

Secondly, in qualitative studies triangulation usually includes a variety of methods such as interviews, observation, collecting documents and recording participant's words verbatim. The aim of triangulating the methods is to overcome the biased single method studies (Polit & Beck, 2008). Method triangulation provides tests to ensure the consistency and coherency of an emerging picture. In this study the researcher used a variety of data sources because each method can contribute to understanding different aspects of research questions. By using different methods such as formal and informal interviews and observation, the researcher discovered a variety of knowledge in relation to verbal and nonverbal behaviour. The design of the observation assisted in grasping and documenting interactions between participants in the field. It also helped the researcher to make decisions about further investigations through focused or selective observations or seeking confirmation and feedback from participants. The researcher also recorded the participant's words verbatim, either in the field or from the transcribed interviews. This method included counting instances of phrases or particular words (Rugg & Petre, 2006). This method provides traceability from the initial stages of the project, where raw information is collected, throughout the analysis phase, to the point where the study's final findings are presented, adding to its trustworthiness. Method triangulation also helps to develop themes and draw relationships with other themes to better understand the phenomenon under investigation. This method

is believed to provide an objective stance captured from different people's perspectives (Guba & Lincoln, 1989).

Finally, the researcher used data triangulation, which involves three main types of data: time, space and person (Polit & Beck, 2008). Time triangulation is when data are collected in different periods of time in the day to confirm data. Usually this method is used to test the reliability of data and whether the phenomenon under investigation, changes at different times of the day or with different circumstances. For example, time triangulation in this study showed that relatives held different roles looking after patients and usually relatives who visited patients during the morning assisted in care more than relatives who visited outside these times. Space triangulation was done in this study by comparing the inquiry in two different settings to test consistency of information or differences. Person triangulation was performed by seeking different viewpoints from patients, their relatives and nurses in both fields, with the aim to test the validity of perspectives.

## **Summary**

This chapter consisted of four main sections. Section one provided a detailed discussion of the research settings, which involved participants' sample size, age, inclusion and exclusion criteria, recruitment procedure, how the researcher gained access to the fields, and ethical considerations. Section two described the three data collection methods: observation, interviews and collection of artefacts. Section three, presented a comprehensive explanation of data analysis techniques and integration based on Spradley's data analysis methods (1979, 1980); the final section provided descriptions and justifications of the processes used to ensure the rigour of this study.

## **Chapter five**

## **Chapter 5: Findings**

### **Introduction**

This part of the findings presents the study's '*social site*'; the Australian setting will be discussed first, followed by the Saudi Arabian setting. It was necessary to present a rich and detailed description of the scene to assist the reader in understanding the nature of both settings. The researcher adopted Spradley's (1976) method of writing ethnography to present the findings of this study. The headings used here to describe the findings such as events, place, actors, activities are adapted from Spradley's method of describing ethnographic settings. This chapter includes two main sections; section one is called the '*cultural scene*' and describes the social scene of both the Australian and the Saudi settings. It begins with the events, giving one example from the observations that took place in each setting. Then it moves on to the place, which aims to provide a detailed report of the site. Subsequently, a detailed explanation of actors' daily activities in the wards is described. Section two is titled '*cultural domains*' and comprises chapter 6 of this thesis. It describes the meaning and form in which relatives were involved in patient care in each setting; this section also discusses how this involvement was enacted and how it impacted on patient care.

### **The cultural scene**

Before discussing the cultural scene it is necessary to provide a description of participant numbers and the number of hours the researcher spent in each field.

#### ***The total number of participants and hours the researcher spent in each medical field***

### **The observation and the interviews**

In this research study, 22 patients, 22 relatives and 11 nurses were observed and interviewed in the Australian setting. In the Saudi setting 48 patients, 52 relatives and 18 nurses were observed and interviewed.

### **Duration of the observation**

In the Australian setting a total of 250.30 hours of observation were undertaken, from 15 August 2013 until 20 December 2013 and then from 28 October until 27 November 2014. In the last month spent in the Australian setting, the hours completed in the field were not included in the total count because the

researcher only spent one to two hours per observation in the setting and this was only to confirm data not to generate new data. In the Saudi setting 295 hours of observation were undertaken, from 4 February until 4 May 2014.

### **The Australian setting**

The following description of an observation was generated from field notes and took place in the medical ward in the Australian setting; it showed a form of relative participation in the care of patients at the unit. The concept of starting the finding with an event from the scene was to provide the reader with an idea of the routines and practices performed in the social site. The involvement of relatives in patient care took a different shape in each case because of the characteristics of nurses and participants, a patient's condition and the time and duration of the visit. The participation or contribution relatives made to patient care in this unit took no consistent form.

### ***The events***

This observation was conducted in the Australian setting on Tuesday 8 August 2013 from 10.30AM to 2.00PM.

In the room there were four patients. All patients were female. The room has a quiet atmosphere, white coloured walls, bright lights and the curtains were closed around two beds. The patients' bed areas had a few machines attached to them for heart and vital sign monitoring. In this bay, there were three patients sitting on chairs next to their beds. There was an elderly patient using her walker to move around in the bay and also a few visitors visiting a patient in the same bay. The patient to be observed was a 73 years old lady, who had been in hospital for twelve days. She suffered from chronic heart disease and hypertension. The patient had been admitted to another ward in the hospital and had been transferred to this unit five days previously. This patient had an intravenous line in her left arm, was wearing a white gown and was sitting on a chair next to her bed when first approached in the morning. The patient looked frail and pale, however, she was easy to speak with and said at the beginning of the observation, '*Ask me if you need to know anything*'. From a few minutes observation the patient seemed to need assistance to get some things from the bedside cupboard but she couldn't move from the chair without assistance. Additionally, this patient mentioned she could eat and drink by herself but she needed assistance from the nurse to have a shower, walk, go to the toilet, and for grooming.

The patient's relative was a middle-aged man; he introduced himself as the patient's son. The relative said he was a tradesman and had the day off and had come to see his mother. The son sat on the edge of the bed; he kept looking on his phone constantly. The patient said, *'My son comes to visit me whenever convenient'*. Then the son said, *'I stay beside my mum as long as she wishes and if I don't have work I would be here 24 hours.'* (He smiled.) The son said, *'I have a partner and a dog and my job is a bit far from where I live...so I come to visit when I can'*. The son's phone rang so he walked out of the bay and answered the phone call. The nurse came into the room at around 11.30 AM and she asked another patient, *'Do you need to go to the toilet?'* The son came into the room and asked the nurse if she knew about his mother condition; the nurse shook her head and said, *'Sorry I'm not assigned to look after this patient'*, then continued, *'the nurse caring for your mother is Sara'* (this is a pseudonym). The son seemed to be searching for the nurse caring for his mother, and after this he found her in the nursing station. Apparently the son asked the nurse about his mother's condition through a glass window and he was pointing at his mother and the nurse was talking and smiling throughout their discussion.

At around 12.00 PM, the son was helping his mother to drink a cup of water; he was standing beside the bed and holding the cup in his hand. The nurse was in the nursing station writing in a file and she was looking at the patients through the glass window. During this time, the son was discussing his personal life with his mother and she gave him some advice. The patient seemed to have difficulty hearing because she asked her son to repeat what he had just said to her a few times. The son asked his mother if she wanted to eat an apple which was on a plate on her bedside table. The patient said, *'Yes but cut the apple into small pieces for me'*, so he did. Then he gave his mother the pieces of fruit until she told him she had had enough, and the son asked the patient if she wanted some water. She agreed so he gave her a cup of water and assisted her in holding the cup. The son asked his mother, *'So what are they giving you for dinner... Did you sleep well last night?'* The son said, *'You have to get well mum...we need you...'* The patient was reassuring her son that she has been feeling better recently. The son asked his mother if she was comfortable sitting on the chair and she replied that she has to sit there until lunchtime. The son brought a blanket that was placed on the side of patient's bed and spread it over his mother's legs and feet. The son then told his mother that he could not visit her the next day because he would be home late but he was going to visit her the day after. He said, *'I will give you a call if I cannot make it'*. Close to 12.20 PM the nurse came and greeted the son and asked the patient if she was feeling good. After this, the son asked his mother if they have changed anything in her medication or care plan. The patient said, *'Nothing changed. It is the same'*. (Field notes, P.9, 10, 11.)

### ***The place (Australian setting)***

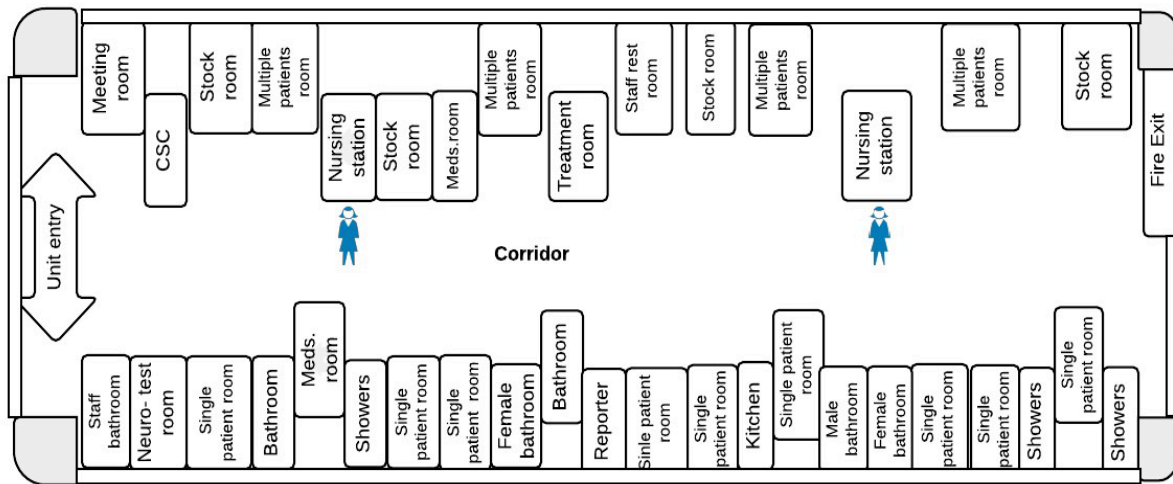
This section aims to provide a description of the social site and to present a comprehensive picture of the Australian setting. This study was conducted in a medical setting in a large metropolitan hospital which was located in the city centre. This hospital provides tertiary health care services, rehabilitation and referral services. The hospital was divided into blocks and buildings and many of the buildings were longstanding and heritage listed, some being more than 170 years old. The selected medical ward is considered to be an acute medical unit. The medical unit received patients with complex and undiagnosed conditions and also patients referred from other hospitals or within departments. The patients were referred to the medical units based on their diagnosis. Furthermore, some medical units receive patients with medical conditions that require constant monitoring and assistance while other units receive patients in need of lower levels of support. Additionally, relatives' visiting hours were different from one medical unit to another. This was based on the type of patient conditions and the needs of patients and visitors. The observed medical unit allowed longer visiting hours for patients who the nursing team thought were in need for constant family support.

The entrance of the hospital gate was located on a main street. When heading towards the hospital there was a bus stop. On the left side of hospital's main entrance there was a café, with an emergency gate on the right. There were two sliding doors to enter the hospital. In the space between these sliding doors stood an ATM on the right and a cafe door on the left. When entering through the second sliding door the first view was of the hospital's main hall. In the middle and to the sides of this hall there were waiting seats. An escalator was situated in the centre of the hall, and beside the escalator there were two screens showing the floor map of the third floor. To the right of the escalator there was a preventative care centre, patient admission area, bank, and a passage that took people to lifts and the outpatient department. To the left side of the escalator there was a newsagents, hairdressing salon, information centre, wellness centre and a walkway where people could exit the hospital. Beside the information centre was a table with different brochures and flyers, and above this table a television hung on the wall. There were seats on either side of the escalator. Behind the escalator there was an area for educational purposes, which had large informative health posters and also seats and a television. A few steps away from the educational area there was the main corridor, which took people inside the hospital. On the way through the main corridor there was an acute medical unit (AMU) on the left; on the right there were radiology, orthopaedic and spinal outpatient departments.

The medical unit was located on the seventh story; the people reached there by stairs or elevators. After exiting the elevators or the stairs there was a sign, which dangled from the ceiling and also another sign on the wall, of the number and direction to the units; there were two other medical units on the same level. The medical unit's access door was made of glass and the inner side of the unit was visible when someone was heading to the unit. There was a power switch key beside the gate from the outside, and when pressed, the unit's gate opened. There was a poster sticker on the unit's entrance, which stated, *Do not forget to close the door behind you*. The shift coordinator had mentioned, '*Some confused patients may walk out of the unit if the electric door was [left] open*'. Therefore, if someone walked into the unit, they needed to watch the door behind them until it closed completely. Inside the unit was a key panel, which was located beside the entrance gate, and the person who needed to leave the unit had to enter a code, and after entering the code of four numbers the electric gate opened. The gate's code was placed beside the key panel on small stickers.

This unit had 27 beds and most days all were occupied. The unit had light blue and shiny coloured floors, white walls and white ceiling. The unit smelled like cleaning detergent but when the researcher took a tour around the unit some areas smelt of food and also isopropyl alcohol. The unit was brightly lit and the temperature in the unit was cool, as it was wintertime. The walls or almost 75% of the unit were covered with boards for educational posters, stickers, nursing information posters, and guideline posters. Beside the main unit access gate, there was an area with small shelves holding educational flyers, information papers, and pamphlets. There were a few fire extinguishers placed within arranged distances between each other, and also disinfectant gel placed at the unit entrance and in each patient's inlet. Lights were placed in the ceiling, which showed the patient's room and bed number; there appeared to be call bells to notify the nurses when patients needed assistance. These call bell lights kept flashing until the nurse turned the call bell off from patient's bedside. Below is a picture of the Australian unit floor plan, which assists the reader to view the field.





***Figure 3: The floor plan of the Australian setting***

On the right side of the unit, for people who were coming from outside the unit, there were single patient rooms, and bathrooms and toilets for male and female patients beside each single room. The majority of patients in the single rooms had visitors most of the day. There were trolleys and monitor machines placed in spaces beside each single room. The nurses placed these trolleys and machines beside the single rooms because there was more space between these rooms than between the multiple patient rooms, as stated by some nurses. A few nurses stated they placed these trolleys beside the single rooms to make them visible to all nurses when they needed them. The shift coordinator indicated that some patients needed the machines more than others and they placed them close to certain patients' rooms. On the left side of the unit's hallway there were rooms that had five or six patients in each bay. Every patient had their own bedside lockers, bedside computer used as clinical device, and there was a hand basin located in each room. On the left side from the main unit gate was a small hallway, which led to a room labelled 'meeting room'. This room had a large white rectangle table and a number of chairs, a blackboard and a projector light in the ceiling. This meeting room was used for nursing handovers, meetings or lectures.

After leaving the meeting room hallway, on the left side there was a unit coordinator's office. On the door there was a sticker with the coordinator's name on it; the office was closed when the researcher first arrived and had been for several weeks. There were two nurses' stations in the unit; one placed beside the first room, which was a few steps away from the main entry to the unit, and the other station located before the end of the unit's hallway. The nurses in each station seemed to look after certain patients beside each station; both stations had glass windows. Through this glass window the nurses could observe the patients when they were sitting in the nursing area. In each nursing station there

were tables, chairs, computers, folders and shelves with files on them. There were nurses and doctors in each station and also other healthcare workers. The nurses spent their time in the nursing station when they were not working with patients; they also did their documentation in the base. This place could be busy at times and nurses might ask other health team members to provide them with space if they had no urgent duties.

There was one neurology examination room in the unit, located to the right of the first single bedroom from the main gate. The door was locked, and beside this examination room there was a box of gloves in different sizes and an X-ray light. The patients in the single rooms appeared to gain closer attention from the nursing team, as assistant nurses placed their chairs and a table beside each room door. They informed other nurses in the ward when they had to leave this place for a few minutes. In this unit, beside each room there was disinfectant gel in dispensers, and instructions on how to use the gel. Additionally, there were boxes of gloves of different sizes, boxes of protective blue gowns, and instructions on the visitation times for the visitors.

The people who came to the unit could see posters placed on the door of each room telling them that visitors were allowed to visit from 10.00AM to 1.00PM and from 3.00PM to 8.30PM. In between the day visiting hours, from 1.00PM till 3.00PM, patients were expected to have their own quiet time. There was a big board hanging on the wall beside the nursing station. This board had chart tables and these tables included a room number, bed number, patients' surnames and the name of the nurse assigned to look after the patient. The researcher observed the shift coordinator erasing nurses' names from the board and the names of patients after admissions or discharges. On the left side of the first nursing station was a room for taking samples; it had a toilet seat, bed basins, empty bottles, plastic cups, glove boxes, and a thermo oven. In the centre of the unit, there was a tearoom for the nurses, with two couches, one large table and a few chairs, television, and lockers for the nurses. Each locker had the nurse's name and some nurses had attached pictures to them. There were pigeonholes for each nurse with their names on them, where nurses received their mail or work-related information. There was also a big board on the wall; it had information about new courses, patient care or announcements. The health teams who visited the unit used this tearoom for eating, drinking or resting.

Near the nurses' tearoom there was another room, which was used for unit's waste. It had three different coloured bins; one was green for medical waste, yellow for glass and aluminium waste and a small yellow bin for sharp waste. Furthermore, nurses used this waste room as a stock room because it had lockers and shelves with new medical items. In front of the stock room there was a large trolley with

clean sheets, pillowcases and blankets, and beside the sheet trolley there was another trolley with multiple drawers, an intravenous pole, cardio pulmonary resuscitation board, ambo bag and stethoscopes. This trolley was used as emergency cart but there was no label on it. The shift coordinator was observed checking this trolley and recording what was available or missing in a form. After this, almost to the end of the unit's hallway, there was a room with a blue door. It had a key panel similar to the ones on the safe box, and this storeroom was used for medications or for medical tools. The nurses used this room a few times a day especially before they administered medication to patients; only nurses had the password for this room.

The environment of the unit was very quiet most days; it was unusual if anyone heard loud voices, unless these were sounds of patients who were confused or in pain. The unit could be very busy especially from 1.00PM to 3.00PM. This was one of the busiest times in the day, especially when doctors came to the unit to examine their patients. It was also the time when the afternoon shift nurses arrived to take over responsibilities from morning shift workers. Additionally, few visitors came around to visit patients around 12.30PM and remained for hours. Sometimes during visiting hours the unit's hallways were congested with patients and their relatives, and patients' rooms were very quiet. Some days in the unit seemed to be busier than others, perhaps because of the constant change in the types of condition suffered by patients, number of patients, and number of nurses.

### ***The actors***

The focus of this research was on patients, their relatives and nurses therefore they were the main actors of this study. The actors in the medical unit who dealt with patients and their relatives were many, from nurses, doctors, social workers, occupational therapists, clerks, nursing students, and graduates. The unit had registered nurses and enrolled nurses and they worked directly with patients and their relatives. Registered nurses wore white shirts with blue stripes and navy blue pants or skirts and they had hospital identification cards. The enrolled nurses wore a similar uniform to the registered nurses; however, the stripes in their shirts were light green. The assistant nurses dressed in light blue shirts or T-shirts; the nursing students and graduates wore white shirts with their University logos on them.

The doctors wore casual clothes and they had their own stethoscopes, and a few held files or bags. They spoke with the responsible nurse before they saw patients. The doctors looked confident, came to the unit for short times and a few doctors gave nurses orders. They walked into the unit in groups; a

few of them were medical students and graduates. The doctors also came to the unit at different times of the day, and asked the nurses to accompany them to the patients' bed. The cleaners wore dark blue uniforms and they mopped the floors a few times a day. They looked happy and they smiled at people who passed by them and they kept telling people to watch the floor where they had just mopped, because the floor was wet. The clerk dressed in casual clothes and was placed in an office located beside the nursing station, and she spent her time on the computer or compiling documentation. The social workers, occupational therapists and physiotherapist assisted patients and sometimes their relatives when they visited the medical unit.

### **Actors group one: Patients**

The reasons patients had been admitted to the unit varied; there were patients suffering from mild medical conditions to patients awaiting surgery or recovering from surgery. The unit had older aged patients; it had agitated, confused patients, patients with dementia, and a few patients were dependent on others for their fundamental care needs. There were two rooms for patients with infections such as methicillin resistant *staphylococcus aureus* (MRSA); they were separated from other patients in the unit. However, the unit had some days and weeks without any MRSA patients. The patients accommodated in single rooms, either had an infection, were agitated or needed special care or monitoring from nurses. The patients in the multiple bays had mainly stable conditions; a few patients needed little assistance or complete assistance in their basic needs. The majority of patients in the unit were elderly; furthermore, the number of female patients appeared to be more than males most days. It was obvious that the nursing team managed to place the same gender in rooms together; however, sometime it was difficult, especially there were more female admissions than males. The nursing team placed the patients in areas based on the complexity of diagnosis and care; however, sometimes this could be unmanageable because the situation could be unpredictable because of the diversity of patients referred or admitted to the unit.

The patients in the unit were mostly relaxed. A few patients wore hospital gowns, but the majority preferred to wear their own clothes. Some patients had a longer stay than others in the unit. Patients who spent three days or beyond in the unit looked more relaxed compared to others. The relationship with ward nurses was friendly and it mainly revolved around the care. Most of the time, the conversation and interaction between patients and unit nurses occurred before or during nursing care. The characteristics of patients in terms of age and type of illness influenced the depth and range of interactions between patients, their relatives and the nursing team. Additionally, patients' level of

dependency on others to look after them also varied. Some patients depended on nurses completely to attain their daily needs, and some relied on nurses partially, as they could feed themselves but could not take showers unaccompanied. A few patients preferred particular assistance from their relatives, for instance, feeding or body massage. Patients from specific ethnic groups such as Indian and Italian expressed the need for assistance from their relatives more than others. Additionally, some patients desired to have assistance from nurses in their daily needs even when their relatives were around them. These were generally patients at risk of falls; with bone fractures or the potential for them; who were heavy; recovering from surgery; or who required constant monitoring from nurses.

### **Actors group two: Relatives**

Relatives came to visit patients at the permitted times or between the permitted visiting hours, based on patient needs. The unit allowed relatives to spend longer hours with patients whenever necessary. The majority of relatives were close family members or relatives and a few friends. Close family members were husband, partner, mother, daughter, son, sister, and in laws. Moreover, the type of relationship seemed to be deeper with close relatives and this impacted on the type of assistance or help offered to patients. For most days of this study, there were more female visitors than male visitors in the unit; also female visitors contributed more in terms of assisting patients physically, than males, such as assisting patients to eat and drink. It appeared also that elderly visitors stayed longer than young or middle-aged visitors. However, middle-aged visitors contributed to physical care more than the elderly. The majority of elderly visitors came to visit in the morning because they were non-working family members.

The ethnicity and the age of the patient influenced the frequency and duration of the visits. Relatives of those Australians with ethnic origins from Italy, Spain or India visited regularly and for longer hours, and in large numbers and assisted patients' physical needs. Relatives from these ethnic groups explained that assisting patients was a social norm and tradition. It suggests that family bonds are expressed differently in different cultures; it also showed that the meaning of hospital visits differed from one relative to another. In this unit, some patients had many visitors, some had few, and some had none during the visiting hours.

Visitors might spend a few minutes to a few hours with patients, but when they visited patients for a few hours, they provided them with more physical care. The relatives who came to visit patients in the unit undertook similar tasks such as assisting patients with physical and emotional needs. A few relatives appeared to have an idea of what they could do to assist patients during their visit; they looked self-

confident when providing assistance. Furthermore, relatives did not help patients with regular tasks when they were visiting. Instead, the majority of them offered help to patients in general and constantly asked patients if they needed to eat, drink, walk, or go to the toilet. Relatives also offered patients different kinds of assistance such as looking after their belongings.

Some relatives who came for the first time appeared to be puzzled, always looking for someone, trying to speak to nurses or waiting for the right moment to ask nurses questions. The relatives who spent some time in the area looked more relaxed than relatives who were visiting for the first time. The first time relatives visited they tended to ask others questions to familiarise themselves with the place and also introduced themselves as new visitors. A new visitor may start a conversation with a comment on what another visitor was talking about with the patient, for example they may comment on the weather. Relatives who visited patients with stable conditions looked more relaxed than those who visited patients with acute conditions. The relatives reacted in a similar manner when they first arrived in the unit; they greeted the nurses in the nursing station on their way to patients' rooms, asked the patients how they felt and sat beside them, then before they left the unit they spoke to the assigned nurses about the patient's condition. Additionally, relatives who came to the hospital several times were of great help to those relatives or visitors who came to the hospital for the first time.

The relative who intended to spend some time with the patient sat on a chair placed beside each bed or on the bedside if the patient was using the chair. Because there was only one chair beside each patient's bed. Additionally, a few relatives came in to intentionally feed patients, spend time with them, provide them with support or bring them clean clothes. Some relatives stated they had prearranged plans for their visits, mainly to spend quality time with their loved one, such as taking the patient for a walk, reading a book, or doing the crossword. Some relatives spent a few minutes only with patients because of the distance of the hospital from their workplace or homes, car parking fees, family commitments or other responsibilities.

Generally, relatives showed their compassion and concern for other patients in the room. They would ask other relatives or patients about their condition, length of stay and discharge time. A few relatives who came for repeated visits wanted an update on the welfare of other patients and their relatives in the same room or even in other rooms. Additionally, there were a small number of relatives who supported other patients and their relatives, providing them with uplifting words and encouragement. Relatives and patients usually communicated very well with others in the same room. Relatives would usually discuss common topics with patients, such as occupational therapy, ongoing treatment, or

nursing care. Some relatives were listeners; they agreed with other relatives' advice and recommendations, while other relatives acted more as advisors because they had previous experience in the matters discussed. A few relatives showed a lack of interest in having conversations with other relatives. They pulled the curtains around the patient's bed every time they came for a visit; they preferred peace and quiet when they visited their patient.

### **Actors group three: Nurses**

The morning shift started from 7.00AM to 3.30PM, the afternoon shift from 1.00PM to 9.30PM, and the night shift from 9.00PM to 7.30AM. On the morning shift there were nine nurses who were either registered or enrolled nurses. This number was usual for the morning shift; however, this could change for any reason. On the afternoon shift there were seven nurses and four nurses on the night shift. The afternoon shift nurses started their shift at 1.00PM; this gave them two hours and thirty minutes working alongside the morning shift team. The nurses in this unit were allocated four patients and the allocation was done by the nurse-in-charge (shift coordinator). In this unit, there were more female nurses than males. There was only one male registered nurse who was seen repeatedly during the shifts, and a few male nurses came to cover shifts from other units. Both registered and enrolled nurses took full responsibility for patient care, but the registered nurses directed the enrolled nurses in the unit. Usually the assistant nurses would look after patients that needed to be constantly observed. In every shift there was one nurse assigned to the shift coordinator's role. The shift coordinator was a senior registered nurse with more experience in the unit. During the morning shift, nurses had more time-consuming activities to perform such as changing bed sheets, showering patients, preparing a number of patients for procedures and taking samples (blood, urine) before or after surgery. Additionally, there were common nursing responsibilities such as writing nursing notes, administering medication, care plan implementation, and also following up admission and discharge responsibilities.

All nurses in the ward had identification badges (IDs) and they placed them on different parts of their shirts or lower outfit. The nurses' names on the IDs were sometimes unclear, because they were printed in small letters and some hung them opposite to the viewing side. However, it was necessary for IDs to be placed where everyone could see them, so that the health teams' positions and roles could be identified. To the people who worked on the unit, identifying each other from the IDs was easy; they knew how to distinguish workers from visitors for security reasons. Some health personnel wore badges to show their position; their position titles were typed in large, red letters; for example the clinical nurse consultant. In the unit, the shift coordinator placed a white sticker marked 'shift coordinator' on her

shoulder. The nurses who held the role of shift coordinator were the same in every shift except if they had days off, and then another nurse was selected for this role. Replacement shift coordinators were the next in the queue in terms of nursing experience from the main shift coordinator, and this nurse was known to the nursing team.

The shift coordinator (during the observation there were only women in this role) was responsible for the nursing team and was allocated specific responsibilities in the unit. She was also responsible for allocating nurses to patients. The shift coordinator was a role model for the nursing team; she acted as leader and gave orders and the nurses usually referred back to her for decision-making or where errors or any difficulties had occurred. The shift coordinator also had the role of looking after unit nurses and making sure the nurses were able to do their work efficiently. Additionally, she ensured that patients' care needs were addressed. The shift coordinator went around the unit to ensure a safe environment for the nursing team, health workers, patients, and visitors. Moreover, she provided constant feedback to the nurses and supported them if necessary. She was also responsible for communicating with doctors, nurses, patients and their families. Furthermore, she gave nurses assistance in revising care plans and treatment for patients. Nurses in the unit would discuss matters with the shift coordinator such as shift allocation or challenges with other team members.

Registered nurses were assigned to look after patients and their needs; they also monitored patients' care, such as patients' diet, activity, recovery, progress and treatment; they were also responsible for making decisions about patients' care plans. Therefore, registered nurses are at the front line of care delivery. Registered nurses demonstrated the ability to manage different caregiving duties. Registered nurses also maintained accurate records, observing and documenting any progress or changes to a patient's condition. Additionally, they communicated directly with doctors and informed them of any changes to a patient's condition and responded to doctors' orders.

Registered nurses were also responsible for supervising less skilled nurses, nursing students, and graduate nurses. Additionally, it was the responsibility of registered nurses to prepare rooms for patients, ensure supplies were stocked and that instruments and machines were in shape and well maintained. Registered nurses also referred patients and their relatives to health resources and community agencies and gave them guidance in these matters. Furthermore, they discussed the safety of patients during their shifts and ensured that essential infection control techniques were implemented in the unit.



## ***Activities undertaken by nurses and relatives***

The next description shows the actions or activities presented by the two main actors in the unit, the nurses and patients' relatives.

### **Nursing activities**

Nurses operated as a team and looked after patients' needs. They had duties and activities that were fixed and repeated every day, and other activities that changed according to patients' conditions.

Nurses started their duty with a hand over; firstly they were assigned to patients. Assigning nurses to patients was not random, as some nurses had more experience than others in dealing with particular patient conditions. In the unit, the nursing team assisted each other to look after patients; some nurses were able to assist nursing colleagues even if they were not assigned to look after particular patients. However, other nurses were not willing to assist team members in patient care if they were asked, because they were not assigned to look after those patients. When a nurse needed assistance from other nursing team members, this nurse could easily identify those nurses who were willing to help. Cooperation between nurses occurred repeatedly during certain shifts, or in between specific nursing groups. The level of cooperation between the nursing team had a huge impact on how smoothly care was delivered to patients. With less cooperation, patient care could be time consuming; a few nurses took a long time to deliver care and this caused delay in their other care responsibilities.

More nursing staff were employed on the morning shift compared to the other shifts because more surgical procedures or investigations took place in the morning. Morning care took many hours of a nurse's scheduled time for morning duties and included activities such as showering patients, changing clothes, changing bed sheets, taking blood, urine, sputum samples or swabs and preparing patients for surgical procedures and investigations. Generally, the morning shift nurses were the ones who complained about work overload and time constraints around their duties. Furthermore, these nurses also undertook routine procedures such as taking blood glucose levels for diabetic patients, and applying wound dressings for others.

Adding to the nursing workload was that fact that the majority of patients in the unit were frail and elderly; they often needed help in their daily needs. The enrolled nurses assisted patients with early showers and clothes changing, as well as taking certain patients for walks and undertaking other duties allocated to them. After morning care, nurses started monitoring patients' vital signs, documented their

assessment or observations, and checked whether patients needed assistance to have breakfast. Some patients had to be mobilised daily but this was based on their condition; for example if they had limited ability to move they would be assisted to sit on a chair and if they were able to move around with assistance then they would be helped for a walk when they were ready. Additionally, some patients needed to be fed by nurses, and a few patients needed limited assistance such as being given cutlery or having the food tray brought closer to them. The nursing team had to ensure all patients had their meals before the medications were administered.

A few patients needed close attention and continuous monitoring from the nurses; they were observed physically for any abnormal deviations or behavioural changes, respiratory or heart monitoring. For patients following surgery, there was close observation and care involved. The nurse who cared for patients after medical procedures was allocated few other responsibilities because monitoring patients was time consuming. Additionally, the nurses who looked after acute patients had to be close to them and whenever they wanted to leave for a break or other duties they made arrangements with other nurses to look after these patients. Nurses spent time documenting patients' records; for example by monitoring vital signs, observations, medication administration, and intake and output records. Nurses also took other notes continuously, from care plans, treatment plans, nursing care and procedures. These records made the process of care easy for nurses and enabled other health team members from different shifts to follow and improve patient care plans. Patients received their lunch around 12.30PM, and following this the nurses were expected to be in the patients' rooms to administer medication. The majority of the nursing team used to take lunch breaks around 12.30PM as well. Then, the afternoon shift nurses arrived around 1.00PM, had their tea break, and after this they received the handover from the morning staff.

The nursing team had to know which patients were supposed to be visited by other health team members and needed to prepare patients for these consultations. Some patients had appointments with physiotherapists, occupational therapists, and social workers at different times in the day, most commonly during the morning shift. Sometimes health personnel planned to visit patients while family members were also visiting. The reason for this was to be certain that the education and care given to patients continued after discharge. The afternoon shift was quieter than the day shift in terms of nursing workload; the nursing team over this duty period had fewer responsibilities compared to the morning shift.

Nursing duties during the afternoon shift varied from monitoring patients, documentation, assisting patients in their daily needs such as, feeding and drinking, toileting or walking, medication, and urgent or scheduled care. Dinner was served around 5.00PM, and some relatives helped patients to reach their food or fed them. Nurses on this shift assisted patients to change their clothes in readiness for bed; they also checked whether they needed to go to the toilet and checked their intake and output charts. This nursing team also seemed more relaxed compared to the morning shift workers. However, communication between the nursing team and patients and their families was at the same level on both the morning and the afternoon shifts. The unit had more visitors in the afternoon on some days from 2.00PM to 7.30PM; however, the unit had visitors in the morning every day. Additionally, during visits hours the majority of nurses remained in the nursing station, some using the time to finish their documentation while taking a sneak peek from their spot to make sure the patients still had family company.

The night shift started at the end of visiting hours, and during this shift the nurses left patients to have quiet time and sleep. The nursing team on this shift frequently monitored and observed patients. They were also ready for any emergency event or urgent care. After making sure that patients were prepared for sleep, nurses usually turned the lights off in patients' rooms. For patients who wanted to continue reading, a nurse would turn on a patient's personal light near the bed. However, all patients were encouraged to get to sleep early. The nurses acted like guards, monitoring the unit continuously and observing the patients without disturbing them. Sometimes nurses had to turn the light on in a patient's room, when her or she needed assistance. They had numerous responsibilities such as filling water jugs, putting the call bell in reach of patients and assisting patients to the toilet before bedtime. The nursing team did not expect any patients to come to the nursing station to ask them for assistance; they expected patients to use the calling bell instead. Nurses would be concerned if they saw a patient walking in the hallway at night seeking assistance; they constantly informed patients to ring the bell when they needed help. Nurses also documented their duties and patients' observations throughout the night, especially for patients who needed constant monitoring. After the end of the night shift, nurses were usually ready to hand over their patients to the morning shift nurses at around 7.10AM, sometimes a bit earlier or later. During the handover, the nursing team discussed patients' conditions; care plan, progress, changes, doctors' instructions and patients' medication.

Generally, the nursing team focused on a few major tasks, delivering care to patients including continuous monitoring; implementing safety and preventive measures such as infection control and pressure ulcer care; also receiving and giving information. Nurses combined all their tasks such as

assessment, intervention and preventative care, and this was shown in each of their roles; for example, they applied safety measures during nursing care such as using lifting techniques. In terms of communication, the nurses provided information to and received information from other nurses and health team members, communication with patients and their relatives only happened when nurses were asked questions, during visits, bedside handover, before or during care.

### **Relatives' activities**

The activities undertaken by relatives were predominantly positive; they mainly provided emotional support for their loved ones. For instance, family members spent time listening to patients and discussed different matters with them and patients expressed that this assisted in their recovery. However, relatives also provided a lot of physical assistance to patients during their visits; this assistance differed from one relative to another and the frequency also varied. Physical assistance involved helping patients to meet their physical needs such as feeding, drinking, going to the toilet, and mobility. Relatives who visited more frequently also participated much more in the physical care of the patient. Furthermore, the time of the visit had a significant impact on the extent to which a relative helped. For example, relatives who visited patients at mealtimes were more likely to assist the patient in feeding. Also, assistance varied from one relative to another based on a patient's condition and a patient's level of dependency on others for help. Some relatives only handed patients what they needed from the cupboard, a few helped patients to sit up in bed or covered them with blankets. A few relatives took patients for walks to the main front gate of the hospital to enjoy the sun or have a cup of coffee from the hospital café. Additionally, a few brought food from home for patients and took their clothes to the laundry. All relatives who were present during nursing care asked nurses if they needed any assistance.

Relatives described what they might do to assist patients as '*simple things*' or '*simple care*'; this explained the extent of their assistance to patients. Relatives expressed different thoughts about the assistance that could be provided to patients. For instance, some relatives could not assist the patient to move from the bed to the chair without the nurse while others thought doing this was fine. Relatives who spent longer periods of time visiting patients constantly asked patients if they needed any help, and their assistance increased progressively. This may have happened because the patient had needs, and the first person they communicated with and who knew about their needs was the visitor. This made relatives' participation in care more likely, as some patient needs seemed possible to achieve without a nurse's help; for example, giving the patient a cup of water, assisting the patient to sit up in

bed, assisting the patient to reach something from the bedside table or even taking the patient for a walk.

Relatives asked patients regularly about the care received from nurses, and asked patients what had happened during the doctor's visits. The majority of relatives showed their appreciation to the nursing team and thanked the assigned nurse for providing help to the patient. The relatives also encouraged patients to eat, drink, walk, follow the health team's instructions, and take medication. There were relatives who repeated nurses' and doctors' instructions to patients to be certain that patients understood the instructions. Additionally, a few relatives also performed body and breathing exercises together with the patient during the physiotherapy sessions to show their encouragement. Moreover, some relatives discussed treatment and discharge plans with patients' doctors and nurses. Few relatives discussed the patients' post discharge rehabilitation and care plans with occupational therapists. Mostly, when a doctor came for a patient's check-up and the family of this patient was present, the family spoke directly with the doctor and asked questions for the patient. Relatives also represented patients, as they sometimes explained a patient's needs and wishes to the nurse, doctor or health team members.

Commonly, relatives asked nurses' permission or advice before they helped patients, for instance before taking a patient for a walk, helping a patient to the bathroom, or giving a patient water or food at any time or after a surgical or medical procedure. However, a few relatives helped patients without gaining the permission of a nurse, specially those relatives who had helped a patient repeatedly, or in cases where they had no personal fear about assisting a patient, such as where patients were at risk of falls. It was not surprising to watch relatives assisting patients, especially at meal times or after meals where relatives organised patients for rest time. There were a few patients who insisted on having their shower and clothes changed by their relatives, who would arrive in the morning to assist with care. However, these relatives usually deferred to the nurses or discussed health care matters before giving any help. Some relatives came to visit their patients once a day to assist them to eat or to go for a walk, and a few came twice a day, in the morning and the afternoon.

A small number of relatives came to the unit to visit patients before they went into surgery or to have minor surgical procedures that required fasting. Usually, surgical patients' relatives were present in the room when or after patients arrived back from the operation room. Some relatives sat on a chair near the vacant bed and waited for the patient to come back from the surgical or medical procedure. This showed how much the relatives cared for patients, and the majority of these relatives assisted patients

to drink or eat after the procedure, and they also listened to patients' complaints and reassured them. It was common to see those relatives calling the nurse for patient assistance.

Communication was an essential activity undertaken by relatives; they tried to communicate effectively during any healthcare routine involving the health team in order to facilitate patient care. The majority of relatives had a formal relationship with nurses and would only interact with them around matters concerning patient information. Sometimes relatives asked other visitors in the room questions, probably to get quicker answers, such as where to find blankets. Most commonly, relatives initiated conversations with the health team and nurses in particular, to find information and gain an update on the patient's condition or to explain the patient's desires. It was also common to see patients' relatives standing at the door of the nursing station, or looking for a particular nurse to seek information or gain an update about their loved one. Additionally, some relatives expressed the desire to have more contact with the nursing team, during daily discussions with each other. Relatives also wanted to speak with the doctor or wanted to know what the doctor's instructions were. Relatives constantly discussed their concerns with doctors and also asked nurses for an update on the doctor's examination or visit. Most commonly, interactions between relatives and nurses would be about the doctor's visit and instructions.

Some relatives felt confident to assist patients because they had previous experience as patients themselves, or had spent considerable time visiting family members in the hospital. A few relatives felt they could contribute to patient care because they had gained information in previous years, from having been ill themselves or having had other family members in hospital; as such, they had clearer views on their responsibilities as family members. Elderly visitors commonly thought they could provide only emotional support and they came to the hospital only to chat with patients; they always expressed their inability to assist the patient because of their old age. For example, an elderly visitor came to visit her sister, and after a few minutes the patient asked this visitor for help to the toilet, so the visitor called the nurse to assist the patient. The visitor looked embarrassed and told everyone in the room she could not help because she had back pain and was a frail lady. It was common to hear elderly visitors apologise to patients for their inability to provide help, but they always offered to call the nurse for help instead.

Finally, relatives who had some health knowledge were less likely to help patients because they feared interfering in the health team's work. They also expressed an understanding that the aim of their visits was to provide emotional support only. For relatives who came to visit from a far place, they were

unlikely to stay with patients for longer periods of time and were unlikely to become involved in patients' physical care. Relatives who parked their cars in the hospital car park would also be in rush because of high car park fees.

## **The Saudi setting**

This part of the findings focused on the second social site of this study, which was the Saudi Arabian setting.

### ***The events***

This observation was conducted in the Saudi Arabian female medical ward on Tuesday 10 February 2014 from 8.00AM to 4.00PM.

At the beginning of the observation it was hard for me to see clearly what was happening because the curtains were kept around patients most of the time; it seemed that patients kept the curtains around them for privacy. Sarah (pseudonym), the patient's companion told me, *'I couldn't keep the curtains open because I didn't want anyone to see us without a hair scarf.'* I asked both the patient and the relative, *'You mean [you want to stop] the nurses [from seeing you]?' The patient, Aisha (pseudonym) said: 'No not the nurses. I'm worried that men may come into the room.'* I asked *'Is it possible?'* She said, *'I don't know, maybe. I'm cautious, but I feel better like this.'* At about 8:15AM two nurses from morning shift came into the room to make the beds. One of the nurses asked Sarah, *'Do you need new sheets for your sister?'* Aisha said, *'No it's clean we don't need new sheets.'* The nurse said, *'Okay... then we have to change them tomorrow.'* Aisha said, *'Thank you sister'* (sister is the nurse). The nurses changed the bed sheets for the second patient in the same room and one nurse asked the cleaner to take the dirty sheets to the dirty utility room. The nurses then left the room.

At about 8:30AM the graduate nurse came to the room. Sarah was looking at the graduate nurse. She said, *'Would you please tell us if the blood pressure is good?'* Sarah asked the graduate nurse, *'Do you need any help?'* Then Sarah asked a second time, *'Can you tell me the reading of the blood pressure?'* Sarah asked the graduate nurse, *'Is it normal?'* The graduate nurse said, *'Yes it is normal.'* After some time, Sarah told Aisha, *'I will sleep until the doctor's visit [at] around 10.00AM, and after this I should help you to have a shower.'* Aisha said, *'All right then.'* At about 9.30AM, the nurse came into the room and told everyone that the doctors had arrived. *'Aisha and Sarah, the doctor is here.'* The other relatives in same room pulled the curtains around their relative patients. The nurse pulled the curtains

open. Sarah sat up on the bed and fixed her hair cover and face cover. Aisha covered her body with a blanket and fixed her hair cover. Then the nurse said, *'Are you both ready?'* Sarah said *'Yes we are ready'*. A male doctor, with a group of male medical students, came inside the room after the nurse told them the patient was ready. Sarah told the doctor, *'Doctor, Aisha cannot move her leg and she was in pain last night'*. The doctor asked Aisha; *'How much out of 10 is your pain? Give me a number'*. Aisha said: *'I think 7'*. Then Sarah asked the doctor; *'What about this thrombus in her leg? Is it going to go soon?'*

I had a discussion with Aisha about the routines in the medical unit. Aisha mentioned how depressed she felt in the hospital because she was away from her newly born child. Aisha said, *'I don't speak a lot with the nurses unless I want to know anything about my condition, and they don't speak to me very often except when they help me with something'*. Aisha said, *'There is one nurse on the night shift'. 'She is very good'. 'She speaks to me and she asks me frequently if I am in pain, and when she measures my blood pressure, she tells me the reading'*. At about 11.30AM, Sarah helped Aisha to the wheel chair. She wanted to help Aisha to have a shower, and Sarah got clean undergarments from the closet and a clean hospital gown. At about 11.55AM, Sarah came out from the bathroom to look outside before she helped Aisha from the bathroom to the bed. Sarah closed the room door and pushed the wheel chair to Aisha's bed. She helped Aisha to get back into bed and covered her with a blanket. Sarah went back to close the room door and she closed the bathroom door as well. Sarah removed Aisha's hair scarf and she combed her hair and tied her hair at the back and returned the hair scarf again. Sarah said, *'I will go to take a shower now...'*

At around 12:30PM lunch was distributed to the patients and the kitchen personnel gave Aisha and Sarah their lunch trays. I asked Sarah, *Do you get all the meals in here?* She said yes, then continued, *'When I first came into the hospital the nurse filled out paperwork for me as a companion'*. *'One of the things I can get in here are the meals'*. Sarah removed the cover placed on Aisha's lunch tray and she pushed the bed table close to Aisha and she gave her the spoon and put a straw in the juice. Sarah said to Aisha, *'You should finish your lunch because you didn't eat very well at breakfast time'*. At about 12:45 PM the nurse came and gave Aisha tablets and told her to drink lots of water after the tablets. The nurse asked Sarah to make sure that Aisha took the tablets straight away after lunch. Aisha took the tablets a few minutes later. Aisha asked Sarah to help her to the toilet, and she said to Sarah, *'I need to brush my teeth and I need to use the toilet'*. Sarah assisted Aisha to the toilet and went inside the toilet with her. Aisha and Sarah told me they needed a nap after lunch before the start of visiting hours. (Field notes, P.2, 3, 4).



## Overview

The field notes outlined the social site for the second part of this study which was a medical unit in the Saudi Arabian setting; these notes also presented an example of relatives participating in patient care. The culture of the social site in Saudi Arabia was unlike the Australian setting, the reason being that relatives in the Saudi setting spent longer hours with the patients. Relatives joined the patient in the hospital stay; relatives sign paperwork in order to be admitted into the hospital with the patient. Relatives in Saudi Arabia are expected to stay in the same room until patients are discharged from hospital. Sometimes other relatives exchange places with the family member who initially cares for the patient; the new family member takes over the role during the remainder of the patient's stay in hospital. Relatives played different roles and took on different responsibilities in this setting, similar to the Australian setting. There was no specific form in which relatives participated in patient care.

The next section provides more detail about the social site:

### ***The place (Saudi Arabian setting)***

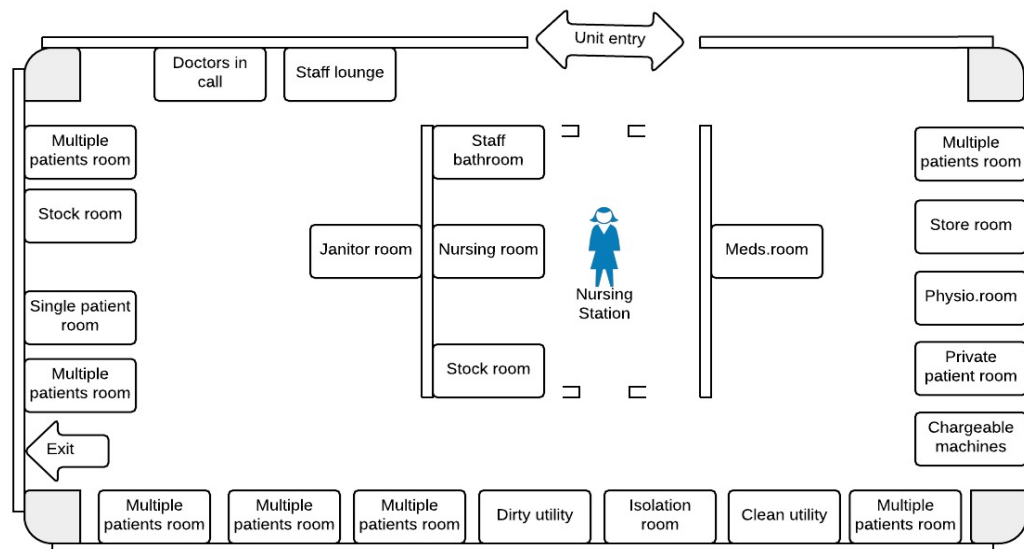
The Saudi hospital was located in a large metropolitan area. This hospital was less than ten years old and had 300 beds; thirty beds were allocated for female patients in the medical ward where this study took place. The hospital provided tertiary health care services, rehabilitation and referral services. The hospital was classified as a public governmental hospital, meaning it provided services for Saudi patients for free; however, non-Saudi patients pay for the hospital's services. This hospital had two medical wards; these wards were divided by gender. Segregation by gender is adopted for religious and cultural reasons. The researcher was permitted to perform the study in the female medical ward. The medical ward was an acute medical unit; the cases admitted to this ward could be described as mixed cases, from mild to complex and included undiagnosed conditions. This hospital received emergency patients who had arrived directly via the emergency room, from primary health centres or by referral from other hospitals in the area. The acute medical conditions that could not be treated in this hospital were referred to another large hospital that was 35 kilometres away.

The main entrance of the hospital opened onto a large car park. There were administration offices on the right side of the entrance, and on the left side there was an information desk. Inside the entrance there were stairs and an elevator to the medical unit. At the top of the elevators in each floor there was a guard. When someone used the elevators they could head directly upstairs but after emerging from

the elevators visitors had to pass through security. There was a male guard who sat on a chair beside the door to the stairs. No one could use them before they were checked. Security was placed on the main gates and departments to prevent any people other than workers from entering the buildings. The first security guard beside the stairs asked the researcher to show her ID and to state the ward on which she was working and the purpose of entering the building. After a few visits to the hospital, the security guard permitted the researcher to enter the building showing her ID only.

People without invitations from health team members (unless these people were hospital workers) were not permitted to enter the units. These people were asked to come at the visiting hours if they were visitors and to provide letters if they came to the hospital without invitation. On the researcher's first visit, security guards asked about the purpose of her visit and showed the researcher the location of the female medical unit. It was located on the right hand side of the stairs and the elevators. The walls had signs which hung on the ceiling indicating the location of the units. The gate to the female medical ward was made of opaque glass, and after entering the gate there was a guard. The female guard asked the researcher a few questions; her identity, the reason for her visit, the length of the visit, she was also asked to show her identification card. After going through security, there were a few offices to the right and left side of the corridor for the doctors, and these offices were divided by gender as well.

On the way to the female ward, there was a large sign which indicated that the female medical ward was on the left side of the gate and a female surgical ward on the right. Posters were placed on the walls here to show the importance of visiting patients, and posters presenting some of prophet Mohammed's sayings about the blessing the person may get from visiting patients. There was a framed picture showing the fire assembly areas and the location of exits during any emergency. The nursing station was the first place which could be seen from the entrance to the medical ward. Nurses would be able to see anyone coming to the ward easily from the station. On the left side of the entrance was room number ten, another two rooms located on the left beside room number ten, one for doctors on call, the nursing lounge and room number one. The ward had light blue coloured walls with dark blue handrails on the sides of the walls and the floor was shiny light blue. The majority of rooms had multiple patient beds; the rooms could be managed as single rooms when needed, and there were two rooms for conditions that needed isolation. Below is a plan representing the layout of the Saudi setting, which assists the reader to view the unit.



**Figure 4: The floor plan of the Saudi Arabian setting**

The nursing station was in the centre of the unit and was surrounded by rooms; the location of the nurses' station made it easy for nurses to observe all patients' rooms. In the nursing station there were four computers. The doctors spent some time using these computers during their visits, and also the registered nurses used them frequently to document new orders or notes. Posters were scattered on the walls of the nursing station and were about infection control and the hospital's new policies. The majority of posters placed on the walls of the ward were religious. Additionally, there was one board, which stated patients' bed and room numbers, and the nurses assigned to each patient. On the wall there was a schedule for the current month, showing the names of nurses assigned to different shifts and their vacations. In the middle of the station were shelves for patient files and documents. The nurses did not allow anyone other than nurses and doctors to use their desks for documentation; they asked health team workers to leave the station if it became crowded. On the left side of the station was the nurses' meeting room. It was small with a few chairs and one large desk. There was a large shelf for forms used for care purposes. Near the nurses' meeting room there was a room used for storing care instruments and medication. It was locked and the key was kept with the head nurse and there was another set of keys kept in the unit. The nursing handovers took place at the front of the nursing station every shift.

From the front side of the nursing station was the female surgical ward which also has a nursing station which could be seen clearly from there. There were ten rooms in the medical unit and each room had five beds, except two rooms which had one bed for isolation cases, and one private room for patients

who wanted to pay for their care. On the left side of the unit, there were patient rooms which had five beds in each room. Every room has its own bathroom. Both patients and their relatives used this bathroom, and the hand basin was located next to the bathroom door. There was one locker with multiple shelves placed near each patient's beds. This locker was used for a patient's clothes and relative's clothes and bedding. On top of the door to the room were the call bell lights. These lights flashed if a patient needed help in the room. The walls inside the rooms were covered with light blue paint, the curtains were made of washable blue fabric and the floors were a shiny light blue. Inside the rooms, there were TVs suspended from the ceiling and they could be turned to different angles of the room.

This unit had two isolation rooms and these rooms were mainly used for respiratory infectious diseases. These rooms were set up with negative pressure for infection control reasons. The researcher observed relatives sitting with patients in these rooms. However, the head nurse said they did not encourage relatives to stay in the rooms where patients had infectious diseases but also that they could not prevent them. The nurses placed posters with precautions in the isolation rooms, which described what people needed to do before and after visiting the patient. Visits to these rooms were permitted under strict instructions; the nurses encouraged visitors to use hand gel sensitiser before and after their visits and also to wear gown and face masks. The hand gel sensitiser was placed in each room and in the hallway, and beside each dispenser they placed posters to describe the correct method of sensitising hands. It was easy to identify the isolation rooms because of the posters on the door and also boxes of gloves and gowns located beside the rooms.

Room number one was located on the left side of the unit; this room was specifically for acute medical patients, or those patients who needed constant monitoring from nurses. Relatives were allowed to stay with patients with acute conditions; these patients were unconscious and relied on machines for their survival. The nursing team stated they had a capacity for four acute patients and the rest were referred to another hospital. The room for patients with acute conditions was equipped with machines and medical instruments and the beeping of the machines could be heard from the hallway. The door to this room was always closed. The head nurse explained this was because relatives were staying with their loved ones inside the room and they wanted to remove their Abaya (black traditional dress) for their own comfort. In the acute room and beside each bed the nurses placed gloves and gowns for each patient. The crash cart, which was a trolley equipped and used for emergencies was placed in the storeroom and the head nurse had the responsibility to check the trolley and make sure it was prepared and ready for use.

The storeroom was beside the acute patients' room; the nurses' store of instruments, machines, wheel chairs, and walkers was located in this room. In front of the storeroom, the dressing room had one bed and dressing trolley and the nurses performed wound dressing in this room. The physiotherapy room was located beside the storeroom and the physiotherapist used this room to assist patients to do physical exercises; this room also had physiotherapy equipment and one bed and two chairs. In front of the physiotherapy room was the medication room. This room was opened and then locked again before medication was administered, and it had a medication trolley, fridge, and a few lockers. On the corner of the medication room, the clean utility room was used to store clean sheets, pillows and blankets and the dirty utility room was used for dirty sheets; these two rooms were locked and the nurses had the keys. On the right side of the unit there was a room for the unit's cleaner. This room had a desk, one chair, cleaning products and equipment. The patients and their relatives were not permitted to enter any rooms other than patients' rooms. The head nurse held the keys to the storerooms and kept the keys in a place where the nurses could find them.

The visiting hours started in the hospital at 4.00PM and finished at 8.00PM. Before and after these times, entry to the units was denied to visitors. The female guard at the entrance of the female units searched visitors for food, which they brought from home. At the time of the visits the female guard came to the unit and informed the nursing team that visiting hours had started; she also shouted into the patients' rooms '*Visiting hours have started*'. The reason for this was so that female patients and their relatives could cover their hair and faces before any male visitors entered the unit.

Usually the unit was busy at around 10.00AM because health team visits from doctors, physiotherapists and social workers started at this time. Patients and their relatives had some quiet time after their lunch meal; the room doors were kept closed and the unit at this time felt quiet. The patients and their relatives considered this rest time; some used this time to relax, and some relatives placed their blankets on the floor and took a nap until the start of the visits. From 1.00PM until around 3.30PM the unit was very quiet. After this the environment of the unit was busy and crowded with people throughout the visiting hours; even patients in isolation rooms had visitors but the number of visitors was limited to close family members. The patients in the unit had many visitors during the visiting hours, from family, relatives, friends, and even neighbours and these visitors spent around three to four hours visiting.

## ***The actors***

In the Saudi Arabian setting, the unit was unlike the Australian unit in terms of the nursing team. The Saudi unit only had registered nurses to look after patients; there were no enrolled nurses or assistant nurses in this unit during the data collection period; however, there were assistant nurses in some other units. Graduate nurses looked after patients under the supervision of registered nurses. Patients in this unit were all female and were accompanied by female relatives; the nursing team consisted of only female members. The male visitors were permitted to visit their female relatives but only during visiting hours.

The female health workers from Saudi and Arabic countries wore white coats, pants or skirts and covered their hair and face with black fabric, females from different countries wore white headscarfs. Graduate nurses dressed in the same uniform as the Saudi nurses; the only difference between them was the University logo on their IDs. Clerks dressed in casual clothes and they had their own office located on the first floor, but they could be seen frequently in the unit completing documentation. Staff from the nutrition department dressed in pink coats. Cleaners wore navy pants and light green coats. Physiotherapists wore white coats and black skirts or pants. The social worker had a long white coat and a black skirt. Sometimes it was hard to differentiate between the health personnel because the majority of them wore white coats, the only difference between them being the IDs. The majority of male Saudi doctors dressed in white traditional Saudi outfits, which consists of a white or coloured long dress called a *Thawb*, with a white doctor's coat on top. Usually, the social workers, infection control, physiotherapists pre-arranged their visits to the female medical unit before they met with the patients.

### **Actors group one: Patients**

This unit had 30 beds and the maximum number of patients was 20 to 24. The case mix in this unit included both mild conditions (for example, respiratory, urinary and gastric illnesses) and acute medical conditions (such as, unconscious patients reliant on machines for their survival). The patients' ages varied with the youngest being 16 years old age and oldest approximately 80 years old. The majority of patients were admitted to this unit via the emergency room, but there were patients who had been referred from other hospitals from primary health care centres or from units within the hospital itself. The majority of cases in this unit were considered stable. During this study the researcher only saw two confused patients admitted to the unit during the three month observation. Patients who were diagnosed with serious infectious diseases were placed in the isolation room, but only one room was

equipped with negative pressure systems. Generally, the infectious cases admitted to the unit were diagnosed with respiratory diseases and the head nurse also stated that patients with a low immune system could be placed in the isolation rooms to protect them from other patients.

There were teenaged and middle-aged patients observed in the units who were in a stable condition and although these patients could perform their daily needs with no assistance, they still depended on their relatives to perform duties for them. The majority of patients spent the day resting on their beds because they were worried about being exposed to male health team members. Additionally, patients and their relatives were not allowed to leave the unit without permission from the nursing team. Patients and their relatives were only permitted to have a walk inside the unit and the guard in the hallway would not allow any people to come in or leave the unit without permission, except for health team personnel. The majority of patients dressed in hospital gowns; the gowns were closed from all sides, and were pink and long. The patients also covered their hair with hair scarfs and did not leave the room without these and face covers. Additionally, patients did not leave their rooms except for a walk, for medical or surgical procedures or discharge. The patients visited other patients or relatives in other rooms but informed someone in their rooms before they left in case the nurse came looking for them.

Many patients relied on their relatives to speak for them even when they could speak for themselves. The age of the patient impacted on this; for example, patients in their twenties or above 60 years old relied on their relatives to talk on their behalf. However, chronic patients who had been admitted to the hospital a number of times before, believed they had sufficient experience of the hospital and therefore spoke on their own behalf and would encourage and reassure patients in the same room. In the unit, patients informed relatives of their need to notify the doctor or the nurse of the next visit and patients also asked relatives to call nurses when they needed help. A few patients in this study communicated directly with the nurse or the doctor, but in most cases the relatives took on this responsibility. The patients tended to remember the ward schedule such as morning care and other care times, doctors' visits, visiting hours, meal times and rest times. Patients who had spent a few days in the unit were able to tell new patients what to expect from the daily routines.

The elderly patients enjoyed talking with other patients or relatives closer in age or from similar tribes in the region. Patients who were teenagers and University students or graduates also enjoyed spending time with peers, these being patients or relatives of a similar age. A few patients visited other patients or relatives in other rooms because they were close in age or education. However, in terms of care, the majority of patients wanted to have their showers, change of clothes or assistance in eating or drinking

performed by their relatives. The majority of patients had issues around exposing their bodies, even in front of female nurses, for cultural reasons. Only the patients who were at risk of falls or injury and were also unaccompanied by relatives had nurses assist them in their daily living activities. However, relatives were present during nursing care in most cases. Elderly or overweight patients had both nurses and their relatives assisting them in their daily living activities. A few patients had two relatives for assistance, and this was allowed for heavy or disabled patients or both and also unconscious patients. Two relatives would assist nurses to remove, clean or change patient's clothes. Communication between patients and the health team was less frequent because relatives usually did most of the interaction. It was customary for the patients to be reliant on relatives to achieve their needs, and the health team were familiar with this.

### **Actors group two: Relatives**

It is essential to make explicit that relatives had two main roles in the Saudi Arabian context, one was the required 'companion' role and the other was the 'visitor' role. Relatives who stayed with patients were called companions, watchers, relatives, family, attendants or sitters. Relatives who accompanied patients could be divided in to three categories. Firstly, very close relatives, such as mother, sister, or daughter accompanied patients and were more likely to sit with the patient if they had no reasons to stop them from sitting with the patient. The second category comprised more distant relatives such as stepdaughter, stepmother, sister-in-law and daughter in law. This category of relative was more likely to sit with the patient if the patient had no close relatives in the family, or the close family had strong reasons for not sitting with the patient. The third category were unrelated carers; this person was paid or hired to sit with the patient and they could be a carer, maid or contracted person. The carers observed and interviewed in this setting did not necessarily have experience assisting patients with their care. In the third case, the state of the patient was more likely to be chronic, meaning the patient had been in the hospital for more than two months, was bed ridden, confused or unconscious. However, there were a few unconscious patients with a family sitter who stayed for more than two months. A few relatives with jobs or responsibilities hired a maid or another person to look after the patient. People who originated from specific provinces, which were distant from the city, had stronger family bonds than others. The families who were religiously strict were unlikely to leave the patient alone in the hospital because they believed they would be blessed from Allah (God) if they stayed alongside the patient. Working relatives also accompanied and visited patients in this unit.



In the Saudi setting, during the observation, relatives seemed to have divided their roles into complementary and compulsory. They presented with anxiety when they delayed or failed to perform a compulsory role such as assisting patients in showers. Complimentary activities were those the relatives was not required to undertake such as handling the patient's oral medication after the meal. However, relatives considered feeding the patient, changing clothes, showering, assisting patients to the toilet or walking as compulsory care. The role relatives undertook in the hospital environment in terms of assisting patients were limited by a patient's conditions. For example, if the patient was at risk of falls then the relative was unlikely to assist the patient in walking or going to the toilet without the nurse's permission or supervision. In most cases Saudi relatives acted as assistants to nurses and were involved in nursing care. Many relatives presented with more anxiety when they were involved in additional physical care, more than they were used to doing during their stay in the hospital. The majority of relatives had the ability to distinguish between types of patient care and referred to nurses for guidance. Relatives usually referred to nurses in some cases of physical care, which they found difficult to perform, or feared might harm patients if performed. The relatives showed their respect to the nursing team and presented their acceptance to their guidance. In the ward, relatives sat next to the patient on a chair during the day, and during the night they were given two blankets and a pillow. At night relatives placed the blankets on the floor next to the patients' beds to sleep. Relatives received their meals at the same time as the patients. They also placed their clothes with the patients in the same lockers.

Male visitors could visit patients in the unit within these times, but they had to inform the nursing team they were in the unit. Before male relatives entered the patients' rooms they created sounds such as calling the patient or the relative to inform other female patients they were around. Usually the relative of this male visitor would check with other patients and relatives in the room if they were ready so the male visitor could come inside. Patients and relatives would either pull curtains around patients' beds or cover their hair and faces with black covers and dress in the traditional long, black dress (Abaya). Male visitors would withdraw from a patient's bedside when nurses came to deliver any care during visiting hours; this was part of the culture as well. The majority of patients at the time of visits would have their curtains pulled around their beds. A few relatives who came to visit patients in this unit brought food and hot herbal drinks with them, and some relatives said they managed to hide these from the unit's guard, because the food was not allowed inside the unit. Many visitors looked relaxed even when they were new to the hospital or came to visit patients for the first time. Relatives (companions) who could not stay in the hospital for two consecutive days exchanged their responsibilities and places

with one another during the visit hours. Usually, those relatives had obligations to perform such as responsibility for home, parents, children and work.

The relationship between relatives (both those in companion role and those who were visiting) and the nursing team was formal, meaning it was based around the patients' condition. The majority of the relatives expressed the need for guidance and supervision from the nursing team, especially when they acted as assistants to nurses in patient care. Gaining updated information about patients from the nursing team was not necessary, since most relatives were already abreast of all of the information because of the nature of their presence during any care or doctors' visits. Interaction and the communication among all patients and relatives in the unit was frequently reported. Relatives also kept themselves updated about the other patients in the same room or other rooms. A few relatives rushed to other patients after doctors had visited, to find out what had happened or what had been discussed. Relatives also offered other relatives and patients their assistance and food and drinks as well. Additionally, relatives who had spent some time in the field or had been admitted to the hospital a few times with a family member gave other relatives advice in regard to the stay in the hospital. Elderly relatives adopted leadership roles; sometimes they spoke for other patients and relatives in the same room, also providing advice, guidance, and support to others. Younger patients and relatives usually listened to elderly relatives and asked them for guidance in their social lives. New companions who came to the unit for the first time looked stressed and asked others for direction and advice.

### **Actors group three: Nurses**

In this unit, the registered nurses were wholly responsible for looking after their patients; therefore they constantly mentioned time constraints on their work. Four registered nurses were allocated to patients on the morning shift, three on the afternoon shift, and three on the night shift. There was only one head nurse for this unit and she worked on the morning duty, but also managed the shifts' roster for all nurses in the unit. The morning shift began at 7.00AM to 4.00PM, the afternoon shift from 3.00PM to 11.00PM; the night shift was from 11.00PM to 7.00AM. There were more nurses allocated to the morning shift. The head nurse stated she could request more nurses when they needed more help and this was based on the availability of the nursing team and the number of patients in the unit. The nursing handover for the morning duty started at 7.15AM, the afternoon handover began at 3.00PM and the night handover from 11.00PM. In the unit the majority of the nursing team were from Saudi Arabia, and no male nurses were permitted to work in the female unit. There were only three Saudi graduate nurses in this unit; no other nationalities were allowed to practice in this hospital.

The head nurse in this unit had the responsibility for allocating other registered nurses to their duties in the unit. The head nurse was also responsible for scheduling nurses in the unit to their duties on a monthly basis. Usually, the nursing director allocated the head nurses to their position; this position was similar to the shift coordinator role in the Australian setting. Despite the head nurse on this unit being of similar age and experience to other nurses, the majority of head nurses were assigned to this role because they had more experience and a higher level of education than others. The head nurse could be contacted at any time after her shift ended. Additionally, she was responsible for communication between other units, and usually represented other registered nurses in the unit. Doctors communicated directly with the head nurse if they needed any information. In addition, she was responsible for ordering the unit's instruments, machines and care supplies. She also made frequent checks on the cleanliness of the unit and maintained infection control appliances. She performed checks of unit machines and ensured they worked efficiently, and was supposed to solve any deficiencies in stock.

The head nurse also answered the questions from the relatives or patients because she was in the nursing station most daylight hours and she was able to assist patients or their relatives frequently. Registered nurses came to the head nurse for advice, guidance or decision-making regarding patients' care plans or general care. Registered nurses asked the head nurse for assistance in patient care. The head nurse had to be present in case there were issues or complaints from the nurses, patients or their relatives. Furthermore, she was responsible for adding or taking away other responsibilities from nurses. She assisted other registered nurses to document patient admissions, care plans, and discharging patients from hospital. Graduate nurses were assigned to patients and were supervised regularly by the head nurse. She was also responsible for recording, sending and receiving orders to and from other departments. Relatives were supposed to ask permission from the head nurse before they left the unit. Moreover, the head nurse had to be informed of any changes to patient companions in the unit. She evaluated the nursing team in her unit, and had the ability to reject any nurse she thought was unsuitable to work in the unit. The nursing team would ask for the head nurse's permission for any urgent leave, annual leave, or change of schedule. She was also responsible for solving any problems within the nursing team before the matter went to the nursing director.

The registered nurses started their duty with the handover and they were able to choose patients by mutual agreement. This depended on their experience, ability to look after patients and convenience. Nurses who had the experience to deal with acute medical conditions were assigned to these cases repeatedly. They checked patients and informed each other of any care needs or updates. In this unit

the nursing team had routines which they performed every day and it started at the same time every day such as bed making, monitoring vital signs and administering medications. But there was also some care that could not be planned or occurred unexpectedly such as medical and surgical procedures. The registered nurses monitored the progress of patients' conditions and performed their care plans accordingly. Registered nurses documented all of their nursing duties frequently; they also monitored patients' diet, mobility, ability to speak and informed doctors frequently of any changes. Nurses with more experience assisted others with less experience and some nurses observed others during care for guidance. In this unit, the nurses looked busy most of the time; they did not have time to sit or talk with each other, and the nurses expressed their feeling of being overworked frequently. Similar to the Australian setting the morning shift nurses complained about work overload more than other registered nurses working on other shifts. The registered nurses from all shifts looked friendly and assisted and offered help to one another.

Registered nurses carried out doctors' orders, delivered nursing care, maintained the safety of nursing care delivery, and monitored infection control systems in the unit. They performed admissions, care plans, discharge and scheduled patients for outpatient department appointments as well. Registered nurses were responsible for guiding graduate nurses; every graduate nurse had a buddy nurse for support and practice. Registered nurses organised patient appointments in other departments such as booking medical and surgical appointment. Additionally, registered nurses dealt directly with patients' relatives and answered their questions. They also informed relatives directly of any changes in care or patient appointments. Some registered nurses assisted the head nurse in her responsibility of looking after the requests forms for the unit's instruments or supplies. Registered nurses cooperated very well with the head nurse and helped her in many duties. Additionally, they recorded the relatives' names in the hospital system electronically so they could receive their meals and assistance from other departments when needed. Registered nurses also escorted male doctors to patients' rooms and ensured that female patients and relatives' were ready before doctors' visits. Additionally, they had the responsibility of enforcing quietness in the unit and preventing any uncontrolled behaviour such as when relatives gathered in the rooms at night.

### ***Activities undertaken by nurses and relatives***

This section illustrates the activities undertaken by nurses and patients' relatives in their respective roles of providing direct patient care.

## **Nursing activities**

Patient care roles were allocated evenly between nurses. The nursing team usually discussed what had happened on their shift in terms of duties, patient progress, modifications, nursing care plans and medication. The head nurse took into account nurses' opinions in relation to which patients they wanted to look after. Nurses were assigned to particular rooms, meaning that if a nurse was assigned to Room one, she would look after all patients in that room. In this unit, each nurse was assigned to look after four to five patients; however, a nurse might look after more patients in a situation where there was a shortage of nurses or an increased number of patients. Similar to the Australian setting, the nurse who looked after patients with acute medical conditions took the responsibility for a smaller number of patients because of the nature of care the acute patients might require, such as continuous monitoring and nursing care.

After the morning handover at around 7.45AM nurses started their nursing rounds. During the nursing rounds, nurses greeted patients and their relatives, checked patients' needs and also asked all companion relatives to wake up and get ready for the day. Usually, the nursing team encouraged patients and their relatives to finish their breakfast if the meal trays looked untouched; the breakfast was distributed to patients at around 7.00AM. After this the head nurse would assign the graduate nurses to patients and explain to them their duties. Usually graduates started the day by taking patient's vital signs and recording them on patients' charts. After the morning visits to patients the nursing team started the bed making. The nursing team had the responsibility to keep patients' rooms in order, but they did not perform this duty. They asked patients' relatives to tidy around patients' beds. Nurses then spent time observing whether the rooms were organised. Most commonly when nurses did their morning visits to change bed sheets, relatives would still be still sleeping on the floor. During the study observation, nurses entered the rooms and said '*Salam Alykom*', which are greeting words in Arabic, '*How are you everyone, wake up, the morning shift has started*'. The non-Saudi nurses learned a few Arabic words to assist them to communicate with patients and their relatives. The majority of the non-Saudi nurses who worked or covered shifts in this unit spoke little Arabic.

As part of the morning routine, the nursing team returned to the rooms over and over again to confirm whether relatives had woken up or not. After this the nursing team started to check whether patients had had their oral morning medication, because some patients delayed breakfast and therefore their medication as well. The nursing team encouraged relatives to assist patients in their showers and changing their clothes, except for a few patients with acute medical conditions whom the nurses

believed needed close attention and care from them. After this, nurses prepared the patients who required surgical or medical procedures. Nurses did not assist patients with companions who required assistance in their physical needs such as feeding, drinking, toileting, walking, showers, or changing clothes. The nursing team only assisted patients in their daily needs if they were in the following categories: at risk of falls, physically disabled, unconscious or overweight. These patients were still attended to with the assistance of patients' relatives. The nursing team seemed to be reliant on relatives to assist patients with their physical needs or morning care if they were not included in the categories stated above.

Doctors attended the unit at around 10.00AM. Sometimes visits by doctors started earlier, at a doctor's convenience. After the doctors' visits the nurse usually explained the doctor's instructions and discussed any matters with the patient and her relative. Usually nurses then recorded their nursing notes in the nursing meeting room at around 12.30PM. The majority of the nursing team discussed patient matters with a patient's family. For instance, if a nurse needed to deliver information to the patient she would speak directly to the relative. The nursing team treated relatives as care assistants; in the observation some nurses asked for relatives' assistance; however, on most days assistance from relatives happened spontaneously. Lunch was distributed to patients and relatives around 12.30PM. Before this, at around 12.00PM the nursing team distributed oral medication and informed patients and their relatives that it had to be taken after lunch. After lunch the nursing team, with the graduate nurses administered other forms of medication such as intravenous medications. The lunchbreak for nurses started at around 1.00PM. Only two nurses were allowed to go for a lunch break at a time so the other nurses could look after patients. The nursing team gathered in the nursing station and completed what was left of their duties and they also discussed some care and treatment plans.

At around 3.00PM the afternoon shift nurses arrived at the unit, and the handover took place. After the nursing handover, nurses made a quick visit around patients' rooms, to greet patients and check whether they needed anything. After this the nurses usually monitored patients' vital signs, monitored acute patients and completed documentation. Nurses on this shift were generally the same every day for the time period of data collection. When visiting hours started at 4.00PM the nursing team tended to remain in the nursing station till the visit time ended, especially if the patients had male visitors. The nursing team finished their responsibilities before the start of the visits so they would not have to perform any care during this time unless necessary. After this, the dinner meals were distributed to patients and relatives at 7.30PM and medication administered to patients after this. The visitors left the

hospital at 8.00PM after the female guard came to the unit to inform everyone that the visiting time had finished. She then ensured that all visitors had vacated the premises.

After 8.00PM nurses continued to monitor patients and complete documentation; they also encouraged patients and relatives to be quiet and go to sleep early. Nurses helped those patients who were in need of their assistance to go to the toilet, change their clothes and put them to bed. Usually, the nursing team tried to prevent gatherings in patient rooms at night to allow patients to sleep. Visits from any other health personnel were unlikely to happen after 8.00PM, except where there was an urgent need for the doctor. Therefore, relatives and patients relaxed after 8.00PM with some going for a walk inside the unit or visiting patients and relatives in other rooms.

The nursing team would speak to relatives and patients about noise in the unit. Nurses turned the lights off in patients' rooms around 9.30PM but some relatives and patients stayed awake until midnight. The unit was very quiet by 11.00PM and all lights were turned off except the nursing stations and the main hallways in the unit. Nurses encouraged their patients to use the call bell when they needed assistance. The night shift nurses arrived on the unit at around 11.00PM and received handover from the afternoon shift at 11.10PM most days. The night shift was quiet and the nursing team had less responsibilities. Their nursing duties revolved around monitoring patients, providing urgent care and documentation. Nurses also gave bed baths to unconscious patients around 2.30AM in the morning; they explained that they bathed them early because they had no time to perform bed baths at any other time. After 3.00AM the nurses organised the storeroom, completed their nursing notes and tidied the nursing station. They also gathered at a few times for discussions, drinks and food, and a few nurses from other departments came to chat. At around 5.30AM the nursing team went to patients' rooms to wake patients and their relatives to perform the morning prayers. After the end of the night shift, nurses were ready to discuss their duties with and hand over their patients to the morning shift nurses.

### **Relatives' activities**

Saudi relatives were required to accompany patients during their stay in the hospital, and any relative who chose to be a companion had to sign a 'companion authorisation' form (Appendix 20: Companion Authorisation Form). This form was given to relatives to read and sign when patients were admitted. This form was written in Arabic only and the researcher took a copy from the social worker, as she was the one responsible for distributing this form to relatives in the unit. This form stated that the companion should contact the director of the hospital when they needed to leave the hospital and they were not

permitted to enter the unit after 8.00PM. The form also indicated that the companion should not walk in the hospital's hallways and this form would not authorise their presence if they were caught walking. The form also stated that companions should not bring any food from outside into the hospital, and stated that only one companion was permitted per patient, and when the patient was discharged the form should be submitted to the Department of Patients' Affairs. Relatives' activities took different forms. Some relatives assisted patients in care such as helping patients to eat and drink and others assisted patients to take bed baths, turning on the oxygen and even wound dressing. The researcher also observed that relatives assisted nurses to undertake their nursing care duties; during the care they followed nurses' guidance and instructions.

Relatives seemed to be happy to assist patients or nurses in patient care at any time. Relatives spoke to each other about the blessings they received from Allah when they looked after patients. Relatives were also observed providing emotional support for patients. The majority of relatives stood up close to patients' beds when nurses approached patients and some removed their Abaya as a sign they were ready to assist. If two nurses came to a patient's room to provide care, usually the relative would not stand up, because the relative thought two nurses would not need her assistance. Conversely, when one nurse came to provide care for a patient a relative would offer help or assistance without asking the nurse if she needed it or not. One or two relatives could be looking after a patient. If relatives chose to stay with a patient every second day, then the exchange between relatives would happen during visiting hours. Relatives who exchanged places would give each other a full description of a patient's condition before they left the unit. This description included what had been done to the patient that day or the previous night, the medication, and plans for the next day. In some circumstances one patient could have two companions at the same time and in these cases this would usually involve a relative and a paid maid. Additionally, a few relatives sometimes assisted others in the same room to undertake physical care such as changing soiled bed sheets, changing patients' clothes and transferring patients from bed to chair or vice versa.

Generally, as stated previously, relatives slept on the floor on top of blankets. However, if there was a vacant bed beside the patient then the relative might use this bed. In cases of a new admission the relative who occupied the vacant bed was asked to vacate the bed and the cupboard immediately. Relatives shared a patient's cupboard, bedside table, toilet, showers and hand basin, which were located in each room. The majority of relatives woke up for the morning prayer and remained awake until breakfast was served, usually feeding patients or assisting them, having their own breakfast, giving the patient oral medication if available and going back to sleep again for few minutes or hours. At



around 8.00AM all relatives were expected to be awake; around 8.00AM relatives usually folded their blankets and placed them with the pillow in the patients' cupboard. A few relatives had food containers and hot thermos placed on the floor or on patients' tables. They also collected these and hid them in the cupboards as well. Relatives had to clean up around patients and their bags and personal belongings had to be kept hidden as well. Relatives remained beside patients until after bed making had occurred in case nurses needed help with patients. After this, some relatives assisted patients in their showers and changed patients' clothes. Additionally, some relatives helped the patients to the toilet or for a walk, while some patients preferred to remain in bed. Relatives preferred to keep the doors to their room closed until they finished patients' showers and changed clothes.

Relatives supported patients before and after nursing care and surgical and medical procedures. Many relatives preferred to be around patients during nursing care and for specific procedures; they also questioned nurses before any procedure occurred, especially relatives who were new to the unit. Relatives also represented patients on many occasions, from providing nurses with the patient's history to discussing the care plan, treatment, and discharge plan. Relatives spoke on behalf of patients in cases such as when patients were shy or in pain, and they also communicated patients' wishes and needs to the health team. During doctors' visits, relatives interpreted for patients, clarified, or repeated things after the doctor had spoken. Doctors spoke to patients' relatives directly; some doctors explained the treatment plan to relatives and left them with the responsibility to explain it to the patient. Doctors usually discussed matters such as a forthcoming operation or surgical or medical procedures with patients and their relatives. Additionally, the family, especially the male guardian such as a father, husband, brother or son had the right to consent to a patient's operation or surgical procedure, and the matter was discussed and confirmed with the guardian.

During the day, relatives remained inside patients' rooms but were seen regularly in the nursing station if they needed nurses' assistance. They also followed patients to the treatment room and remained close to them. The majority of relatives attended surgical or medical procedures, which happened inside the unit. Relatives left their rooms during the day only occasionally as this showed their respect for cultural manners. Certain relatives showed high levels of stress, especially those who accompanied chronic patients, because of the difficulty they had in leaving the patient's side. Some relatives could not leave the patient, even to get fresh air. Many relatives were unable to sleep at night time because they needed to constantly observe the patient and because they feared the sounds made by the machine alarms, even though these were sometimes false alarms.

Relatives maintained the privacy of patients regularly; nurses did not worry about providing privacy on most occasions especially during nursing care because relatives looked after this for them. Before the male doctor visited, the relatives wore hair and face covers; they also assisted patients to cover their hair but not their faces. Other relatives in the same room provided privacy to patients by pulling the curtains around their patients, but the curtains around the examined patient remained open. Generally after the doctor's visit, relatives and patients in the same room asked the examined patient questions to gain an update on her condition. Communication between relatives happened regularly; they exchanged their past experiences of the hospital, gave advice, and provided each other with emotional support. They offered each other food, drinks, and assistance to look after each other's patients. Relatives looked after their own needs as well but their needs were secondary to a patient's needs; for example, they took their showers after all patients had had theirs in the room. Relatives did not want to keep the bathroom busy because the priority was for the patients in the room; they also asked other patients in the room if they needed the toilet before they used it.

During meal times all relatives fed their patients first or assisted them before they started their own meals, and some relatives assisted unaccompanied patients in the same room to eat. Many visitors shared hot herbal drinks and traditional food with patients and relatives in the unit. Usually, visitors spent time in discussions with patients and were not involved in any physical care. During the visits a few visiting relatives approached the nursing station to ask questions, usually about doctors' appointments or surgical and medical procedures. After the visitors left the unit completely around dinner, patients and relatives prayed the night prayer. It was common to see the gatherings of relatives and patients at night time, especially between 8.00PM and 10.30PM. Some relatives spread a blanket on a room's floor and brought foods or hot drinks and spent a few hours talking. Some also brought their chairs and met with each other in the rooms, while others preferred to watch TV or spoke with family members on the phone. Some relatives were loud and also kept patients awake until late. The researcher observed that a few patients and their relatives asked others to keep their voices down or let them sleep. After the nursing team turned the lights off in the rooms some relatives turned them on and kept the doors shut.

At bedtime relatives assisted patients to the toilet and helped patients change into their nightgowns and placed them in bed. After this relatives put the blankets on the floor, pulled the curtains around the patients' beds, turned the lights off and slept. There were some relatives who stayed awake all night because they were concerned about the safety of patients. Additionally, relatives also asked for nursing

assistance at early hours in the morning. They also assisted patients to the toilet or helped them to have a cup of water throughout the night.

## **Summary**

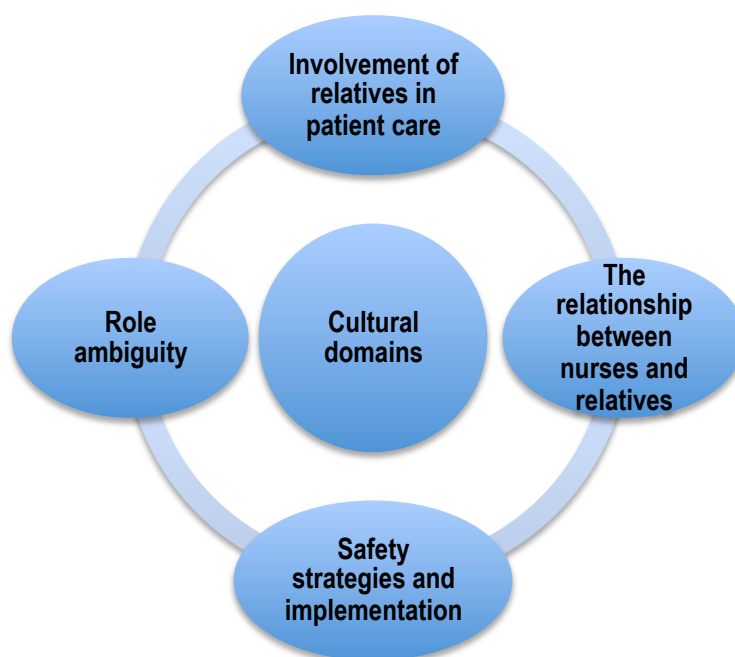
The first chapter of the findings described the cultural scene of the Australian and Saudi Arabian settings. The first segment included rich descriptions of the scene, participants and activities. The majority of patients in the Australian unit were elderly and frail. The unit's layout allowed nurses to observe their patients and helped to ensure their safety. The Australian setting was an environment in constant change and patient load put continuous strain on nurses to maintain quality of care. Nurses in this setting seemed overloaded with multiple tasks; however they appeared to manage working with patients and their relatives well. Relatives came to visit patients at scheduled hours; however, some relatives were permitted outside of these hours when patients required their presence. Relatives were observed performing many tasks to assist patients in meeting their needs. The Saudi scene was different to the Australian setting in many respects; in this setting all patients were females and the majority of patients were middle aged. The layout of the unit also allowed the nurses to observe patients' rooms but also to observe people coming in and going out of the unit. The environment was busier during visiting hours because of the large number of visitors and it was obvious that nurses were more stressed at this time. Nurses appeared under pressure due to a high workload and they constantly stated they needed more nursing staff. Relatives were present in the unit with patients from the time of admission until discharge and were more involved in patient care than in the Australian setting. Finally, The relatives in Saudi were responsible for performing many patient care tasks but the extent of these tasks was not prescribed.

## **Chapter six**

## Chapter 6: Findings

### Introduction

This chapter examines the elements that were essential to form an understanding of the nature of relatives' involvement in the care of patients in each medical setting. In this study, it was necessary to develop a theoretical framework or working model to bring together all the elements that contributed to the 'cultural domains' and which explained the nature of relatives' participation in patient care. The components of the figure below helped the researcher to understand the culture of both fields.



*Figure 5: The cultural domains which influenced relatives' involvement in patient care in both settings*

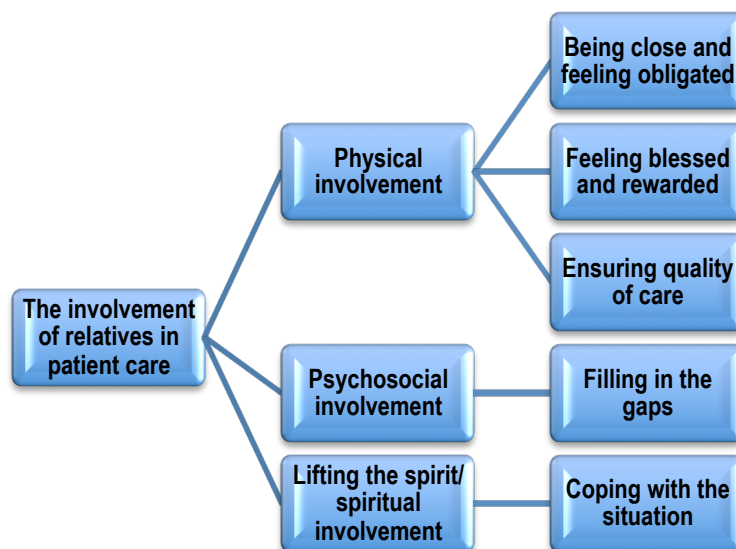
### The cultural domains for both settings

Four main domains were generated from the findings to represent the cultural aspects of the fields in regard to relatives' involvement in care. The first domain includes a description of the type of involvement and assistance provided by relatives to patients. The second provides a description of the relationship between nurses and relatives in the two units. The third domain depicts the different strategies implemented by nurses to maintain patient safety whilst relatives were involved in patient

care. The last domain describes the ambiguity relatives felt about their role in patient care in both settings. In order to achieve the aims of this study it was essential to consider participants' perceptions about the role relatives play in patient care. The data from both settings are assembled under same cultural domains, as the researcher found more similarities in the themes than differences.

### **1. The involvement of relatives in patient care**

This domain illustrates the actual role played by relatives in both settings; it focuses on the way in which relatives are involved in patient care and explains what patients and relatives gained from their involvement. In both settings relatives undertook diverse roles and responsibilities. Some of these activities were deemed to be appropriate by nurses, but relatives and patients had no shared understanding of a 'relative's role'. Relative's involvement in patient care is characterised in this study on the basis of the type of contribution made. For example, their involvement is described under the themes physical involvement, psychosocial involvement and lifting patients' spirits or spiritual involvement. Below is a diagram that portrays these themes and subthemes.



**Figure 6: The types of involvement relatives had in patient care**

It is essential to point out that relatives' involvement in the Saudi Arabian unit was extensive and at times extended beyond safe practice, and at the same time, the majority of nurses in this setting felt that it was not part of their nursing responsibility to manage the behaviour of relatives. Whereas in the Australian field, on most occasions, the involvement of relatives was believed to be under the control of nurses, with relatives being included or excluded in care at the nurses' discretion. Relatives in the

Saudi setting, as stated previously, had two roles, that of a companion and a visitor. Relatives were more involved in patient care because of the nature of family bonds, beliefs and culture. Most frequently their involvement was a social expectation and it was unusual for relatives not to take part in direct patient care. In cases where relatives were not involved in patient care, some nurses and relatives considered this to be a sign of having weak family ties and relationships. In contrast, relatives in the Australian setting appeared to feel less obligated towards patients and their care, so their participation was considered to be positive, voluntary and was appreciated; this also reflected on how their involvement was displayed in the field. It was observed that personal commitments were prioritised over family care in the Australian setting and that this was a culturally justified position which relatives took. For example, the lack of participation in care or visiting was because of the relatives' inability to balance their life obligations such as work and family commitments with their ability to provide care to their ill family members. Similarly in the Saudi field the family structure had a huge impact on how involvement was regarded, but life obligations did not prevent Saudi relatives from undertaking the caring or visiting role. Saudi relatives adjusted their personal lives to ensure a family member was 'cared for'. In the Saudi setting companions with jobs were able to gain paid leave during the period of their companionship in the hospital and this enabled them to worry less about their careers. Whereas in the Australian setting, relatives at times could not afford time off and were worried about their work security.

The next paragraphs will describe how relatives were involved in care and the reasons relatives were involved in both fields, with their similarities and differences highlighted. But before presenting this data, it is essential to illustrate the different roles relatives undertook in both scenes; these roles were demonstrated by relatives during data collection in both fields and are presented in the table below:

| Relatives' roles in both settings | Examples   |
|-----------------------------------|--|
| <b>Assistant</b>                  | '...I assist her to dress in clean clothes, feeding her, giving her tea or water, massaging her feet...' (Relative 16 interview, the Saudi setting on 4/03/2014, at 10.30AM, p. 32, L. 17-18).   |
| <b>Companion / visitor</b>        | 'I have been here for two days, my brothers and sisters come to visit at visit times.' (Relative 4 interview, the Saudi setting, on 13/02/2014, at 2.30PM, p. 7, L. 4-5).  |
| <b>Connector</b>                  | '...When we need information and we don't get it from the patient then we discuss this with their family...' (Nurse 2 interview, the Australian setting, on 6/09/2013, at 3.00PM, p. 4, L.5-6).  |
| <b>Supporter</b>                  | '...I keep my sister calm, and I give her advice...' (Relative 2 interview, the Saudi setting, on 11/02/2014, at 7.00PM, p. 3, L. 29).   |
| <b>Protector</b>                  | '...We have to make sure she is protected and safe' (Field notes, the Australian setting on 15/08/2013, p. 7, L. 22-23).   |
| <b>Partner</b>                    | 'They help us understand many things around here, also patients' wishes and also perhaps things we cannot comprehend' (Nurse 6 interview, the Saudi setting, on 20/2/2014, at 8.00AM, p. 10, L. 8-9).  |
| <b>Mediator</b>                   | '...She was scared. I convinced her to let the nurse insert the intravenous cannula in her arm. She needed some supportive words. I gave them to her' (Relative 11 interview, the Saudi setting, on 27/02/2014, at 12.00PM, p. 22, L. 20-21).                        |
| <b>Interpreter</b>                | '...I repeat for my sister what they want from her' (Relative 2 interview, the Saudi setting, on 11/02/2014, at 7.00PM, p. 3, L. 29). 'I explained for her their instructions' (Relative 1 interview, the Australian setting, on 20/08/2013, at 1.30PM, p. 1, L. 22) |
| <b>Advocate</b>                   | '...She was in the ER. Her husband is the one who spoke with the doctor. My sister is very shy, she can't talk much, she tells me what she needs and I ask for her' (Relative 1 interview, the Saudi setting, on 10/02/2014, at 2.30PM, p. 1, L. 9-10).              |

**Table 9: The role relatives play in each setting by category**



## Physical involvement

The theme of physical involvement encompasses the assistance provided to patients to maintain their physical needs such as feeding, showering or toileting. Relatives in both settings were observed providing patients with help but this happened more frequently in the Saudi setting. Some relatives were confused as to whether some of their activities were considered nursing care. In many cases relatives perceived their physical assistance to patients as more important than psychosocial and spiritual assistance, because they thought their visits alone would provide emotional support. Additionally, some relatives in both settings were pleased when they contributed to physical care because they observed the immediate significance of their help, especially when patients were satisfied. This subtheme was focused on how relatives felt and their reasons for assisting in patients' physical care and this will be explained in the following section. Below a table illustrates some of the activities performed by relatives in the Australian and Saudi fields:

| Physical activities undertaken by relatives | Australian setting | Saudi setting |
|---|--------------------|---------------|
| Combing hair                                | 5                  | 5             |
| Assist to brush teeth                       | 2                  | 2             |
| Wiping mouth                                | 5                  | 8             |
| Assist in shower                            | 4                  | 42            |
| Massaging                                   | 7                  | 19            |
| Apply moisturiser                           | 5                  | 28            |
| Maintain privacy                            | 13                 | 52            |
| Support pts. back during standing           | 5                  | 32            |
| Take pts. for a walk                        | 9                  | 35            |
| Give pts. their belongings                  | 15                 | 52            |
| Assist pts. to drink                        | 13                 | 32            |
| Feed pts.                                   | 10                 | 32            |
| Open food packages/cut food                 | 12                 | 48            |

|                                   |    |    |
|-----------------------------------|----|----|
| Bring food close                  | 14 | 52 |
| Cover pts. with blanket           | 17 | 35 |
| Bring blanket to pts.             | 7  | 13 |
| Lower or elevate bedhead          | 12 | 32 |
| Lower or elevate side rails       | 3  | 8  |
| Assisting pts. from bed to chair  | 7  | 30 |
| Assist to change position in beds | 6  | 26 |
| Assist pts. to changing clothes   | 7  | 40 |
| Assist pts. to the toilet         | 5  | 37 |
| Assist pts. to stand on a walker  | 3  | 32 |
| Assist pts. to exercise           | 3  | 8  |
| Wound dressing                    | -  | 3  |
| Assist in wound dressing          | -  | 4  |
| Administering eye drops           | -  | 3  |
| Administering oxygen              | -  | 12 |
| Stop intravenous fluids           | -  | 13 |
| Exposing body for examination     | -  | 43 |

**Table 10: Physical activities undertaken by relatives in both settings**

There were a range of physical activities undertaken by relatives. However, the frequency of physical care was much higher in the Saudi setting. There were many reasons for this; Saudi relatives performed a greater variety of caring tasks, the period of time relatives' spent with patients was longer, and the number of Saudi relatives present in the hospital setting was higher than in Australia. Saudi relatives also undertook some activities, which were not observed in the Australian setting at all such as wound dressing, administering eye drops, applying oxygen and ceasing intravenous fluids. The table is not intended to compare both settings in relation to the frequency of activities occurring during a scheduled time frame; however it aims to capture the type of activities undertaken by participants and the number of relatives who assisted in these activities. In the Australian setting, this involvement in physical care was recorded based on the time relatives were present, so the observation time was

unequal for each participant. In Saudi Arabia the activities were observed during the morning shift for three hours, and this is where most activities happened. While the observations were undertaken for three months in both settings, the researcher considers that a comparison of activities may be biased as the observation periods were not exactly the same and the time relatives were present with patients, the number of participants and the nature of involvement varied. However, the table does demonstrate some overall differences in the frequency and types of activities performed by relatives.

The next section presents the reasons and advantages of relatives being involved in physical patient care:

### ***Being close and feeling obligated***

It was observed that relatives assisted patients physically because this activity appeared to make them feel close to their ill family member. Many relatives felt the illness of family members created anxiety and assisting patients relieved this. This pressure also influenced relatives' changing roles in both settings. Relatives adopted new roles when they assisted patients physically and some said they shared the responsibility as much as possible. Many relatives in both settings felt they were separated from patients physically when they were admitted to hospital. The contribution to physical care gave them a feeling of closeness they had lost due to being physically distant from patients. Furthermore, patients who received physical assistance from relatives felt loved and reassured during their stay in hospital. Some patients highlighted the importance of demonstrating how precious they were to their families.

Patients in both setting believed this period of time in hospital was associated with changes in the family social network as family members could become either closer or more distant than ever. In addition, relatives' contribution to physical care was more apparent when patients had difficulty achieving their needs independently or were viewed as vulnerable. Relatives felt anxiety for family members who were vulnerable and their contribution to physical care gave them a feeling of satisfaction. They wanted to watch patients closely and being near helped them to understand more about a patient's condition and progress. Additionally, contributing to physical care gave relatives a comprehensive picture of a patient's physical needs. The ability of relatives to provide care to patients gave them a feeling of fulfilment which helped strengthen their social relationships, as interaction was involved in physical tasks such as feeding and walking patients.

The responsibility relatives took on board was expressed and reported frequently in both settings. This feeling also showed in their demeanour and many relatives appeared content after being involved in every day practical tasks. Usually, close relatives expressed this feeling, since friends and acquaintances felt no obligation towards a patient's care. In the Australian setting different ethnic groups felt more obligated to look after their relatives than others. The reasons relatives felt more obligated towards patients related to culture, the patient's age (such as if a person was elderly), their personal needs or vulnerability. But there were other reasons for feelings of obligation such as when patients had unmet needs or the response from nurses was delayed. Three relatives in the Saudi setting expressed the view that they gained satisfaction from helping patients with their physical needs but this became a burden when their responsibility became more extensive and then this responsibility became overwhelming. This was similar for several Australian relatives who said they felt overwhelmed because they could not balance their responsibilities or lacked personal time. One relative thought that contributing to patients' physical care required long periods of time in hospital, and this could not be always achieved because of work commitments.

It is important to add that some relatives who provided physical care to patients for a long time complained of pains and aches in their shoulders or backs, and some relatives forgot to eat their meals and take their prescription drugs because they were busy caring for patients. Feeling guilty also contributed to relatives becoming extensively involved in physical care. A few relatives in both settings appeared to compensate for a feeling of guilt by being more involved, especially because this gave them satisfaction. This guilt was linked to experiences where relatives had not been available to support their loved ones at other times in their lives. The following extracts demonstrate the guilt which some relatives felt. *'I wasn't there for her,'* one relative stated (Field notes, the Australian setting, on 15/08/2013, p. 8, L. 2-3). Another relative said, *'It's time to show her how much I love her'* (Field notes, the Australian setting, on 1/09/2013, p. 31, L.10-11), and *'I didn't realise how frail she had become and how much she needed me in the past few years'* (Field notes, the Saudi setting, on 13/02/2014, p.13, L.13-14).

### ***Feeling blessed and rewarded***

Another subtheme of physical involvement was a feeling of being blessed and rewarded in life when a relative assisted patients with their needs. This was apparent at times when patients chose particular relatives to be part of their care; this was an acknowledgment from patients that their relative was special and generous. It also meant that these patients trusted their relatives to be involved in their life

journey. It was evident this assistance gave relatives a sense of importance as they shared the responsibility with nurses in looking after patients. Additionally, the health team consulted these relatives when making decisions, giving information and during the care process generally. In both fields there were times when some relatives felt they would be rewarded for their good deeds, especially when they were involved in certain types of care such as assisting patients in eating, toileting and hygiene. This care was considered to be basic self-care.

One relative from an Indian background in the Australian setting stated that the more patience she showed towards her mother during her mother's illness, the more reward she would get when she got old. She also believed that her belief in a future reward was a coping strategy that enabled her to continue to contribute to her mother's care without hesitation or a second thought. Equally some Saudi relatives felt similarly about assisting patients in their physical needs. There were expressions relatives made during interviews in both settings which showed a relationship between giving care and being rewarded in the future such as '*I feed her now, there will be a time when she looks after me*' (Relative 5 interview, the Australian setting, on 10/09/2013 at 2.10PM, p. 9, L. 8-9). Another relative said, '*My kids will be good to me when I get old. I was always good to mum*' (Relative 3 interview, the Saudi setting, on 12/02/2014, at 10.30AM, p. 6, L. 5-6).

Relatives also associated feeling blessed with constant presence, long visits and physical care. Many Saudi relatives and also people from Indian, Asian, and Italian backgrounds in the Australian setting felt blessed by God when they stayed beside patients for long periods of time and gave them care. Having a connection with patients at this stressful time was believed to be connected with being blessed in life. Most participants in the Saudi setting agreed that if you looked after elderly people or patients you would not be abandoned when you needed others for help. These relatives had a religious explanation for participating in care giving; however, looking after patients and elderly people is also imbedded in Saudi traditional culture, and it is perceived as a blessing if this role is fulfilled.

### ***Ensuring quality of care***

In both fields the extent of relatives' involvement in patient care was connected to whether they believed patients were receiving good care or not. This also reflected what relatives thought about quality care or a best practice approach to healthcare; however, there was ambiguity in terms of what 'quality care' meant. Some relatives thought quality care was related to whether nurses treated patients with compassion, competence and respect. However, relatives' views varied. Generally relatives'

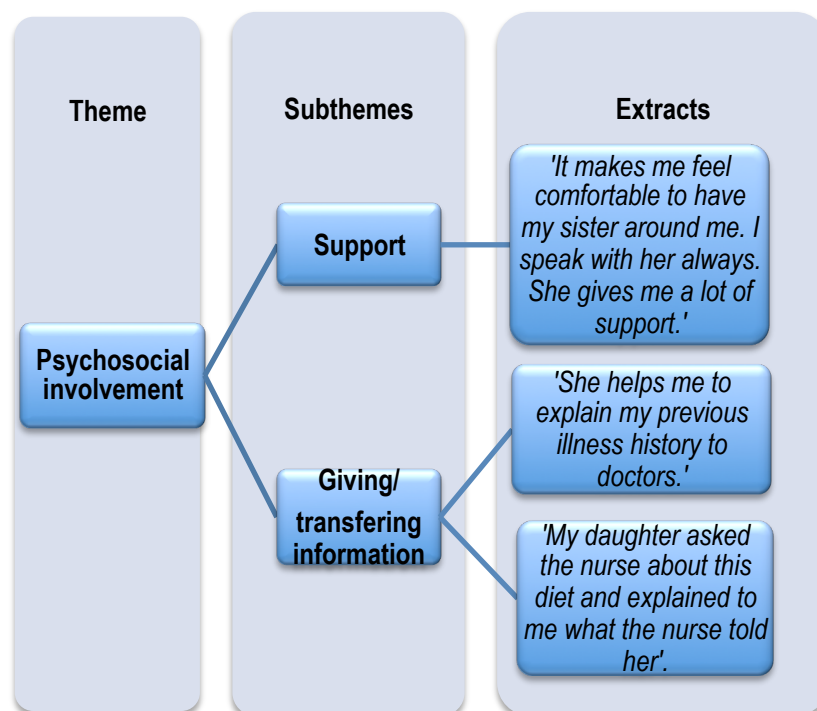
expectations, social background and lifestyle influenced their opinions regarding care. Additionally, relatives thought the only way to ensure good care delivery was to take an active part in it. There were expressions that showed how relatives thought they influenced quality of care. These quotes were extracted from both settings and included expressions like *'I fight for this'* (Relative 18 interview, the Saudi setting, on 6/03/2014, at 7.00PM, p. 8, L. 37), *'I keep asking'*, (Relative 18 interview, the Australian setting, on 11/11/2013, at 4.30PM, p. 29, L.23). *'I had to complain'* (Relative 5 interview, the Saudi setting, on 14/02/2014, at 2.45PM, p. 8, L. 22) and *'I get a bit unsure of the care I'm not usually like this'* (Relative 13 interview, 1/11 2013, at 2.00PM, p. 23, L. 23-24). Relatives thought they needed to be persistent at times to attract the attention of nurses and doctors. At times some relatives thought being persistent worked in their favour to ensure patients received care; however, nurses described some relatives as *'over demanding'*. These relatives had only one concern, which was their loved one and their needs. They did not consider the needs of other patients and therefore undervalued the work nurses did, as well as their extensive workload.

Relatives also asked many questions about medication, meals, care, and treatment planning. They thought their assistance in care familiarised them with what to expect from being in the unit and how nurses treated patients. In the Australian setting four relatives said they visited for longer to begin with and wanted to assist in care, to ensure their loved ones received optimal care. A few relatives also discussed previous negative experiences in hospitals and wanted to make sure this would not happen again. Many relatives in both settings reflected on the nurses who they liked and felt provided good quality care as *'good nurses'*. While *'other nurses'* or *'pay check nurses'*, were terms used to reflect on nurses who relatives thought did not deliver good care to patients. Relatives wanted to be more involved in care and more present at times when *'those nurses'* looked after patients. This was linked to trust issues as relatives could not trust *'those nurses'*. Additionally, a few relatives in both settings believed nurses changed the way they treated patients in their presence; this was why they wanted to be more involved. However, the researcher could not confirm whether nurses provided better care when relatives were present, during the observations. In the Saudi setting relatives did not leave a patient's side so it was hard to differentiate between the two situations. However the opinions of Australian' relatives about this subject came from what patients had told them.

### **Psychosocial involvement**

Psychosocial involvement was any participation believed to sustain patients' psychological and social needs such as support, providing or transferring information or speaking for patients when they were

unable to speak for themselves. Patients often experienced stress and fear in the hospital environment and the presence or visit of their family members helped them to adjust to their stay. Age, fear, stress, pain, embarrassment and shyness were factors which contributed to patients' inability to provide comprehensive information to the health team. On many occasions the health team in both settings used the ill person's relatives to acquire information which assisted them to make decisions about the treatment plan. Some relatives took on the role of a mediator because they knew how to approach their loved one because of their closeness to the patient. Furthermore, some patients in the Australian setting and all in the Saudi field preferred their close relatives to be involved in their care; this reassured patients during their stay in hospital, especially in relation to decision-making. Furthermore, in both settings when patients were asked who they preferred to speak with about personal troubles or feelings in the hospital, the majority answered that they preferred family members. They justified this because of the love, relationship, mutual understanding and acceptance they shared. This showed that relatives engaged in many psychosocial roles and the next few paragraphs will explain some advantages of this type of involvement. The diagram below shows a sample and analysis of psychosocial involvement from both settings.



*Figure 7: A sample of psychosocial involvement from both fields*

The next section presents the reasons and advantages of relatives being involved in psychosocial care:

### ***Filling in the gaps***

It was difficult for nurses and health professionals to understand all patient needs, which meant that they were not able to tailor their care to meet all of a patient's necessities. Therefore, it was essential to involve relatives in aspects of care where there were shortfalls, for example where emotional support and care was required. The vast majority of relatives provided patients with support in psychosocial care. One example was advocacy. Relatives were observed '*asking the health team questions*', '*interpreting doctors' orders*', '*repeating given instructions*' and '*translating for patients*'. Relatives contributed to a good relationship between the patient and the health team. In addition, relatives in both settings were observed reminding patients about information they had forgotten after a doctor's visit or health team discussion. Relatives and patients remembered different parts of patient history or information, which facilitated information-gaining process. In many instances relatives explained to patients the meaning of questions asked by the health team and encouraged patients to express and speak their minds. In the Australian setting patients often informed their relatives of any changes which had occurred since their last visit. It was the role of relatives to take on this information and refer back to nurses for elaboration because often nurses gave patients information in a very hurried manner.

Sometimes nurses used jargon that was familiar to them but not to patients or relatives, so relatives thought it was their role to interpret this information or ask for clarification. The majority of patients in both settings said their close relatives encouraged compliance with their treatment plans and medication. Additionally, in both setting patients acted in a dependent manner in the presence of their relatives, however, this was more apparent in the Saudi unit. Nevertheless this behaviour was also apparent in the Australian setting during visits. Relatives took on the responsibility of representing patients during their presence; some nurses encouraged this behaviour when they directed information and questions to relatives.

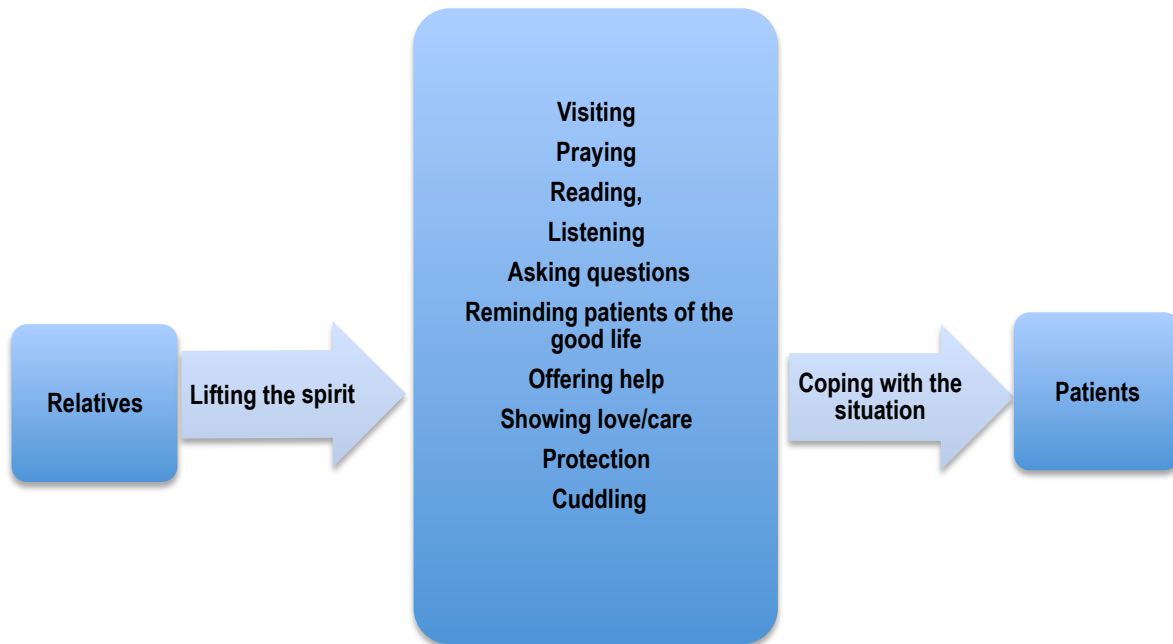
Some patients believed their relatives' presence gave them confidence and encouraged them to speak for themselves. In addition, many patients were observed to be happy and cheerful during visits. This even lasted after visiting hours and was also observed when patients were expecting visitors. In the Australian unit some patients kept their needs and wishes on hold until their relatives arrived. Some patients did not want to eat without a family member because they considered meals to be a social event. Others waited for their relatives to bring them food from home on ceramic plates and so they could use household cutlery, which gave them a taste of home. Very often relatives brought books or magazines and provided patients with educational booklets or notes. Some relatives in both settings



had a very special touch in making the surrounding of patients' beds look homely which added to patients' comfort. They also ensured patients felt comfortable in their bays. A relative in the Australian setting was observed asking a nurse if there was a possibility of changing the patient's room because there was a confused patient beside her loved one's bed and she feared him at night. Relatives contributed mainly by communicating with health team professionals. Furthermore, nurses in both settings used relatives' assistance to comfort patients during procedures, especially those that were particularly invasive. A few nurses in the Saudi setting asked relatives to explain healthcare decisions to patients if they had not listened to their instructions.

### **Lifting the spirit and spiritual involvement**

This theme was apparent when relatives stood by a patient's side and enhanced the ability of a patient to manage their stay in hospital and deal with sickness. Patients spoke about the stressors they felt in the hospital environment such as dealing with illness and their worries about their lives outside the hospital. In both settings, some patients had constant pain and needed help in their daily needs, or had social and financial problems. This increased the stress of their hospitalisation. Some patients expressed or presented with fear, anxiety, tears, restlessness, anger, sadness, fatigue or depression. At times these emotions were part of their journey in the hospital, adding to feelings of boredom, loneliness and disempowerment. Many patients preferred relatives' support because their relatives understood how they felt. Additionally, many relatives thought they had a comprehensive understanding of patient's likes, dislikes, and interests; therefore, they knew how to approach patients and decrease their stress. Relatives undertook many roles that appeared to lift patients' thoughts and spirits. Many nurses indicated that relatives made a big contribution to the emotional wellbeing of patients and the great feeling some relatives left on patients and the environment. Many nurses wanted to work in a happy or relatively manageable environment and this was more possible with the help of relatives. The next diagram represents a sample of the mechanisms used by relatives to lift patients' spirits, which was evident in both settings.



*Figure 8: A sample of the way relatives uplifted patients' spirits, in both fields*

The next section presents the reasons and advantages of relatives being involved in lifting the spirits of patients:

### ***Coping with the situation***

This subtheme represented the advantage of this type of involvement. Close relatives were usually aware of how patients felt, their daily life and past experiences and therefore had a better understanding of how to deal with patients at times of stress. Relatives provided comfort to patients on certain occasions, especially when they were anxious. In the Saudi setting one patient expressed her inability to tolerate the hospital stay without a relative and this was related to her unfamiliarity with and fear of hospital environment. The presence of relatives gave patients a feeling of comfort around others, allowed them to express their feelings, and reassured them. There were times when some patients lost their appetite or ate less because they were feeling anxious. These emotional drawbacks affected patients' wellbeing and progress. In both settings some nurses thought patients without visitors were bored, sad and lonely and this added to the workload of nurses as they had to spend time reassuring patients.

Relatives were observed saying encouraging words to patients and reminding them of their happy life and accomplishments. Many patients believed they could not speak to others in the ward about their

problems as it was difficult to explain their issues from the start, yet with relatives they did not have to do this. Some relatives in the Australian setting said they were not religious but they prayed with patients and read segments of holy books such as Quran and the Bible because it encouraged patients and appeared to brighten their lives. Some patients expressed their striving for closeness with God during their sickness because they felt lonely, sad or angry and felt happy when their relatives encouraged this. Many nurses in the Saudi setting thought it was relatives' responsibility to support patients spiritually. In contrast, in the Australian settings some nurses said that there were services to support patients spiritually if needed. Nurses believed that relatives' spiritual support contributed greatly to a patient's progress and also helped nurses to focus on care delivery.

## **2. The relationship between nurses and relatives**

This domain aims to describe the relationship between nurses and relatives in both fields and how this impacted upon relatives' involvement in caregiving. Whenever nurses spoke about having good relationships with relatives they connected this to good communication and an understanding between them *'two sides of the same coin'*. Nurses and relatives highlighted the positive influence of a good relationship and communication on patient care; however, data from both fields showed some poor communication which impacted relationships. Some nurses in both settings also linked the good relationships between nurses and relatives with quality of care. It also appeared that the good relationships between nurses and relatives had a positive impact on the nursing' role: *'...good relationships with the families facilitates my job'* (Nurse interview 6, the Australian setting, on 15/10/2013, at 3.00PM, p.18, L. 5). Nurses thought that good communication with relatives helped them to understand more about their patients. However, it seemed that nurses only acknowledged this relationship when they used relatives as a resource for information. Many nurses thought their interaction or communication with relatives served a purpose, which was patient care, but that the relationship should not go beyond this as it might progress and lead to emotional involvement. The following extract illustrates this view.

*'...The relationship between them and us should be restricted to work, no one needs to get involved'...I believe the nurses should not get emotionally involved with the families because it interferes with them delivering care'* (Nurse 3 interview, the Australian setting, on 10/09/2013, at 11.00AM, p. 6, L. 17-18, p. 8, L. 21-24).

When nurses described their jobs, some said they were caregivers and needed to measure and monitor patients' conditions and most importantly, administer medication. They focused less on the importance of communication. A few nurses in both settings explained how they felt about communication with patients' relatives. On many occasions nurses felt they only delivered doctors messages to relatives and vice versa. Some nurses in both setting thought relatives did not value the nurse's role because most frequently relatives only asked them about doctors' opinions and visits. This impacted on interaction and relationships with relatives, as nurses felt less important. However, relatives expressed the need for information from doctors about more crucial matters such as the patient's condition, medical instructions, medication, treatment plans, surgery, and discharge. These matters seemed to be more critical to patients' relatives, as the doctor is the one who gives the orders and plans the treatment, while nurses deliver the required care. During interviews in both settings all nurses expressed their awareness of the importance of having a good relationship and communicating with relatives. However, relatives sought more effective communication and interaction from nurses.

Relatives also thought communication was a significant element of building a good relationship with the health care team. Most important to relatives was the need to be provided with updated information, followed by a desire for trust and support; they also wanted continuity in relation to these aspects of the relationship. It was apparent in both settings that relatives wanted to have a good relationship with nurses in particular because they worked directly with patients. These selected quotes from relatives in both settings present the relatives' desire to be part of the nurse/patient's relationship:

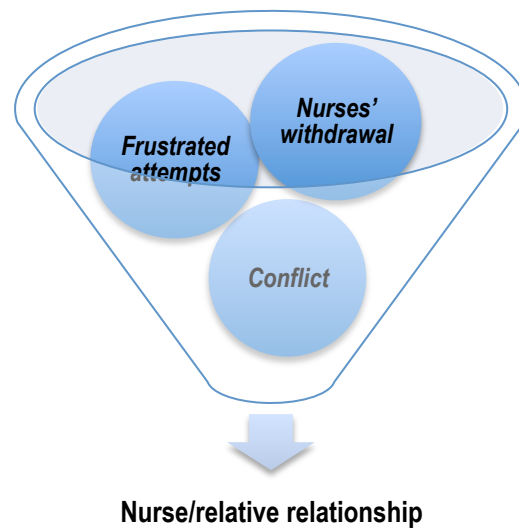
*'I want to be in the same picture'* (Field notes, the Australian setting, on 15/08/2013, p. 7, L. 22), *'She is my mother'* (Field notes, the Saudi setting, 23/02/2014, p. 27, L. 11), *'Please let me know'* (Field notes, the Saudi setting, 23/02/2014, p. 27, L. 12), *'I need to know'*, (Relative 2 interview, the Australian setting, on 21/08/2013, at 3.30PM, p. 3, L. 3-4), *'I felt ignored'* (Relative 5 interview, the Australian setting, on 10/09/2013 at 2.10PM, p. 11, L. 8-9), and *'I'm here if you need to know anything'* ( Field notes, the Saudi setting, on 23/02/2014, p. 27, L. 28-29).

There were also quotes from nurses' interviews that reflected the current relationship with relatives:

*'They might take what I have to say out of context and use it against me for anything'* (Nurse 6 interview, the Australian setting, on 30/10/2014 at 12.00PM, p. 28, L. 11-12), *'They think you ignore them and get upset'* (Nurse 1 interview, the Australian setting, 2/09/2013 at 11.00AM, p. 2, L. 9), *' They don't understand our job'* (Nurse 6 interview, the Saudi setting, on 20/2/2014, at

8.00AM, p. 11, L.6-7), *'I try to avoid getting into conflict with relatives'*, (Nurse 6 interview, the Australian setting, on 30/10/2014 at 12.00PM, p. 28, L. 12-13) *'They are not our responsibility'* (Nurse 7 interview, the Saudi setting, on 20/02/2014, at 8.45 AM, p. 13 , L. 6) and *'I'm careful because I had two complaints from them'* (Nurse 16 interview, the Saudi setting, on 3/04/2014, at 3.30PM, p. 30, L.14-15).

These quotes demonstrate that nurses were sceptical about their individual interactions with relatives and some of them felt there was a need to be careful around relatives. However, nurses did not deny their caring relationship with relatives was beneficial to patients. These sorts of perceptions reflected a gap in the relationship between nurses and relatives. It seemed relatives wanted a relationship with nurses; however, some nurses withdrew themselves from this relationship. The next subthemes present some features reflective of the nurse-relative relationship.



**Figure 9: Subthemes: Features of the nurse/relative relationship**

### **Nurses' withdrawal**

In both settings the researcher noticed that many nurses tended to stay in the nursing station and they seemed occupied when relatives were present. Some nurses approached patients if they were called or whenever necessary and many of them had less contact with patients during this time. A few took their notes and sat in the nurses' meeting room where no one could see them. In the Australian setting some nurses preferred to provide patient care without the presence of the relatives, but they understood their presence could be a necessity at times. The nurses in both units defended their approach to relatives

and justified their decision to *'withdraw'*. Some nurses linked the constant flow of visitors with restricting patient care:

*'...If we allow them to come any time they will be here all day and it is not convenient for us because we need to do things around here and we're somehow restricted on what we can do within these hours'* (Nurse 3 interview, the Australian setting, on 7/10/2013 at 9.30AM, p. 7, L. 6-9).

Some nurses felt uncomfortable providing patient care during the visits and preferred providing care before or after visits. In both settings, there were some nurses who believed the limited space beside patients' beds restricted their movement around patients. Some also believed nursing care took longer when relatives were present because they had to provide extra explanations to relatives. A few feared being judged negatively by relatives in the case of unintentional mistakes; some feared verbal conflict, or being instructed how to do their job. Additionally, some nurses thought they were being observed by relatives. In the Australian setting some nurses stated positive reasons for their withdrawal from the field during the visits such as privacy. They thought visiting hours were for family and patient time.

*'I delay things until they leave. They want to spend some time with their families'* (Nurse 4 Interview, the Australian setting, on 9/10/2013, at 9.10AM, p. 11, L. 9-10).

Moreover a few nurses delayed patient care or giving information to patients because they could not identify the visitors and they spoke about the patients' right to privacy during care and communication. In these cases, nurses believed patient care and information should be considered a private matter. In both setting some nurses thought that during visits there was no need to constantly observe patients, as relatives would inform them if patients needed help. In the Saudi setting, Saudi nurses in particular avoided any interaction with patients and relatives during the visits because they wanted to avoid comments or being criticised by visitors, especially male relatives:

*'Look, I avoid male relatives in particular. They might think I don't have morals because I work here. You see, no matter what I wear, look at me, I cover myself from head to toe, I speak quietly, but still they might talk badly about me because I'm a nurse, you know what the reputation is like. If I spoke with those men in that room or went around those patients they might say something bad or leave the room. A male visitor gave my friend that look, you know, like saying you're bad, and one 'Muttawa' (a name for a strict Muslim male), he came to visit his wife, he gave us a*

*lecture about how awful we were, so better to avoid putting myself in this situation in the first place*'. (Nurse 16 interview, the Saudi setting, on 3/04/2014, at 3.30PM, p. 31, L. 6-13).

Many relatives in both settings thought the nurses' withdrawal gave them a sense that nurses wanted to avoid them, but the nurses stated that their avoidance of relatives was not intended. In most cases nurses were not aware of this behaviour. Some relatives in both settings explained how hard it could be to gain information from nurses during visits. Three relatives in the Australian setting said it was easier for them to find out information by calling the unit and a few relatives in both fields felt unsatisfied when they did not see the assigned nurses during their visits.

During fieldwork in both settings the researcher observed some non-verbal behaviour by nurses towards relatives that gave relatives a feeling the nurses did not want any interaction with them. For example, nurses speaking to relatives when they were walking away from them, not making eye contact, failing to introduce themselves, leaving in silence with no response to questions, looking at the relative briefly and then carrying on their work without response. Furthermore there were some quotes from nurses which highlighted their withdrawal, such as, *'I don't know'*, *'I'm busy'*, *'That's not my job'*, *'I have other things to do'*, and *'I have some work [to do] here'* and, *'ask the doctor, don't ask me'*. Relatives stated they usually did not disturb nurses with many questions or requests during visits especially when they looked busy, the reason being that nurses appeared to be short tempered during the visits. Some Saudi relatives said the nurses' attitudes changed during visits as nurses became overwhelmed and conveyed their stress to others; this made relatives avoid interaction with nurses during visits. This withdrawal or avoidance impacted negatively on the relationship between nurses and relatives.

In most cases withdrawal by nurses seemed to be related to the hectic pace of work and busy environment associated with visits. Frequent issues emerged on the surface from a lack of interaction between nurses and relatives, most significantly because relatives wanted to know more about patients and wanted to be on the same page. Many patient and relative participants believed their relationship with nurses could not be called a partnership as there was a lack of effective communication. To explain what was going on in both fields it was necessary to highlight the reasons for this withdrawal. The following table shows other reasons for what seemed to be *'nurses' avoidance'* of relatives' during the visits.

| Category                           | Reasons nurses avoided relatives during visits   |
|------------------------------------|--|
| Nurses attitudes during the visits | <ul style="list-style-type: none"> <li>• The patients' condition was stable so there was no need for constant care.</li> <li>• Ability of nurses to use this time for completing documentation.</li> <li>• Patients did not require any care during visits.</li> <li>• Patients did not ask for any assistance during visits.</li> <li>• If patients needed any help visitors would inform the nurses.</li> <li>• Nurses delivered necessary care before the visits.</li> <li>• Most patients were given care during the day.</li> <li>• Nurses expected the patients to inform them if they need anything, <i>'Please let me know if you need anything, press the buzzer'</i>.</li> <li>• Nurses thought that some nursing duties could not wait, while some could, <i>'Some patients' care could wait until the end of the visits'</i>.</li> <li>• A few visitors pulled the curtains around patients' beds; this gave nurses the impression to <i>'not interrupt'</i>.</li> <li>• Nurses judged situations from their experiences of the past. In cases where relatives could be demanding, a few nurses avoided going to see patients during visits to avoid conflict.</li> <li>• Thoughtful attitudes such when some nurses believing patients had only 4 hours to see their loved ones, which was short time.</li> <li>• Some relatives arrived only to visit for few minutes or they were in rush, which did not give nurses time to interact.</li> </ul> |

**Table 11: Reasons nurses avoided interacting with relatives during visiting hours**

### **Frustrated attempts**

Repeated attempts by relatives to assist patients in meeting their needs and wishes sometimes impacted the nurse/relative relationship in a negative manner, especially when patient care required the presence of a nurse. Some relatives tended to assist patients even if they were informed to leave the care for nurses. This behaviour changed how nurses managed their relationship with relatives as they became less trusting and watched relatives more closely. The main reason relatives behaved in this way was because patients were constantly requesting help from nurses during a relative's presence and sometimes the required help was delayed. This led to frustration for relatives, endangered patients and put nurses under pressure. For example, patients have constant needs and when relatives are present they tend to provide the assistance to patients themselves or look for help. This behaviour was less common in the Australian setting as relatives were less commonly present. In the Saudi setting this happened constantly because relatives remained beside the patients during their stay in the hospital; therefore their attempts to assist patients were more frequent. In the Saudi setting relatives were commonly the first people to hear patients' requests followed by the nurses. Usually in both units, after



the patient asked for help, relatives weighed up what they could do for the patient based on their own perceptions of what was simple and what was complex. These perceptions may or may not have been correct. This meant that if the patient had asked for a cup of water, a relative might think this was a simple request and provide it to the patient while another relative may seek the nurse's assistance or permission. The following examples from the observation notes give a description of what relatives did after a patient requested their help:

*... The patient said I want to have a walk for a few minutes. The patient's daughter said, 'I will call the nurse to disconnect your fluids' line. 'You know I cannot do this'. The daughter went immediately to the nursing station to call the nurse for help... (Field notes, the Australian setting, on 12/09/2013, P. 56, L.31, p. 57,L. 1-2).*

Also there were many examples in the Saudi setting,

*At around 1.30PM, Aziza, (the patient, asked Fatima, the relative, to assist her to the toilet. Aziza sat at the edge of the bed and said to Fatima I feel a bit dizzy, Fatima asked Aziz, 'Shall I call the nurse for her help?' Fatima said, 'I will be OK'. After five minutes Fatima walked Aziza to the toilet. A few minutes later, Fatima came out from the bathroom and rushed to the nursing station. A nurse came to assess the situation. The nurse went outside and brought a wheel chair and helped Aziza back to her bed. She covered her with blanket and brought the vital signs machine and checked her blood pressure. The nurse told Fatima, 'You should have called me before you took her to the toilet. Next time if she feels dizzy call the nurse first' (Field notes, the Saudi setting, on 12/02/2014, p.12, L.16-23).*

As can be seen in the examples above, relatives assessed what they could and could not do for patients and reacted accordingly. In both fields the nurses thought if relatives assisted patients without their knowledge this could jeopardize the safety of the patient. This could then reflect poorly on the relative and the nursing care provided. Relatives expressed their desire to assist patients immediately and they felt frustrated when they were unable to help. In these cases nurses were firm with relatives and this impacted their relationship with relatives.

When there was a delay in the nurse responding to requests for assistance this caused significant anxiety and frustration for relatives and patients. Many relatives expressed their concerns when nurses delayed assistance because it could negatively impact patient, and many said it showed nurses were

inconsiderate to patients. Delays sometimes resulted in relatives assisting against their better judgment. Their requests could become issues if they were unmet by nurses and relatives acted in the interim, especially when some requests were considered cases that 'can wait' by nurses. Nurses categorised calls for help depending on the nature of help required and whether it was urgent or not. The length of time relatives waited before assisting themselves or seeking further assistance varied from one relative to another. In most cases ten minutes was considered too long from the perspective of relatives; however, many nurses in both fields did not think a five to ten minute delay was a problem. Most nurses treated all calls for assistance as immediate but would not defer what they were doing unless the call for another patient's assistance was considered more urgent. Nurses prioritised their work and if they thought the patient who asked for help could wait they would continue the work at hand; however, many relatives did not want patients to wait. One nurse stated:

*'They can be a little impatient with things. I think sometimes when you're close to someone they think only of that person, but we have four or other people we are looking after at the same time and try our best to get everything done. That can get a little bit... I think they can be a bit anxious at times'* (Nurse 10 interview, the Australian setting, on 18/11/2014 at 3.00PM, p. 39, L. 20-24).

The following extract is from the Saudi field and involves a relative's angry response because a nurse was not able to come and assist the patient immediately after they called for help. Sometimes this was even more frustrating for relatives when they thought a nurse was doing less important work at the time of their request. In fact, a lack of response from nurses to relatives' calls for help increased patients' dependency on relatives:

*'You know I called the nurses to fix the intravenous line when the fluid was not running anymore, if I can fix the intravenous line! It will take nurses a long time to come here and do the job. Sometimes I cannot wait. I want things to be done immediately. It's my mother, you know, I only have one mother and I need to protect her'* (Relative 5 interview, the Saudi setting, on 14/02/2014 at 2.45PM, P. 8, L. 9-12).

Many relatives in the Australian field also spoke about how long patients might have to wait before receiving help from nurses:

*'I don't see them... if she needs anything this has to be done immediately. I don't wait for the nurse'* (Relative 3 interview, the Australian setting, on 2/09/2013 at 3.30PM, p. 6, L. 6-7).

Relatives frequently stated that they excused nurses as they were busy, but this comment was not reflected in their demeanour when they had to wait for a nurse's help. It was clear that delays left them feeling unsatisfied with the care their loved ones received. The researcher observed that the period of time patients and relatives waited for assistance was critical to how the standard of care was regarded by patients and their relatives. Nurses in both settings said in some cases this affected their relationship with relatives because even if they explained and apologised for the delay, this would not ease the situation with the relatives.

## **Conflict**

Nurses did not always perceive relatives' involvement as positive, especially in providing quality care; some thought relatives could be a disturbance, especially during times when work was hectic. In both settings nurses spoke about issues they experienced when they dealt with relatives. All nurses in this study could remember some undesirable interactions with relatives and these experiences impacted their relationships with relatives. Surprisingly, one of the dominant issues for nurses was relatives asking many or repetitive questions. In both settings nurses said that when relatives asked them '*too many questions*' this created work disruptions. Nurses explained how the amount of questions wasted their energy and time caring for patients. A few nurses in both units considered asking or repeating questions a demanding behaviour from relatives.

In both settings nurses refused to provide repeated information to relatives and thought they should listen when information was first given to them. Additionally, nurses felt negative about relatives because of the poor timing of relative's questions. Two nurses in the Saudi setting said relatives interrupted them while they were attending to other patients to ask questions, and a nurse in the Australian field said nurses experienced interruption to meetings or shift handovers to answer relatives' questions. In contrast, relatives thought they should be able to ask questions without restrictions as they were only visiting for a short time or had their own concerns at the time. The researcher observed more interruptions or interference in the Saudi setting. The constant presence of relatives in their 'companion' role in the unit created continuous interactions with nurses but not always positive ones.

In the Saudi unit, nurses thought that some relatives created a negative environment for patients by being constantly over protective:

*'... Sometimes they could be too protective. If they were protective then the patient would not receive complete care because the nurses may avoid the patient or could be very cautious with the family'* (Nurse 16 interview, the Saudi setting, on 3/04/2014 at 3.30PM, p. 30, L. 13-14).

Many nurses believed overprotective relatives were either insecure or mistrusted nurses' efforts. The nurses were also pressured and frustrated when relatives interfered in their nursing care. One nurse in the Saudi setting spoke to a relative in a loud tone because she was disturbed during the insertion of intravenous cannula. Another nurse described relatives' over protection as a *'nightmare'*. She also said the following:

*'I have had experience of them refusing certain caring approaches, medication, signing consent [forms], and surgeries'*. (Nurse 3, the Saudi setting, on 12/02/2014, at 3.00PM, p. 5, L. 25-26)

Some relatives believed that what they did was beneficial to patients' wellbeing. However, nurses feared that relatives' over protection could lead to more controlling behaviour by relatives. A few nurses in the Saudi setting believed relatives' over controlling behaviour towards patients did not make relatives their partners in care. Four nurses in the Saudi setting thought that relatives' presence in the unit should be restricted to visiting hours and agreed that some relatives' protective behaviour had inhibited patients' progress in the past. Nurses in both settings considered behaviour that disrupted the course of care as interruption and interference.

The next table presents some challenges relatives presented to nurses during patient care:

| Included terms  | Semantic relationship | Cover term   |
|---|-----------------------|--|
| <ul style="list-style-type: none"> <li>• Asking many questions</li> <li>• Instructing nurses</li> <li>• Interrupting, refusing or interfering with care, verbally or physically</li> <li>• Mumbling</li> <li>• Sighing</li> <li>• Asking the nurse frequently if care had been completed</li> <li>• Giving orders (demanding)</li> <li>• Blaming the nurse for patient's pain or deterioration</li> <li>• Accusing the nurse of being rough or incompetent</li> <li>• Comparing one nurse with another</li> </ul> | Kind of               | Challenging behaviour of relatives during nursing care |

**Table 12: Challenging behaviour of relatives during nursing care in both settings**

Relatives denied any interference in patient care and believed such behaviour could negatively impact on a patient's progress and relationship with nurses. In the Australian setting relatives respected a patient's independence and ability to make the right decision. Patients usually made their own personal decisions and it was up to them how far they wanted their relatives to be involved in their care. However, in the Saudi setting many relatives thought they had the right to decide what was best for patients. On some occasions relatives believed they had been accused with interfering in nurses' duties but for them these accusations did not make sense. One relative said the following:

*'I don't interfere in nurses' jobs. Nurses keep telling me I interfered in their jobs. I'm here to look after my sister. I'm not here for problems. They told me to be quiet when I had something to say, how is this right? Well I don't think so. Is telling them be gentle interference? Or is telling them to explain interference? I don't understand. I remember telling a nurse to be gentle when she moved my sister's leg. It was sore. Also I told the nurse in the ER that she [should] not insert the intravenous cannula [on the second occasion she was required to do so] after she missed the vein [the first time around]. Do you think this was interference?' (Relative 1 interview, the Saudi setting, on 10/02/2014 at 2.30PM, p. 2, L. 24-30)*

It was necessary to understand some of the reasons relatives had defensive attitudes towards patients. In both settings it was observed that certain types of patient care caused stress to relatives if they were present during care, such as invasive procedures. Relatives were more likely to show uneasiness during these procedures because they knew it could cause pain or discomfort to patients, such as taking blood and inserting intravenous cannula. Some nurses in both settings reacted positively when they sensed relatives' stress; they reassured relatives or provided detailed information about the procedure they were conducting, which helped to rectify problems at the start. In the Saudi setting there were times when nurses reacted negatively in response to relatives interrupting them. They responded by asking the relative to leave, trying to finish the care quickly, or raising their voice. These reactions appeared to escalate the situation and cause more frustration for relatives and nurses.

### **3. Safety strategies and implementation**

This domain describes how nurses managed relatives' participation in both fields in the absence of policies to guide their involvement. In both settings, there were an absence of policies and guidance about the role played by relatives in patient care. There was a gap in nursing care surrounding the role relatives play in care; this issue contributed to the ambiguity about nurses and relatives roles and created safety issues. The absence of policies in both settings also permitted variations in the involvement of relatives in patient care and resulted in diverse perceptions of what a relative's role might or should be. In these matters the only guidance nurses had were personal views; these were influenced by cultural variations in each setting and safety measures. In both settings nurses assessed patients individually to distinguish their needs. This helped them to classify the involvement of relatives on the basis of patient safety; based on initial interaction with relatives and patients they developed a report for the nursing care plan. Based on nurses' classifications they either *encouraged* or *limited* relatives' participation in the care.

In terms of safety in the unit, nurses were in charge of assessing and identifying hazards and eliminating them to create a safe environment for all. In both settings the nursing team imposed physical and psychological safety measures in care delivery covering nurses, the environment, the health team, and visitors as well. On many occasions relatives observed nurses using integrated safety strategies to undertake patient care, but these were not necessarily clear to patients or relatives. Many of the safety skills practised by nurses in the hospital environment were considered vague or patients and relatives were not aware of them. Therefore, it seemed that direct and specific information contributed to relatives' understanding of safety more than nurses' behaviour when giving care.

Relatives mainly received or learned safety measures verbally, in the form of instructions, questions and answers, information or recommendations. They also gained safety knowledge physically, such as when nurses demonstrated care procedures or where relatives were given written material, for example posters or brochures.

It is important to identify the safety strategies used in both settings before describing the subthemes associated with this domain. The following descriptions of the Australian and Saudi settings demonstrate how nurses managed the involvement of relatives from the time patients were admitted.

### **Safety strategies: An overview of the Australian setting**

There were no policies to describe a relative's role in patient care or the responsibilities nurses had in relation to the involvement of relatives. If relatives wished to assist in care then this was discussed between relatives and the nursing team. Patients were provided with a '*patient information guide*' flyer, which offered information on services and procedures to assist patients and their relatives to easily access information. This guide did not contain any information for relatives about the role they could take if they wished to contribute to patient care. In the unit, the involvement of relatives was not negotiated between nurses and relatives; it was constructed during a patient's stay. If patients wanted relatives to be involved in their care and communication, one member would usually be nominated during admission. Sometimes assistance from relatives was reviewed based on patient needs and changes to their condition. In most cases when the nursing team received patients from other units, they continued to care for the patient based on previous plans. This meant they continued what had been previously planned and added to the plan, because every unit had their own way of involving relatives in care, which suited their particular care environment. Therefore, in this Australian unit, nurses informed new patients and relatives of the routines in the unit and encouraged them to ask further questions.

In cases where the patients were transferred from the emergency room, the medical unit generated a history and care report with new patients and their relatives, and based on this report the needs of patients and relatives were discussed and recorded in the care plan. If relatives informed the nursing team of their need to participate in patient care at any stage then guidance was provided accordingly. In most cases relatives cooperated with nurses' efforts to promote patient health and also followed their instructions. The researcher noted only a few scenarios where relatives were dissatisfied with care delivery and this was associated with personal expectations of care. The Clinical Service Coordinator

(CSC) in the unit followed up any issues with relatives if the nursing team could not progress further. The CSC indicated that she supported the 'family centred care' paradigm and stated that patients and their families should be treated as partners in care. Accordingly, relatives were given the opportunity to be involved in patient care. This involvement was not necessarily physical, but it did involve patients and their relatives making a choice about their participation. There were no descriptions or regulations to guide nurses and relatives through this process, even more so when issues about this involvement arose:

*'...We don't have any strategies on paper to control any mistakes done by relatives, not that I'm aware of'* (Nurse 7 interview, the Australian setting, on 18/11/2014, at 1.45PM, p. 30, L. 6-7).

It is essential to state that relatives' involvement in care was not always communicated to relatives at the admission stage, unless patients or their families raised this subject themselves. This was why many relatives had their own thoughts and beliefs about the nature of their involvement.

### **Safety strategies: An overview of the Saudi setting**

The Saudi Arabian hospital also had no policies covering the involvement or roles played by relatives in patient care. During a patient's admission to hospital relatives were given a form to sign. This form stated several rules to be followed by relatives during their stay. For example, relatives were not permitted to leave the unit without permission from the assigned nurse. This kind of information was given to inform relatives that nurses were in charge of the unit. The Director of Nursing stated that this form was not considered to be a policy but a set of internal hospital instructions which were distributed to avoid any issues which may arise from a relative's presence on the ward. If a patient was admitted to hospital via the emergency room, the relatives interviewed did not receive an explanation of their role or involvement in care or what they could possibly do in terms of care. A relative would usually be designated by the family at the admission stage to accompany the patient during her stay in hospital. After their arrival, patients and relatives in the unit would be given information about what to expect from their stay, such as the time for medication and meals. Relatives were told in patient admission to ask nurses for any further information and to bring up any issues of concern. Typically relatives gained care information from nurses gradually, as instructions, but not in the form of discussions or meetings. Saudi relatives had preconceived notions of their role in the hospital and also how they should behave in the hospital environment and this was influenced by religious and cultural beliefs. A few relatives said

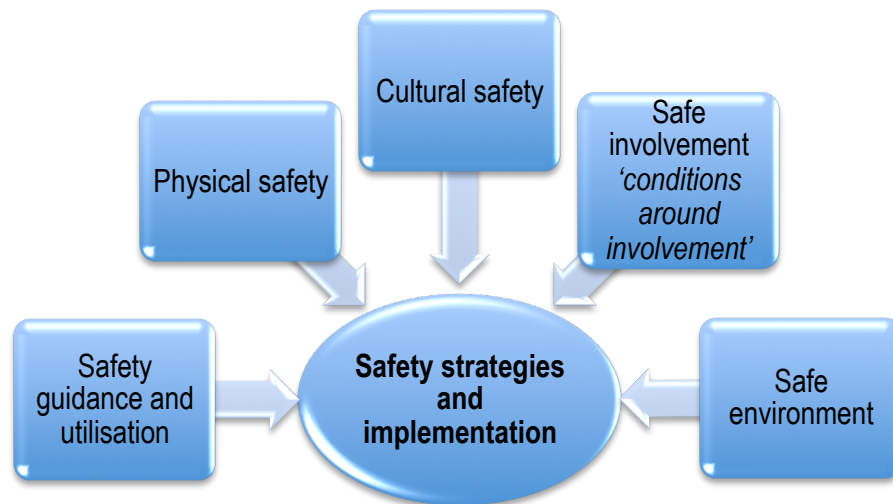


they had an understanding of what they felt they should do in the hospital environment and this was gained from interactive relationships with others, both inside and outside the hospital.

In the Saudi setting there were no measures to regulate relatives' activities in the unit. Nurses imposed some instructions to create order in the unit; however, this was not always effective in managing everyday routines. It was apparent that family bonds and social relationships had a stronger influence on how relatives participated in patient care, than any instructions given by the nursing team. For this reason the head nurse said she received several complaints from nurses about relatives interfering in nursing care, and nurses said they also experienced stress from intrusive relatives. In contrast, some of the relatives' complaints were that nurses acted negligently towards patients and this was the reason relatives' extended their responsibilities in this unit.

Relatives' complaints were not always about nurses and nursing care. Their complaints were wider and included criticism of other aspects of the hospital; for example, they wanted beds to sleep in and waiting rooms in the unit. There were no guidelines for the nursing team to follow in relation to relatives' involvement in delivering basic care to patients. Suggestions and issues in the unit were referred to the head nurse and she took these to the next meeting with the team. The nursing team generally planned a way to solve internal issues before they were raised with the Director of Nursing or hospital management. The head nurse and nurses worked together to enforce safety measures for relatives, such as giving instructions not to lift patients without nurses' assistance; however, sometimes relatives ignored these instructions because they were frustrated by the waiting time. All nurses thought there was a need for official policies from the Ministry of Health to explain relatives' role in the hospital.

The next subthemes show how nurses in both settings managed relatives' involvement in response to the absence of policies. Five subthemes emerged from data analysis but no subsidiary themes emerged from the subthemes. The findings were highlighted according to their appearance in the Australian and Saudi settings. The diagram below presents the subthemes of this domain:



*Figure 10: The strategies considered in the settings for safe involvement*

### **Safety guidance and utilisation**

There was no doubt that safety of all parties involved in care was considered essential in both settings, but this was based on the nature of relatives' involvement and the setting. In the Australian setting, for example, the relatives who wished to be involved, especially in physical care, were given the opportunity to ask questions at the time of care. Nurses gave more elaborative instructions around safe care with those relatives who stayed for extended hours in the hospital, such as relatives of acutely ill patients, or those who were known to provide care for patients. Those relatives were more involved in patient care than others; thus, it was considered necessary for nurses to guide them through care safely. The majority of nurses in the Australian setting were unconcerned about the involvement of relatives because their participation was uncommon and when it happened, it was under their control. In contrast, in the Saudi setting the nurses expressed anxiety and many said they tried to keep patients and relatives safe when relatives were involved in care. Incidents which compromised safety were more likely to occur in the Saudi setting and in some cases were inevitable. As described previously, relatives were not educated directly; it was more a gradual learning process. In both units relatives learned some safe techniques such as hand hygiene and hand sensitising, but this was not necessarily emphasised by nursing instructions and relatives learned this mostly from posters or brochures or watching others.

Additionally, some relatives observed nurses wearing gloves but considered this only a practice for nurses in the hospital. In some cases when relatives were involved in patient care, nurses put on gloves but did not inform relatives to do the same. It was perceived as unnecessary by the relative because the nurse did not ask them to wear gloves. Nurses encouraged relatives to ask questions

frequently and explain concerns; this enabled nurses to understand the deficiencies in a relative's knowledge. This strategy was used by nurses in the Saudi setting, when nurses felt they did not communicate well with relatives. When relatives asked questions and expressed their doubts, this helped the nursing team to comprehend their level of understanding. Nurses took on the full responsibility for bedside care; therefore, nurses considered relatives' involvement an addition to their other responsibilities. Patients and relatives gained information from a variety of sources so what was understood was unpredictable. On some occasions relatives assisted patients in physical care when they had been informed beforehand that they were not supposed to, for the sake of patients' safety:

*'So [if] relatives believe they can do it on their own, things can happen. They can drop a patient or hurt themselves or hurt the patient. They don't really understand [that] while they are under our direct care, [it is] nurses who have to give the care, not them. Until we have worked out a better plan of action, it gets a bit difficult sometimes. They try to do things they shouldn't do'* (Nurse 6 interview, the Australian setting, on 30/10/2014 at 12.00PM, p. 28, L. 22-26).

However, there were only a few incidents in both settings which gave nurses the impression that relatives were uncooperative and these incidents were linked to misunderstanding instructions. In a few instances relatives assumed the information given to them was a short-term instruction because they had not received further instructions:

Nurse one informed a relative it was good to take the patient for a walk during the visits. The next day when the relative assisted the patient for another walk, she was informed by nurse two that she should not assist the patient to walk without permission. The relative seemed clueless and said, *'I was informed this was good for the patient'*. She did not understand why it had been fine to take the patient for a walk yesterday but not today. The patient appeared well and was looking forward to the walk in the afternoon visit (*'I need to get some clean air'*). The nurse had only asked the relative to seek permission before taking the patient for a walk. However she did not explain her instructions to the relative. This situation left the relative confused (Field notes, the Australian setting, on 4/9/2013, p. 41, L. 20-27)

In the previous example the nurse expected the relative to inform her before assisting the patient to walk. The relative was unsure what the nurse's statement meant. Was there a problem assisting the patient? Was the walk itself a problem? Was it the safety of the patient, a change in the patient's condition, or merely an issue of permission? From this example it can be seen that the health team

understood the meaning of the instruction, but it was not understood by the relative. More importantly, instructions changed based on a patient's conditions and differed according to everyday situations. Patients and relatives said they were satisfied when the instructions were specific and conveyed clearly.

Some relatives said they balanced their lack of safety information and practices by ensuring they only acted in the presence of nurses. Most of relatives' fears were connected to safety matters, such as harming patients. Their fears also showed a lack of information about care. However, nurses' attendance during the care with relatives do not always mean safe care delivery. Several relatives in both settings demonstrated a lack of understanding of nurses' instructions during care giving, which could be a concern. Additionally, only a small number of relatives noticed that nurses were implementing safety procedures in the unit or during care. For example when nurses put on gloves before caregiving, and when they gave information about medication, these processes were not perceived by relatives as involving information about safety. Some stated they were encouraged to wash hands when they touched patients. A few relatives rubbed their hands with the hand sanitisers before they left the patients' side. Additionally, one relative said she was told not to use a patient's personal belongings but she did not know the reason.

Inadequate guidance or information and unfamiliarity with care delivery procedures meant that there were gaps in relatives' understanding of safe practices. It was difficult to predict how much information relatives learnt during their visits or stay in the hospital. All relatives interviewed expressed their need to understand how to protect themselves and patients from infection and environmental hazards. It was even more difficult for Saudi relatives as they had little information, which they gathered from discussions with one another. Moreover, some nurses in these settings believed only the patients were their responsibility, not the relatives. This was a reason why they did not offer much guidance to them. In general, at times relatives underestimated the risks associated with providing care to patients because they lacked any awareness of safety.

Relatives stated other problems associated with the way instructions were delivered by the health team, which they believed created gaps in their understanding and misinterpretation of given information. For example, the use of scientific terms made understanding difficult, as did rapid speech, a low tone and a lack of eye contact for people who did not speak the native language (English or Arabic). Additionally, when the safety guidance was unclear for relatives it was for two reasons. Firstly, when instructions were buried in the given information, and not emphasised or explained properly, then it was more likely to be incomprehensible. Secondly, instructions were often given to relatives only once. Problems

emerged for relatives in situations where the condition of the patient they were looking after changed. Often initial instructions were not modified by nursing staff, which meant that relatives continued to act according to the first instructions, when these were no-longer appropriate for delivering safe care. In both units the nurses worked hard to promote safe involvement of relatives, but there were common misunderstandings and misinterpretations and this put nurses, patients' and relatives' safety at risk. Some nurses asked relatives specific questions so that they could recognise whether relatives were able to or wished to be involved in care. Questions such as, '*Are you able to do this?*', or '*Can you do this*' enabled nurses to show consideration for relatives and also to understand whether they needed further information.

The nursing team in both fields adopted techniques to communicate with patients and relatives effectively. This involved direction, instruction, explanation, interpretation, discussion and participating in nursing handovers. The next table presents examples gathered from both settings which show the different ways nurses conveyed information to relatives:

| Type of information | Example  |
|---------------------|--|
| Explanatory         | Showing the patient and her relative a poster explaining the risks of falls  |
| Descriptive         | <i>'I need to use this (lifter, hoist) to prevent my back from injury. If I get a back injury I cannot continue doing this job. I need to look after number one, which is me'</i> (Field notes, the Australian setting, on 21/08/2013, p. 18, L. 7-8). |
| Informative         | <i>'...The doctor said she can not eat the night before she has surgery'</i> (Field notes, the Australian setting, on 5/09/2013, p. 43, L. 5-6).   |
| Specific            | <i>'...She will get her medication after lunch'</i> (Field notes, the Australian setting, on 10/09/2013, p. 50, L.27-28).  |
| Optimistic          | <i>'She will be fine in a while. I gave her painkillers'</i> (Field notes, the Saudi setting, on 10/02/2014, p. 2, L.4).   |
| Investigative       | <i>'Do you know how to do this? What do you know about this, or can you do this?'</i> (Field notes, the Saudi setting, on 22/02/2014, p. 24, L. 17-18).  |
| Diplomatic          | <i>'Don't worry I will do this in a couple of minutes'</i> (Field notes, the Australian setting, on 10/09/2013, p. 49, L. 17-18).  |

**Table 13: Communication techniques used by nursing staff in both settings**

The researcher believes these types of communication assisted patients and relatives to understand certain aspects of care and therefore lessened the occurrence of dissatisfaction, frustration and enhanced the safety. Relatives engaged in care against their better judgment when they were frustrated or unaware of the consequences. It was apparent that when nurses educated relatives or conveyed informative and specific information this increased the satisfaction of patients and relatives. Relatives gave examples of where they had gained constructive knowledge and in many of these cases the information had been conveyed specifically. Being optimistic and diplomatic created positive reactions for a short period of time for patients and relatives, but when nurses did not deliver what they promised '*in a few minutes*' this caused more dissatisfaction, because patients and relatives then realised the information they had been given could not be relied upon. It was necessary to indicate that patients and relatives in the Australian setting listened carefully to nurses during the handovers and experienced this as an informative way of communication. However in the Saudi setting it was not highlighted as important, and many times the handover was not understandable because it was performed in English and many of the patients and relatives spoke no or little English.

### **Physical safety**

Generally nurses in both settings were more likely to encourage relatives' involvement in care if patients were mentally and physically stable. Nurses assessed a patient's condition before they allowed involvement.

*'If I ask the companion for help it's going to be very simple, not challenging... I make sure that a patient's condition [is] stable'* (Nurse 3 Interview, the Saudi setting, on 12/02/2014 3.00PM, p. 5, L. 21-23).

Based on a nurse's judgment, the stable patient has certain characteristics; vital signs should be within normal parameters, the patient should be conscious, and the patient should also be satisfactorily physically well. In cases where the previous characteristics were not present, if patients were independent then they were allowed and taught to help themselves in both settings. When patients had the ability to perform their daily living activities or meet their fundamental care needs relatives' involvement was considered safe because their contribution would be minimal. It was also up to the patient to permit their relatives to assist them in their daily needs.

In the Australian setting patients were encouraged to assist themselves if they were able to and this was considered safe practice. Additionally, patients in the Australian setting were reliant on their relatives during visit times. In the Saudi setting patients were reliant on relatives for their care generally; this was apparent and was considered customary. The nurses in the Saudi field limited relatives' involvement when patients were unstable. In these cases nurses delivered care but allowed relatives to assist. In most instances they did this to guarantee the safety of those patients. In both settings, the nurses often used '*patient stability*' as an indicator to measure the safety of relatives' involvement, but this was not always the case, as patients could be stable but not able to balance themselves or walk alone. However, ensuring physical safety of patients sometimes encouraged nurses to request the help of relatives; for example, relatives provided essential assistance to nurses when stressed patients needed looking after. Nurses involved relatives because they thought this would enhance security and safety in the care provided to patients, as nurses expected relatives to understand the patients' needs and feelings.

### **Cultural safety**

Nurses in both settings promoted another approach to safe involvement in patient care and this was through showing respect to people' cultural differences. A relative's cultural background was observed to impact on the way relatives interacted with the health team and also on the role they wanted to take in care. Usually when nurses respected cultural differences this prevented them from stereotyping relatives and improved encounters between relatives and nurses during the provision of care. The Australian unit was a multicultural setting both for nurses and patients and they interacted with one another and respected each other's differences. Nurses did not have ethno-specific knowledge of their patients; instead they asked patients and relatives to inform them about any cultural requirements, which helped them to promote the effective care delivery. Nurses also involved relatives in care to compensate for their lack of understanding of patients' cultural beliefs and practices; nurses were more self-assured when they involved relatives in care:

*'...What we find more often than not [is] that we have to give information to relatives about expectations because being [in a] very multicultural society, different cultures have different expectations of the family so far. For instance, we've got a Vietnamese lady in the ward today. Her family play big part in her home support so she is 100 years old. In her culture the family stay home, that's what they want, they don't need any support from us but we offered it. We make sure*

*the patient gets the right care at home and the patient is happy. We discuss this with the family'* (Nurse 5 interview, the Australian setting, on 30/10/2014 at 12.30PM p. 25, L.21-27).

The relative in the example above explained to nurses that she needed to take part in care because as a female in her culture she was expected to look after family members. She had her own way to show respect to her mother during care. The nurse who was assigned to look after this patient felt comfortable when the patient's daughter was involved, because she knew what to be careful about culturally during the care. Nurses expressed their awareness of other's cultural beliefs and religion and considered these sensitive matters that needed to be taken seriously during caregiving. Additionally, nurses felt stressed when they encountered situations of a cultural or religious nature which led to patients becoming upset, because they did not know the extent to which they had provoked the situation or caused dissatisfaction. This next example happened in the Australian setting, where the nurse was not sure what she did wrong to upset the relative:

The daughter said to the assigned nurse *'Please my mom needs something to eat, can you get her lunch please'*. The nurse said, *'Yes of course. Oh the lunch is here what's wrong with it?'* The daughter pointed at her mother's lunch plate and said *'This sandwich has bacon in it. My mother cannot eat this sandwich. She can't eat bacon. Please bring my mom a hot meal. Can you call the kitchen please?'* The nurse went to give the kitchen a call. The daughter said, *'I can't believe they brought her bacon. She has been here for a few days, what inconsiderate people. The nurse should know this [as] she is the one who filled the menu form. I feel insulted. She is a diabetic patient and she is starving. They brought her wrong meal'* The daughter was speaking in a loud tone. Everyone in the nursing station looked at her, and she looked stressed and frustrated. Other patients and relatives in the room gave her comforting words and asked her to be calm. (Note that the assigned nurse did not know the patient had just come out of surgery because the nurse had been having her lunch at the time. Another nurse received the patient, connected intravenous fluids to her arm, measured her blood pressure, and said to the daughter that her nurse would be here in a minute). The assigned nurse came again to the room and asked the daughter, *'Can she eat meat?'* The daughter said, *'She can't eat this type of meat, she eats halal meat, love! You should know this by now. She is your patient, you should know her preference. Please bring her a salad if you cannot get her a hot meal'*. The nurse said, *'All right. You could bring her food from the house if you need to cook something for her before you visit'*. The nurse asked again, *'Is she vegan because I'm vegan. I have a preference [for vegan] food my self'*, The daughter replied, *'No love she is not vegan, she is Muslim. She doesn't eat this type of meat. Do you understand?'* The



nurse replied, *'No, not really but I called the kitchen. They will bring her something else, OK?'*  
(Field notes, the Australian setting, on 10/09/2013, p. 51, L. 3-22).

The nurse in the example above felt as frustrated as the relative because she did not understand why the relative was upset with her. Later she came into the room and explained to the relative that she did not mean to cause any problems. However, this explanation was not enough for the relative because she thought the nurse should be aware of these differences, especially as the patient had been staying in the unit for a few days. In the Australian setting, care was provided in respect to cultural differences and also differences in gender. The nursing team segregated patients by gender and by medical condition, although this was not always possible and depended on the availability of beds. Additionally, male visitors were not as fully engaged in patient care as female visitors. Female relatives felt more responsible towards patients and this was linked to their responsibilities and caregiving gender role as females in the family. Nurses encouraged visitors to help patients but limited this when they felt it was inappropriate to promote cultural safety.

Nurses in both settings also involved relatives in care to promote cultural safety when their patients spoke different languages, or spoke little English. This was practical for the health team especially when relatives spoke satisfactory English. In the Australian unit nurses used relatives' presence as an opportunity for translation and interpretation, to ensure nurses received a comprehensive understanding of their patients needs and patients and relatives understood nurses' and doctors' instructions and the treatment plan. Nurses allowed relatives to stay with patients for extended hours if they thought it would help them during the care and reduce their patients' stress. Sometimes when those patients were unattended by their families they became anxious especially when they did not understand the conversations around them or what was required of them by nurses or doctors. Generally those patients experienced stress when any member of the health team approached them and they did not have a relative present. Their stress was expressed nonverbally for example by the use of facial expressions, staring, looking for their phones, or beckoning. Additionally they used verbal cues as well, such as apologising for not understanding (*'Sorry'*), asking for their relative, or repeating the nurses' words. Their tension was even more pronounced when their relatives were expected to attend at an arranged time for a meeting with a health care professional and did not arrive. However, at times in the Australian setting nurses used the help of translators when no one from the patients' family could assist in translation. If patients had a limited understanding of the English language then it was necessary for their relatives to be involved in care giving because it could be challenging task for nurses in the absence of relatives.

In the Saudi unit, nurses who came from different countries, especially non-Muslims, felt pressured at work because they had a limited understanding of the religion, culture and language. Most of health professionals in the Saudi context came from multicultural backgrounds and interacted with Saudi patients and relatives as the Saudi culture was the dominant one in the field. Usually multinational nurses had received some education in their own countries before they came to work in Saudi Arabia, but this was inadequate, and their experience was different when they interacted with real patients and their relatives in the field. Many nurses lacked knowledge of local practices; it was even more difficult for those nurses who only had a few days or months experience. Nurses experienced stress at times when they had been informed by locals that they had behaved inappropriately, particularly during patient care. They felt confronted by cultural and religious matters, especially when they wanted to provide high quality care. Many multinational nurses in their first months of work were hesitant when they approached Saudi patients to provide care because they feared potential cultural conflicts. They believed they were not accepted and experienced recurrent stereotyping by patients and relatives. Many patients and relatives preferred to be cared for by Saudi nurses; they thought Saudi nurses were considerate of their beliefs and culture. All multinational nurses said they experienced cultural conflict multiple times when they cared for Saudi patients. Many of them stated they experienced embarrassment frequently in the field, but they continued to learn from these experiences. However, it was apparent that many patients and relatives were considerate of nurses' lack of cultural knowledge and often helped nurses to understand their cultural practices.

Multinational nurses felt that it was necessary to involve patients' relatives in all aspects of care because relatives compensated for their lack of cultural knowledge. Many nurses asked relatives and patients to inform them if they had special needs or preferences during care. In many cases relatives informed nurses to be attentive to privacy matters such as informing relatives before they allowed male workers into patients' rooms. It was clear that relatives did not want patients' bodies to be exposed entirely in front of anyone, including family members. They also wanted the nurses to say certain words when they started any care routine such as '*Bism Allah*', which means 'in the name of Allah'. A few patients and relatives said they were intolerant of any conflict concerning their beliefs, especially when nurses had worked in the field for extended periods of time or had been informed about their mistakes by relatives on previous occasions.

Care delivery could also be difficult for nurses if they lacked cultural courtesy as well. One relative asked a nurse to leave the patient's side when the nurse had said a word in English which the patient hadn't understood and the nurse had laughed. The relative thought this was a demeaning attitude for a

nurse to have about her patient and her patient's relatives. In this field some relatives said when they provided multinational nurses with guidance on their cultural expectations during patient care this enhanced patients' and relatives' comfort and helped to increase nurses' cultural awareness. Additionally, nurses said they dealt with cultural differences seriously and took patients and relatives' comments on board. Another issue occurred when multinational nurses lacked knowledge of the Arabic language, which acted as a barrier to effective care delivery. The language barrier adversely influenced patients' and relatives' satisfaction with nursing care and their compliance with medical orders. Usually multinational nurses asked nurses who spoke both English and Arabic to translate for them; however, often this was impractical because other nurses had a heavy workload. It was difficult for patients and relatives to communicate with non-Arabic speaking nurses and misunderstandings were common.

There was also another important matter affecting cultural safety in the Saudi unit; this was implemented through gender segregation. Saudi patients, relatives and nurses classified gender separation as a safety measure in the hospital so whenever safety was mentioned, segregation was included in the equation. It is prohibited by law for unrelated men and women to have contact with each other unless necessary and this could happen in the hospital because of the nature of the hospital environment. Female patients and relatives are admitted and leave the hospital accompanied by a male guardian. Therefore, relatives were not allowed to leave the unit without a nurse's permission and this was considered a safety measure. Additionally, relatives had to wear a black dress (*Abaya*) most of time, especially when they left the rooms, and during doctors or visitor visits. Many Saudi patients and relatives preferred female doctors; however, they had no choice but to accept male doctors in the absence of females. Saudi patients and relatives considered contact with male doctors in the hospital a necessity, which is allowed in Islam and in Saudi culture.

The nursing team created safety procedures to facilitate the attendance of male workers on the ward, escorting and accompanying them in the unit. Males were only allowed into the unit during visiting hours and they informed nurses when they entered or left the unit. Nurses were not allowed to leave the male doctors alone with patients and relatives. Other male members of the health team entered the unit with permission from nurses. Additionally, a female guard accompanied the maintenance workers in the unit until the end of their job. Usually female guards ensured that male workers did not leave without being escorted out of the unit. If any male workers were left alone, female patients and relatives could file a complaint against male workers or nurses. Entry without permission was also considered a violation of hospital rules. Nurses stated that when they escorted males it was for their own safety as

well, as this ensured the wards remained female-only spaces. This also limited the potential for accusations of sexual impropriety under the strict laws of gender segregation.

### **Safe involvement or ‘conditions around involvement’**

In both settings nurses linked the involvement of relatives to the safety of patients, meaning if any activity was safe for the patient, then it was permitted. From there it was necessary for nurses to explore what was considered safe involvement in both units, not taking into account a patient’s condition and wishes. Nurses based their understanding of safety on their own experiences in their field; therefore, what was safe practice for patients and relatives was inconsistent or based on a nurse’s personal views. Many nurses answered ‘it depends’ when they were asked about safe practices for relatives involved in patient care. There was also confusion from relatives about the extent to which their involvement might be safe, because what was considered safe at one time could be unsafe at another. Additionally, nurses were indecisive about what safe involvement meant; there were cases where nurses believed involving relatives in physical care was unsafe, however they involved them when it was necessary, such as caring for stressed patients. Regardless of a patient’s condition, nurses considered relatives’ assistance in patient care safe in their presence or with their guidance because they believed this reduced risks to a patient’s wellbeing.

*‘...If the family are there when you’re trying to help the patient to sit up in the bed, I could ask them to help. It’s fine, we don’t expect any problems as long as we observe them’ (Nurse 1 interview, the Australian setting, on 2.9.2013 at 11.00AM, p. 1, L. 17-19).*

In the previous extract the nurse thought involving relatives to help a patient sit upright was safe involvement because she could guide them throughout the process. Close observation was considered a good approach for nurses to take in order to assist relatives to care for patients. Therefore, safe involvement was conditional on the presence of nurses during care. However, especially in the Saudi setting, there were many instances care was still unsafe, even when nurses were present.

There were times when nurses permitted relatives to assist patients in care because they had a shortage in the nursing team or a heavy workload. What was considered safe involvement was also affected by the flow of work and the number of nurses in each shift, as nurses commonly stated that safety ‘*depends on the situation*’. This suggests that what was considered unsafe involvement was acceptable at times when nurses were overloaded during their shifts. However, nurses asserted they

would never permit relatives to assist where they thought this would lead to possible harm for the patient. In the next example, a nurse asked for a relative's assistance when she thought this was safe:

*'...Look, it's unusual if we ask relatives for help. If there is a shortage in nursing staff,[ there is] nothing we can do about it. It's safer to use another nurse for help. If the patient is heavy or very ill we need to do the care ourselves. The patient is our responsibility. But if the care is just cleaning or positioning the patient, or doctor examination, then it's all right to ask for help,[this decision must be based on the] personal judgement [of the nurse]'* (Nurse18 interview, the Saudi setting, on 10/04/2014 at 3.00PM, p. 34, L. 23-27).

In several cases from both settings it was more likely for relatives to offer nurses assistance when a nurse provided the care alone. Relatives believed their involvement was safe when nurses required assistance, especially when care required lifting or moving patients. Usually relatives offered to help nurses and the offer could be verbal or non-verbal, such as a relative standing up beside the patient and folding his or her sleeves. A few relatives in both setting assisted nurses because they thought nurses struggled with patients. In both settings, relatives occasionally stated that they assisted nurses due to nursing shortages or work overload. Nurses in the Saudi unit did not feel worried about involving relatives in care with or without nursing shortages because this was accepted as the norm in the unit.

*'Definitely, we have [a] shortage of nurses here, and I have about five to six patients in the shift. It would be impossible to do all the care, simple or complicated, by myself. I need help from the companions because they are here to help, whether this help is for the patient or for the nurse. In the end the patient is [at] the centre of our care'* (Nurse 9 interview, the Saudi setting, on 26/02/2014, at 9.00AM, p.17, l. 15-18).

Generally, in the Australian setting it was uncommon for nurses to request assistance from relatives unless this involved asking relatives to move or pick up an object. In most cases nurses called another nurse for assistance in care. The nurses in the Australian setting were more likely to get help from one another if they requested assistance because they had sufficient staff, whereas, in the Saudi field, nurses avoided asking for other nurses for help unless they could not manage the care alone or with the help of relatives, because of a shortage of nurses. In the Saudi setting, nurses asked relatives to help in tasks like handling or reaching objects, opening a container, lowering side rails or bringing a blanket. In the interviews in both settings most relatives said nurses did not ask for their assistance, however, they still offered it. Some relatives thought nurses would be offended if they offered help, but

in most cases nurses' accepted relatives' help when offered. Overall relatives thought their involvement was safe for all parties involved, especially when nurses agreed to their contribution.

It was apparent that some relatives in the Australian setting were offered guidance from nurses to promote their own and the patients' safety if they were involved in patient care. The circumstances of these relatives meant that nurses prioritised them in terms of imparting information about safety. Guidance was offered to these relatives because they were responsible for looking after patients once discharged. Nurses stated that they helped these relatives to understand more about safety because these relatives were responsible for the continuity of patient care outside the hospital, and more often than not these relatives also informed nurses of their needs:

*'...But if they want help to learn how to do the care after they leave the hospital, it's all right; I let them contribute if it is helpful for them'* (Nurse 4 interview, the Australian setting, on 14/10/2013, at 9.30AM, p. 15, L. 21-23).

Nurses helped those relatives to learn particular care techniques, for example assisting the patient to transfer from bed to chair. Yet this did not mean relatives understood all aspects of safety or all possible dangers. Patients and relatives could be harmed if relatives assisted patients to become mobile if he or she did not maintain mobility techniques. Even though these relatives were offered more guidance than others they still expressed their concerns. They felt they did not have enough knowledge or equipment to provide the same level of care the patient had received in hospital; they also wanted to learn other methods.

Safety procedures provided strategies for nurses to look after themselves and patients, but these measures didn't include relatives. In both settings relatives were not covered under the hospitals' insurance policy; therefore they were unprotected in cases where incidents occurred during their involvement in care. There were no definite directions given to nurses in relation to risks caused by a relatives' involvement in care. In the Australian setting nurses were asked about the legality of potential or actual incidents caused by relatives delivering care. The majority of them did not know or were unsure. In the Saudi unit the nurses responded to this question by saying, *'It depends on the incident'*. If the incident had not caused harm to anyone then the relative in this case would be warned. Where harm had been caused, a report would be filled out by the nurses and the relative in most cases would be asked to leave the unit.

The researcher did not observe any major incidents involving a relative causing harm to a patient; however, in both units some nurses stated that this had happened in the past. In terms of safety measures in the units there were education courses, supplies and equipment in the hospital for nurses to employ for safety purposes. Being responsible for the welfare of all of the people involved in care, meant that nurses had a greater responsibility to keep relatives' involvement desirable and safe:

*'Of course, if they hurt themselves, our responsibility is to prevent the potential of any one getting hurt, especially ourselves. For the relative, if it's safe for them and the patient then that's really important'* (Nurse 9 interview, the Australian setting, on 18/11/2014 at 2.15PM, p. 35, L. 14-16)

The nurses in the Saudi setting felt burdened by the constant presence of relatives since they could not predict how relatives would behave around patients and therefore could not protect them. Many nurses indicated that there was *'nothing [they could] do'*, as they had little control over the nature of the work with relatives in the unit. Moreover, relatives' lack of awareness of possible risks in the hospital environment and their limited knowledge about care and safety resulted in conflict between relatives and nurses. Nurses thought there was a need to make relatives' involvement in patient care safe and secure, by targeting this population in the education processes of the hospital.

### **Safe environment**

A safe environment is an indicator of safe involvement and these concepts are linked. The following description highlights the safety of the environment, which was believed to positively or negatively impact on relatives' involvement.

#### ***An overview of both settings***

In the Australian setting, at first glance the unit appeared to cover a large area, which meant patients and relatives took time to become familiar with the layout. Relatives also stated the nurses were sometimes hard to find if they were outside patients' rooms, especially during visits when the unit was busy. This was also a reason for the lack of communication or limited interaction between nurses and relatives. The location and the distance between the two nursing stations helped nurses to observe the entire unit. In the Saudi unit, the nursing station was in the centre of the unit and surrounded by patient rooms. This was meant to allow nurses to observe patients' rooms, however on most days the rooms doors were closed, which contradicted the purpose of the design. However, relatives could easily see or find nurses because the nursing station could be seen from all rooms. In both settings, after a visitor

entered the unit, they appeared to wander around, their eyes searching for guidelines, sign posting, instructions or information. It was difficult for visitors to find the patients' beds because they were unfamiliar with the hospital environment. Some relatives entered all rooms to look for their loved ones. A few found it easier to ask nurses to guide them to patients' beds but didn't like to interrupt them. Relatives expected it to be easy to follow signposts and that these would lead them in the right direction or keep them away from hazards.

Posters provided easy access to information; many visitors looked at the unit's posters for information before they inquired from others. The majority of wall posters were printed on A4 size paper or slightly larger paper, and they were hard to read and didn't attract attention from a distance. Posters around patients' beds such as instructions on diet also did not seem to attract patients' or relatives' attention. Some said these belonged to nurses and many said these posters used abbreviations which relatives didn't know the meaning to. The size, colour and location of posters were essential to directing or delivering educational information to patients and relatives. Most relatives expressed the need for educational posters or brochures targeting visitors. As described previously, posters could potentially enhance the safety of the environment, for example, by informing visitors about hand hygiene. They provided a non-verbal tool which could save time and effort for everyone in the unit; they also improved visitors' familiarity with the unit's rules such as visiting hours. In the Australian setting, relatives were unsure if they could use the lavatories across the unit and some used those listed for patients only. When relatives asked nurses for guidance, nurses informed them to use the rest room labelled '*staff toilet*' because it was better for relatives to use this room than patient bathrooms. Furthermore, in the units there were no signs or labels to show visitors where to throw rubbish or recycle objects. Some relatives were observed asking nurses where to throw their garbage as there were no signs to indicate this.

Relatives highlighted other issues within patients' rooms such as bad odour and poor airflow, which created discomfort and a fear of infection. Fear of infection was a great issue for relatives; many of them spoke about their fears constantly. Infection was mainly a concern for relatives in rooms with multiple beds because of unclean surfaces and congested airflow. In the Saudi setting, relatives feared infection because they stayed in the same room as patients with infections and used the same chairs, hand basins, toilets and showers. It was obvious they feared the surfaces of objects as well because everyone in the rooms touched the chairs, bed tables, beds and floors. Some relatives spoke about the floors and their fear of getting an infection while sleeping on them.



*'...I think companions need mattresses or something to elevate them from the floor. You know the floor is very hard, cold, and who knows, sometimes blood or patients' fluids drop on it. You know these things can cause troubles for us'* (Relative 10 interview, the Saudi setting, on 26/02/2014 at 11.00AM, p. 20, L. 10-13).

Many relatives educated each other around infection and control; they were observed having discussions about hand washing, disinfecting surfaces and protecting themselves by wearing gloves during care. However, in many cases relatives provided patients with care without gloves, even when patients were soiled with body fluids and relatives attributed this to the unavailability of gloves in patients' rooms. However, some relatives did not worry about patients' body fluids because they thought patients were their own flesh and blood.

In both settings, another issue for relatives in the environment was finding a quiet place to escape to away from patients' rooms. They wanted a place to regain their strength, away from patients; at the same time, they did not want to draw attention to themselves. At times relatives were stressed from staying in patients' rooms on a continuous basis because of noise (patients in pain), the sounds made by medical equipment (such as alarms), plus the smell of food or substances. Many relatives were unfamiliar with this environment; they feared the hospital machines touching these machines and they feared hurting patients.

In the Saudi setting, patients also felt tired because they were constantly awake and speaking with their relatives. They wanted some time to rest. Neither unit had a place for relatives to eat or wait, apart from patients' rooms where they spent their entire stay or visit. In both settings, relatives wanted kitchens so they could have hot drinks without bringing them from home, a canteen, waiting rooms to relax or read, and meeting place where they could be given some education. Some relatives in the Saudi setting compensated for the lack of these facilities by gathering with others or bringing food and drinks. Many relatives considered gathering in groups as a time to discuss issues with other relatives and to relieve stress, as they were not able not share their concerns with patients. Nurses did not agree with relatives gathering together and this was a source of constant disagreement between the parties.

Privacy was another matter that arose in the hospital environment; some patients thought they were not able to speak to their visitors freely. Many visitors and patients were observed whispering when they spoke to each other. Some patients expressed embarrassment when nurses spoke to them in front of other patients and they thought there was no privacy. Some relatives said they kept the curtains closed because they wanted to have their own space. However, curtains were not always a solution to the

issue of privacy because they did not block out sound or allow for a private environment. When doors or curtains were kept closed nurses could not see or observe what was going on behind them, and for acute or monitored cases this created a stressful environment for nurses. In the Saudi setting, nurses were observed on many occasions asking relatives to keep curtains open in the morning but they failed to enforce this policy.

In the Saudi field, the constant presence of relatives in the field made the place susceptible to noise. Many patients and relatives complained about noise in the rooms especially at bedtime.

*'...Especially the noise, some want to sleep and some [do] not. [A] few relatives here keep us awake till late. The TV [is] so loud. They talk and laugh all night long. It's unfair for us'* (Relative 2, the Saudi setting, on 11/02/2014, at 7.00PM, p. 4, L.20-22).

It was apparent that many relatives and patients found it difficult to wake up early in the morning because they had been awake all night. Nurses remained calm in these situations to avoid conflict with relatives, unless they were approached by relatives for help. In both settings, some patients and relatives spoke about their lack of rest and sleep because of noise from other patients, especially when they were in pain. In the Saudi setting, in the early morning and after lunchtime the relatives blocked the area between the patients' beds and the walls, so nurses only had limited space to move around patients. This area was also not just blocked with relatives' bedding but also with relatives' personal belongings such as bags. This made it even more difficult for nurses because they were unable to approach patients from the blocked side; they needed patients to be more accessible to them during care.

In both settings, the majority of patients were located in rooms with multiple beds. If nurses wanted to perform care during visits they usually asked relatives to move their chairs out of the way to allow them to move around, because the area was too narrow near patients. Some relatives preferred to stand during visits because it was easy to step back when needed. There was only one chair beside every bed; this was due to a lack of space and it helped nurses to move freely around patients' beds or in cases of emergency. In the Australian setting, some relatives said they felt unwelcome and were unable to stay for extended hours due to a lack of seating. Many relatives sat on the edge of patients' beds, especially when patients had several visitors. One patient in the Australian setting stated that she understood the rationale for only providing one chair beside every patient and believed this helped to eliminate noise, as people could gather beside patients and create noise. Noise was the main

complaint made by patients in rooms with multiple beds. In rooms with multiple beds some relatives said they had restricted movement, as they needed to show courtesy to others. Additionally, some relatives experienced stress when they heard the beeping of monitor machines or intravenous infusions in these rooms. This stress was expressed verbally by relatives who asked about the source of a sound or called one of the nurses. Stress was also apparent on relatives' faces; they stared, looked surprised or looked around for the source of a sound or placed their hand on their chest. Those relatives who feared the environment seemed to have shorter visits and participated less in caregiving:

*'My boys don't feel comfortable here; they don't stay long, quarter of an hour [at the] the most'*  
(Patient 19, the Australian setting, on 28/10/2014 at 12.00PM, p. 37, L.8-9).

Many relatives were anxious and felt uncomfortable during visits and this was related to how they felt about the hospital environment. Some relatives also asked patients to go to the café downstairs to relieve their stress. Nurses experienced stress as well, especially when the ward was busy. When nurses spoke about the busy environment they linked this to the multi-bed rooms. The busyness of these rooms, distance between beds, equipment, noise and distraction caused elevated stress levels for nurses, patients and their relatives. Some nurses stated that there was a need for single rooms which would reduce environmental stress. The next example from a nurse's interview showed how safe involvement and a healthy environment including rest was associated with single rooms.

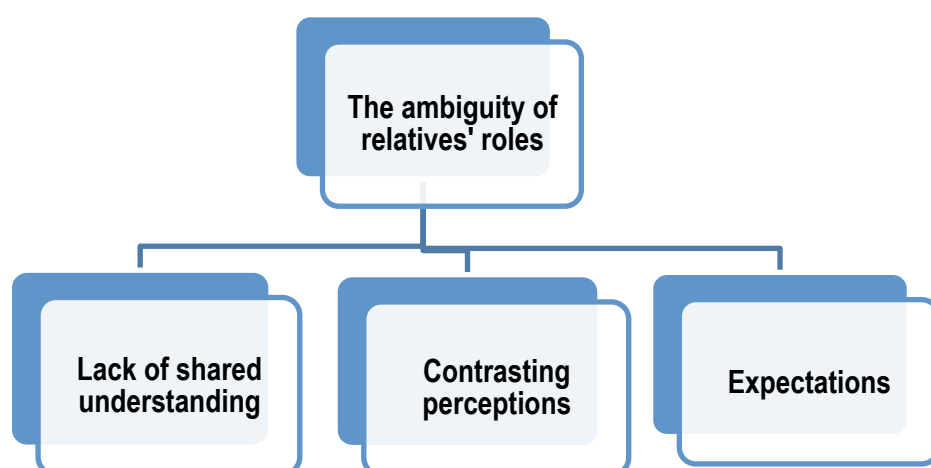
*'I have no problem with that, [family staying long hours visiting] as long it doesn't impact [on] the care of the patient because of the environment. We cannot provide adequate private rooms for the families. I have only seven side rooms. For the family to be a [multi-bed room] is not conducive to a healthy environment for them, and if they don't get enough sleep they get tired, they [can't] look after the family member and they become unwell themselves because they are in [an] environment where people come in acutely unwell and sick and relatives will be susceptible to that'* (Nurse 5 interview, the Australian setting, on 30/10/2014 at 12.30PM p. 27, L.4-10).

Single rooms offered more privacy to patients. Relatives of patients who were located in single rooms said these rooms offered them space and comfort when they needed to spend extended hours with patients. Some relatives in single rooms said they also could move freely in the rooms. There were positives for patients in single rooms, other than privacy and rest. Nurses provided patients in single rooms with more advice and gave them more eye contact. This was attributed to nurses experiencing less interruption in single rooms compared to rooms with many patients. However, the patients in single

rooms had less contact with others and were therefore more reliant on interaction with nurses; they also appeared to want longer visits from relatives. Nurses provided patients in single rooms with constant surveillance because of both the nature of single rooms and the kinds of conditions suffered by patients in these rooms, which made those patients isolated and at high risk of incidents such as falls. Time and energy was required by nurses to keep patients in single rooms safe.

#### **4. The ambiguity of relatives' roles**

This domain describes how participants in the fields perceived the role of relatives in patient care. Observations in both settings indicated there was no consistency in what relatives could or could not do in regard to patient care. Nurses in both settings permitted relatives to be involved in patient care, but their involvement took different forms because of a patient's condition and diverse beliefs about the role relatives should play in caregiving. All nurses included in this study stated that the safety of their patients was a priority; all of the nurses interviewed claimed they did not allow relatives to assist patients if the safety of patients could be endangered. However, the underlying rationale for promoting this involvement was quite different; in the Australian setting it was to achieve a patient-centred approach whereas in the Saudi field it was based on a patient-centred approach, mixed with culture and religion. The majority of participants' opinions on this subject were based on the condition the patient was in and participants' individual preferences. In general, a patient's diagnosis, dependency level, and choice were the measures used to decide the level of involvement of relatives in patient care. The sub-themes below describe how this was perceived.



*Figure 11: Role ambiguity: How participants perceived the role played by relatives in patient care*

## **Lack of shared understanding**

In both settings what relatives should be allowed to do to assist patients was described as 'simple'. However, there was limited shared understanding of what this meant. Many relatives explained the term 'simple' as daily activities that could be done by the patient or with the help of relatives at home. Simple also referred to daily living activities such as eating, going to the toilet and walking. Patients also categorised simple as assistance that could be provided without the help of a nurse, whereas nurses defined simple as those activities that could be exercised repeatedly or did not need their supervision. A relative stated;

*'...Every nurse had her own version of roles for me, it's difficult to satisfy all nurses'* (Field notes, the Saudi setting, 10/03/2014 from 9.00-4.00PM, p.125).

In relation to simple care relatives categorised certain tasks such as taking the patient for a walk or the toilet and feeding as simple. The following examples from both settings highlighted some simple tasks in patients' care:

*'...I remember helping the nurse to change my mom's clothes, very simple. I have been doing simple things when I'm around, like helping her to get ready for [the] doctor's examination. Not a problem, because the nurse is not going to ask me to do heaps. She is not going to ask me to do complicated stuff. It's her job after all. I'm only helping and I know I don't have to'* (Relative 3 interview, the Australian setting, on 2/09/2013 at 3.30PM, p. 5, L. 15-19).

*'...Yes nurses ask for my help in the care, but not in their job. I do simple things, the things I would do in the house'* (Relative 8 interview, the Saudi setting, 23/02/2014 at 1.00PM, p. 15, 5-6).

However, after gaining feedback from nurses around this subject, they stated that some care may look simple for relatives but can cause problems for patients, such as feeding a patient that is susceptible to aspiration of food or fluids.

*'I told a relative to inform me before she [fed] her mother. She thinks she was only giving her mother soup. I need to do this myself to ensure my patient sat well, breathed well and had no problems in swallowing. (The nurse smiled) 'My patient has aspiration pneumonia'* (Nurse 8 interview, the Saudi setting, 23/02/2014, at 11.00AM, p. 16, L. 3-7).

In some cases, nurses thought that in order to ensure the safety of patients and relatives, even basic care should only be delivered by nurses, but this was not always the case. In both settings, all participants referred complex or complicated tasks as a 'nurse's job'; this included those activities which required knowledge and experience. In such cases relatives preferred to take a back seat and chose not to be involved. However, what was considered simple or complex care varied from one participant to another and even more between participants in the two settings. The extract below from the interviews performed in the Saudi setting highlight this inconsistency:

*'Last night I was changing my mom's clothes. I found her wound oozing fluids... I removed the dressing and I cleaned it and put clean gauze and plaster over the gauze. I think I can do wound dressing, [there is] nothing hard [about it]...'* (Relative 5 interview, the Saudi setting on 14/02/2014, at 2.45 PM, p. 9, L. 16-21)

There was no clear definition of when relatives could assist patients with their needs in hospital; instead the role relatives played could change depending on the nurse, patients' wishes, relatives' personal judgment and the situation.

### **Contrasting perceptions of relatives, patients and nurses**

This subtheme illustrates the different perceptions participants had about relatives' roles. These perceptions are presented under the titles 'relatives', 'patients' and 'nurses'. In this study, many participants seemed to assume they understood relative's roles in the hospital. Nurses believed that relatives performed different tasks and this varied from one relative to another. Some relatives thought they should be involved in patient care and others thought they should provide emotional support only. It appeared that the wishes of patients and relatives influenced the assistance given, but this was more evident in the Australian setting because in the Saudi setting it was assumed that relatives would provide care. Most relatives observed offered to assist nurses with care and appeared happy to do so. Relatives thought it was their role to stay with the patient and provide emotional support and many said they assisted patients physically as well. In the following example a relative wanted to stay with her mother in hospital to provide support and care; she also enjoyed helping the nurse:

*'I always help my mother. I assist her in anything. I want to make sure she is OK. I give her a hand if she needs a help. I also help the nurse to care for my mother. I offer help in [all of her]*

*care. I don't want to create any problems for the nurses but I can't help it, it gives me a feeling of relief to help'* (Relative 5 interview, the Australian setting, on 10/09/2013 at 2.10PM, p. 9, L. 20-23).

### **Relatives**

In both settings relatives stated that they helped patients physically because this was their job. Relatives also indicated they would provide assistance to patients or nurses when they were asked. In the Australian setting there were certain features which increased the likelihood of relatives becoming involved in patient care; these were not observed in the Saudi setting. These features increased the role ambiguity experienced by relatives because rules were applied inconsistently to some patients and relatives but not all. For example, where there were '*language barriers*' the team permitted relatives to stay with patients for extended times outside normal visiting hours. This appeared to ease patients' fear and anxiety, with the health team using relatives as translators. Furthermore, as described previously, it was evident that the health team respected different cultural beliefs and norms. Different ethnic groups have different ways and expectations of providing love and care for their family members. People from India, Asia, Spain and Italy were observed to have tight family bonds and usually asked the team if they could stay with patients for extended hours and also verbalised their need to be included in patient care. The nursing team respected this view and allowed them to stay and be involved in patient care and decision-making. This behaviour then became the norm for this patient and their relatives.

In both settings all participants agreed that relatives came to the hospital to provide emotional support for patients and to bring them what they needed from home. However, some relatives in the Australian setting believed their role was to provide emotional support only and not to provide any physical assistance. In contrast, in the Saudi setting all relatives stated they provided patients with emotional support and physical care and believed there were certain aspects of care such as activities of daily living that were part of their role. This showed there was no shared understanding of relatives' roles between the settings. The next example, from the Saudi setting, demonstrates the opinion of a relative regarding her role at the hospital:

*'In my understanding my role is a helper, assistant to the patient. I have full responsibility in the care as a companion. I don't expect the nurses to do everything around here. Nurses have better things to do. Also they have lots of patients. I don't expect them to be here to do the shower or to change the clothes, or to feed the patient. It is the companion's responsibility. If the companion*

*cannot do anything or doesn't want to do anything so why are they here? We are not here just to talk, or to catch up, or eat. We are here to help the patient, the nurses, also to watch the patient if they need anything'* (Relative 6 interview, the Saudi setting, on 23/02/2014 at 10.30AM, p.11, L. 8-15).

Other data from the Saudi setting, suggests that some relatives thought they had to provide care for patients because they had no choice, either because they saw everyone else's relatives providing care or because they were informed by nurses or other relatives that this was required.

### ***Patients***

Patients' opinions of relatives' roles also varied; the majority of patients in both settings agreed that they should be involved in all aspects of care; however, some in the Australian setting said they preferred to be self-reliant as much as possible. In general, all patients stated they enjoyed relatives' visits and company. In the Australian setting a number of patients only asked relatives for help to reach items around them, and some stated relatives should only visit and not to be involved in any care:

*'...I need them to sit down and relax and have a chat together. [I] would like to hear what they have been doing. They shouldn't do anything around here, [there is] nothing for them to do'* (Patient 1 interview, the Australian setting, on 21/08/2013, at 4.00PM, p.1, L.8-9).

This patient said she did not ask her family to be involved in any care, but she might ask them to ensure she was being looked after properly. Most patients requested their relatives to look after their belongings, laundry, house, pets or interests during their stay in hospital, and patients suffered stress when no one was able to do this. However, it appeared to the researcher that activities such as feeding patients, bringing cups of tea, assisting them in walking or going to the toilet were not considered by patients to be nursing care. It was obvious the Australian patients did not have a clear understanding of what a relative's role should be.

The majority of Australian patients expressed the need for their relatives to assist them when they were present, but for various reasons some did not ask for help. For example, one reason a patient didn't ask for help was because her relative had other responsibilities:



*'I would like my daughter to feed me, help me walk to the toilet, but my daughter can't be here all the time. You see, she has a job and when she comes to visit me I don't ask her to do anything for me because she is tired'* (Patient 3 interview, the Australian setting, on 2/09/2013 at 12.00PM, p. 5, L. 7-9)

This example showed that the patient did not want to ask her relative for assistance because she thought it would be an imposition. Another reason not to ask for help was because relatives were only able to visit for a short time:

*'I don't want them to do anything when they visit, and they are here for a short time. We should spend this time talking'* (Patient 14 interview, the Australian setting, on 2/11/ 2013 at 11.00 AM, p.22, L.3-4PM).

All patients interviewed stated they could have asked their relatives to assist them more if they stayed longer. A factor such as car parking appeared to impact on visiting:

*'It's hard to find a car park and it's quite expensive. If I needed something I would do it by myself. I don't ask my husband to do a lot of things for me, because after driving for three hours he needs to sit down and relax...'* (Patient 6 interview, the Australian setting, on 15/11/2013, at 12.30AM, p.11, L. 3-6).

Australian patients expressed other reasons for not asking their relatives for assistance such as their ability to assist themselves, their visitors being elderly, gender differences, distant relationships and the acuity of their illness.

In the Saudi setting all patients are required to have relatives or carers at all times unless this is not possible, which was rarely the case. As stated previously this is a cultural norm and all patients relied on their relatives for their daily needs and activities and also believed it was their relatives' role to be included in care. This next example shows a viewpoint of a patient who was dependant on her sister to assist her to meet her many needs such as showering, walking her to the toilet and opening meal packages for her:

*'I think it's good to have my sister here because she helps a lot. She assists me in everything, even speaking to nurses and doctors. The nurses have too many things to do during their shifts and if I ask for something it takes a while till they do it for me. Look I think the companion is good*

*idea. I don't want anything to change'* (Patient 1 interview, the Saudi setting, on 10/02/2014 at 10.30AM, p. 1, L. 1-4).

The Saudi setting was different from the Australian setting because patients believed the role of the relatives was to be with patients from the start of their journey in the hospital until the end. This included maintaining patients' needs and wishes and ensuring they received the best care; this also involved being their advocate and supporter in this journey. They also believed relatives should be the ones to clarify any information with the health team and provide updates for the rest of the family members:

*'The companions are useful especially when the patients need something and the nurses were busy or away. I feel comfortable because my daughter is here to look after me and tell the nurses when I need anything; she makes sure my needs get managed well'.* (Patient 5 interview, the Saudi setting, on 14/02/2014 at 5.00PM, p. 9, L. 1-4)

Many patients said they did not know how they would manage their stay in hospital without a relative:

*'I can't imagine being admitted to the hospital without any member of my family. It [would be] impossible'* (Patient 4 interview, the Saudi setting, on 13/02/2014 at 1.00PM, p. 7, L. 2-3).

### **Nurses**

The perceptions of nurses were different from one another and it is essential to comment that nurses' actions in the field did not always support their statements. For example, nurses agreed that the interaction with relatives was important but they avoided them. In both settings all nurses agreed that relatives should provide emotional support for patients, but when they were asked to describe relatives' roles in hospital their opinions varied. Generally nurses thought relatives were beneficial for a patient's emotional wellbeing and should also be allowed to be involved in physical care. However, the role relatives played changed based on a patient's needs and wishes.

Nurses in the Australian setting believed that some patients needed the presence of their relatives more than others such as patients with cognitive problems or a language barrier; therefore in these cases it was favourable for the patient and the health team to have relatives present in most care situations. Many nurses described relatives as facilitators, referring to them as being at the *'heart of*

care' at the 'source' of care as an 'interacting person', or an 'interpreter' because they could smooth the process of a patient's treatment:

*'...So I think the relatives especially the family can be [a] good tool for us, because not only [do] they help us facilitate what needs to happen, but also [they] can see what care is provided and see the process involved'* (Nurse 8 interview, the Australian setting, on 18/11/2014 at 2.00PM, p. 33, L. 3-5).

Every nurse had a different description of relatives' roles, but all of them encouraged their involvement. Some encouraged relatives to support patients emotionally and some encouraged them to be involved in particular daily care tasks:

*'We encourage them to help the patients in simple things such as feeding, walking with the patient, playing cards with them to stimulate their thinking, joining in a few exercises, catching air outside the hospital'* (Nurse 1 interview, the Australian setting, 2/09/2013 at 11.00AM, p. 1, L. 7-9).

One nurse stated that relatives generally choose to have no real role in patient care:

*'A lot of relatives come in here and don't really have a role, they don't come to help. There will be the odd one [patient] and completely depend on the family. In general relatives don't offer much assistance in terms of helping their family members; they generally leave that to the nursing staff, until the staff educate the family that they can assist. You don't really get much assistance from them when they come in'* (Nurse 10 interview, the Australian setting, 18/11/2014 at 2.30PM, p. 37, L. 3-5).

Another nurse said that relatives did not participate in care but attributed this to short visits:

*'They really don't get involved in, like, every day hygiene, [and] activities of daily living. They are more, like, support, chatting with patients. Relatives are limited with their car parking and [have] got other things to do, but it's mostly shorter visits, so we don't expect them to do much when they are around. We give them education when the family can stay for longer periods of time so they can assist in the care'* (Nurse 2 interview, the Australian setting, 6/09/2013 at 3.00PM, p. 4, L. 10-13).

In these cases some nurses said they informed relatives that they were allowed to assist with physical care and they only needed to inquire about this when necessary.

In the Saudi setting, nurses held different opinions to the Australian nurses. Relatives in the Saudi setting were expected to be involved in all aspects of care regardless of education or an invitation. However, the majority of nurses thought relatives' roles should be limited to emotional and social support and their involvement in care should be restricted, especially when patients were acutely ill. One nurse said:

*'The role of the relatives is to be a helper to the patient, I mean a personal helper, but not a care helper'* (Nurse 3, the Saudi setting, 12/02/2014 at 3.00PM, p. 6, L.9-10).

The views of nurses were influenced by their current circumstances, meaning that some agreed that restrictions should be applied to regulate relatives' involvement in patient care in the future, but at this time their goal was to minimise possible risks to patients. All nurses indicated that the current accepted role of relatives was not what should happen. A few nurses believed that relatives had no definite role; they were only with patients for company and their real role should depend on what nurses allowed them to do. However, their constant presence meant they took on extended roles and responsibilities.

## **Expectations**

It was clear that participants' expectations contributed to ambiguity around relatives' roles, especially at times when quality of care was based on expectations. The expectations of patients and relatives of the care received in hospital could be very high; therefore this tended to create disappointment when these care expectations were not fulfilled. The researcher believes the high expectations created a difficult working environment, especially when patients and relatives wanted certain aspects of care or treatment to happen the way they anticipated it would. This also created a great pressure on relatives because they were the ones who felt responsible for patients at this stage. The cultural backgrounds and lifestyles of participants affected their expectations of care. In the Australian setting the nurses took into account differences in the patients and relatives' cultural needs in care; this was not the case in the Saudi setting because the majority of people admitted to the unit were Saudis, so nurses interacted with one main culture.

### ***Expectations of patients and relatives***

In both settings nurses stated that dealing with patients and relatives was sometimes difficult when they had personal and cultural expectations of the care and even more when nurses failed to please them. One nurse in the Australian setting stated it would be useful for nurses to inform patients and relatives of what they could expect the hospital to provide in terms of caregiving. Some patients and their relatives were disappointed when nurses failed to understand their values; these values also informed how a relative believed care should be provided. This phenomenon was more apparent in both settings when there was a mismatch between the culture of the nurse and the patient. One nurse said:

*'...Sometimes we have relatives who are really keen to help and they are quite positive and create positive vibes in the environment, and we have relatives who will pick up on every single thing you are doing and say you are not doing that right, you are not doing this right. Those kind of people don't help the situation'* (Nurse 6 interview, the Australian setting, on 30/10/2014 at 12.00PM, p.29, L. 3-6).

Some nurses stated that sometimes relatives stayed extended hours with patients and asked to be more involved in care because they wanted to ensure the care was delivered with respect to their beliefs. In cases where a nurse was from a different nationality or cultural background to a patient or relative, both parties expected the nurse to show cultural courtesy towards them. Relatives expectations of care and their lack of understanding of safety measures was a problem for nurses in providing care:

*'Sometimes it can be a bit of dilemma. We cannot ever do it the way they do it and it can be an issue because we have our ways of doing things in our safety format. For instance, we would not lift anybody if we think they are too heavy or without a lifter or something like that. However, [a person who was] looking after their spouse, they used to lift them without aids at home and wondered why we don't do it, because then we don't respond as quickly as they did. This what we do to keep ourselves safe and your wife safe or whatever maybe, so we don't do that'* (Nurse 5 interview, the Australian setting, on 30/10/2014 at 12.30PM p. 25, L.19-25).

There were other expectations which emerged in both settings such as patients and relatives not expecting to wait a long time to receive help in cases where nurses were required to use equipment to

provide safe patient care. Some relatives thought certain equipment used to transfer patients was unnecessary, such as using a lifter.

### ***Expectations of relatives' extended family members***

The high expectations of extended family members sometimes also resulted in pressure on designated relatives to be present to provide their loved on with assistance in hospital. At times relatives were allocated this responsibility because they were the closest family member to the patient or had fewer responsibilities than others. Some relatives expressed their wish to be involved in care because it was the norm in their family or a culture. This subtheme was more apparent in the Australian setting for people from India, Asia, Spain and Italy; those relatives regarded what other family members had to say about the way they looked after the patient and sometimes they put themselves under pressure to satisfy them. These relatives could be under pressure because they had jobs and families themselves and they had to balance all their responsibilities. Additionally, nurses or a family's designated relative was asked to represent other family members' views and to transfer information or updates on a regular basis to the rest of family; this was stressful role for relatives. Designating one member to represent families was apparent in the Australian setting where nurses thought repeating the same information over and over wasted their time. One relative, a daughter, said her mother's meal had not arrived on time after her mother had come out from a surgical procedure; her mother informed the daughter's brothers and they questioned her ability to look after their mother. This was probably why she reacted unreasonably towards nurses on another occasion when there was delay in the arrival of her mother's lunch. The nurse in this situation reacted in a defensive way and said she had not known the patient had not received her lunch and a five minutes delay should not be a problem (Field notes, the Australian setting, on 1/09/2013, p. 26-27).

In the Saudi setting, the majority of relatives who accompanied patients stated they experienced constant stress, burnout and felt frustrated at some point during their stay in hospital because they worked hard to satisfy family members. The next extract highlights this matter:

*'I'm afraid that something would happen to my mother-in-law. I thought she died one day last month because she couldn't breathe for few seconds. It's terrifying. I feel happy when I leave the hospital every other day because if something happened to her, this would be my responsibility. It's so difficult, my family could think it's my fault'* (Relative 8 interview, the Saudi setting, on 23/02/2013, at 1.00PM, p. 16, L. 16-20).

Some relatives took on many care responsibilities and showed protective behaviour towards patients to impress their families. Those relatives with jobs sometimes took leave from work; some left their young children with the care of family members to be by a patient's side. Many of these relatives were constantly on the phone to ensure their other responsibilities were being managed outside the hospital.

### ***Expectations of other patients and relatives***

In the Saudi setting relatives also considered the expectations and views of other patients and relatives in the same room or unit. Many relatives said patients and other relatives watched them constantly to see if they helped their loved one enough. Targeted relatives were verbally abused, intimidated, criticised, blamed, belittled, or demeaned. Several relatives indicated they experienced exhaustion, stress, powerlessness, a lack of interest, burnout or lack of sleep after working hard to show they were looking after their patient. Additionally, some stated they asked nurses to include them in care because they wanted to perform more tasks. These relatives said when they were more involved in care they stopped hearing negative comments from others. This extended their role and responsibility to look after the patient:

*'...Look there were two relatives from the next room. They came here twice today, to check on us. They asked me if I did this and that (care). They think I don't do much for mom and they laughed when they saw me resting and mom was trying to reach something from the bed table. Yesterday they told everyone I was sleeping. This hurts. I know it's not their business, but now I can't rest. I stay awake all day and I make sure when they come here I do something. It's stressful'* (Field notes, the Saudi setting, on 28/02/2014 from 2.00PM-7.00PM, p.39, L. 6-11).

Relatives feared others' unfair judgment and thought they could please them if they rested less and continued caring for patients. The stress was even more pronounced for those relatives who accompanied their mothers or an elderly person because it was thought '*Allah*' blessed people who looked after parents and the elderly. The researcher observed two relatives and patients who spoke to a patient's son who had come to visit his mother in the afternoon. These relatives and patients questioned him about leaving his mother unaccompanied. They told him they had to look after his mother for him and accused him of negligence. They also told him he was not a blessed son. This relative expressed a great deal of stress from hearing these words. He told them he had no close female relatives to stay with her. In Saudi Arabia, looking after your parents is an obligation and shows

*'noble morals and [a] good upbringing'*, and people who fail to do so deserve no respect. This unaccompanied patient had her sister with her every morning to assist her in showering, walking, and eating and the sister left hospital around 12.00 PM, but this was not enough for the other patients and their relatives. This example illustrates the influence other relatives and patients exerted on some relatives; this was a factor which extended some relatives involvement in care in the Saudi unit. Social pressure also added to the burden of responsibility felt by carers and relatives.

### ***Nurses' expectations of relatives***

Ambiguity around expectations showed in both settings, especially when relatives were unsure about what nurses expected of them and a few wanted to hear what nurses had to say about this. Many relatives interviewed stated they cared what nurses thought of them and wanted to know if they had been helpful:

*'I don't know if they expect me to help in here. They might expect me to visit more and answer all their questions. I don't want to be judged mistakenly by nurses in here because I think I'm doing my best. They told me I can assist if I want to. Does this mean they expect me to help when I come here? Probably! I need to ask them what can I do to assist'* (Relative19 Interview, the Australian setting, on 26/10/2013 at 4.30PM, p. 13, L. 4-9).

The researcher observed a few relatives justifying to nurses their reasons for not assisting patients and apologising for this; the reasons included being tired or in a rush. This indicated that some relatives thought assisting patients was necessary when they came for the visit. One relative in the Australian setting stated she was unsure if she was allowed to assist when a nurse informed her she could. This relative blushed and said:

*'...Shame, they probably think I don't do anything'* (Field notes, the Australian setting, on 24/10/2013, from 10.00 to 3.00PM, p.79).

In the Saudi setting a relative stated that she had assisted her loved one repeatedly to shower and a few days after that another nurse informed her that she was not supposed to assist the patient. This relative said:



*'One nurse told me I can assist and another nurse said I shouldn't assist the patient in the shower without her help because the patient might get dizzy and fall on the floor'. (Field notes, the Saudi setting, 10/03/2014 from 9.00-4.00PM, p.125).*

This relative was confused because she thought she was being helpful and the nurse thought she might create trouble for the patient by helping. This relative said, *'Every nurse had her own version of roles for her [the relative]'* and she did not know what to expect next. She continued, *'It's difficult to satisfy all nurses'* (Field notes, the Saudi setting, 10/03/2014 from 9.00-4.00PM, p.125).

The majority of relatives in the Saudi setting did not expect to be humiliated by nurses; this happened when nurses expected relatives to perform care and it was delayed, such as when patients had not eaten their breakfast on time. The relatives did not have strategies to deal with patients that did not comply with healthcare procedures and that they acted poorly in these situations. Additionally, the researcher was informed by some relatives that they were under pressure from nurses as well, especially when nurses complained to other family members about them. Relatives often felt that they had failed nurses' expectations. Thus, relatives worked hard to please nurses and this was apparent in their demeanour:

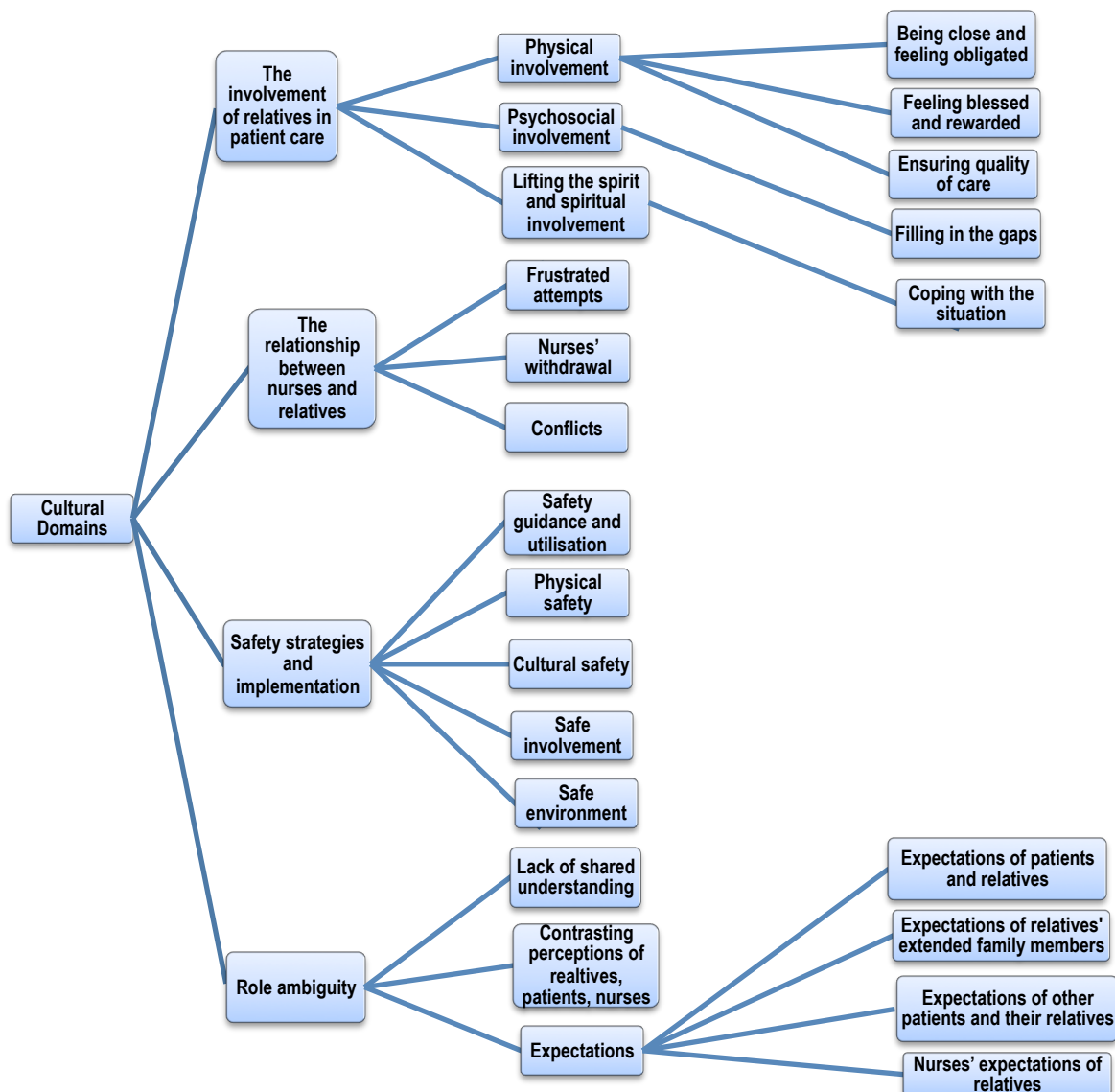
*One patient said; 'Look I'm under pressure from my family. I think I need help from nurses here. The nurse told my brother, I'm not being helpful to my mother. It hurts so much. The nurse doesn't know my family well. This is my mother, my family would think I'm not being good. I promise I don't sleep at night because I think mom may need something. She continued, 'I tried to walk my mother to the toilet. My mom was tired so she sat on the floor before she reached the bed. After sometime I told my mom please get up [but] my mom won't listen to me. She said she was tired, she could not walk. The nurse came in the room and she saw my mother on the floor. The nurse was angry. She asked me what happened, and she blamed me for assisting my mom to the toilet without telling her. I don't know what happened, and I don't know why the nurse was so upset with me' (Fields notes, the Saudi setting, on 28/03/2014 at 10.00AM, p. 64, cultural domains notes).*

As we have seen in both setting the relatives were confused as to whether they could assist patients and whether they were doing the right thing. Mostly, nurses in both settings forgot to provide relatives with clear instructions or explain their expectations, if they had any; this had relatives guessing their responsibilities. This was even more confusing when nurses' expectations were different from one

another. Relatives had a need to understand what they could do to assist patients and nurses, and why they were allowed to help one day but on other days were not permitted to.

## Summary

The second chapter of the findings provided a description of the cultural domains; these domains were essential to understanding the nature of relatives' involvement in patient care. There were four elements in this section: the involvement of relatives in patient care; the relationship between nurses and relatives; safety strategies and implementation; and role ambiguity for relatives in patient care. The figure below provides a picture of the taxonomy of cultural domains in relation to relatives' involvement in patient care in both settings.



*Figure 12: The involvement of relatives in patient care: A taxonomy of the cultural domains.*

The first domain, 'involvement of relatives in patient care' focused on the types of involvement relatives had in both settings and what nurses and relatives thought about this involvement. It appeared that relatives in the Saudi setting were more involved in care than Australians. Saudi relatives took on more responsibilities, some of which were considered to extend beyond safe practice. Family ties and relationships between relatives and patients seemed to impact on relatives' involvement. The relatives in Saudi Arabia also felt more obligated to look after sick family members, whereas in the Australian setting the majority of relatives felt it was voluntary, except for a few from particular ethnic groups. There were various roles observed and the researcher categorised these under names such as 'assistant' and 'supporter'. The subthemes in this domain were organised based on the type of activities that took place in the ward such as physical involvement, psychological involvement, and lifting the patient's spirit. The subcategories for these subthemes mainly focused on why relatives wanted to be involved and how this made them feel.

The second domain was the relationship between nurses and relatives and this domain focused on the impact of nurse/relative relationships and its influence on relatives' involvement in patient care. Nurses and relatives linked a good relationship and communication with high quality care. Many relatives expressed the desire to have a good relationship with nurses through discussions and communication; however, many nurses presented with avoidance behaviour. 'Nurses' withdrawal' was the first subtheme under this domain and it described how nurses withdrew themselves from interactions with patients and relatives, especially during visits hours. The reasons for this withdrawal were different from one nurse to another in both settings. 'Frustrated attempts' was another subtheme. This section presented attempts made by relatives to help patients in the field and the reasons relatives acted the way they did. These actions were often taken without a nurse's permission and this section described how this negatively impacted the nurse/relative relationship. The last subtheme under this domain was conflict; this described how nurses perceived some relatives' behaviour and also some reasons relatives reacted negatively towards nurses during care.

The 'safety strategies and implementation' subtheme focused specifically on safety measures implemented by nurses to regulate relatives' involvement. Nurses in both units classified their patients' needs and after this decided whether involvement was safe. This section also explained whether information about safety was given to relatives and how relatives perceived this information. Furthermore, effective ways of delivering information was discussed. The 'physical safety' section focused on aspects of safety such as when nurses assessing a patient's condition before they allowed involvement. The 'cultural safety' subtheme explained the importance of respecting cultural differences

and the impact relatives' involvement had on safe practice. Nurses' perceptions of safe involvement were inconsistent and these divergent views were presented in the subtheme 'safe involvement and conditions around involvement'. The subtheme 'safe environment' showed how the structure and layout of each unit had an impact on patient care and on the wellbeing of families and nurses. There were times when participants thought the environment was critical to the safe involvement of relatives. Elements such as single rooms, multiple rooms, and fear of cross contamination were critical to environmental safety and care delivery. In the Australian setting, less fear of infection and better interaction with patients and relatives were linked to single rooms.

Ambiguity about the role relatives play in patient care was another theme; this section looked at how different participants perceived relatives' roles and how these views led to ambiguity about the role. Clearly there was a lack of shared understanding of relatives' roles among participants in both fields. Additionally, the activities relatives were allowed or encouraged to perform were classified as 'simple'; however, this had varied meanings based on each participant's opinion. Rules regarding involvement in patient care were applied to some relatives but not to others; for example some relatives were allowed to visit for long hours because patients spoke less or no English and they required the support of their relatives to communicate with staff. Some Australian patients were reluctant at times to ask for assistance from their relatives whereas Saudi patients relied completely on their relatives' help. There were also other factors which contributed to role ambiguity such as the expectations of patients, relatives and nurses, especially when these expectations were not discussed openly. Expectations of patients and their relatives could be very high and nurses had difficulty meeting these. Additionally, the fact that nurses did not discuss their expectations of relatives meant that relatives were left guessing where their responsibilities lay in patient care.

## **Chapter seven**

## Chapter 7: Discussion

### Introduction

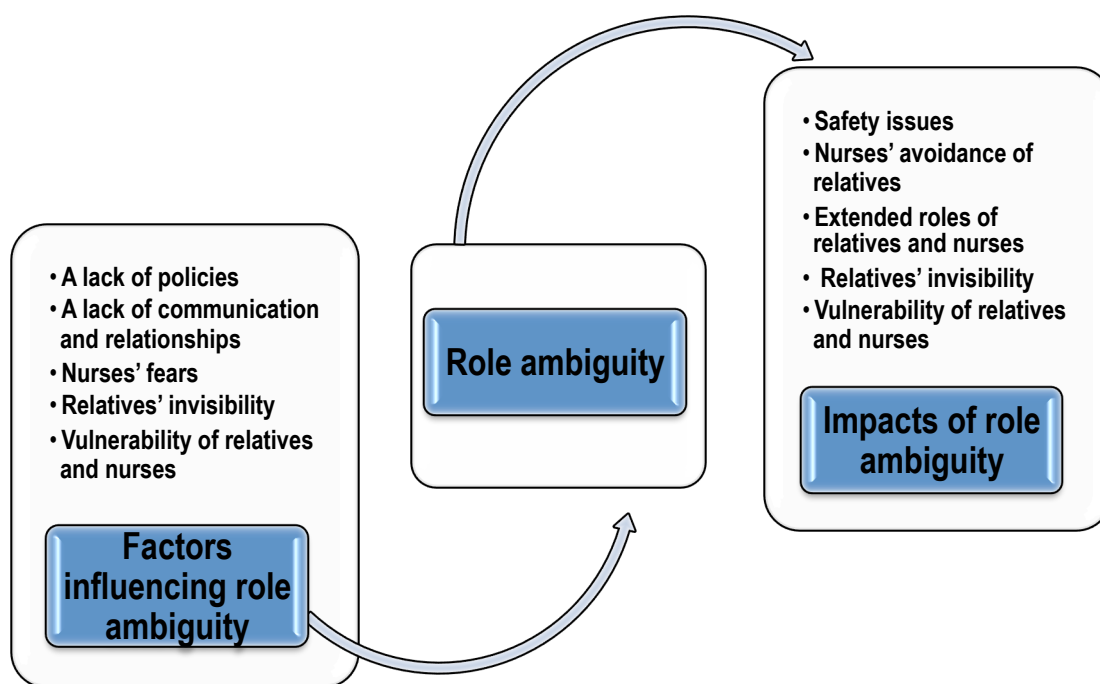
This study examined the role relatives play in the care of patients in medical settings in Australia and Saudi Arabia, and explored the attitudes of nurses, patients, and relatives themselves about their involvement. An ethnographic method was used to approach this study, which was ideal for an in-depth analysis of the culture of both hospital settings, the interactions and attitudes of the participants.

This study was designed to investigate relatives' involvement in patient care and the relationship between nurses and relatives. This is an important topic given that current patient centred care guidelines emphasise the importance of relatives' involvement in care and call for partnerships with relatives to improve care services (Australian Commission on Safety and Quality in Health Care, 2012; Epstein & Street, 2011; Johnson et al., 2008). Although there are a number of studies investigating the involvement of relatives in patient care, these studies have only considered their involvement in critical care, neonatal and paediatric settings, (Engström & Söderberg, 2007a; Engström, Uusitalo & Engström, 2011; Fegran & Helseth, 2009; Söderbäck & Christensson, 2007; 2008), and mental care (Wilkinson & McAndrew, 2008). It appears that there are only a few studies exploring relatives' roles in the care of patients in general medical units (Allen, 2000; Cioffi, 2006).

The most important issue which emerged from the findings in both settings was role ambiguity. While there have been many studies investigating relatives' experiences of different aspects of care in hospitals and the home, there are few studies which have explored the role ambiguity experienced by relatives caring for patients in hospitals. A study on the topic of the 'needs and experiences of family members of adult patients in an intensive care unit' (Verhaeghe et al., 2005) highlighted the need for relatives to understand the contribution they make to patients' lives. The study confirms the view that relatives need to know what their role in patient care entails; however it does not emphasise role ambiguity. Another study by Agård and Harder (2007) investigated relatives' experiences in intensive care units. The study results reported that relatives felt anxious and uncertain about whether patients would survive their illness, but again did not highlight role ambiguity. Role clarity is important because when it is absent it leads to confusion and exposes patients and relatives to the possibility of harm. Additionally, in this study it was found that nurses lacked awareness of their responsibility to manage relationships with relatives, which had a detrimental impact on the way relatives participated in patient care. There was a significant lack of communication between nurses and relatives and this caused confusion and misunderstanding. Overall, the absence of a role description for relatives' heightened

this ambiguity as well. Furthermore, in this research, the way relatives became involved in patient care was also informed and shaped by the diversity of participants. There were a variety of approaches taken to patient care and this was due to variations in the beliefs and assumptions of all participants, and the behaviour of nurses, patients and relatives at the two sites.

There were other factors and consequences, which arose from this study and contributed to role ambiguity. In the following discussion, role ambiguity is divided into two major sections. Part one describes the factors influencing role ambiguity. The second part focuses on the consequences of role ambiguity. Because of the complexity of this issue, factors and impacts are sometimes interrelated. The diagram below presents the main discussion points of this chapter.



*Figure 13: The factors and impacts contributed to role ambiguity*

## **Role ambiguity**

In both fields nurses and relatives faced ongoing ambiguity about the role relatives should play in the hospital environment and nurses were challenged by the unpredictability of relatives' participation in patient care. The term 'ambiguity', identified in this study could be defined as 'the absence of information, and the difference between the information required to perform a task and the amount of information already possessed by the organisation' (Galbraith, 1973 cited in Grote, 2009). The 'fear of taking responsibility' and uncertainty about their responsibility towards, relatives led nurses to take a varied and individualised approach to the involvement of relatives in patient care. This also caused

nurses to withdraw from interactions with relatives. Indeed, nurses feared the consequences of involving relatives in care because there was no protection for them in existing policies or guidelines. This was similar to the findings of a study by Vaismoradi, Salsali and Ahmadi (2011). The study took place in medical and surgical units of one teaching hospital in Iran. The study describes nurses feeling uncertain in their clinical practice in terms of interacting with patients and their relatives. Nurses found themselves in caring situations where there were no definite strategies or guidance and feared the consequences of their personal interventions in relation to care (Vaismoradi, Salsali & Ahmadi, 2011).

Ambiguity also impacted upon relationships between nurses and relatives; nurses believed these interactions added to their tasks. Therefore, on most occasions nurses felt this relationship was a burden and appeared to avoid it, resulting in relatives feeling invisible in the hospital environment. In addition, nurses were unable to communicate consistently and effectively with relatives because of fear, and issues related to work overload and a lack of time. For example, some nurses believed interactions with relatives created an additional workload. The lack of any sort of relationship between nurses and relatives contributed to nurses' fear of taking responsibility for relatives and this impacted on their communication with relatives. In addition, relatives lacked information around their role, which led to ambiguity about patient care. Relatives were unclear about how to behave in the role, what the needs of patients were, and whether they were contributing to care and this increased their frustration. The findings showed that there was a lack of clarity about the role relatives play in patient care and nurses' responsibility towards relatives. The following discussion elaborates on these issues.

### ***Factors influencing role ambiguity***

This category focuses on the reasons for role ambiguity. The diagram below represents the factors influencing role ambiguity.





*Figure 14: The factors influencing role ambiguity*

### **A lack of policies**

In both fields, safety standards and quality care implemented by both hospitals were the standards the nursing team used to manage the involvement of relatives. But, the link between a nurse's role in looking after patients and the organisational objectives that encourage partnerships with patients and their relatives was unclear and this created confusion for nurses. As discussed, some nurses had a positive attitude about the involvement of relatives but even these nurses had concerns regarding safety and the legality of this involvement. For instance, nurses feared being held accountable for any harm to patients or relatives which may arise from the participation of relatives. A lack of strategies to deal with the involvement of relatives highlighted in a study by Paliadelis et al. (2005); nurses were concerned about their ability to provide quality care to patients when relatives assisted in this care. The study indicated that nurses feared they couldn't control the healthcare environment because the process of managing the involvement of relatives was not discussed (Paliadelis et al., 2005; Pryzby, 2005). Each nurse had an individual understanding of a relative's role and how their interactions and relationships with relatives should be managed. Inconsistency in decision making in relation to the participation of relatives was raised by the study which was also similar to the findings from Hickey & Lewandowski (1988).

Another study by Stayt (2007) explored nurses' experiences of caring for families of patients in intensive care units; interviewed nurses said they referred to self-imposed standards and expectations because of a lack guidelines. This made nurses less confident approaching relatives in the ICU; these nurses also stated that the expectations of relatives sometimes prevented them from fulfilling their role of providing standard care. Role conflict made nurses feel torn between their caring role and their responsibilities towards patients' families. These studies confirmed the importance of clear standards and guidelines to lessen the confusion experienced by nurses (Stayt, 2007; Al Mutair et al., 2014a).

In this current study, nurses sometimes experienced stress when relatives were involved in care. In some cases nurses stated that care took twice as much effort with relatives participating than when nurses performed it by themselves. This was because they gave relatives guidance, and needed to protect both relatives and patients from harm. Additionally, Paliadelis et al., (2005), considered the lack of policies and structured guidelines provided to nurses regarding the role of families as a barrier to effective interaction and intervention. In this study, there were no clear policies or guidance and because of this there were misunderstandings and disagreements. Similarly, some relatives, especially in Saudi Arabia, reported stress and feared harming patients when they performed daily care. This study suggests that relatives' stress was at least partially due to a lack of understanding of their role.

Guidelines or policies are essential for a shared understanding of relatives' responsibilities and accountabilities. In the Al Mutair et al. study (2014a) healthcare providers and nurses were stressed about including families in daily care in the ICU, because they could barely manage the critical issues of patient care which they were already experiencing. The researchers called for public education and policy development around the presence of families and their involvement in daily care. This suggests that guidelines and policies would promote safety and overcome the fear and confusion which results from the involvement of relatives in hospital settings. These studies (Al Mutair et al., 2014a; Stayt, 2007; Paliadelis et al., 2005; Pryzby, 2005) confirm the findings of the current study, which recommends the creation of policies that can clearly articulate the roles and responsibilities of nurses and relatives. Although previous research was not aimed at studying the impact of a lack of policy on the participation of relatives in patient care, the findings of these studies do provide an understanding of aspects of this issue.

## **A lack of communication and relationships**

Effective communication between nurses and relatives has been cited in some studies as a way to assist relatives to gain clarity and make decisions regarding the care of their loved ones (Fox, 2014; Fry & Warren, 2007; Khalaila, 2013). There was no doubt that effective communication is critical to building good relationships between nurses and relatives in the field and vice versa. This was demonstrated when nurses used effective strategies to deliver information to relatives such as being specific, informative and answering questions.

Clarity and consistency of information helped relatives significantly, to understand their role and the contribution they could make to patient care. In addition, communication between relatives and nurses in both fields was challenging and needed dedicated time and effort from nurses. Not exchanging information or poor interaction caused misunderstanding and sometimes resulted in conflict between nurses and relatives, which was highlighted in the findings. In this study, relatives needed to have information regarding a patient's condition, care and progress provided, and wanted to have their questions answered. This result was supported by the findings of several previous qualitative studies which highlighted relatives' need to receive information about patient care from care providers (Takman & Severinsson, 2006; Fry & Warren, 2007; Linnarsson, Bubini & Perseius, 2010; Obringer, Hilgenberg & Booker, 2012). On many occasions relatives accepted not interacting with nurses regarding their own needs such as emotional support from nurses, but wanted to be certain about a patient's condition and this was a similar result to a study conducted by Omari (2009).

Lack of communication and a lack of information made relatives uncertain about their loved one's medical condition and the possible outcome of their stay in hospital and therefore increased stress. This was also reported in a study performed by Takman and Severinsson (2006). The researchers found some relatives were stressed because they lacked pertinent information about patients' conditions. Meetings were arranged with social workers for those relatives in order to decrease their stress. The researcher stated that relatives' stress could be reduced, if they spoke to the staff involved in patient care or were given the information they required from nurses (Takman & Severinsson, 2006). This suggests that relatives can be reassured by the use of effective communication. The literature reviews available regarding communication focused on intensive care units and palliative care (Söderström, Saveman & Benzein, 2006; Lowey, 2008) where effective communication is used to help relatives to cope with the nature of a patient's illness and the likely outcome of their condition. Additionally, communication and information delivery were at the centre of a health team's attention in

these units because they commonly turned to relatives for surrogate decision-making. This is in contrast to the findings of this study where communication appeared to be of more importance to relatives than nurses. Most importantly, the lack of communication between nurses and relatives was problematic for relatives, but they could not speak about their dissatisfaction because this threatened their relationship with nurses (Rainey et al., 2015). This is because relatives were dependent upon nurses for information and updates about their loved ones. This added to the problems between these parties and left some of the miscommunication unresolved.

### **Nurses' fears**

Evidence from the current study confirms that nurses feared taking responsibility for relatives' involvement in care. For instance, fear was a contributing factor in making nurses hesitant to endorse interaction with relatives. Nurses' fear of taking responsibility made relatives' roles unclear and created many assumptions around their involvement. The results highlighted several distinctive aspects of a nurse's fear of this responsibility; one aspect was a fear of becoming emotionally involved. This fear manifested in a perception that becoming emotionally involved conflicted with a nurse's professional role. The attempt to avoid any emotional interaction with relatives made some nurses reserved with relatives. This prevented them from forming relationships with relatives and consequently relatives felt distant from nurses (Stayt, 2007). Nurses were challenged by needing to create relationships with relatives and their patient care tasks (Holden, Harrison & Johnson, 2002). They believed that the emotional impact of a relationship with relatives could impact on their ability to make decisions. Therefore, some nurses seldom asked relatives questions of a personal or emotional character (Takman & Severinsson, 2006). These findings are supported by the results of Stayt (2009). The author stated that nurses in the ICU remained reserved during interactions with patients' families to keep control of this relationship (Stayt, 2009). Nurses feared taking responsibility because they did not want the emotional burden that could result from this relationship.

The results also indicated that conflict with relatives was a part of the working environment; however, this was more evident in the Saudi field. Nurses feared taking responsibility for relatives who were involved in caregiving because they had experienced previous conflict with relatives. Nurses also did not want to be involved in time-consuming tasks. The negative past experiences of nurses also made them cautious in their dealings with relatives. They feared conflict and preferred to remain distant from relatives who were viewed as the source of a problem. Many nurses did not want to be involved in arguments with relatives because of the negative influence this had on their work such as stress. In this

research, nurses relied on their leaders to resolve any conflict that occurred. This showed that nurses did not know what a suitable reaction to a problem might be and feared personally intervening. Nurses also feared the uncertainty that comes from lack of understanding of hospital processes designed to resolve conflict with relatives. In addition, they were uncertain where these conflicts could lead. A study by Stayt (2007), described nurses' experiences of caring for patients' relatives in an intensive care unit in a large teaching hospital in the UK. The author stated that nurses lacked the confidence to approach families because they were fearful of saying the 'wrong thing'. This study highlighted the lack of guidance provided to nurses to deal with patients' families in their daily practice (Stayt, 2007). Stayt's (2007) findings are also supported by the current study.

### **Relatives' invisibility**

The invisibility of relatives was both a factor and an impact of role ambiguity in both settings. It was apparent that relatives played a significant role in patient care and wellbeing, but their contribution to this care was invisible. First there was invisibility in terms of relatives' partnerships with nurses. There were information sheets available for consumers which provided a framework for consumer partnerships with care providers in health care services (Australian Commission on Safety and Quality in Health Care, 2012). These could also be accessed online. However, this information sheets did not specifically refer to relatives' roles in patient care. Even though some information was available about partnerships between nurses and relatives, there was a clear gap between partnership guidelines and current practice. It was clear that the complexity and dynamics of interpersonal relationships and interactions in the field made the enactment of partnerships difficult. Relatives held an unclear position in relation to nurses. This meant that relatives were sometimes facilitators in patient care but at other times were viewed by nurses as a burden. Although health institutions recognised relatives as partners there was no clear understanding of the responsibilities and roles under the term 'partnerships in the field'.

Relatives were also invisible in terms of the time dedicated to relatives as partners in care. Nurses did not allocate time to communicate with relatives; therefore, there was lack of time to promote relatives' contribution to patient care. The data shows that ambiguity around this involvement meant that nurses did not feel committed to relatives, as many nurses felt they had no real obligations towards them. This finding was more evident in the Saudi field, as some nurses did not want to take any responsibility for relatives at all and ignored them. Many nurses argued that the patients were their first and only priority in care delivery. These views were similar to the results found in a study by Stayt (2009) which showed

that nurses had limited time for relatives in the field and they considered patient care to be their most important duty. Nurses in this current research used their responsibility towards patients as an excuse to interact less with relatives and to limit their obligation to relatives in both fields. In the Australian setting the nursing team did not complain of nursing shortages on most days but they did experience issues resulting from a lack of interaction with relatives. This suggests that failing to dedicate time to interact with relatives in both fields was not always because of workload.

Another issue was invisibility in relation to support and physical resources for relatives. The majority of relatives from both settings were not aware of any support services tailored to relatives in the field. Lack of resources was evident in both fields, but this was more apparent in the Saudi setting. There were no facilities designed for relatives in the field such as places to rest, and no effort made to educate, and counsel or support them. This was a surprising finding because relatives have been involved in patient care in Saudi Arabia for many years. Additionally, relatives experienced constant discomfort and were dissatisfied with the lack of resources provided to them. The Saudi relatives had some facilities such as three meals and showers; however, they slept on the floor and wanted beds. They also needed relative-centred facilities such as individual support. In the Saudi unit relatives seemed to be ignored by the hospital system even though their presence in most cases was a requirement. Additionally, in both fields, a lack of resources provided to relatives made relatives feel unwelcome. The need for physical resources was also highlighted in a study by Takman and Severinsson (2006) which investigated the perceptions of the needs of 'significant others' in the ICU. The researchers stated that Norwegian providers highlighted the need for a well-equipped field to facilitate the involvement of relatives in care, such as a place to sleep and rest (Takman and Severinsson, 2006). Acknowledging the contribution made by relatives through the provision of facilities may legitimise relatives' caregiving roles.

### **Vulnerability of relatives and nurses**

The invisibility experienced by relatives in both fields resulted in some vulnerability. This was also a influencing factor and impact of role ambiguity. In some cases relatives felt empowered to be fully engaged in patient care despite the lack of support and knowledge they received, but their role in care was still ambiguous. This vulnerability meant that relatives and nurses were unable to interact properly, and this created feelings of doubt and issues of transparency in the relationship. Vulnerability was expressed differently in each setting. For example, in the Australian setting, relatives were vulnerable because they only had a short time during the visits to contribute to patient care. Relatives used these few hours to gain information, interact with the health team, develop relationships with nurses and

assist patients. Relatives felt responsible for promoting their values and their input into patient care within these few hours. Moreover, relatives felt responsible for interacting and communicating with nurses. The findings showed that relatives experienced ambiguity about their contribution to patient care when they spent such a short time in the field (Rainey et al., 2015).

On many occasions relatives felt stressed when their involvement in the caring process and their relationship with nurses was not satisfied in such a short time. Some research articles highlighted that relatives felt stress and guilt when an ill family member was hospitalised (Eriksson, Bergbom & Lindahl, 2011). However, there is a significant lack of research exploring the impact of short visits on the role or contribution relatives make to care. The available studies explore the visitors and visiting hours in terms of patient needs, policies and restrictions; these studies have also focused only on intensive care units, paediatrics and palliative care (Gray et al., 2011; Whitton & Pittiglio, 2011; Harth 2010; Cooper et al., 2008). It is clear that many of these studies focus on patient vulnerability in the context of long or open visits and discuss the desire of relatives to be with their family members in such critical situations, but do not explicitly study patients' relatives. In the Saudi settings, the implemented visiting hours did not impact upon visitors or their contribution to care because they relied on patients' companions to transfer information to them and to undertake care as well.

In the Saudi setting, relatives were vulnerable to bullying. Some relatives were a target of bullying by other relatives and patients in the field who justified this behaviour as a way of showing care for patients. In most cases the victim was bullied because she had failed to achieve the expectations of the bullies. Bullying was apparent in actions such as verbal abuse, intimidation, criticism, blaming, belittling, and making demands. Some of the bullying relatives and patients encouraged others in the field to follow their behaviour, which made the environment more stressful. Additionally, the bullying had profound effects on the victims; for example, they experienced feelings of powerless, a lack of interest in sitting with patients, stress, lack of rest and sleep, exhaustion, burnout, and fear of being judged by others. Moreover, the negative impact of bullying on victims could be a potential threat to a patient's wellbeing, because the victims then tried to prove they could do more caregiving, even where this was inappropriate or unsafe. Bullying is an issue receiving increasing focus among nurses and in workplaces generally and has been frequently discussed in the literature (Cleary, Hunt & Horsfall, 2010; Frederick, 2014; Murray, 2009; Granstra, 2015). However, there is lack of research investigating bullying of and by relatives or patients in the field. Bullying increased in the Saudi setting because relatives formed groups and subgroups in the field. In this study victims did not report the issue of

bullying to anyone, including the nurses. Nurses in the field turned a blind eye towards this behaviour and preferred not to be involved in the issue to avoid conflict.

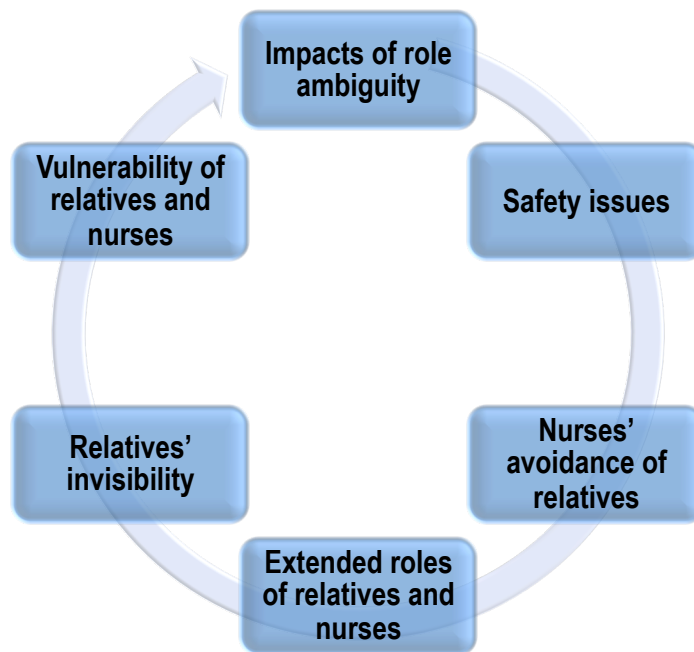
Another example of vulnerability in both fields was cultural. The results show that cultural diversity had an impact on conflict and misunderstanding between nurses and relatives in both fields. The lack of understanding of the culture and beliefs of patients and their relatives created ambiguity for nurses and relatives. Patients and relatives did not believe nurses could provide culturally competent care and in some cases they felt demeaned by nurses. Additionally, nurses felt embarrassed and stressed when they demonstrated a lack of understanding of patients' and relatives' cultural or religious beliefs. This made both nurses and relatives vulnerable to stress and caused misunderstanding and confusion.

The findings of this study are similar to the results from research performed by Hart and Mareno (2014), which provided a qualitative description of the challenges and barriers nurses face in providing culturally competent care in the field. They reported that nurses' lack of knowledge and understanding of cultural diversity impacted care delivery and communication. The authors called for educational programs to help nurses understand the social and cultural needs of patients and their families (Hart & Mareno, 2014). There are many authors who have discussed cultural diversity in healthcare services and how nurses can provide culturally competent care by preserving and maintaining people' cultural beliefs (Wehbe-Alamah, 2008; Hussein, 2000; Kulwicki, Miller & Myers-Schim, 2000; Luna, 1989; Luna, 2002; Leininger, 1995; Leininger & McFarland 2002; 2006). Despite the increased attention given to cultural diversity in the literature there are few studies exploring the challenges faced by nurses and relatives in terms of cultural or religious differences and the impact this may have on the involvement of relatives in patient care.

### ***Impacts of role ambiguity***

This section focuses on the consequences of role ambiguity. The diagram below shows these consequences.





*Figure 15: The impacts of role ambiguity*

## **Safety issues**

Despite the positive outcomes patients receive as a result of the involvement of relatives, the study findings indicated that relatives suffer stress, fear and find care a burden. Personal safety was an issue faced by relatives, which emerged from the study; the issue of personal safety was exemplified in cases where relatives felt emotionally burdened and this combined with fearfulness and stress, not only from undertaking the caregiving role but lacking education and support as well. This finding was present in both settings but for different reasons. In the Saudi setting some relatives became increasingly distressed because they could not escape the responsibility of caring. In the Australian setting, relatives reported the difficulty of maintaining their work and responsibilities while caring for patients. This indicates the stress in trying to balance their personal responsibilities with the caregiving role. As a consequence relatives sometimes paid less attention to their own needs and health to concentrate on helping patients. The emotional burden of caregivers was highlighted in a study performed by Rha et al., (2015). The authors used the Zarit Burden Interview, which is a scale used to measure the burden experienced by informal carers in relation to the caregiving role. This scale measures social and family life, and the burden in the relationship carers have with ill family members; these issues are categorised as emotional issues, loss of control, and financial issues. The authors stated other issues which affected carers; for example, the health consequences of physical inactivity as a consequence of caregivers looking after the chronically ill (Rha et al., 2015).

This current study found that some relatives forgot to eat, take their own prescription drugs, rest, or sleep, and were distressed about other personal matters. Additionally, some relatives expressed feelings of worry, stress and limitations to their personal time. All of these issues could have consequences for relatives' mental and physical wellbeing and could impact upon their caregiving role and ultimately harm patients. The findings of this study are in contrast to those of a research study using mixed methods design, performed by Geere et al., (2013), where some family caregivers denied any negative impact to their own persons from the caregiving role. However, the authors stated that family caregivers had other issues, which affected them, apart from their caring role such as work demands (Geere et al., 2013). There are multiple studies highlighting interventions to increase the knowledge and support given to relatives during their caregiving role, in order to lessen their burden (Janze & Henriksson, 2014; Rha et al., 2015). However, these interventions were not always implemented in practice and lagged behind the recommendations made by a variety of studies.

Another issue was the safety of patients and relatives during care. This was evident in both settings; however, this appeared to occur more in the Saudi setting. Relatives' involvement raised the potential for harm or injury to patients and their relatives, such as infections and falls. In the Saudi setting relatives took responsibility for patients' daily living activities. Safety issues emerged because nurses neglected to communicate safe practices to relatives and explain the role relatives should take in care activities and guide them when they took on these responsibilities. It is essential to keep in mind that relatives lacked the problem solving skills and education that nurses had when potential problems occurred during care. Additionally, in the Saudi setting, some nurses blamed relatives for neglect when relatives failed to report changes in a patient's condition. This was a serious concern because it showed that nurses were reliant on relatives to monitor patients' progress or regression, without regard for the fact that relatives had limited knowledge and instruction. It was clear that many relatives were not capable of noting changes in a patient's condition, which could then delay an appropriate response. For example, if relatives were undertaking skin care or hygiene they would be best placed to note changes in the patient's skin condition. In cases where family caregivers received guidance from nurses as they undertook a patient's daily living activities, the quality of life of patients increased and the burden experienced by families decreased (Roldán-Merino et al., 2013). This suggests that engagement in these activities by nurses improves quality of care given to patients, which was also recommended by Cho et al., (2015).

In both settings some nurses thought that many daily living activities were simple tasks which relatives could do. However, those nurses did not recognise the difficulties or stress relatives could experience

when they assisted with these activities; for example, the process of giving the patient a shower or bath. On some occasions these simple tasks could result in upsetting events such as patient falls or increased pain and distress to patients. Moreover, in both settings relatives assisted in positioning patients in beds or helping them to move from beds to chairs. Relatives not only lacked knowledge about how to assist patients with their mobility but also demonstrated a lack of awareness about their own posture and movement during care.

In the Saudi setting some relatives complained of back, shoulder and neck pain a short time after they helped patients with physical activities. Similar issues with family carers were raised by Geere et al., (2013). The authors highlighted that family carers complained of musculoskeletal pain during their care giving roles because they lacked knowledge on how to promote their own physical health. The authors also stated that pain affected the ability of family carers to provide care to their loved ones (Geere et al., 2013). In the Australian setting some relatives who cared for their chronically ill family members preferred to continue caring for them when they entered hospital, and some of them believed they were experts in care and disagreed with the approach of some nurses to care, such as using machines to lift patients. This raised safety issues because it is possible relatives did not know why nurses use these machines; this points to a lack of knowledge about safety and the failure of nurses to educate relatives in better caring practices.

### **Nurses' avoidance of relatives**

Nurses in both fields seemed busy when relatives were present. Many relatives thought nurses were avoiding them and withdrawing from them. This perceived avoidance created communication issues and adversely impacted upon relationships. Furthermore, relatives thought some nurses were short tempered so were cautious when approaching them. There has been a lack of research conducted in general wards such as medical units investigating nurses' and relatives' behaviour during visiting hours. However, there are many articles investigating the perceptions of patients, families and staff of visiting hours. Most of these studies were conducted in palliative care and intensive care units where patients' families are always present in the field (Gray et al., 2011; Taylor, 2008; Tayebi et al., 2014; Whitton & Pittiglio, 2011).

In this study, relatives reacted to the avoiding behaviour of nurses with frustration or by being reluctant to approach nurses. These results were similar to the findings from a study completed by Rainey et al., (2015). The data for this study were collected through interviews and the research was conducted over

twelve months. The authors stated that when nurses appeared busy, this decreased opportunities for communication between nurses and relatives because relatives had the impression that nurses were overburdened (Rainey et al., 2015). Similarly some relatives were concerned about the way nurses' responded to them if they approached them while they were busy (Rainey et al., 2015). Additionally, relatives felt rejected or isolated if they were avoided by nurses in the field (Jamerson et al., 1996). It appears that lack of information provided to relatives created trust issues for relatives in relation to nurses and uncertainty regarding their role.

The findings of this study showed that nurses held diverse perceptions about their own behaviour during visits. The majority of nurses were not aware they were avoiding relatives. In addition, many nurses in both settings were busy during the visits, as they took the opportunity to do other tasks such as documentation when they believed the patient had someone with them. Unexpected issues arose in both settings and were a reason nurses deliberately avoided or limited their interaction with relatives, such as relatives asking too many questions. Some nurses avoided establishing communication with relatives because it created opportunities for relatives to ask questions. It appeared from the findings that nurses were irritated by relatives' questions and repeated requests for information, especially when they were busy. Furthermore, it was apparent that nurses wanted to control this interaction by avoiding discussions that could lead to extended dialogue. Nurses believed answering too many questions and repeating information was a time-consuming and frustrating task. This result accords with a study by Wong et al., (2015) who found that when nurses were abrupt during information delivery this prevented families from asking further questions. Relatives could have perceived this abruptness as rudeness or busyness; in both situations this impacted upon interactions in a negative manner.

### **Extended roles of relatives and nurses**

In the Saudi setting it was evident that relatives sometimes took on 'extended roles', meaning they performed activities beyond their expertise, resulting in safety issues such as performing a wound dressing. In both settings nurses believed that when relatives performed caregiving activities without their knowledge this interfered with their nursing duties and gave them extended roles such as continuous visits to patient rooms to observe relatives' activities. The behaviour of relatives also impacted on interactions between nurses and relatives. Bøttcher and colleagues (2014) found that non-compliance by relatives of professional healthcare rules was considered an interfering behaviour; as a result health professionals inhibited relatives' involvement in patient care (Bøttcher, Lindhardt & Frederiksen, 2014).

There are few studies exploring relatives' interference in care and its impact on the nursing role (Robinson & Thorne, 1984; Shoqirat, 2015). This issue was also one of the reasons for conflict between nurses and relatives in the Saudi setting. Relatives explained that their interfering behaviour in nursing care was a way to show dissatisfaction with the care given to patients or was undertaken purely to assist patients. Reeves et al., (2015) suggests that relatives wanted to ensure that patients' needs were met promptly. This was often a way for them to show support and protect patients. Frequently, relatives were frustrated when nurses delayed meeting patients' needs. It is essential to state that nurses viewed the behaviour of some relatives as interference and as a hindrance to patient wellbeing and nursing work. However, the interfering behaviour of some relatives could also be construed as a productive means of influencing the patients' experience of their illness and time spent in hospital. In addition, relatives' interference might reflect their dissatisfaction with care and health care relationships (Robinson & Thorne, 1984). There is a suggestion that relatives' interference in caring tasks is due to trust issues that emerge from nurses' poor communication skills (Shoqirat, 2015). The current study also found that views about relatives' interference in care changed according to the nature of patients' conditions and the caring activities undertaken by relatives.

Taking responsibility for the basic daily needs of patients was a requirement in the Saudi setting. Relatives' continuous presence was a reason for this norm. Remarkably, many relatives believed that daily or basic care was their responsibility as family members, although some questioned themselves at times whether they should be doing particular tasks. The findings showed that relatives felt overwhelmed by the caring responsibilities they had in the field but some felt they had no option but to continue to provide care. Additionally, nurses transferred most of their nursing obligations in terms of providing basic care, to the relatives accompanying patients. On many occasions nurses believed some of the patients were stable and did not need their assistance in basic daily care. Many nurses in the Saudi setting believed if there were more nurses, the caring duties would not be left to relatives. It was unknown if the shortage of nurses in the Saudi setting contributed to the extended roles relatives undertook in the field. Similar claims were the target of inquiry in a study performed by Cho et al., (2015); the data of this study was collected by survey. The study discussed implementing policies to increase the number of nurses employed and to decrease informal caregiving, for the purpose of increasing the quality of care delivered to patients. The authors stated that nurses give less priority to patients' basic needs because the patients' sitters do this for them (Cho et al., 2015). However, it is unknown whether an increase in the number of nurses would result in nurses taking more responsibility for delivery basic nursing care.

## Summary

This chapter discussed the factors that impacted upon the role relatives play in the care of patients in medical settings in Australia and Saudi Arabia. The findings revealed one major discussion point, which was critical to understanding the inquiry of this research, and this was role ambiguity. Role ambiguity had a significant impact on nursing care and relationships between nurses and relatives. Nurses and relatives faced ongoing challenges because relatives' involvement in care was unpredictable. The ambiguity of relatives' roles meant that nurses assumed that interactions with relatives would add to their workload, and they were concerned about constraints on their time. Relatives also lacked information about their role, which led to ambiguity about patient care; they were unclear about how to behave in the role, what the needs of patients were, and whether they were effectively contributing to patient care. The discussion chapter provides evidence that the undefined responsibilities of both nurses and relatives caused frustration and conflict in the relationship.

This chapter also highlighted the factors influencing role ambiguity. Nurses did not understand their duty towards relatives and relatives did not understand their responsibilities, due to an absence of policy. Another cause was a lack of communication and poor relationships between nurses and relatives. Lack of communication was a reason nurses were unable to understand how they could assist and support the involvement of relatives. Secondly, nurses held fears about the involvement of relatives which were a cause of role ambiguity. The invisibility of relatives was both a cause and effect of role ambiguity. Vulnerability of relatives and nurses was another cause and effect of role ambiguity. Vulnerability made both relatives and nurses incapable of creating transparent relationships.

The chapter highlighted the consequences of role ambiguity. The first consequence was safety. This section discussed relatives' mental and physical safety. It appeared that involvement in patient care created emotional burdens, fear and stress for relatives. Secondly, the fact that nurses avoided interacting with relatives created communication issues, which adversely impacted relationships. One effect of role ambiguity was that the roles of relatives and nurses expanded. Relatives extended their role when they helped patients beyond what constitutes safe practice. Nurses believed that this approach interfered in their nursing duties. This interference appeared to cause conflict between nurses and relatives, especially in the Saudi setting. Nursing shortages were a contributing factor to this issue; however, it is unknown whether a bigger nursing team would decrease relatives' responsibilities in basic care.

## **Chapter eight**

## **Chapter 8: Conclusion**

### **Introduction**

This chapter summarises the major findings of this study and their significance, and highlights the strengths and limitations of this research. Next, the implications will be discussed and recommendations offered.

### **Summary of the major findings**

This study was designed to investigate the role relatives play in the care of patients in medical settings in Australia and Saudi Arabia also to explore the attitudes of nurses, patients, and relatives about the involvement of relatives in patient care. Additionally, the research aimed to investigate the impact of relatives' involvement on care and the differences between participants' attitudes in Australia and Saudi Arabia. This study adopted an ethnographic approach; this involved an in-depth investigation of the culture of both fields and shed light on relatives as partners in care. This approach provided a sophisticated understanding of the topic in two medical contexts, one in Australia and one in Saudi Arabia. This is the first study investigating relatives' role in patient care in medical units in Saudi Arabia and the first study comparing two countries in terms of relatives' roles.

The findings indicated that the role relatives play is complex and undefined. It is important to state that even though the two settings were different in terms of relatives' roles and the way these roles were implemented, there were more similarities than differences between the Australian and Saudi Arabian fields. A patient's condition and a relative's background, culture, experiences, expectations and type of relationship with the loved one, had a great impact on how the role was applied and perceived in both fields. The perspectives and attitudes of relatives and patients indicated they considered the role to be important. On the other hand, nurses held mixed views since their experiences had not always been positive. Many nurses felt unprotected under the hospitals' current systems and were uncertain about how to approach and deal with relatives. Some nurses experienced interaction difficulties with patients and their relatives because they lacked cultural education and knowledge.

Similarly, relatives lacked an understanding of their rights and responsibilities under the term 'partnership'. The dynamics and complexity of interactions in both fields created gaps in the partnership concept. In the field, there was a lack of communication between nurses and relatives, which impacted upon their relationships with each other. Both nurses and relatives perceived communication as



important for patient care; however, relatives appeared to need this more than nurses. Additionally, relatives believed nurses avoided interacting with them, whereas this was not conscious behaviour, from the perspective of nurses. In this study, a lack of acknowledgement of the work undertaken by relatives resulted in poor communication; they did not receive the support or education they needed about patient care. A lack of acknowledgement also made relatives feel invisible in the patient care context and created issues which made them vulnerable in a variety of ways.

This research was designed to explore whether nurses delegated care activities to relatives. The findings indicate that there was no formal delegation of care. In the Australian setting relatives were sometimes asked to perform certain activities; however, in the Saudi setting it was assumed relatives would provide basic care. Relatives took part in certain types of care activities such as assisting in patients activities of daily living; however, in the Saudi setting they were sometimes involved in more complex care, resulting in unsafe practice. There were times when caregiving made relatives feel stressed and burdened. Relatives in the Saudi setting were exposed to more stressful situations than relatives in the Australian setting, such as bullying from fellow relatives and patients, fear, and lack of rest.

In both settings limited attention was given to relatives in regard to physical facilities and support; relatives in Saudi Arabia had no facilities provided for them except meals and blankets, although they had been part of hospital care for many years. In terms of role perceptions, this study showed that what was considered to be a relative's role was highly subjective and varied among participants and even more so between the two settings. This variance of views among participants resulted in different assumptions and expectations of the role. As a result there was confusion, conflict and misunderstanding when the participants' expectations of this role were not satisfied. Additionally, safety issues arose because relatives misunderstood and were confused about their responsibilities. The results indicate this confusion may have developed because of a lack of guidance and policies. A lack of policies contributed to nurses feeling fearful of taking responsibility for relatives and being uncommitted to their involvement. As a result, relatives remained unaware of their position in patient care. Finally, it was found that the context and busyness of the ward had a significant impact on the involvement of relatives and added to the complexity of relatives and nurses' relationships.

### **Study strengths and limitations**

This section presents the strengths and limitations of this study

## **Strengths**

One of the main strengths of this study was that it used an ethnographic approach to investigate the complexity of relatives' role and involvement in care. This approach was important to reveal the intricacies and impact of the culture of each unit on participants' behaviour and interactions. This approach was implemented through multiple data collection methods. Frequent visits in each field, long observations and time spent in each setting assisted the researcher to gain an authentic, cultural understanding of the topic. The interviews gave the inquiry a subjective point of view and supported the analysis of other research results. Spradley's (1979, 1980) process of interpreting data was used to develop, analyse and confirm the results. Since the method of analysis followed a systematic and emergent way of interpreting data, the results were consistent. Reflexivity used in data collection and analysis assisted in verification of the results.

The approach of non-participant observations helped to gain a naturalistic and objective view of the field. It also meant the researcher had time to immediately write down what she had observed in the settings. The researcher was not directly involved in the activities, which occurred in the fields; therefore, this helped her to pay attention to details such as behaviour and interactions, since this was one of the main aims of this study. Non-participant observation also assisted in gaining an *etic* point of view; the views of the researcher as an outsider assisted in obtaining an unbiased account. Additionally, the researcher had not worked in either field; therefore she was able to ask nurses questions in a naive fashion, allowing nurses to elaborate when giving their answers.

At the beginning of the observations there was a need to create a tool that would be useful in collecting data, as the observation and documentation progressed. The researcher gathered and modified guidelines for the observations (Appendix 13: Observation guidelines); this was helpful for collecting useful data in both fields. The guidelines assisted the researcher to focus and gather data that was relevant to the inquiry of this research and which provided clarity to the outcomes.

This is a comparative study; it compared a Western and a Middle Eastern country, and it also shed light on some similarities and differences between cultures, views, nursing activities, environments, and facilities. This study also provides a comparison between Australia as a developed nation and Saudi Arabia as a developing country. Interesting paradoxes arose from the data for the ethnographer, such as with respect to multiculturalism in the Australian setting and the domination of Saudi culture in the Saudi field. The cultural and religious data revealed in this study provides a valuable source of

information for nurses and hospitals on issues of diversity and differences between patients, their relatives and nurses as well. The study also generated some new insights into relatives' role and involvement in care.

### ***Limitations***

The patients in this study were all female; therefore the findings may reflect the perspectives of this gender alone. The findings also reflect the attitudes of relatives and nurses towards female patients only. However, the sample provided rich data from a variety of the population. In this study the focus was on the complexities of the relationships between nurses, patients and relatives and relatives' roles in care.

During the interviews with Saudi relatives and patients, participants were constantly asking the researcher if she was from the administration and whether she had concealed her identity to gain practice-related information from them. It might be argued that this could have limited participants' openness to the researcher because they feared creating problems for nurses. Being aware of this possibility, the researcher explained to participants the nature of the inquiry, showed them the Nursing School ID, and presented them with the acceptance from the hospital for the researcher to perform the study. This was to confirm to patients and relatives that the researcher was independent and not from the hospital's administration. However, it could be suggested that this possible limitation may have minimal effect on the results as time spent in the fields increased acceptance. Given that participation in this study was completely voluntary, relatives and patients approached the researcher repetitively to provide her with feedback or information, and this gave depth to the data collected from the fields.

A few patients in the Australian setting refused to be part of the study and stated clearly it was because of the Islamic background of the researcher; however this did not impact on the data collection progress.

This research investigated two medical settings only; therefore the findings may not be representative of different populations or settings.

During observation the researcher spent long time in both fields; therefore patients and their relatives became familiar with the researcher. There were times when they asked her personal questions or

asked for help as well. This stopped when patients and relatives understood the reason the researcher was present in the environment.

## **Implications and recommendations**

This research set out to investigate the role relatives play in two different countries, in one medical unit each, and the implications and recommendations are based on the findings of this study. Significant issues are addressed after careful consideration of the findings of this study. The recommendations should improve the following aspects of patients', relatives and nurses' interactions and experiences:

- Relatives' involvement in patient care
- Nurses' role towards relatives as partners and their involvement in patient care
- Safety associated with the involvement of relatives, and
- The resolution of issues that have arisen as a result of the involvement of relatives in patient care.

The subsequent section presents as follows, recommendations for nursing practice, organisations, the hospital environment, nurses and relatives' education, and research:

### ***Recommendations for nursing practice:***

This part of the recommendations section, focuses on *interactions and communication issues* between nurses and relatives as this was a major issue discovered in this study. The need to develop nurses' assessment and interpersonal skills is a key recommendation. Efforts from nurses in care guidance, education and interaction can make the role of relatives more understandable in the field, since this had an impact on their role as well.

In order to implement this, the following recommendations are suggested:

- A code of behaviour for nurses, relatives and patients should be developed; this code should contain information of what constitutes acceptable involvement in the field. This code could be based on meetings between advocates from each party.
- Nurses should be more welcoming when they interact with relatives; for example, introducing themselves when they see relatives coming into the field or at the beginning of every shift.

- Nurses should gain relevant information about patients' relatives, and involve relatives in the nursing handover. This would allow relatives to interact with nurses and allow them to ask questions, and would also save nurses time repeating information.
  
- A relative's role could be discussed at the time of a patient's admission, and negotiations should be permitted, including allowing relatives to ask questions if they have any. Relatives should be given clear information about what is expected from them and nurses should also listen to their expectations. Additionally, nurses should discuss safety measures and implementation with patients and relatives. Information could be documented and passed between the assigned nurses in every shift to maintain the clarity and consistency.
  
- Nurses should explain to relatives what they are doing if they are busy when relatives approach them, to avoid negatively impacting upon the relationship. To avoid conflict and interference from relatives, nurses need to give a rationale to relatives about why they should wait until nurses arrive. Waiting times should be realistic and when nurses cannot adhere to these, they should provide reasons. They need to recognise that extended waiting increases anxiety for relatives and patients.
  
- Nurses should understand that when relatives are present for long hours in the field the possibility that they will become involved in patient care increases. Therefore, there is a need for them to make their contribution to the care known to the nursing team; this could be by agreement between nurses and relatives.
  
- Nurses need to ask relatives how they want to be involved in patient care, and indeed if they want to participate in care or not. Some relatives experienced pressure from the caregiving role and some were involved in patient care because they were obliged to, such as in the Saudi setting.
  
- Nurses should not assume that relatives understand what is going on and should provide education about complex care such as invasive procedures. One of the main reasons for confrontations between nurses and relatives was because relatives lacked an understanding of the complexities of nursing care.

- Nurses should understand that relatives and patients may hide information from them because they are worried that fellow patients and relatives might hear them.
- Nurses should use simple language and examples in their discussions with relatives and avoid using scientific terms or acronyms.
- Nurses should ask relatives for culturally specific information to reduce misunderstandings and to make patient care culturally appropriate. Nurses should be able to access cultural or religious information to raise awareness of the importance of this matter and to incorporate cultural competency into their practice.
- There is an immediate need to raise nurses' awareness of cultural differences to avoid conflict and misunderstanding, which occur from a lack of knowledge. Nurses were aware of the cultural differences of field populations but still experienced misunderstandings about patients and relatives' cultures and beliefs. Additionally, there is a need to take into account the cultural needs of patients and relatives without undermining nursing care.
- Nurses need to pay attention to non-verbal communication and the unconscious messages they are conveying to relatives.
- It is also essential for nurses to separate their personal expectations and perceptions from their interactions with relatives. Nurses need to acknowledge that their views of the role and involvement of relatives in patient care were based on previous or negative experiences.
- Nurses need to understand that partnerships cannot be achieved if they avoid their partners during care. The investigation showed that there was a gap between nurses' perceptions of the involvement of relatives and their actual actions in daily practice, as some had poor interactions with relatives.
- Patients should be asked if they want their relatives to be involved in care; a key relative should be nominated if patients want their involvement.
- A relative's capacity to provide patients with care should be assessed before they take part in a patient's care as many lack information about caregiving or remain unconvinced that the

approach of nurses to the delivery of care is appropriate; this would allow open discussions and the sharing of views between nurses and relatives.

- It is essential to give relatives education so that they can increase their familiarity with the hospital environment. Relatives had worries and fears about the hospital environment and machines used in the field.
- There is a necessity to raise relatives' awareness of infection. Relatives were susceptible to contracting infection in the field; one main issue was a lack of knowledge. Another issue in the Saudi setting was that relatives had to use patient facilities.
- There is a need for a formalised system to elicit feedback from patients and relatives. This could improve nursing care and interactions between relatives, patients and nurses.
- The reason some patients are treated differently should be made clear to all patients and relatives to avoid the frustration felt by relatives and patients, who tend to compare their treatment with the treatment of others. There were circumstances where nurses treated relatives and patients differently from others because a patient was in a critical condition, which required consistent attention from nurses and relatives, or where relatives stayed beside patients for long hours such as in the Australian setting.

### ***Recommendations for organisations***

The recommendations in this section highlight the importance of policies in providing clarity to relatives' roles, also to helping relatives and nurses in the field to understand their responsibilities towards patients and each other. The findings showed that a lack of policies and services around relatives' roles meant that the partnership between nurses and relatives was less recognised in the field; there were no consistent views or actions taken to deal with relatives or their involvement in either setting. Initiating policies and services should provide some clarity and consistency whenever relatives are involved in patient care.

The following recommendations should be considered when creating policies and services for relatives:

- Policies need to identify relatives' responsibilities in patient care in the hospital, and these need to be made available for relatives who want to be involved. This information should be clear,

understandable and available in different languages. Information should be easy to access through written materials or the Internet. Well-designed policies would ensure that nurses were not fearful to take responsibility for this involvement. These policies would provide structured material for nurses since nurses need knowledge and confidence to react promptly and to make decisions when they come across conflict or unwanted outcomes associated with a relative's involvement.

- Create a relative information sheet that includes important information which relatives should know in the hospital.
- Relatives are not specifically insured or protected under hospital policies as carers; therefore this could be considered in future plans.
- In Saudi Arabia there is a need to consider the Saudi culture when making policies to improve the conditions of relatives' involvement in patient care. It was common that some guidelines that were created by nurses in the field were rejected by patients and their relatives simply because they did not reflect the reality of Saudi's culture.
- In the case that a hospital moves to an open visiting policy there is a need to differentiate between relatives roles as a 'companion' and a 'visitor'.
- Initiate relative support group meetings and education sessions to raise awareness and knowledge of important matters in the field. Creating support groups would help uncover issues relatives face in the field and help to find immediate solutions.
- Availability of services is very important for relatives. There is a need for a department in the hospital to represent relatives and stand up for their rights and assist them to solve their personal issues. As the study showed, some relatives were vulnerable, especially those relatives who were bullied in the Saudi setting. Additionally, considering that many relatives experienced anxiety or a feeling of being burdened, there is an immediate need for these relatives to access help and support from a definite source in the hospital.



### ***Recommendations for the hospital environment***

This study showed that the environment was a critical issue for relatives involved in both settings. These recommendations highlight the needs of Australian and Saudi participants in both medical settings.

The following recommendations should help to improve the environment of each setting and make it more welcoming and safe for relatives during their time in hospital; this can be done by providing resources and facilities for relatives:

- Relatives wanted to feel welcome in both fields and providing them with a communal space would be beneficial; the space could also be made useable for educational purposes. Additionally, there is a need to provide separate physical resources for relatives during their stay in hospital such as waiting rooms, prayer rooms, kitchens, washrooms, and toilets. There is a need to provide pull down beds or sofas that convert to beds for relatives, beside patients' beds, to enable relatives to have their own space and help them to get rest.
- Nurses need to be equipped with communication aids or ways to enable them to monitor the single rooms such as phones that relatives and patients could use to call the assigned nurses. Data showed that single rooms were isolated and this added to nurses' worries because they were unable to be observant about what was happening in these rooms. Increasing the visibility of single rooms by constructing glass windows could assist in this matter. Additionally, nurses could monitor these rooms by making constant visits.

### ***Recommendations for the education of nurses and relatives***

This section is primarily concerned with recommendations for the education of nurses; this would enable nurses to interact well with relatives and to guide those relatives who are involved in caregiving

- Nurses need to become educated about relatives' roles, their responsibilities towards relatives and how to interact with relatives; this should be instilled in Nursing Schools at an undergraduate level to help young students who pursue nursing to be confident in their interactions with patients and their relatives. Additionally, continuing education, assessment of nurses, and raising awareness of their interactions with relatives may improve their

interpersonal skills. Providing regular courses or role play sessions would help nurses to develop confidence, critical thinking, and decision making when dealing with relatives.

- There is a need to continue implementing fundamentals of care in the education of nursing students and to raise their awareness of the importance of this care. In addition, fundamentals of care are perceived as involving simple tasks when in reality they can be quite complex and therefore relatives' involvement sometimes results in safety concerns.
- The actions of relatives in the hospital environment are essential to the quality of care, safety and effectiveness of health care and some unwanted actions by relatives could be related to poor health literacy. A consultation paper by the Australian Commission of Health on Safety and Quality in Health Care (2013) titled, 'Consumers, the health system and health literacy: taking action to improve safety and quality,' discussed the importance of raising the health and care literacy of people who are using or accessing health services. With recent demands and complexities in health systems there is a need to find a way to measure the health literacy of relatives and to improve it through education, information and support services.
- The role of nurses as educators and facilitators of relatives is essential so that relatives can become more competent in 'care literacy'. It may be that hospitals across the world will begin to take a more eclectic approach to fundamental care, using a mix of relatives and assistants in nursing under the guidance of registered nurses.

### ***Recommendations for future research***

This section is primarily concerned with recommendations for future research into the roles played by relatives in patient care.

- Many issues about the role and involvement of relatives in caregiving have been documented in this research; however, there is a need for further studies to explore relatives' involvement in care. Future research should focus on studying the interaction between nurses and relatives in the field, and could develop some of the findings of this study. Studies to explore the safety of relatives are required. The multiculturalism and its effect on interactions between nurses and relatives need to be investigated, to gain knowledge of different cultures and to assist nurses to develop skills in relationship-building.

- There is a need for studies investigating communication and its impact on relatives and nurses in general medical contexts, since many studies focused on critical settings, where interactions with relatives for decision making purposes and delivering information to relatives, is crucial.
- The needs of relatives in critical settings such as intensive care units are discussed extensively in research but not in acute settings; therefore, it is necessary to perform studies exploring the needs of relatives in acute and general settings.
- There is a need for studies to explore the different challenges nurses and relatives face in the general medical field such as relationships.
- Bullying of some relatives by others was a finding which emerged from this study; there is a need for studies to target and explore bullying of relatives in this context to provide clarification and best practice solutions.
- These findings highlight issues of cultural sensitivity in both fields. There is a need for research to look at the involvement of relatives in patient care from religious and cultural perspectives.
- There is a need for a national study in the Saudi hospital context to compare the role companions play in different settings and hospitals.
- The data showed the stress female nurses felt dealing with male relatives as well as the stress female patients and relatives felt during interactions with male health professionals. Therefore, there is a need for research to explore how gender issues affect male and female relatives, nurses and patients in hospitals, as well as its impact on care delivery.

## **Summary**

This chapter discussed the major findings of this study and their significance, and then stated the strengths and limitations. This study contributed to in-depth investigation of relatives' roles in two medical settings, one in Saudi Arabia and one in Australia. This study was able to reveal information about the cultural meaning and context in which relatives undertake their role in patient care. This chapter also outlined the implications of the study and recommendations for the future. The first

recommendations proposed were for nursing practice and mainly targeted the communication and interactions between nurses and relatives, which formed a significant part of this study. Then, recommendations were made for health organisations in a position to make changes to hospital policies; these recommendations discussed the importance of creating policies and services in hospitals to clarify relatives' roles and the approach nurses should take in regard to this involvement. Next, recommendations were made for changes to the hospital environment. Lastly, this section offered recommendations for future education and research.

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## Appendices

### Appendix 1: Ethical approval the University of Adelaide



RESEARCH BRANCH  
OFFICE OF RESEARCH ETHICS, COMPLIANCE AND  
INTEGRITY

PAULA ROSENBAUER  
ACTING SECRETARY  
HUMAN RESEARCH ETHICS COMMITTEE  
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SA 5005  
AUSTRALIA  
TELEPHONE +61 8 8313 6028  
FACSIMILE +61 8 8313 7325  
email: paula.rosenbauer@adelaide.edu.au  
CRICOS Provider Number 00123M

30 May 2013

Associate Professor J Magarey  
School of Nursing

Dear Associate Professor Magarey

**PROJECT NO: H-2013-039**  
***The involvement of relatives/carers in the care of patients in medical settings in  
Saudi Arabia and Australia - a critical ethnography***

I write to advise you that the Human Research Ethics Committee has approved the above project. Please refer to the enclosed endorsement sheet for further details and conditions that may be applicable to this approval. Ethics approval is granted for a period of three years subject to satisfactory annual progress reporting. Ethics approval may be extended subject to submission of a satisfactory ethics renewal report prior to expiry.

**The ethics expiry date for this project is: 31 May 2016**

Where possible, participants taking part in the study should be given a copy of the Information Sheet and the signed Consent Form to retain.

Please note that any changes to the project which might affect its continued ethical acceptability will invalidate the project's approval. In such cases an amended protocol must be submitted to the Committee for further approval. It is a condition of approval that you immediately report anything which might warrant review of ethical approval including (a) serious or unexpected adverse effects on participants (b) proposed changes in the protocol; and (c) unforeseen events that might affect continued ethical acceptability of the project. It is also a condition of approval that you inform the Committee, giving reasons, if the project is discontinued before the expected date of completion.

A reporting form for the annual progress report, project completion and ethics renewal report is available from the website at <http://www.adelaide.edu.au/ethics/human/guidelines/reporting/>

Yours sincerely

Dr John Semmler  
Convenor  
Human Research Ethics Committee



RESEARCH BRANCH  
OFFICE OF RESEARCH ETHICS, COMPLIANCE AND  
INTEGRITY

PAULA ROSENBAUER  
ACTING SECRETARY  
HUMAN RESEARCH ETHICS COMMITTEE  
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email: paula.rosenbauer@adelaide.edu.au  
CRICOS Provider Number 00123M

Applicant: Associate Professor J Magarey

School: School of Nursing

Project Title: *The involvement of relatives/carers in the care of patients in medical settings in Saudi Arabia and Australia - a critical ethnography*

---

THE UNIVERSITY OF ADELAIDE HUMAN RESEARCH ETHICS COMMITTEE

Project No: H-2013-039 RM No: 0000016444

APPROVED for the period until: **31 May 2016**

Thank you for your response dated 30.5.13 to matters raised by the Committee. It is noted that this study will involve Shadia Hamoud Zaye Alshahrani, PhD Candidate.

Refer also to the accompanying letter setting out requirements applying to approval.

Dr John Semmler  
Convenor  
Human Research Ethics Committee

Date: 30 May 2013

## Appendix 2: RAH Ethical approval



Government of South Australia

SA Health

REF: HREC/13/RAH/233

24 June 2013

**Ms Shadia Alshahrani**  
**PhD Candidate**  
**School of Nursing**  
**UNIVERSITY of ADELAIDE**

Dear Ms Alshahrani,

**Re: "The involvement of relatives/carers in the care of patients in medical settings in Saudi Arabia and Australia – an ethnographic study."**

**RAH PROTOCOL No: 130612.**

I am pleased to advise that your protocol has been granted full ethics approval on the above date. The following documents have been reviewed and approved:

- **Protocol, 18 June 2013**
  - Letter of support – Christine Economos
  - Observation Sheet
  - Frequency of nursing care activities
  - Data Dictionary
  - Observations Schedule / Protocol
  - Information sheet for Patients and relatives/carers
  - Information sheet for Nurses
  - Relatives/Carers Questionnaire
  - Patients Questionnaire
  - Nurses Questionnaire
  - Consent Form
  - Contacts for Information on Project and Independent Complaints Procedure

Please quote the RAH Protocol Number allocated to your study on all future correspondence. Research Ethics Committee deliberations are guided by the NHMRC National Statement on Ethical Conduct in Human Research 2007.

### GENERAL TERMS AND CONDITIONS OF ETHICAL APPROVAL:

- Adequate record-keeping is important. If the project involves signed consent, you should retain the completed consent forms which relate to this project and a list of all those participating in the project, to enable contact with them in the future if necessary. The duration of record retention for all clinical research data is 15 years.
- You must notify the Research Ethics Committee of any events which might warrant review of the approval or which warrant new information being presented to research participants, including:
  - (a) serious or unexpected adverse events which warrant protocol change or notification to research participants,
  - (b) changes to the protocol,
  - (c) premature termination of the study,
  - (d) a study completion report within 3 months of the project completion.
- The Committee must be notified within 72 hours of any serious adverse event occurring at this site.
- Approval is **ongoing**, subject to satisfactory annual review. Investigators are responsible for providing an annual review to the RAH REC Executive Officer each anniversary of the final approval date using the Annual Review Form available at: <http://www.rah.sa.gov.au/rec/index.php> The REC must be advised with a report or in writing when this study is complete so that the file can be closed.

Yours sincerely,

**Dr A Thornton**  
**CHAIRMAN**  
**RESEARCH ETHICS COMMITTEE**

Central Adelaide Local Health Network

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**Research Ethics Committee**

Level 3, Hanson Institute

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## Appendix 3: Site Specific Assessment Review



Government of South Australia  
SA Health

10 October 2013

Miss Shadia Alshahrani  
The University of Adelaide  
Level 3 Eleanor HARRALD Building  
North Terrace, SA  
5000

Central Adelaide Local Health Network  
Research Governance Office  
Level 3, IMVS South Building  
Frome Road, Adelaide SA  
Australia 5000  
T : 08 8222 3839  
F : 08 8222 3414

Dear Miss Alshahrani

**HREC reference number:** HREC/13/RAH/233

**SSA reference number:** SSA/13/RAH/393

**Project title:** The involvement of relatives/ carers in the care of patients in medical settings in Australia and Saudi Arabia - an ethnographic research

**RE: Site Specific Assessment Review**

Thank you for submitting an application for authorisation of this project. I am pleased to inform you that authorisation has been granted for this study to commence at the following site: **Royal Adelaide Hospital**

The following conditions apply to the authorisation of this research project. These are additional to those conditions imposed by the Human Research Ethics Committee that granted ethical approval to this project:

Please note the following conditions of authorisation:

1. Authorisation is limited to the site/s identified in this letter only.
2. Project authorisation is granted for the term of your project outlined in Section 9 of the SSA, or until the project is complete (whichever date is earlier).
3. The study must be conducted in accordance with the conditions of ethical approval provided by the lead HREC, SA Health policies, and in conjunction with the standards outlined in the *National Statement on Ethical Conduct in Human Research (2007)* and the *Australian Code for the Responsible Conduct of Research (2007)*.
4. The Coordinating Principal Investigator is responsible for notifying the institution via this Research Governance Office of any changes to the status of the project within a timely manner:
  - a. Proposed amendments to the research protocol or conduct of the research which may affect the ethical acceptability of the project, and which are submitted to the HREC for review, are copied to this research governance office;
  - b. Proposed amendments to the research protocol or conduct of the research which only affects the ongoing site acceptability of the project, are to be submitted to this research governance office;
  - c. Proposed amendments to the research protocol or conduct of the research which may affect both the ongoing ethical acceptability of the project and the site acceptability of the project are to be submitted to this research governance office after a HREC decision is made.
5. A copy of this letter should be maintained on file by the Coordinating Principal Investigator as evidence of project authorisation.
6. Notification of completion of the study at this site is to be provided to this Research Governance Office.

Should you have any queries about the consideration of your Site Specific Assessment form, please contact this Research Governance Office. The SSA reference number should be quoted in any correspondence about this matter.

Yours sincerely

Bernadette Swart

Manager Research Governance, IP and Contracts  
Royal Adelaide Hospital and SA Pathology  
Ph: 8222 3890  
Email: [bernadette.swart@health.sa.gov.au](mailto:bernadette.swart@health.sa.gov.au)  
Email: [rgipc@health.sa.gov.au](mailto:rgipc@health.sa.gov.au)

## Appendix 4: Ethics approval (IRB Saudi)



King Fahad Specialist Hospital - Dammam



KFSH-D Institutional Review Board (IRB)  
National Registration Number (H-05-D002)  
IRB Number (IRB00008686)

إدارة الأبحاث  
RESEARCH ADMINISTRATION

### APPROVAL OF PROTOCOL

January 20, 2014

Shadia Alshahrani  
[alshahrani009@gmail.com](mailto:alshahrani009@gmail.com)

Dear Shadia Alshahrani

On 14/01/14 the IRB reviewed the following protocol:

|                       |  |
|-----------------------|--|
| Type of Review:       | Indicate Initial   |
| Title:                | The involvement of relatives in care of patients in medical settings in SA and Australia |
| Investigator:         | Dr. Shadia Alshahrani  |
| IRB ID:               | MOH0158  |
| Funding:              | MOH  |
| IND:                  | none   |
| Duration of Research: | One year   |
| Documents Reviewed:   | Protocol version one<br>Consent form Arabic and English V.1                              |

The IRB received reply to the contingencies on 12/01/2014. The IRB approved the protocol from 20/01/14 to 19/01/15 inclusive. Before 19/01/15 or within 30 days of study close, whichever is earlier, you are to submit a completed "FORM: Continuing Review Progress Report" and required attachments to request continuing approval or closure.

If continuing review approval is not granted before the expiration date of 19/01/15 approval of this protocol expires on that date.

Attached are stamped approved consent documents. Use copies of these documents to document consent.

In conducting this protocol you are required to follow the requirements listed in the INVESTIGATOR MANUAL.

Khalid Bel'eed-Akkari, FRCP (Lon), MBA  
IRB Chairman  
KFSH-D

Mohamed Sager, MD, PhD  
Director, Research Administration  
KFSH-D

1-1

IRB-MOH0158

Issued by IRB OFFICE  
Telephone: +966-3-8431111 Ext: 2978- 2904- 2903  
Email: IRB@kfish.med.sa

## Appendix 5: Ethical approval (MOH Saudi)

الرقم  
التاريخ  
المشرفو

الإدارة العامة للبحوث والدراسات  
القيده: 112239  
التاريخ: 25-03-1435 هـ - 26-01-2014 م  
مرفقات: 14



المملكة العربية السعودية  
وزارة الصحة  
الإدارة العامة للبحوث والدراسات

المحترم

سعادة/ مدير عام الشؤون الصحية بمنطقة عسير

السلام عليكم ورحمة الله وبركاته،،،،

إشارة إلى موضوع الطالبة / شادية حمود زايح الشهراني ، مبتعثة من جامعة الملك خالد لدراسة درجة الدكتوراة في تخصص تمريض عام بمدرسة التمريض بجامعة أدليد بأستراليا ، رقم السجل المدني (١٠١٤٨٨١٢٤٥) ، والرقم الأكاديمي (١٢١٦٩١٠) وعنوان الرسالة :  
" مشاركة الأقرباء والمرافقين في العناية بالمرضى في أقسام الباطنة في مستشفيات السعودية وأستراليا "

"The involvement of relatives/ carers in the care of patients in medical settings in Saudi Arabia and Australia- an ethnographic research."

نحيطكم علماً بأن المذكورة قد إستوفت كافة المستندات المطلوبة وتمت مراجعتها من قبل اللجان المعنية (مرفق صورة)، وتمت الموافقة على تسهيل مهمة إجراء هذا البحث، وحيث أن المذكورة عاليه ستنفذ دراستها في مستشفى خميس مشيط المدني و مستشفى عسير المركزي.

نأمل التفضل بالإطلاع والإيعاز لمن يلزم بتسهيل مهمتها لجمع البيانات اللازمة بما يضمن أن لا يكون هناك أي تأثير على خدمة المراجعين خلال قيامها بمهام بحثها، مع العلم بأن وزارة الصحة لا تتحمل أية أعباء مالية أو إدارية في البحث.

ولكم أطيب تحياتي ،،،

مرفق طيه ملخص للمقترح البحثي،،،

مدير عام  
الإدارة العامة للبحوث والدراسات

هاتف: ٠١١٤٧٣٥٠٣٨

فاكس: ٠١١٤٧٣٥٠٣٩

ص.ب الرياض: ٢٧٧٥

الرمز البريدي: ١١١٧٦

e-mail: research@moh.gov.sa

## **Appendix 6: Information sheet for the patients and relatives**

Dear Participants

My name is Shadia Alshahrani and I am a PhD student at the University of Adelaide, South Australia; I would like to collect information related to daily routines in the medical ward for nurses, patients, and their relatives/ carers. I would like to do this by watching the care patients receive from nurses and their relatives/ carers and by conducting short interviews.

My role is to:

Observe the relationships between nurses, patients and their relatives/ carers. I would like to be around for few days to observe what is happening and to write down information related the observations. I may ask you some questions or ask you to give me feedback on certain occasions, I only need to clarify or understand things related to my research. I will not write any information that may identify any person. I will not intrude if there is anything you don't want me to observe, and if you feel uncomfortable at any point you are free to say so. Personal activities such as showering and toileting will not be observed.

This research may:

Improve the way nurses, patients and relatives/ carers work together, and help nurses to gain more understanding of the needs of patients and their relatives/ carers. It may help nurses to improve their practice of delivering the care, also would assist in gaining a better understanding of the role of nurses and the relatives at hospitals. My research may improve patients' safety and wellbeing and may improve the quality of care provided to patients at hospitals.

I assure you that

No individuals will be identified. All participants will remain anonymous, and you will not be asked to provide your name. I will only observe the daily routines in the medical ward and no descriptions that may identify the participants will be documented. This study is voluntary and you have the right to ask any questions. You have been given a complaint sheet so you will have the opportunity to express your

opinions or concerns to the researcher, supervisors or the Human Research Ethics Committee. You have the right to withdraw from this study at any point until the publication of this research.

The interviews:

Patients will be interviewed at the bedside, and nurses in the nursing meeting room, the interviews will be conducted to discuss interactions between nurses, patients and their relatives/ carers in providing the care. The interviews will take approximately 30 minutes. If you want to participate in the interviews please sign the attached consent sheet.

Thank you for being a part of this study. I appreciate your help.

If you have any further inquiries please contact the researcher

Shadia Alshahrani: Phone number (+61 8 8313 24928) [shadia.alshahrani@adelaide.edu.au](mailto:shadia.alshahrani@adelaide.edu.au)

If you feel you want to contact someone other than the researcher you may contact the

Supervisors:

Associate Professor Judy Magarey: Phone number (+61 8 83136055) [Judy.magarey@adelaide.edu.au](mailto:Judy.magarey@adelaide.edu.au)

Professor Alison Kitson: Phone number (+61 8 83130511) [alison.kitson@adelaide.edu.au](mailto:alison.kitson@adelaide.edu.au)

## **Appendix 7: Information sheet for nurses**

Dear nurses

My name is Shadia Alshahrani and I am a PhD student at the University of Adelaide, South Australia; I would like to collect information related to daily routines in the medical ward for nurses, patients, and their relatives/ carers. I would like to do this by watching the care patients receive from nurses and their relatives/ carers and by conducting short interviews.

My role is to:

Observe the relationships between nurses, patients and their relatives/ carers. I would like to be around for few days to observe what is happening and to write down information related the observations. I may ask you some questions or ask you to give me feedback on certain occasions, I only need to clarify or understand things related to my research. I will not write any information that may identify any person. I will not intrude if there is anything you don't want me to observe, and if you feel uncomfortable at any point you are free to say so. Personal activities such as showering and toileting will not be observed.

This research may

Improve the way nurses, patients and relatives/ carers work together, and help nurses to gain more understanding of the needs of patients and their relatives/ carers. It may help nurses to improve their practice of delivering the care, also would assist in gaining a better understanding of the role of nurses and the relatives at hospitals. My research may improve patients' safety and wellbeing and may improve the quality of care provided to patients at hospitals.

I assure you that

No individuals will be identified. All participants will remain anonymous, and you will not be asked to provide your name. I will only observe the daily routines in the medical ward and no descriptions that may identify the participants will be documented. This study is voluntary and you have the right to ask any questions. You have been given a complaint sheet so you will have the opportunity to express your opinions or concerns to the researcher, supervisors or the Human Research Ethics Committee. You have the right to withdraw from this study at any point until the publication of this research.

The interviews:

Patients will be interviewed at the bedside, and nurses in the nursing meeting room, the interviews will be conducted to discuss interactions between nurses, patients and their relatives/ carers in providing the care. The interviews will take approximately 30 minutes. If you want to participate in the interviews please sign the attached consent sheet.

Thank you for being a part of this study. I appreciate your help.

If you have any further inquiries please contact the researcher

Shadia Alshahrani: Phone number (+61 8 8313 24928) [shadia.alshahrani@adelaide.edu.au](mailto:shadia.alshahrani@adelaide.edu.au)

If you feel you want to contact someone other than the researcher you may contact the Supervisors:

Associate Professor Judy Magarey: Phone number (+61 8 83136055) [Judy.magarey@adelaide.edu.au](mailto:Judy.magarey@adelaide.edu.au)

Professor Alison Kitson: Phone number (+61 8 83130511) [alison.kitson@adelaide.edu.au](mailto:alison.kitson@adelaide.edu.au)

## Appendix 8: Information sheet (Arabic version)



### موافقة خطية على بيئة للمشاركة في الدراسة

عنوان البحث: مشاركة الأقرباء والمرافقين في العناية بالمرضى في أقسام الباطنة في مستشفيات السعودية واستراليا

#### الجزء الأول: معلومات للمشاركة في البحث:

##### أ. الغرض من البحث:

مشاهدة العلاقات اليومية بين المرضى والمرافقين والممرضات ، الباحثة تريد معرفة الروتين اليومي في قسم الباطنة من ناحية العناية التمريضية، التعاون بين المرافقين والممرضات من ناحية الرعاية الصحية بالمرضى في القسم.

##### ب. وصف البحث:

البحث عبارة عن استبيانات ومشاهدات يتم تعينتها بشكل يومي من الباحثة، الاستبيان عبارة عن الأنشطة اليومية التي تدور في قسم الباطنة من ناحية العناية بالمرضى المقدمة من الممرضات والمرافقين. جزء من جمع المعلومات يتمثل في محادثات بسيطة بين الباحثة والمرافقين، المرضى، وكذلك الممرضات، المحادثات تدور حول الروتين اليومي في قسم الباطنة والرعاية الصحية المقدمة للمرضى من الممرضات والمرافقين.

##### ج. المخاطر والانتزاعات المحتملة:

لا يوجد مخاطر من المشاركة في البحث، حيث أن الباحثة سوف تتواجد لجمع معلومات تخص البحث، البحث يتمثل في جمع معلومات في نماذج تخص الدراسة وكذلك محادثات. الباحثة لن تتواجد الا في حالة موافقة المشاركين ، وفي حالة عدم رغبتك في المشاركة الرجاء إبلاغي وسوف أتوقف عن تعبئة النماذج فوراً ودون أسئلة. في حالة رغبتكم في المشاركة سوف اجمع بيانات تخص العناية اليومية بالمرضى، لن أتواجد في حالة تقديم العناية التمريضية الخاصة كالأستحمام أو أي عناية تمريضية قد تسبب للمرضى الأخراج. هويتك سوف تكون سرية ولن اطلب منك تزويدي باسمك ولن اكتب أي معلومات شخصية تخصك أو تخص قريبتك.

##### د. الفوائد المحتملة:

من فوائد البحث تحسين عمل المرافقين و الممرضات مع بعضهم البعض، كذلك معرفة احتياجات المرضى، والمرافقين. مساعدة الممرضات على فهم احتياجات المرضى ومرافقيهم وكذلك تحسين أداء التمريض في تقديم الرعاية التمريضية للمرضى. مساعدة الممرضات على التعامل مع المرافقين بدون التأثير على دورهم التمريضي. تحسين مستوى تقديم الخدمات الصحية ودعم الرعاية الصحية المقدمة للمرضى.

##### هـ. البدائل عن المشاركة ( إن وجدت ):

لا يوجد بدائل

##### و. التكاليف / التعويضات المالية:

لا يوجد تكاليف أو تعويضات مالية تقدم من خلال مشاركتك في البحث

21 JAN 2014

Approved  
11/A



ز. إنهاء المشاركة ( إذا أمكن ):

عزيزي المشارك، المشاركة في هذا البحث تطوعية، و عدم رغبتك في المشاركة حق طبيعي لا بد من احترامه، وفي حال رغبت في المشاركة ثم قررت بعد بداية جمع البيانات عدم رغبتك في الاستمرار بالمشاركة سوف أتوقف عن تعبئة البيانات وبدون أسئلة .

ط. المشاركة التطوعية:

المشاركة في هذه الدراسة طوعيه وإذا قررت عدم المشاركة فانك لن تتعرض لأي مضايقات أو لفقدان حقل المشروع في المعالجة ، كما أن قرارك بالانسحاب من الدراسة لن يؤثر علي تلقيك لخدمة علاجية بديلة متوفرة في مستشفى خميس مشيط المدني سيتم إبلاغك بأي نتائج جديدة هامة تظهر خلال تطورات البحث مما قد يؤثر بطريقة معقولة على رغبتك في الاستمرار بالمشاركة في هذه الدراسة.

ي. السرية:

كمشارك في هذه الدراسة ستكون هويتك ومحتويات ملفك الطبي سرية في جميع المنشورات المتعلقة بنتائج الدراسة، ويمكن الاطلاع عليه من قبل ادارة الأبحاث ولجنة الأخلاقيات الطبية والأبحاث أو الجهة الداعمة للدراسة في حدود النظم والقوانين المطبقة بهذا الخصوص.

ك. الأشخاص الذين يمكن الاتصال بهم:

في حالة أردت الاستفسار، السؤال، او الاعتراض على أي أمور تخص البحث الحالي الرجاء الاتصال على الباحثة شادية الشهراني على رقم ٠٠٩٦٦٥٥٧١٩٥١٢٣ [shadia.alshahrani@adelaide.edu.au](mailto:shadia.alshahrani@adelaide.edu.au)

في حالة وجود أي استفسار عليك الاتصال على قسم إدارة الأبحاث بمستشفى الملك فهد التخصصي على هاتف رقم ٠٠٩٦٦٣٨٤٣١١١١ تحويله رقم ٢٨٩٠/٢٩٧٨ ذلك لتوجيه أي أسئلة عامة تتصل بالبحوث أو تتعلق بحقوق المشارك. سيتم تزويدك بنسخة موقعة من هذا الاقرار.

21 JAN 2014  
Approved  
N.A

### Appendix 9: Consent Form

PROTOCOL NAME: The involvement of relatives/ carers in the care of patients in medical settings in Saudi Arabia and Australia- an ethnographic study

INVESTIGATORS: Judy Magarey (+61 8 83136055) Judy.magarey@adelaide.edu.au

Shadia Alshahrani (+61 8 8313 24928) shadia.alshahrani@adelaide.edu.au

- Alison Kitson (+61 8 83130511) alison.kitson@adelaide.edu.au

1. The nature and purpose of the research project has been explained to me. I understand it, and agree to take part.
2. I understand that personal benefit is unlikely to be gained from taking part in the trial.
3. I understand that, while information gained during the study may be published, I will not be identified and my personal results will remain confidential.
4. I understand that I can withdraw from the study at any stage and that this will not affect my medical care, now or in the future.
5. I have had the opportunity to discuss taking part in this investigation with a family member or friend.

Name of Subject: \_\_\_\_\_

Signed: \_\_\_\_\_

Dated: \_\_\_\_\_

I certify that I have explained the study to the patient/volunteer and consider that he/she understands what is involved.

Signed: \_\_\_\_\_

Dated: \_\_\_\_\_

(Investigator)

## Appendix 10: Consent form (Arabic version)



الجزء الثاني : موافقة خطية على بيئة للمشاركة

1. أقر بأنني قد قرأت أو قد شُرحت لي بلغة أفهمها جميع المعلومات المتعلقة بالمشاركة بالبحث والمرفقة، وأن شادية حمود الشهراني قد أوضحت لي ماهية وطبيعة الإجراءات المذكورة في نموذج المعلومات للمشاركة والغرض منها والفوائد المرجوة منها والطرق العلاجية البديلة لها والمخاطر والانزعاجات المتوقع حدوثها وكذلك احتمال حدوث مضاعفات لأسباب معروفة أو غير معروفة نتيجة لذلك. - كما أنه قد أتاحت لي الفرصة الكافية لعرض الأسئلة فيما يتعلّق وتلقيت الإجابات الكافية عنها.

أقر بأنني أنا المريض أشارك في الدراسة بمطلق حريتي وإن الباحثة أخذت موافقتي للحديث مع مرافقتي/قريبتي عن أي أمور تتعلق بحالتي الصحية قبل البدء بجمع الملاحظات والمحادثات التي تخص الدراسة.

أقر بأنني أنا القريب/المرافق أشارك في الدراسة بمطلق حريتي

2. وأفهم أن لي مطلق الحرية بسحب موافقتي وقطع المشاركة في أي وقت. وقد شُرحت لي جميع العواقب والمخاطر المترتبة (إن وجدت) على انسحابي من الدراسة. - كما أفهم بأن انسحابي من هذه الدراسة لن يؤثر على حقّي في تلقّي العناية الطبية اللازمة (كنتيجة للمشاركة في هذه الدراسة). أو التي تمنح للمشاركين بالدراسة أو التي أستحقها في الأحوال العادية.

3. بهذا أؤكد بأنني قد قرأت (أو قرأ لي) هذا التفويض وأن جميع المعلومات اللازمة قد تمت تعبئتها بدقة قبل توقيعني عليه.

اسم المريض، القريب/المرافق بالكامل: .....

التوقيع: .....

التاريخ: .....

4. أؤكد بأنني قد قرأت/ ترجمتُ جميع المعلومات المذكورة بدقة للمريض أو، القريب/المرافق.

الاسم بالكامل: .....

رقم البطاقة: .....

توقيع الشاهد: .....

التاريخ: .....

5. أقر بأنني قد شُرحت بصورة كاملة للمريض / أو قريبه (ولي أمره) طبيعة والغرض من الدراسة من المفهوم لديّ بأن المريض المذكور أعلاه (أو قريبه أو ولي أمره) قد فهم طبيعة الدراسة والهدف منها والفوائد والمخاطر المترتبة على المشاركة فيها قبل توقيعيه على الموافقة بالمشاركة. وقد تمت بتوضيح استعدادي للإجابة على جميع أسئلة المريض/ قريبه/ ولي أمره بالإجابة على تلك المتعلقة بموضوع الدراسة وقيمت فعلاً بالإجابة كاملةً على جميع الأسئلة بطريقة واضحة ومرضية.

21 JAN 2016

Approved  
N.A

## Appendix 11: Complaint sheet

The University of Adelaide

Human Research Ethics Committee (HREC)

*This document is for people who are participants in a research project.*

### CONTACTS FOR INFORMATION ON PROJECT AND INDEPENDENT COMPLAINTS PROCEDURE

The following study has been reviewed and approved by the University of Adelaide Human Research Ethics Committee:

|                         |   |
|-------------------------|---|
| <b>Project Title:</b>   | The involvement of relatives in the care of patients in medical settings in Saudi Arabia and Australia- an ethnographic study |
| <b>Approval Number:</b> |   |

The Human Research Ethics Committee monitors all the research projects which it has approved. The committee considers it important that people participating in approved projects have an independent and confidential reporting mechanism which they can use if they have any worries or complaints about that research.

This research project will be conducted according to the NHMRC National Statement on Ethical Conduct in Human Research (see <http://www.nhmrc.gov.au/publications/synopses/e72syn.htm>)

1. If you have questions or problems associated with the practical aspects of your participation in the project, or wish to raise a concern or complaint about the project, then you should consult the project co-ordinator:

|               |  |
|---------------|--|
| <b>Name:</b>  | Assoc. Prof Judy Magarey DipN, BN, CCC, MN (Research), DNurs<br>Shadia Alshahrani, DipN, ADN, RN, BN, MNursSc, PhD candidate, The University of Adelaide.<br>Professor. Alison Kitson RN, BSc (Hons) DPhil, FRCN, FAAN   |
| <b>Phone:</b> | Judy Magarey (+61 8 83136055) <a href="mailto:Judy.magarey@adelaide.edu.au">Judy.magarey@adelaide.edu.au</a><br>Shadia Alshahrani (+61 8 8313 24928) <a href="mailto:shadia.alshahrani@adelaide.edu.au">shadia.alshahrani@adelaide.edu.au</a><br>Alison Kitson (+61 8 83130511) <a href="mailto:alison.kitson@adelaide.edu.au">alison.kitson@adelaide.edu.au</a> |

2. If you wish to discuss with an independent person matters related to:

- Making a complaint, or
- Raising concerns on the conduct of the project, or
- The University policy on research involving human participants, or
- Your rights as a participant,

Contact the Human Research Ethics Committee's Secretariat on phone +61(8) 8313 6028. Email address [hrec@adelaide.edu.au](mailto:hrec@adelaide.edu.au)

### Appendix 12: Observation Sheet

Name of observer

Date

| Bed & Ward | Time | Nursing care Activities | Care provider | Relatives behaviour | Observational notes | Comments |
|------------|------|-------------------------|---------------|---------------------|---------------------|----------|
|            |      |                         |               |                     |                     |          |
|            |      |                         |               |                     |                     |          |
|            |      |                         |               |                     |                     |          |
|            |      |                         |               |                     |                     |          |
|            |      |                         |               |                     |                     |          |

Frequency of nursing care activities

Name of observer

Date

| Nursing Care Activity | Patient 1 | Patient 2 | Patient 3 | Comments |
|-----------------------|-----------|-----------|-----------|----------|
|                       |           |           |           |          |
|                       |           |           |           |          |
|                       |           |           |           |          |
|                       |           |           |           |          |
|                       |           |           |           |          |
|                       |           |           |           |          |
|                       |           |           |           |          |

## Data Dictionary

| <b>Data</b>                                 | <b>Code Number</b>  | <b>Details</b>                             |
|---|---------------------|--|
| <b>Time</b>                                 | 1                   | 7.30am-2pm                                 |
|   | 2                   | 3pm-7pm                                    |
|   | 3                   | 4pm-9pm                                    |
|   | 4 (Specify 1, 2, 3) | Weekends                                   |
| <b>Bed</b>                                  | 1                   | Patient                                    |
|   | 2                   |  |
| <b>Ward</b>                                 | Red                 | Hospital 1 (Saudi)                         |
|   | Blue                | Hospital 2 (Australia)                     |
| <b>Care Provider</b>                        | 1                   | Nurses                                     |
|   | 2                   | Relatives                                  |
|   | 3                   | Nursing team + Relatives                   |
|   | 4                   | Delegated by nursing team to the relatives |
|   | 5                   | Independent Patient                        |
| <b>Relatives' Behaviour During the care</b> | 1                   | Cooperative                                |
|   | 2                   | Uncooperative                              |
|   | 3                   | Assisting the nurse in the care            |
|   | 4                   | Requested assistance from the nurse        |
|   | 5                   | Assisting patient without the nurse        |
|   | 6                   | Waiting for nurse assistance               |
|   | 7                   | Demanding                                  |
|   | 8                   | Disruptive                                 |
|   | 9                   | Other (describe)                           |



|                                |                  |  |
|--------------------------------|------------------|--|
| <b>Nursing care activities</b> | 1. Observational | <ul style="list-style-type: none"> <li>a. Face</li> <li>b. Extremities</li> <li>c. Activity</li> <li>d. Breathing</li> <li>e. Colour</li> <li>f. Oedema</li> <li>g. Position</li> <li>h. Other (describe)</li> <li>i. Other</li> </ul> |
|                                | 2. Bed making    | <ul style="list-style-type: none"> <li>a. Occupied bed (patient on the bed)</li> <li>b. Unoccupied bed</li> </ul>  |
|                                | 3. Bath          | <ul style="list-style-type: none"> <li>a. Shower</li> <li>b. Sitz bath</li> <li>c. Complete bed bath (hair +body)</li> <li>d. Body bed path</li> <li>e. Other</li> </ul>   |
|                                | 4. Hair care     | <ul style="list-style-type: none"> <li>a. Shampoo</li> <li>b. Comb</li> <li>c. Apply hair products (Serum, Cream etc..)</li> </ul>   |
|                                | 5. Facial care   | <ul style="list-style-type: none"> <li>a. Wipe the face</li> <li>b. Wipe the eyes</li> <li>c. Cleaning the nose</li> <li>d. Moisturise the lips</li> <li>e. Shaving</li> <li>f. Face cream</li> <li>g. Other</li> </ul>                |
|                                | 6. Mouth care    | <ul style="list-style-type: none"> <li>a. Brush teeth</li> <li>b. Wipe teeth</li> <li>c. Denture care</li> <li>d. Mouth gargle</li> <li>e. Observe oral cavity</li> <li>f. Other</li> </ul>  |
|                                | 7. Back care     | <ul style="list-style-type: none"> <li>a. Clean the back</li> <li>b. Cream or powder</li> <li>c. Message the back</li> <li>d. Back percussion</li> </ul>   |
|                                | 8. Skin care     | <ul style="list-style-type: none"> <li>a. Lotion</li> <li>b. Message</li> </ul>  |

|                                       |  |   |
|---------------------------------------|--|---|
| <p><b>Nursing care activities</b></p> | <p>9. Positioning</p> <p>10. Exercise</p> <p>11. Transferring the patient</p> <p>12. Oxygen</p> <p>13. Suctioning</p> <p>14. Feeding</p> <p>15. Collecting samples</p> | <p>c. Tracheostomy care<br/> d. Wound care (specify)<br/> e. Hot or cold applications<br/> f. Stockings<br/> g. Other</p> <p>a. Lift<br/> b. Turn<br/> c. Sit up<br/> d. Other</p> <p>a. Passive (no assistance from patient)<br/> b. Active (by patient)<br/> c. Assisted<br/> d. Breathing exercises<br/> e. Other</p> <p>a. To a chair<br/> b. Another bed<br/> c. Toilet<br/> d. X.ray<br/> e. Operation Room<br/> f. Other (describe)</p> <p>a. Nasal cannula<br/> b. Face mask<br/> c. Oxy-meter electronic device<br/> d. Other</p> <p>a. Oral<br/> b. Nasal<br/> c. Tracheal/endotracheal<br/> d. Other</p> <p>a. Spoon feeding<br/> b. Drinking<br/> c. Nasogastric tube feeding<br/> d. Gastrostomy feeding<br/> e. Other</p> <p>a. Sputum sample<br/> b. Urine sample<br/> c. Stool sample<br/> d. Other</p> |
|---------------------------------------|--|---|

|  |                  |  |
|--|------------------|--|
| <b>Nursing<br/>care<br/>activities</b> | 16. Urinary      | <ul style="list-style-type: none"> <li>a. Toilet</li> <li>b. Bedpan</li> <li>c. Bed side commode</li> <li>d. Perineal care</li> <li>e. Catheter care</li> <li>f. Other</li> </ul>  |
|  | 17. Elimination  | <ul style="list-style-type: none"> <li>a. Toilet</li> <li>b. Bed pan</li> <li>c. Colostomy</li> <li>d. Enema</li> <li>e. Fleet enema</li> <li>f. Other</li> </ul>  |
|  | 18. Temperature  | <ul style="list-style-type: none"> <li>a. Oral</li> <li>b. Axillary</li> <li>c. Rectal</li> <li>d. Electronic device</li> <li>e. Other</li> </ul>  |
|  | 19. Medication   | <ul style="list-style-type: none"> <li>a. Oral Medication</li> <li>b. Eye medication (drops or ointments)</li> <li>c. Ear drops</li> <li>d. Suppositories (specify)</li> <li>e. Topical (cream or ointments)</li> <li>f. Injections (Heparin, Insulin)</li> <li>g. Other</li> </ul>  |
|  | 20. Monitoring   | <ul style="list-style-type: none"> <li>a. Intake and output</li> <li>b. Intravenous site</li> <li>c. Intravenous infusion pump</li> <li>d. Intravenous line</li> <li>e. Heparin drip</li> <li>f. Insulin drip</li> <li>g. Narcotic drip</li> <li>h. Pain</li> <li>i. Vital signs (manually/ electronic device)</li> <li>j. Electronic device alarms</li> <li>k. Detected changes of patient</li> <li>l. Other</li> </ul> |
|  | 21. Psychosocial | <ul style="list-style-type: none"> <li>a. Advocacy</li> <li>b. Comfort</li> <li>c. Reassure</li> <li>d. Support</li> <li>e. Maintain Privacy</li> <li>f. Maintain Safety</li> <li>g. Relief pain</li> </ul>  |

|  |                   |   |
|--|-------------------|---|
| <b>Nursing<br/>care<br/>activities</b> | 21. Communication | <ul style="list-style-type: none"> <li>h. Fulfil needs</li> <li>i. Other</li> <br/> <li>a. Health education</li> <li>b. Enhance understanding of care</li> <li>c. Clarify misunderstanding</li> <li>d. Explain doctor orders</li> <li>e. Revise care plan with the patient</li> <li>f. Discuss patient outcomes</li> <li>g. Assessment of patient needs</li> <li>h. Discuss discharge plan</li> <li>i. Other</li> </ul> |
|--|-------------------|---|

### Observations Schedule

#### Red Hospital

| Date | Time Code | Hours | Patients/Relatives<br>Carers | Nurses |
|------|-----------|-------|------------------------------|--------|
|      | 1         | 6     | 2                            |        |
|      | 1         | 6     | 2                            |        |
|      | 1         | 6     | 2                            |        |
|      | 2         | 6     | 2                            |        |
|      | 2         | 6     | 2                            |        |
|      | 2         | 6     | 2                            |        |
|      | 3         | 6     | 2                            |        |
|      | 3         | 6     | 2                            |        |
|      | 3         | 6     | 2                            |        |
|      | 4         | 6     | 2                            |        |

#### Blue Hospital

| Date | Time Code | Hours | Patients/Relatives<br>Carers | Nurses |
|------|-----------|-------|------------------------------|--------|
|      | 1         | 6     | 2                            |        |
|      | 1         | 6     | 2                            |        |
|      | 1         | 6     | 2                            |        |
|      | 2         | 6     | 2                            |        |
|      | 2         | 6     | 2                            |        |
|      | 2         | 6     | 2                            |        |
|      | 3         | 6     | 2                            |        |
|      | 3         | 6     | 2                            |        |
|      | 3         | 6     | 2                            |        |
|      | 4         | 6     | 2                            |        |

## Observation Protocol

- Request hospitals' management permission for the observations
- Provide the nurse director with the information about the observations, the type of the observations, who is involved in the observations, time, location
- Request the management to inform the medical ward nurses of the observations
- Meet the nurse director to answer any inquiry about the observations
- Introduce the observer to the nurses
- Provide nurses with the observation criteria and schedule
- Distribute the information sheet on nurses
- Answer any enquiries for nurses
- Distribute the information sheet to the nurses in every shift and make specific time for them to decide if they want to be involved in the study
- Inform the head nurse or nurses of the recruitment policy
- Request the head nurse or nurses to recruit the patients and relatives/ carers for the observations
- Position the observer in the medical ward in the selected bay
- Introduce the observer to the patients and their relatives/ carers in the presence of head nurse or assigned nurse
- Provide patients and relatives/ carers with information regards the observations and answer any questions
- Distribute the information sheet, and complaint sheet and ask them to read the information sheet and decide if they want to participate in the study
- During the observations focus on nurses activities
- Focus on patients and their relatives/ carers following observation criteria
- Write down the notes
- Inform nurses when observations starts and for how long it lasts
- Ensure nurses informed when observations are completed in each day
- Ask nurses for feedback every observation for any suggestions or inquiries

## Appendix 13: Observation guidelines

### Observation guidelines

- Roles of participants
- Relationships, communication
- Behaviours

Day:..... Time: ..... Code: SA/AU Duration:.....

### The patient

- Dependency level (help self, needs assistance).....  
.....  
.....
- Patient's condition (stable, mild, acute).....
- Patient looking (happy, bored, sad, in pain, other).....
- Patient asks relatives for assistance in their presence.....
- Patient's behaviour in the presence of relatives.....
- Patient's communication with the nurse in the presence of relatives.....
- .....
- .....
- Notes.....  
.....  
.....

### The Nurse

- The nurse appeared to be (introduced self, happy, relaxed, quiet, busy, other).....  
• .....
- Nurse behaviour in the presence of patient's relatives.....
- Gave patient's, or relatives encouragement, specify.....  
• .....
- Show respect to patient's, relatives (requests, wishes).....  
• .....
- Immediate action taken or delayed.....
- Giving education to patient, relatives about (patient's symptoms, problems, condition).....
- Giving information to relatives about what they can do to help patient.....  
• .....

- .....
- Speaking with patient and relatives during the visits, or handover.....
- .....
- Provide care in the presence of patient's relatives, specify.....
- Explain the care to the patient, relatives before start,.....
- .....
- .....
- Ask for relatives' assistance during the care, specify.....
- .....
- The relationship with the relatives as appeared during the observation.....
- .....
- Any particular event or interaction happened during the visits, or presences.....
- .....
- The environment in the bay when this event happened.....
- Nurse's response during the event.....
- Poor explanation level, body language during the event.....
- .....
- Notes.....
- .....
- .....
- .....

**The relatives**

- The relative appeared (calm, happy, demanding, protective, other).....
- .....
- .....
- Time/ length of the visit.....
- Show respect to the nurse.....
- Offer assistance to the patient.....
- Assist the patient (type of assistance, support).....
- .....
- Ask the nurse questions (can do, care, patient's condition, other).....
- .....
- Appeared to know what they do when assist the patient.....
- .....
- Ask for nurse's assistance.....
- .....
- Any particular event or interaction happened during the visits or presence
- .....
- .....



.....

- The environment in the bay when this event happened.....
- Relative's response during the event.....
- .....
- Type of communication with the nurse.....
- The relationship with the nurse as appeared in the observation.....
- .....
- .....
- Notes.....
- .....
- .....
- .....
- Remarks for next observation.....
- .....
- .....

### **Appendix 14: Relatives' questions**

1. Are you visiting or accompanying the patient voluntarily?
2. What do you do when you are with the patient?
3. Have you been educated by any health team members about your role in the hospital?
4. Do the health team include you in discussions about the patient's condition?
5. Do the health team ask for information about the patient's history or condition?
6. When you are around the patient do you offer help in any way? What sort of help?
7. Have you been asked to help the health team in the care given to the patient?
8. How do you feel when you are asked to help the nurse in doing something for the patient?
9. What do you think of the nursing care given to the patient?
10. Have you been in a situation where you felt you wanted to intervene in the care given to the patient? Can you describe please?
11. How do you express your concerns to the health team?
12. Do you think nurses expect you to provide some care for the patient? Give me an example?
13. What kind of support do you receive from the health team? Examples, guidance, education, coping mechanisms.
14. Is there anything the health team can do for you in providing support for the patient?

## **Appendix 15: Patients' questions**

1. Do you like to have a relative/ carer with you at the hospital? Why?
2. How does it make you feel to have a relative/ carer with you at the hospital?
3. What kind of care would you like the nurse to do for you? And relatives/carers to do for you? What kind of care would you like your relative/ carers to assist the nurse with?
4. Do you feel comfortable receiving care from the nurse while your relative/ carer is present? Why?
5. When you have a relative around or visiting, how does this change the way nurses treat you?
6. When your relative/ carer is around do nurses talk to you directly or to your relative/ carer? Do they discuss things such as treatments with you or with your relative/ carer?
7. Do you involve your relatives/ carers in decision making in regards to treatment, surgery? Why?
8. Would you prefer nurses to ask your permission for your relative/ carer to be around when the nursing care is given to you? And what kind of care?
9. When you feel sad or angry who would you like to talk to? The nurse or the relative/ carer?
10. Do you ask for your relative's/ carer's help to express your opinion or to understand things that have been discussed with the health team?
11. Who do you ask to help if you need something related to your treatment or care plan?

## **Appendix 16: Nurses' questions**

1. How do you feel about the presence of the patients' relatives/ carers in hospital?
2. Do you think their presence should be limited to a visitation time or should be permitted at anytime? Why?
3. How do you feel about relatives/ carers' involvement in the care of patients?
4. Do you mind a relative/ carer presence when you give the care to the patient?
5. Do you ask the patients if they mind their relatives/ carers to be around during the care?
6. Have you asked relatives/ carers to help you in the care given to patients? Why?
7. If you asked a relative/ carer to help you in the care of the patient do you give them any education or guidance?
8. How do relatives/ carers react when you are giving the patient care?
9. Do you involve the relatives/ carers in discussions related to patients' conditions?
10. To what extent do you agree or disagree with this statement 'nurses should develop a good relationship with the relative/ carer to deliver good care'?
11. What sort of support do you provide to the relatives/ carers?
12. From your perspective what is the role of relatives/ carers at hospital?

## Appendix 17: Relatives' questions (Arabic Version)

### أسئلة المرافقين

- ١ الدرجة العلمية، الحالة الاجتماعية، العلاقة العائلية بالمريضة، السكن قريب أو بعيد
- ٢ عندما تكونين مرافقة مع المريضة هل تقدمين المساعدة لها؟ ما نوع المساعدة؟
- ٣ كم تتراوح الفترة التي قضيتها مع المريضة كمرافقة/زائرة؟
- ٤ هل تقوم الممرضات بنتقيفك عن دورك أو واجباتك أثناء تواجدك مع المريضة؟
- ٥ هل تقوم الممرضات بمناقشتك عن حالة المريضة؟ هل تقوم الممرضات توجية أسئلة لكي عن تاريخ المريضة الصحي؟
- ٦ عندما تتواجدين مع المريضة أثناء تقديمهم الرعاية التمريضية لها هل تقدمين المساعدة للممرضات؟
- ٧ هل تقوم الممرضات بطلب مساعدتك للكشف أو تقديم الرعاية الصحية للمريضه؟ ما نوع الرعاية الصحية؟
- ٨ كيف تشعرين عندما تطلب منك الممرضة المساعدة في العناية التمريضية المقدمة للمريضة؟
- ٩ هل تتحدثين بالنيابة عن المريضة؟ لماذا؟ وماهي الحالات التي ممكن ان تمثلين فيها المريضة؟
- ١٠ ما رأيك بشكل عام في الرعاية الصحية والتمريضية المقدمة للمريضة؟
- ١١ من وجهة نظرك ماهو دورك في المستشفى كمرافقة؟
- ١٢ هل تشعرين أحيانا بالرغبة في التدخل أو الاعتراض على العناية التمريضية المقدمة للمريضة؟ اشرحي ذلك؟
- ١٣ هل تعتقدين أن الممرضات يتوقعون منك مساعدتهم في العناية التمريضية بسبب تواجدك مع المريضة؟ اشرحي ذلك؟
- ١٤ هل هناك أي شئ تعتقدين أن بإمكان الفريق الصحي وخاصة الممرضات تقديمه من اجل الارتقاء بالخدمات الصحية المقدمة للمريضة؟

## Appendix 18: Nurses' questions (Arabic Version)

### أسئلة الممرضات

- ١ ما رأيك في تواجد المرافقين أو الأقارب مع المريضات؟
- ٢ هل تعتقد أن تواجد المرافقين من الأفضل ان يكون مسموح في جميع الأوقات أو مفتوح خلال الزيارات فقط؟
- ٣ ما رأيك في مشاركة أو مساعدة المرافقين للممرضات في العناية بالمريض في المستشفى؟
- ٤ ما رأيك في تواجد المرافقة مع المريضة خاصة عندما تقدمين الرعاية التمريضية للمريضة؟
- ٥ هل تقومين بطلب المساعدة من المرافقة عندما تقومين بالعناية التمريضية؟ أمثلة
- ٦ في حالة طلب يد المساعدة من المرافقة هل تقومين بتوجيهها أو تثقيفها صحيا قبل البت بالعناية التمريضية؟
- ٧ هل بالإمكان تزويدي ببعض الأمثلة لتصرفات المرافقين الغير مرغوبة عند تقديم العناية التمريضية؟
- ٨ هل تقومين بسؤال المرافقة عن معلومات تخص المريضة كحالتها المرضية أو تاريخها المرضي؟
- ٩ ماهي الاستراتيجيات التي تقومين بعملها لكسب تعاون وثقة المرافقين وأقارب المريضة؟
- ١٠ ما نوع الدعم أو التشجيع الذي تقدمية للمرافقين أو أقارب المرضى؟
- ١١ من وجهة نظرك ماهو دور المرافقين والأقارب في حالة تواجدهم أو عند زيارتهم للمريض بالمستشفى؟

## Appendix 19: Patients' questions (Arabic Version)

### أسئلة المرضى

- ١ هل تعتقد أن تواجد المرافقين مع المرضى فكرة جيدة أم لا؟ لماذا؟
- ٢ كيف تصفين شعورك عند تواجد مرافقتك معك بالمستشفى؟
- ٤ هل تشعرين بالراحة عندما تقوم الممرضة بتقديم الرعاية التمريضية لكي خلال تواجد المرافقة أم بدون تواجد المرافقة؟ لماذا؟
- ٥ هل تواجد المرافقة معك يغير من تعامل الممرضات أو لا يشكل فرق في التعامل؟
- ٦ عندما تريد الممرضة سؤالك عن صحتك أو التحدث لك هل تقوم بذلك مباشرة معي أو تتحدث للمرافقة؟ مثل مسائل العلاج، العناية التمريضية؟
- ٧ هل تفضلين أن يشاركك الأهل والأقارب تحديد قرارات خاصة بالعلاج أو العملية أم لا؟ لماذا؟
- ٨ هل ترغبين في أن تقوم الممرضة بسؤالك عن رغبتك في أن تتواجد المرافقة أثناء العناية التمريضية؟ الرجاء تزويدي بالأمثلة؟
- ٩ عندما تكونين في حالة نفسية غير مستقرة إلى من ترغبين في التحدث عن ذلك؟ الممرضة، احد أعضاء الفريق الصحي، المرافقة؟
- ١٠ هل تطلبين من المرافقة التحدث بالنيابة عنك أو مساعدك لتوضيح شئ أو فهم شئ عند التحدث مع الفريق الصحي؟
- ١١ ممن تطلبين المساعدة عندما تريدين الاستفسار عن أمور تخص العلاج أو الرعاية الصحية؟
- ١٢ كمريضة مالذي ترغبينه من الممرضات اثناء أشرفهم على حالتك؟ ما رأيك في طريقة التواصل مع الممرضات؟

## Appendix 20: Companion Authorisation Form

|   |  |   |
|---|--|---|
|  | <h3 style="margin: 0;">COMPANION<br/>AUTHORIZATION<br/>FORM</h3> |  |
|---|--|---|

### 1. Companion Authorizing

1. مشهد مرافقة مريض

|                  |      |       |      |                 |          |              |
|------------------|------|-------|------|-----------------|----------|--------------|
| Patient Name     |      |       |      | اسم المريض      |          |              |
| Chart No.        | Sex  | الجنس |      | رقم الملف الطبي |          |              |
| Nationality      | Age  | العمر |      | الجنسية         |          |              |
| Ward             |      |       |      | القسم           |          |              |
| Companion's Name |      |       |      | اسم المرافق     |          |              |
| DIAGNOSIS        |      |       |      | التشخيص         |          |              |
| Duration of Stay | From | /     | 1434 | 1434/ /         | بداية من | مدة المرافقة |
| I.D. No.         |      |       |      | رقم الهوية      |          |              |

(تعليمات هامه)

- 1- لا يسمح باستخدام هذا المشهد لغير صاحبه الموضح اسمه اعلا و داخل المستشفى فقط .
- 2- على المرافق في حاله الرغبه في الخروج من المستشفى التواصل مع المدير المناوب او مدير شؤون المرضى .
- 3- يمنع منعاً باتاً الدخول بعد نهاية وقت الزيارة و ذلك الساعة الثامنة .
- 4- على المرافق عدم التجوال في اقسام المستشفى و من يخالف ذلك سوف يتم سحب مشهد المرافقة منه .
- 5- على المرافق عدم ادخال الأطعمة للمستشفى .
- 6- يسمح بمرافق واحد لكل مريض .
- 7- عند خروج المريض على المرافق تسليم مشهد المرافقة للمدير المناوب او مدير حقوق و علاقات المرضى .
- 8- أي شطب او تعديل بالمشهد يعتبر لاغي .

اسم المرافق ..... التوقيع : .....

|                    |           |                    |
|--------------------|-----------|--------------------|
| Treating Physician | Signature | الطبيب المعالج     |
| Patient Relation   | Signature | موقف علاقات المرضى |
| Head/Pt. Relation  | Signature | مدير علاقات المرضى |

الختم الرسمي

| ساعة الخروج | التاريخ | ساعة الخروج | توقيع مدير حقوق و علاقات المرضى او المدير المناوب | ساعة الخروج | التاريخ | توقيع مدير حقوق و علاقات المرضى او المدير المناوب |
|-------------|---------|-------------|---|-------------|---------|---|
|             | 1434    |             |   |             | 1434    |   |
|             | 1434    |             |   |             | 1434    |   |
|             | 1434    |             |   |             | 1434    |   |
|             | 1434    |             |   |             | 1434    |   |

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