

Experiencing Intensive Care: Women's voices in Jordan

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Abstract

This study explores women's experiences of critical illness in Jordanian intensive care units. A narrative approach was employed to access Jordanian women's stories of their critical illness and to study how these accounts changed during the period following their discharge from intensive care. The study was conducted in two hospitals in a major Jordanian city. A purposive sample of 16 women who had spent at least 48 hours in intensive care was recruited over a period of six months, with each woman taking part in between one and three interviews during the six month period. Two focus group discussions were also conducted with 13 ICU nurses drawn from the hospitals in which the women had been patients. These had the aim of encouraging discussion about the development of new supportive care strategies for critically ill women in Jordanian intensive care units.

The study findings revealed three main areas: the women's experiences of suffering and pain; their experience of body care; and the impact of the ICU experiences on their lives after discharge home. Experiences of suffering were pervaded with physical, emotional, social and temporal dimensions, interlinked with pain that was often severe, overwhelming, and disturbing to their sleep. The notion of 'nafsi' suffering was employed to describe emotional and social losses, such as loss of family support, which the women experienced. The notion of 'vicarious death' was used to explain the mortal fear women experienced in witnessing the death of others. Loss of body control, the unfamiliar ICU environment, and the sudden onset of illness made it difficult for the women to make sense of their experiences.

This study shows that cultural norms and religious beliefs shape the ways in which these Muslim women made sense of their bodies. An analysis of the concept of 'body work' is presented: the 'dependent body' captures the women's experiences of changes of their physical status, which meant that from being care providers, they became those in need of care. This involved the experience of a sense of paralysis or disablement, and a complete dependence on their family or nurses. The 'social body' describes the women's feelings and emotions toward their family members. The latter assisted in the care of the women's bodies, but distress, frustration and a sense of loneliness were experienced by the women as a result of the loss of verbal

communication with their relatives. The ‘cultural body’ describes the effect of cultural norms and Islamic religious beliefs on the women’s interpretation of their experiences, and the interpretation of male nursing care in the ICU. The ‘mechanical body’ describes the women’s experiences of the ICU machines as extensions of their bodies, and the senses of limbo and ambiguity they encountered during their ICU stay.

The recovery period raised many physical, emotional, social, and spiritual issues, which in turn impacted on the women’s experiences of their everyday lives. Weakness and tiredness accompanied with difficulties in eating and sleeping made some women feel frustrated and uncertain about their health. Some felt they were a burden upon their families. The meaning of the critical illness experiences were interpreted by some women as an opportunity to value family unity and neighbours’ support. For other women, the illness experiences gave them lessons which strengthened their role as mothers and helped them to think positively about their future.

This study highlights the importance of considering the cultural and religious preferences among Muslim women in critical care settings. The study recommendations focus on the need to base nursing care on an understanding of the physical, emotional, social, and religious elements of suffering, by exploring the potential of a palliative care approach for nursing critically ill people.

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Chapter 1

Introduction

The potentially life changing nature of experiencing critical illness includes sudden and unexpected changes and losses. These may include: physical, emotional, social, and existential crises for the person who is ill and their family. Yet, until comparatively recently little was known about patients' accounts of their experiences; how they make sense of, or understand, what has happened to them or how they might come to terms with the sometimes profound changes wrought by critical illness. Nor was there knowledge about the issues that reflection on the close encounter with death may raise for them. Recently, there is a growing body of knowledge directed towards understanding the patients' experiences in Intensive Care Units (Rier, 2000, Gramling, 2004, DIPEX, 2007). This body of work primarily examines peoples' experiences in Western countries such as the USA and the UK. Muslims as a group have not been a focus of research and that Muslim women are especially excluded from study. The absence of research into Muslim women's experiences of critical illness may impact on the care the Muslim women receive in intensive care units and other acute care settings in many countries in the world.

Western ideas of how ICU care is delivered and organised have been dominant, with ICUs organised according to western principles regarded as unproblematic in Eastern countries, such as Jordan, even though the wider cultural context is very different. Moreover, the paucity of qualitative research in Jordan, especially in relation to patients' experiences may mean that opportunities to improve patient centred approaches to care via access to a rigorous understanding of the range of their experiences of illness have been missed. This study sheds light on women's experiences in the Jordanian ICU and indicates a fundamental need for new model of nursing care that aims to meet the women's physical, emotional, social, cultural, and religious needs.

This study focuses on the experiences of 16 Muslim women who spent more than 48 hours in the ICU before being transferred to a ward. I applied a longitudinal narrative approach to investigate the women's recollections of their critical care experiences

over a period of between one and six months. I used a narrative approach in the belief that through sharing in the women's stories, I would be able to study the interpenetration or inter relationship between their Islamic beliefs, cultural norms, and the women's accounts of their experiences of critical illness. While this study does not represent the entirety of the women's lives, it captures their experiences of critical illness through their vivid stories.

In order to elicit and interpret the women's stories regarding critical illness I developed rapport with these women over a period of months, listening actively to their stories. In my first meeting with each woman, which took place in the hospital, I introduced myself and provided an overview about my research. This was followed by the arrangement of the first interview if the woman agreed to participate. The first interview was conducted in the ward within 2-3 weeks of the woman's transfer from ICU. One to two follow up interviews then took place in the women's homes. The long engagement with the women provides rich accounts of the women's individual experiences and how these experiences changed over time.

A primary emphasis in this study is to 'voice' the subjective experiences of these women; one aspect of this involved sharing part of their stories to ICU nurses. A complementary second stage of this study aimed to develop a supportive care strategy through discussion of the women's stories with the ICU nurses working in Jordan. This involved two focus group discussions, conducted with a total of 13 ICU nurses drawn from the two hospitals in which the women received their care. Although developing a full supportive care strategy for these women was not possible in the time I had to complete the study, it was possible to point to principles which may inform the development of supportive care strategy based on the nurses' discussions and the women's accounts. Moreover, these discussions enhanced the nurses' awareness of the women's needs, and helped them think about solutions which would help future female patients in their units.

This chapter discusses the genesis of my research project and some of the influences which led me to undertake the study. I will present my early personal influences and background, and then I will outline the structure of each chapter in the thesis.

1.1. The Personal influences and my background as a researcher

Exploring my personal biography is important since my cultural background, past experiences, and personal beliefs influence the way I see the world and influenced the choice of my topic of the study, the method employed to research the topic, and the research relationships with the women whom I interviewed.

I am a Jordanian Muslim woman and have lived all my life within the eastern Jordanian culture. I graduated from a school in a major Jordanian city, and then I decided to study nursing. Nursing shaped many aspects in my life; I learned how to communicate with all levels of the community, especially with patients. After graduation, I worked in general private hospitals in emergency and coronary care units, and then I moved to the largest governmental hospital to work in paediatric ICU. During that time I focused on developing myself as a professional nurse. I undertook many training courses in intensive care, including: advanced cardiac life support (ACLS), electro cardiography (ECG), haemodynamics, and open heart surgery nursing, while I was a paediatric nurse. Although I was interested in my work and was aware that the children received the majority of their care and the love they needed from their mothers and I did not think very deeply about how they saw my care as nurse.

Later, I worked as a bedside registered nurse in an adult ICU, and I found that the needs of adult patients were very different to those of children. Adult patients who were able to communicate liked to tell me about their suffering and needs and this seemed to help them to cope with their situation and the ICU environment. However, I found it difficult to relate to patients who could not speak or who were unconscious, or who were on mechanical ventilation. This raised questions about how those patients felt about my care, and how I could better meet their needs.

While I was working in the ICU, I decided to continue my Master's degree in clinical nursing and within the critical care settings. The Master's programme provided me with a background in critical care theories, nursing theories, research methods, and ethical theories. As a requirement for graduation from the programme, I conducted a

descriptive quantitative study about patients' stressors in ICU in five intensive care units in a major Jordanian city. I used a 50-item questionnaire developed by (Cornock, 1998) which explored stressful experiences during an ICU stay. When I was conducting the study, I found that patients' experiences exceeded the list of items present in my questionnaire and that patients tried to tell me about their illness and how they see the nursing care in those units while I was trying to check the items present in the questionnaire. I realized that a great deal of important knowledge was being missed otherwise and thus I was motivated to apply these observations in my PhD study.

After graduation, I worked as a clinical instructor for master's students in the intensive care unit for both male and female patients, where there were only curtains separating their beds. Patients had to use a unisex gown and were cared by any available nurse. This led to some female patients attempting to pull the curtains around their beds most of the time, as they said it made them feel more comfortable. I also noticed that the majority of the nurses working in the ICU were male nurses. These observations may be unique to the intensive care units in Jordan since, when patients are transferred to the general wards in Jordan, these are divided by sex. Female patients have a separate section to male patients and are cared for only by female nurses. I felt that there were tensions between the patients' needs and the ICU nursing care policy. Although I felt that my knowledge and experiences in investigating the patients' experiences were limited and had involved the application of only quantitative methods, these observations challenged the way I understood nurses' care. I started to think about how patients within the Jordanian culture see the intensive nursing care from their perspective.

I decided then to improve my research knowledge and skills about the application of qualitative research methods, partially because there are a few qualitative research studies conducted in Jordan (Halabi, 2005). The majority of researchers adopt quantitative methods in conducting their studies and there are no taught courses about qualitative methods at the postgraduate level. I anticipated that studying in the UK would give me an excellent opportunity to learn and develop my understanding of the patients' experiences using qualitative methods.

In 2005, I started my MPhil program at the University of Sheffield, where during the same year I had the opportunity to attend a workshop about “Recovery from the ICU” at Homerton University Hospital, London. In that workshop, I met two women who had spent more than two weeks on mechanical ventilation in a high dependency unit. After their recovery from the ICU, the two women agreed to present at the workshop and to tell their story about their experiences in the ICU. Two things struck me from that meeting: first, the women described how they tried to protect their body especially when cared for by a male nurse, while he performs physical care. I thought it was only within the Jordanian culture that women tend to cover their body, but I noticed that this may be the experience of women who were admitted to the ICU whether they are from western or eastern culture. Second, they made it clear that upsetting experiences in the ICU affected their life after discharge. One of them explored how her perception of self has changed. She had difficulties in coping with life after discharge. This experience affected my way of thinking about women patients in the ICU. I started to ask myself how patients see our care as nurses, and how the critical experiences affect the Jordanian women’s life after discharge. This lack of knowledge about women understandings of their experiences in ICU, particularly within the Jordanian culture, and how these experiences affect their life after discharge, has been a fundamental impetus in shaping my research questions. I also acknowledge the influence of excellent supervisors at the University of Sheffield who help me to develop my understanding in the qualitative methods and successfully gain my MPhil degree in nursing research.

1.2 An overview of the thesis

My thesis has nine chapters. Following this introductory chapter, the second chapter provides the background to the study. Chapter 3, discusses my methodology. The findings are discussed chapters 4 to 8, and finally, chapter 9 is the conclusion chapter. Below I outline the structure of each chapter.

Chapter 2 aims to contextualise the study from the range of theoretical and clinical perspectives presented in the literature and identifies gaps within the reviewed literature. The chapter includes four main sections. Section 1 gives an overview of the Islamic view of illness and death and the status of Muslim women. Section 2

starts with an overview of the Jordanian community and culture, women's status in Jordan, the health care system in Jordan. I then provide a brief history of the intensive care unit, and the nursing care. Section 3 reports on existing research relating to patients' experiences in the ICU. This latter section includes: patients' memories of ICU, the lived experience of patients in the ICU, patient- nurse communication, ICU delirium, and the long term impact of being in the ICU. Section 4 discusses the use of stories to convey the patients' experiences in the ICU.

Chapter 3 provides an overview of the philosophical and methodological positions that underpin this study and my reflection on conducting narrative research within the context of Jordanian culture. The chapter has three main sections: section 1 highlights the philosophical position that underpins this study and the history of narrative. I then discuss the use of narrative in research and the application of a narrative approach to this study, including the strengths and the limitations of applying a narrative approach. In section 2, I discuss my reflections on conducting the study, issues relating to data collection within the context of Jordanian culture and my experiences of translating, transcribing, and analyzing the data. Section 3 discusses how I conducted two focus group discussions with the ICU nurses in the hospitals from which I recruited the women whom I interviewed.

Chapter 4 is a preliminary chapter to enable understanding of the data analysis process. Here, I introduce all the cases in the study and reflect on how the 16 women who participated in the study aided the development of my understanding about patients' experiences in the ICU. In this chapter I provide a description about the context of each interview.

Chapter 5 discusses the women's experiences of suffering. It begins by describing the difficulty of analyzing the overlapping themes and issues within the women's experiences. I then consider the literature I drew upon that helped me to interpret these issues. I discuss three main themes of women's experiences: the first theme discusses the multidimensional experience of suffering, including the impact of physical pain, the loss of family support on the women's experiences in the ICU and the interconnection between the ICU nurses' care with the women's suffering. In the second theme, I discuss the women's experience of vicarious death. This explores the

experience of uncertainty and the fear of dying which was associated with witnessing the death of other ill people, and the experience of death as manifested through the women's 'hathayan'. The third theme explains the temporal dimension of suffering. The discussion here includes the notions of 'lost' time, which was when women lost consciousness and of 'suffering' time, which women often experienced as lengthy. I also discuss the varying ways in which the sequence of events was related within women's accounts.

Chapter 6 examines the notion of 'bodywork' in the context of the women's experiences of nursing care in the ICU: a concept described initially by (Lawler, 1991) and (Twigg, 2000). The concept is used in this study as a means to gain insight into the women's experiences of their own bodies during illness, and their interpretation of the nursing care of their bodies. The concept of 'body work' consists of four sub-concepts: the dependent body, the social body, the cultural body, and the mechanical body. Each sub-concept is discussed in detail and then I draw on the interconnections between these sub-concepts and discuss them within the context of the wider literature.

Chapter 7 discusses the impact of the ICU experiences on the women's every day life after they are discharged home. The first section discusses the change in their body experiences especially as related to difficulties in eating and sleeping, and to changes in their home environment. This section also includes the emotional experiences that the women faced at home. The second section discusses the meanings of the ICU experiences from the women's perspectives. The meaning of critical illness includes resuming social life, being good mothers, and surviving the critical illness. The final section includes a summary and discussion of the findings in the context of the wider literature.

Chapter 8 discusses the ICU nurses' reflections on the women's experiences and includes three sections: In section 1, I describe the nurses' reflections on participating in the focus group discussions. Section 2 discusses the nurses' reflections on three main topics: nurse-women communication, the women's need to cover their bodies, and the women's need to care for their children. In section 3, I

reflect on the nurses' views after attending the focus group discussions and my own experiences in conducting focus group discussion.

In chapter 9, I draw together the conceptual insights and my analysis of the findings in presenting conclusions of the study. I then examine the implications of the findings for nursing practice and identify principles to inform the development of a supportive care strategy for women who are admitted in the ICU. Finally, I reflect upon my own experience in conducting this study and highlight some recommendations for future research.

Chapter 2

Background to the study

2.1 Introduction

The historical roots of the development of intensive care units (ICU) can be traced from the mid-20th century, when, especially during the Second World War many ICUs were developed in the UK and USA to provide medical and nursing care for those needing artificial ventilation and intensive medical and surgical procedures (Seymour, 2001). This occurred simultaneously with the poliomyelitis epidemic in Denmark where hundreds of people were in need of artificial ventilation (Takrouri, 2004). The care provided within these units was based on the medical model of care that aims to cure patients' life and prevent death (Seymour, 2001). The patients' bodies were classified into pathophysiological diseases, with the role of physicians being to treat such symptoms by using highly technological devices and medication. The biomedical model of care fundamentally takes a perspective which views all patients with the same disease as having the same problems regardless of their individuality, region, culture, or ethnicity (Annandale, 1998). The biomedical model of care as a principle for organising intensive therapy was later adopted by many developing countries, including Jordan. Unfortunately, the model could not change or even adjust to the cultural needs of Jordanian patients.

This review draws on literature from sociological, nursing, medical, and psychological resources to contextualise the research presented in this thesis within range theoretical and clinical perspectives available in the literature and to define gaps which this study seeks to address. The chapter includes four main sections. The first section gives an overview of the Islamic view of illness and death and the status of Muslim women. The second section provides an overview of: the Jordanian community and culture, women's status in Jordan, the health care system in Jordan, the history of the intensive care unit, and nursing care. The third section reports on existing research relating to patients' experiences in the ICU. This latter section includes: patients' memories of ICU, the lived experience of patients in the ICU, patient- nurse communication, ICU delirium, and the long term impact of being in

the ICU. The fourth section, stories and illness, discusses the use of stories to convey patients' experiences in the ICU.

The literature reviewed in this chapter is interconnected with other literature reviewed and presented in the findings chapters. Chapter 5 includes literature related to the patients' experiences of suffering and pain; chapter 6 examines patients' experiences of body changes and the concept of 'bodywork' and chapter 7 discusses the long term effect of the patients' experiences in the ICU. Chapter 8 discusses nurses' experiences and reflections of supporting and caring for the ICU patients.

The literature search is based on a comprehensive search using medical, social, and nursing databases. The key terms used were: 'intensive care', 'critical care', 'comprehensive care', 'patient memories', 'patient recollection', 'patient experiences', 'stress', 'ICU delirium', 'post traumatic stress disorder', 'relocation stress', 'women', 'women experiences', 'narrative'; 'illness narrative', 'storytelling', 'story', 'supportive care', 'nursing care', 'reflexivity', 'reflective practice', 'Muslim', 'Muslim woman', 'Islam and illness', 'Islam and death', 'Jordan', 'Jordanian woman'. The search was conducted in three main stages: First, I searched through the electronic databases such as Medline/Pub Med; Cumulative Index of Nursing and Allied Health (CINHAL); EMBASE/BIDS, Web of Science library; Blackwell Synergy; Science Direct; Index to Thesis; Cochrane Library; EMRO; the World Health Organisation (WHO) for electronic resources and I used the electronic searching as a guide to map the terms in the study. Second, I searched manually through the British library, the University of Nottingham catalogue, for related books, unpublished theses, and other resources. The search process included searching within the World Wide Web pages such as Google scholar and Yahoo for some grey literature and Arabic resources that are related to the historical data about Jordan, and the perception of health and illness in Islam. Third, I searched manually for articles and journals such as Sociology of Health and Illness, Journal of Advanced Nursing, Critical Care Nursing, Sociology, Social Science and Medicine, Intensive and Critical Care Nursing, and the Journal of Development Studies.

2.2 Muslim beliefs including those about Illness and death

A Muslim is a person who believes in the five Pillars of Islam, accepts Islam as a religion and considers it a vital part of his/her identity (Lemu and Heeren, 1978). The word 'Islam' means peace and submission to the will of Allah (the God) (Gheraghi, et al, 2006). There are many types of Muslims, such as the Sunnis, Shias, the Mystics, and the Sufis (Puchalski and O'Donnell, 2005). The five pillars of Islamic beliefs are as follows: the first is the strong belief that there is only one Allah and that the prophet Mohammed (mercy upon him) is Allah's prophet. The second pillar is that Muslims should pray five times a day. The third is to fast during the month of Ramadan¹. The fourth is the 'Zaka', which is the obligation to give money for poor Muslims. The last pillar is taking part in 'Hajja' or the pilgrimage to Mecca at least once in a Muslim's lifetime (Lemu and Heeren, 1978, Hasna, 2003). These pillars contribute to a community of Muslims called the 'the Umma', which infers the unity of all Muslims in the world (Hasna, 2003). This community consists of Muslim brothers (male Muslims) and sisters (female Muslims) who share respect and provide help and support to each other (Al- Gazali, 1983). There are between 1.1 -1.8 billion Muslims in the world, making Islam the second largest religion in the world after Christianity (Anon, 2008)².

Muslims beliefs are influenced by the Islamic philosophy of the nature of the person. A famous Islamic philosopher, Al- Kindi argues that the person has three main components: the 'Aql' or the mind, the 'Jesm' or the body, and the 'rough' or the soul (Al- Kindi Philosophy [373BA] cited in Al-Gazali, 1983). The mind provides the reasoning and thinking (Al- Kindi (373BA) cited in Al- Gazali, 1983). The body has two parts: the physical and social; both regulated by Islamic law (Al- Gazali, 1983). Part of the duties that are shared between all Muslims are that they have the obligation to protect their bodies physically: a Muslim is prohibited to eat any kind of meat unless it is killed according to the Islamic law (halal), apart from eating pork or pork products which is prohibited, as is the consumption of alcohol (Rassool, 2000; Sarhill, 2001). Cleaning is part of bodily protection; Muslims have a duty to

¹ Ramadan is one of the months in Arabic calendar days. During this month the Holly Qur'an sent from Allah to the Earth.

² Available [online] from http://www.adherents.com/Religions_By_Adherents.html. Accessed in [March, 8th, 2008].

clean parts of their body before each prayer, which means five times a day, bathing is also mandatory to maintain cleanliness (Hawa, 1979).

Part of the Islamic law also regulates the relationship between family members and considers the family as a basic unit of the community (Hawa, 1979). The relationship between the man and the women in the family should be built on mutual respect, sharing intimacy, comforting each other, and protecting each other from any offences (Hoodfar, 2007). The husband has the full responsibility for maintaining family unity, supporting the family financially, and protecting family members. The wife, on the other hand, has a complementary³ role, she has the duty of taking care of the children, making sure of their health through proper feeding, taking care of their physical hygiene, and then teaching them Islamic morals Lemu and Heeren, 1978, Brown, 2006). The children have a duty to respect their mothers and fathers and take care of them when they become older. A sexual relationship without the worshipped bond of marriage is prohibited and no sexual relationship between couples of the same sex is allowed (Yasin, 1992).

Muslims also have a model concerning death and the process of dying. The fundamental belief is that death is inevitable and that every creature will die one day (Sarhill et al., 2001). All Muslims believe in the Day of Judgment and life after death, and that death is a passage between two segments of continuous life. Therefore, each Muslim is encouraged to prepare for life after death (Al- Gazali, 1983). The life and death is related to the 'soul' part of the person which nobody can own or know its nature (Al- Gazali, 1983). A person does not own his/her life and therefore cannot end it (Puchalski and O'Donnell, 2005). There are many rituals related to how Muslims face death, what they should do, and how to treat the dead body; this is beyond the scope of this study.

³ The concept of 'complementary' is first discussed by Brown (2006:424) she explains that complementary means 'the way how Muslims understand the relationship between sexes as operating in harmony. According to an Islamic perspective, the woman is a complement to the man in two main arguments: the first is that the woman is biologically different than the man and therefore she can never be like a man. The second is that society should be ordered for the fulfilment of men's regency on earth, which means that women have to fulfil their role on earth by becoming a mother or a wife'.

Personal illness in Islam has a special status and is considered under what is called the ‘Darourah’ status (Shaqrah, 2008)⁴. The ‘Darourah’ is an Islamic law that reflects the status of a Muslim person during illness; the sick person does not have an obligation to follow Islamic rules when he/she cannot physically do it. For example, a Muslim (woman or man) has an obligation to fast during the month of Ramadan, but if a woman cannot fast because of illness or pregnancy, then ‘Darourah’ law gives her a permit to break the fasting and maintain her immediate health. However, as an alternative, she needs to give money to the poor. Muslim believers accept illness as atonement for their sins, one basic belief is that those who became sick are not responsible for their illness (Shaqrah, 2008), personal interview). A sick person is tested and purified from sins, and accepts the will of Allah and bear his/her ordeal patiently (Rassool, 2000; Adib, 2004).

2.2.1 Muslim women

Although there are limited publications related to Muslim women’s experiences during health and illness, here I will describe some perspectives from Islamic sources related to women’s rights and their status during the onset of illness. In Islam, women have rights, duties, and roles. The Muslim woman is considered an equal partner to a man in relation to rights and certain duties, with some of these rights being the right to have a name and a family, to live in dignity, to receive protection and help from the community, to continue her education, to have welfare and live in a healthy environment (Daoud, 2003).

The Islamic view also shapes part of the behaviour and modesty of women; they are expected to wear modest clothing and to cover their body and hair. The woman has an obligation to cover her body by wearing a hijab⁵, which is considered part of a Muslim woman’s identity. One of the verses in the Qur’an says:

⁴ This part of the review is related to a telephone interview with Sheik Mohammed Ibrahim Shaqrah, a Sunni Sheik in Jordan.

⁵ The hijab is the cloth that covers the whole of a woman’s body, except for the face and hands.

‘And say to the believing women that they should lower their gaze and guard their modesty; that they should not display their beauty and ornaments except what (ordinarily) appear thereof; that they should draw their veils over their bosoms and not display their beauty except to their husbands, their fathers, their husbands' fathers, their sons, their husbands' sons, their brothers, or their brothers' sons, or their sisters' sons, or their women, or the slaves whom their right hands possess or male servants free of physical needs, or small children who have no sense of the shame of sex; and that they should not strike their feet in order to draw attention to their hidden ornaments. And O ye Believers! Turn ye all together towards Allah that ye may attain Bliss’ (Holly Qur’an [Al-Noor, verse 30], cited in Yusuf- Ali translation, 2008).

The hijab is seen as part of a Muslim woman’s construct in certain Western countries. In Canada, Ruby (2006) explored the meaning of the hijab by using a focus group involving immigrant Muslims living in Canada. The women revealed that the hijab is considered a symbol of a Muslim woman’s identity and modesty. Most of the women said that the hijab provides them with a sense of control over their lives and helps them to accept themselves as a ‘respectful person’ (Ruby, 2006). Some studies suggest that the Islamic identity, as connected to the female desire for wearing the hijab, is requested by young Pakistani women in the UK (Brown, 2006; Cooke, 2007; Modood, 2007). For example, Brown (2006:427) analyses the way in which the female Muslim identity interconnects within the UK community in relation to their employment and education, reporting that young Muslim women assert that the hijab is ‘a symbol of the Muslim women’s right to express their identity as they wish in public-political share’, with the women revealing that their right to receive education is inseparable from their right to wear the hijab at school because it represents female modesty and the religious obligation of all female Muslim believers in the UK.

During illness, a Muslim woman should first seek treatment from a female Muslim doctor or nurse but, if she cannot find a female doctor, then she is allowed to receive treatment from a male practitioner (Shaqrah, 2008). A similar view is identified by (Hammoud et al., 2005) who describe female Muslim patients’ needs in American hospitals and stress that Muslim women prefer to wear a hijab that covers their hair and clothes that cover their arms and legs. Hammoud et al (2005) also observe that Muslim women in the hospital feel more comfortable if the health care provider

gives some advance notice of coming to see them, so that they are able to cover themselves or wear a headscarf. In addition, the women report a preference to receive treatment from a female health care provider.

2.3 Jordan- the community and the culture

The Hashemite Kingdom of Jordan is located in Southwest Asia, in the North-West part of the Middle East. The country is boarded by Syria from the North, Saudi Arabia from the East and South, Iraq from the East, and Palestine from the West, with access to the Red sea through the Gulf of Aqaba (CIA, 2007). Jordan's population is about 6.1 million, with the population is distributed within 12 regions. The majority of the population (70%) is concentrated in three regions: Amman- the capital, Zarqa- the second largest city, and Irbid- the largest city in the North (Department of Statistics, 2007).

The Jordanian community is characterised as young, with 37.1% of the population being children below the age of 15; 59.1% of the population aged between 15 and 64, and 3.8% aged more than 65 (Ministry of Health, 2008). The population is comprised of approximately 90% Muslims and 10% Christians (Miller and Petro-Nastas, 2002). The majority of Jordanians are Sunni Muslims, with less than 1% being Shias (The World Factbook, 2007). Islamic rules and beliefs shape most of the cultural and social values in Jordan. At a socio-cultural level, the Jordanian community is a mix of Bedouin tribes, Palestinian refugees, Caucasians (from Russia), with a minority of recent Iraqi refugees (Department of Statistics, 2007). The Arabic culture and its values shape most of the traditional customs and values, especially the value of family unity (Soussi, 2005).

Most Jordanian families are large extended families, especially in rural areas that are populated by Bedouin tribes and farmers (Sonbol, 2003). The average family household is 5.7 persons (Department of Statistics, 2007). Kinship is one of the principles that are shared within families. Each individual belongs to what is called the 'Aileh' or the nuclear family; the 'Aileh' is the basic unit of the community and usually consists of the father, the mother, and their children living together in the same house. The 'Aileh' is connected to a larger group of families who share the

same surname which is called the 'Ashirah'. The 'Ashirah' provides its individuals with protection, reputation and honour (Batieha, 2003).

Historically, Jordan was ruled by the Ottoman Empire and then followed by a British mandate until 1921 when King Abdullah I established the first Emirate of Transjordan. In 1946, the country gained independence and became the Hashemite Kingdom of Jordan, with Abdullah as its first King (The World Factbook, 2007). Two years later the Arab-Israeli War started and more than 1.5 million Palestinian refugees moved to Jordan; this was followed by the immigration of half a million Palestinian refugees after the second Arab-Israeli War in 1976 (Sonbol,2003). During the Iraqi-Kuwaiti conflict even more Palestinian refugees moved to Jordan. The current Iraqi War has negatively affected the economic status of the population, due to thousands of Iraqi refugees escaping conflict and moving to Jordan (The World Factbook, 2007).

During the past few years (2003-2008) Jordan has seen fast economic and social growth, and significant increases in domestic revenues, government expenditure, and the gross domestic product (Jordan-Times, 2008).The global increase in social-economic living costs has increased the living costs for the majority of Jordanian families in general and the status of women in particular (Batieha, 2003). Many women have started searching for a job to help with the financial expenses of the family (Batieha, 2003). The 'Aileh' (the nuclear family structure) has been split due to the need to move and live in an area close to their work place. This change has affected the status of women in the community (Batieha, 2003).

2.3.1 Women's status in Jordan

Jordanian women represent approximately half (47%) of the adult population (CIA, 2007), with the majority being Sunni Muslims, 53% of whom are married, 38.7% single, and 2% divorced or widowed (Department of Statistics, 2007).

As part of the influence of Islam on the culture, many Jordanian women wear the hijab and cover their bodies; which in turn has become a cultural norm (Sonbol, 2003). Taking care of children is also a fundamental duty for a woman who is also the primary carer for all the family members (Gharaibeh et al., 2005). Although

Muslim women are obligated to wear the hijab as part of Islamic law, this is not applied in particular Muslim countries like Jordan. The cultural norms shape part of women's modesty; for example, older women are expected to wear a long dress and a head scarf that usually covers the whole body (Hasna, 2003). Younger women although needing to dress in a modest manner do not always wear a long dress (Sonbol, 2003). As mentioned in the section on Muslim women, Jordanian women as part of their Islamic beliefs adhere to the norm of not exposing their bodies in front of strangers or men, other than those among her family and relatives (Sonbol, 2003). However, within the Jordanian governmental law, there is no obligation for Jordanian women to cover their bodies or to wear hijab in the public areas; instead it depends on the woman choice (Yasin, 1992).

Although Jordanian women play a major role in society and are legally regarded as equal partners to men, according to traditional cultural norms the father or the husband has authority in the family (Yasin, 1992). The father is responsible for supporting his wife and children, and sometimes close relatives such as the mother, the grandmother, and aunts (Sonbol, 2003). Cultural norms shape what women are expected to do or which job to choose (Yasin, 1992). For example, the public believe that a woman's capacity is inferior to that of a man, especially in the field of politics and when making decisions (Shtewi and Daghestani, 1994). Leaving the children with no support or protection for the sake of working or studying is regarded by many as culturally unacceptable and shameful (Gharaibeh et al., 2005).

On the other hand, Islamic and cultural roles do not appear influence female freedoms to undertake higher education: about 28.8% of women in Jordan having higher than a Diploma degree (Department of Statistics, 2007). The majority live a free life and have all the rights to continue their education, vote, and run in the general election (Queen Rania, 2007). A woman can choose to work in any place that she wishes, as long she preserves her dignity and dresses modestly. Currently, women in Jordan are working in many fields side by side with men. Statistics indicate that women work in manufacturing (9.8%), trade and administration (13.7%), education (28%), and health and social work (14.4%) (Department of Statistics, 2007).

2.3.2 The health care system in Jordan

The health care system in Jordan started after the First World War although the first hospital was built in 1896 under the Ottoman Empire to serve the Ottoman soldiers during the war (Ababneh, 2008). Following this, a British army health care centre was built in 1906 to serve British soldiers (Ababneh, 2008). The first hospital built in 1926 which was accessible by Jordanian citizens was funded by the Italian Government (see below for a further discussion).

Jordan now is undergoing rapid social and demographic changes, which have had an impact on the health care system. King Abdullah II recently set out his vision to improve health care services and develop the quality of care within the public health services (Amman-Mission, 2005). The health care system is one of the best in the Middle East, with people from most of the neighbouring countries (the Gulf countries) receiving their medical treatment in Jordan (BBC- News, 2008)⁶. The main provider of health services in Jordan is the public sector, complemented by the private sector, international and charitable organisations such as the United Nations Relief and Works Agency (UNRWA), and other charitable societies (Batieha, 2003). The health care system operates through health insurance schemes (Ministry of Health, 2008). The schemes run through three main sectors. Firstly, the private health sector which covers about one third of the population and has 54 hospitals and 23 primary health care facilities distributed throughout the country (Department of Statistics, 2007). Secondly, public health services which are provided by the collaboration of the Ministry of Health (MOH), the Royal Medical Services (RMS) and two university hospitals (the Jordan University Hospital and the King Abdullah Hospital) (Batieha, 2003; (Ministry of Health, 2008). These services provide free health services to children below five years of age and the elderly above the age of 65 (Prime Ministry, 2008). Thirdly, the Royal Court insurance provides funds for 90% of the costs for all cancer patients (King Hussein Cancer Center).

2.3.3 The history of intensive care units

The development of the intensive care units in Jordan is not documented in published resources. However, some grey literature suggests that the first ICU in Jordan was

developed after the Second World War when the Italian Government built and funded a hospital and sent five Italian nurses and nuns to help Jordanian citizens during the War (None, 1926). It used to have one room that took care of critically ill patients, and included two beds that were not fully equipped. These units were run by the sisters and were organised according to the Western Italian model⁷. Seven months later, the first governmental hospital was built in the capital Amman and had a total of 20 beds. This hospital developed an intensive care unit after the Arab-Israeli War, but had limited number of beds (four) that were insufficient to hold most of the injured soldiers arriving from the War (Ababneh, 2008). Accordingly, the government built the first Royal Medical Hospital in 1948, with an ICU capacity of 12 beds. The hospital was organised according to the needs of military personnel (Ababneh, 2008).

The number of hospitals had increased by the year 1990 - up to 50 private hospitals were built during that period. The Directors of Nursing for most of these hospitals came from Canada and the USA and, as a consequence, western models of care provision were reinforced, and this was reflected in the organisation of intensive care (Batieha, 2003). The ICU in each hospital usually includes an open area with eight electronic beds; each bed is surrounded by computer monitoring system that is connected to the central monitor in the nurse station (Jordanian Nursing and Midwifery Council, 2006). The majority of the ICU equipment is imported from American companies and the language of these devices is English which is not familiar for most of the patients and not the first language of most nurses in Jordan (Jordanian Nursing and Midwifery Council, 2006).

Currently, Jordan has more than 98 ICUs distributed throughout the country, with the vast percentage located in the capital Amman. The ICU units have become more specialised; there are now Medical ICUs, Surgical ICUs, Neuro ICUs, Open heart ICUs, and Paediatric ICUs (The University of Jordan, 2005). The hospital organisation system for most of the governmental and educational hospitals runs

⁶ Available [online] from BBC news, <http://search.bbc.co.uk/cgi-bin/search/results.pl?scope=all&tab=all&recipe=all&q=The+Hashemite+Kingdom+of+Jordan+%2B+the+health+services>, [Accessed in Jan. 20th, 2008]

⁷ I have limited resources about how that model works in Jordan.

according to American Nurses Association (ANA) policy, but there is no specific policy related to the ICU nurses (Aqel, 2007).

2.3.4 Nursing care

Nursing training and education in Jordan has developed rapidly. The first nursing faculty started at the University of Jordan in 1976, with the first graduates being 12 female and 12 male nurses (The University of Jordan, 2005). This increased to 8 nursing programs for the bachelor's degree in nursing by the end of 2006. The number of nurses has increased each year; for example, in 2006, 2200 students were estimated to be enrolled in the BSc programmes (Jordanian Nursing and Midwifery Council, 2006). In contrast to any other country in the world, the number of male nurses in Jordan has increased significantly during the last few years (2003-2007). In 2007 the nursing council announced that the percentage of male nurses in relation to the registered nurses in Jordan was 46% [5771 out of the 12520 total registered nurses] (Jordanian Nursing and Midwifery Council, 2007). In addition, the number of male nurses who enrolled in the university also increased. In 2005 the number of male nurses who enrolled in Bachelor degree programmes at the universities was 65% (Ahmed, 2007). These percentages provide an indication that nursing in Jordan could have more male nurses than female nurses in the future. Additionally, the number of male nurses with a Masters Degree in critical care is also increasing. The first programme began at The University of Jordan in 1988 with 8 nurses, but by 2007 the number of nurses enrolled in the program increased to 39 nurses who specialised in different intensive care areas (The University of Jordan, 2005). The increased numbers of male nurses in Jordan may be a significant development which may impact on the delivery of care (especially when dealing with female patients). It is also a relatively new career pathway for men. The impact to these developments is yet to be researched in any depth. To date, there are no published studies which address Jordanian patients' experiences of nursing care in the ICU, with exception of one quantitative study explored the Jordanian patients' perception of ICU stressors (Hweidi, 2007).

2.4 A review of patient experiences in the ICU

The focus of this review is on the patient's subjective experiences of illness during their time in the ICU and after discharge. The review of the available literature commences with a discussion of how the patients experience their critical illness after they are transferred from the ICU to the ward and then after their discharge home. An overview of the studies related to patients' experiences, memories, recollections, and perspectives in the ICU shows that more than 850 studies were conducted between the periods 1966-2008. Of these, 118 studies are particularly closely related to ICU patients' experiences; these are drawn upon in this chapter. The studies can be categorised in six main themes, these are: patient memories of ICU experiences, the lived experience of patients in the ICU, patient-nurse communication, ICU delirium (syndrome), the long term impact of ICU experiences, and illness and stories. A brief summary of the conducted studies will be provided below for each theme, followed by a detailed description of each theme in a separate section.

First, a number of studies which were conducted in early 1990s mainly in the USA and the UK, examined negative experiences in the ICU by quantifying the number of patients who recalled their experiences in the ICU. These studies used different methods such as rating scales, questionnaires or survey questions to find factors that patients perceived as stressful within the ICU environment. Factors such as noise, pain, lack of sleep, lack of communication were most often reported as source of stress (Hewitt, 1970; Heath, 1989; Johnson, 1990). The review of the literature relating to this theme provides a historical background into the development of quantitative studies focusing on ICU patient experiences.

Second, the development of a phenomenological movement has had a significant influence on studies conducted to explore ICU patient's experiences. There emerged a body of literature between 1992 and 2003, which was strongly influenced by two phenomenological philosophers, Edmund Husserl (Husserl, 1920) and Martin Heidegger (Heidegger, 1927). These studies have multiple foci and aims; but their main emphasis is on a retrospective examination of patients' perspectives of their experiences in ICU, in relation to specific phenomenon in the ICU (Chen, 1990;

Burfitt, 1993; Papathanassoglou, 2003; Johnson, 2004). The patients' lived experiences in the ICU section reported below focuses on how patients make sense of their experiences in the ICU in relation to their cultural backgrounds. The studies included in this section all relate to patients' experiences from a few days to five weeks after illness, and were mostly conducted in hospital wards.

Third, much literature emphasises patients' experiences of the nursing care they receive and issues in nurse-patient communication. Studies about the verbal communication from the patient's perspective fall into two main topics: the feelings that the patients experience when they cannot communicate verbally, and the patients' description of their experiences when ICU nurses do not meet their needs or/and cannot understand them (Elpern et al, 1992; Lawrence, 1995; Menzel and Milwaukee, 1998; Johnson, 1999; Russell, 1999; Odell, 2000; McKinney, 2002). The majority of these studies were conducted retrospectively with patients who had been on mechanical ventilation or those who suffered loss of consciousness in the ICU (Thomas, 2003; Shatell, 2004). Another research focus is on the phenomenon of ICU delirium and the psychological experiences of patients in ICU settings. These studies emphasis on the need to develop psychological support for the ICU patients, with the studies falling in to three types: firstly, phenomenological studies that explore the lived experience of patients in the ICU in relation to ICU syndrome (Granger et al., 1996, Granberg et al., 1998, Granberg et al., 1999, Axell, 2001, Ringdal et al., 2006, Mckinney and Deeny, 2002), secondly, studies that aim to understand phenomena based on the theoretical explanation that the ICU environment causes different psychological problems to the patients (Dyer, 1995a, 1995b; Dyson, 1999; Justice, 2000), and thirdly, studies that follow up patients who were diagnosed with delirium in the ICU for a period of months or years (Granberg-Axell et al, 2001; Jones et al, 2001; Griffiths, 2002).

The fifth theme concerns the long term physical and psychological effects of ICU experiences on the patient's life after they have been discharged home, as well as the phenomenon of post traumatic stress disorder (PTSD). Most of these studies were conducted between 2000 and 2008. Many studies have shown that patients face physical problems during their recovery time and focus on improving the quality of the patients' life after discharge (Green, 1996; Saarmann, 1993; Hall-Smith et al.,

1997; Russell, 1999; Granja et al., 2005; Johnson et al., 2006). The physical recovery for many patients is described as slow, and is characterised by their feelings of tiredness and weakness (Jones et al, 1998, 2001). The recovery process also includes psychological issues that could develop into PTSD. A large number of studies use longitudinal quantitative approaches to investigate the phenomenon of PTSD (Stoll, 2000; Griffiths and Jones, 2002; Jones, 2003; Schelling, 2003; Capuzzo, 2005; Granja et al, 2005; Griffiths, 2006; Löf et al, 2006; Pattison et al, 2007). The emphasis of these studies is to use patients' accounts as evidence which can improve the quality of the medical care. A limited number of studies use qualitative approaches (mainly phenomenology) to explore the long term impact of the ICU experiences on patients lives after discharge (Maddox, Dum, and Pretty, 2001; Adamson et al, 2004; Storlu, et al, 2008).

The sixth theme emerges from studies based on a broadly sociological stance which discuss patients' stories as a source for developing practitioners' health care practices. This category of studies is a more recent development and emphasises how stories can be seen as a way to share the illness experience between the patients themselves and their health care providers and to engage the patient as an active contributor to the healthcare organisation. The discussion of this section includes the use of stories as an out- narrative (Douglas, 1989; Smith, 1987; Frank, 1991, Richman, 1996; Rier, 2001), and the narrative of people discharged from the ICU and using the internet a tool to communicate their narratives (DIPEX, 2007; Patients' Voices, 2007).

2.4.1 Patient memories of ICU experiences

The experiences of patients in ICU were first published in 1970 in the UK, when Hewitt (1970), a senior registrar at Guy's Hospital in London, conducted a survey of 100 patients who had had cardiac or thoracic surgery and were staying in the surgical intensive therapy unit. A small scale questionnaire was used to ask the patients about the cause of their discomfort in the ICU. The survey revealed that 77% of patients found the nursing staff sympathetic and efficient. However, many reported discomfort and worries about suction procedures (16%), noise from the machines (10%), and having difficulty in sleeping (26%). Ninety two percent of the patients reported that they were happy about the number of visits that relatives were allowed

to make. Hewitt's description of patient stressors in ICUs was particularly influenced by Lazarus and Hagens' study conducted in 1968 in two American hospitals (Lazarus and Hagens, 1968). Lazarus and Hagens were two American psychologists who worked in the mental health department and investigated those factors that may increase or decrease the development of psychosis for patients after they had open heart surgery. Based on Lazarus' theory of stress and coping process, they described the environmental stressors that can contribute to the development of psychosis after the patient who has had open heart surgery is transferred to the recovery room (Lazarus and Hagens, 1968).

Lazarus' theory of stress and coping is based on two assumptions; the first is that patients use cognitive processes to evaluate whether particular environmental 'encounter' (stressors) affects their health, and secondly, that patients use cognitive and behavioural efforts to overcome these stressors (Lazarus, 1981; Lazarus and Folkman, 1984; 1968). Based on these theoretical assumptions, the majority of the studies conducted between the 1970s and early 1990s which emerged from the USA and the UK, placed particular emphasis on the assumption that the ICU is a stressful environment. In these studies, patients were asked to check certain items related to environmental stressors in the ICU, or rank these stressors from the most stressful to the least one (Jones, 1979; Ballard, 1980; Heath, 1989; Bergbom-Engberg and Haljamae, 1989; Cochran and Ganong, 1989; Turner, 1990). Items studied included physical stressors (lack of sleep, noise from machines or staff conversation, difficulty in speaking when the endotracheal tube was connected, bright lights, and physical pain) and physiological stressors (fear, feeling of isolation and feeling of panic) (Jones, 1979; Ballard, 1980; Heath, 1989; Bergbom-Engberg and Haljamae, 1989; Cochran and Ganong, 1989; Turner, 1990; Elpern, 1992, Turner et al, 1992). Two examples of this type of study are briefly reviewed below. A study conducted in the UK by Jones et al (1979) explored the recall of 100 patients discharged from the ICU at St. Mary's hospital and used the questionnaire developed by Hewitt (1970). The findings reveal that 41% of the patients had physical pain, 25% of the patients found it difficult to sleep, and 75% could not lie comfortably. Similarly, Cochran and Ganong (1989) used a Likert- scale questionnaire that includes 42 items of environmental stressors in the ICU. Their aim was to measure the most stressful events in the ICU and their findings showed that patients ranked the items 'having

tube in your nose or mouth', 'being stuck with needle', 'being in pain', and 'not able to sleep' as the most stressful environmental factors.

The development of nursing theories influenced the development of nursing research within intensive care settings between 1992 and 2000 (Alligood and Marriner, 2002). The emphasis of these studies moved from listing ICU stressors to developing better nursing care for those who have experienced the ICU environmental stressors. Many of the quantitative studies conducted during this period attempt to provide a description of large numbers of patients affected by ICU stressors and the need to develop care for them during their presence in ICUs (Clark et al, 1995; Soehren, 1995; Watts and Brooks, 1997; Cornock, 1998; Hall- Lord, 1998; Topf, 2000). For example, in a UK study, Cornock (1998) differentiates between patient and nurse perceptions of ICU environmental stressors. Cornock used Cochran and Ganong's questionnaire (1989) to compare nurses' and patients' perception of the ICU stressors. The questionnaire was completed by 71 nurses, and then 71 patients discharged within one week from the ICU. This comparison showed that nurses gave higher ranking to the physical needs of their patients, such as 'the inability to communicate' and 'pain', whilst patients give priority to their psychological needs. Cornock (1998) recommended that improving understanding of the psychological needs of such patients is fundamental.

A shared element among this type of study is that nurses' care, when based on the medical model of care that focuses on the pathophysiology of diseases, cannot adequately consider needs arising from individual patient differences. The majority of the studies were conducted in the in the UK (16 studies) and the USA (10 studies), with fewer studies conducted in other countries such as South Africa (Turner, 1990), Sweden (Bergbom-Engbom and Haljamae, 1989; Hall-Lord, 1998), Australia (Russell, 1999; Daffurn et al, 1994), Netherlands (Van de Leur et al, 2004), China (So and Chan, 2004), Jordan (Hweidi, 2005), Canada (Gelinas, 2007), and Turkey (Agars and Aztecan, 2007). One study conducted within a Jordanian community (Hweidi, 2007) involved a cross-sectional study of Jordanian patients' perception of stressors in the ICU. Hweidi used the questionnaire developed by Cochran and Ganong (1989) as a tool for data collection. A total number of 165 patients, who had spent more than two days in the ICU, were asked to rank 42 stressors and nominated

‘the presence of the endotracheal tube’, ‘being in pain’ and ‘not able to sleep’ as the most acute stressors in the ICU. Hweidi highlights the need for supporting Jordanian patients in the ICU through decreasing such environmental stressors.

Studies such as these provide an overview of some aspects of the experience for a large number of patients in the ICU. However, they fail to identify how individual patients derive meaning from their experiences, what strategies are used by individual patients to cope with the upsetting experiences, and how the patients recall these experiences in the context of their wider lives.

2.4.2 The lived experience of patients in the ICU

The development of a phenomenological movement has had a major influence on studies conducting into patient experiences in ICUs. Many studies use a phenomenological approach which emphasise the experience of patients from their own viewpoint, with this type of studies retrospectively describing or interpreting the meaning of these experiences for patients in relation to a specific phenomenon. Some of these phenomena include patients’ experiences of their bodies and selves (Burrill et al, 1993; Chaboyer and Johnson, 2002; Papathanassoglou and Patiraki, 2003); patients’ experiences of ventilator machines (Johnson, 2004); patients’ experiences of their condition after liver transplants (Forsberg et al, 2000; Barrio et al, 2004; Claesson et al, 2004); and patients’ experiences of social support (Chin, 1990, Hupcey, 2001).

The majority of these studies, which were conducted between 1992 and 2007, draw influence from two phenomenological philosophers, Edmund Husserl (1920) and Martin Heidegger (1927). Phenomenological research ‘aims to gain a deeper understanding of the nature or meaning of our every day experiences’, with the meaning of the phenomenon based on ‘consciousness’, which is considered the only point of access when the human ‘being in the world’ (Van Manen, 1990:9).

One of these studies explores ICU patients’ experiences in Spain. Barrio et al (2004), describe the experience of 10 patients after having a liver transplant and being transferred to the ICU. Two themes emerge from to this study: ‘the caring behaviour of the nursing staff’, and ‘support from the environment and religious beliefs’. Barrio

et al highlight key aspects of patient accounts; the first is connected to their hope that they will recover and the operation will positively impact on their life after discharge, and the second is connected to their perceptions of support from their family. This is considered by patients as a primary means of overcoming the difficulties they faced during the ICU. The family provides a sense of happiness and a sense of harmony and cheerfulness and the first time they recalled a family gathering was considered as a 'rebirth' for some participants. The second theme relates mainly to religious support, with some patients finding that the meaning of their experiences is closely connected to their Christian beliefs and the sense that they were in need for the God's support. This gave them a sense of peacefulness, with some patients mentioning that they prayed to God many times during their stay in the ICU. On the other hand, some patients offered a negative meaning to their experiences of the changes in their bodies, and physical discomfort, especially when they could not drink or eat after surgery. However the majority of participants did not reveal their physical pain experiences. Of those that experienced changes in their bodies after the operation, they connected these experiences with worries about how their loved ones would accept them after the operation. The nurses' support was seen as especially important in this context, with participants recalling that the nurses were kind and sensitive and helped them to discuss their worries. As a result, the presence of the ICU nurses around them gave them a feeling of safety. Barrio et al's study draws attention to the way in which family support and nursing care may be of primary importance to patients and how the meaning of ICU experiences derives from the personal, social, and religious meanings given to it by these patients.

The findings of Barrio et al reflect those from an earlier study conducted among Taiwanese patients in ICUs. Chen (1990) describes the social context being a source of support among 35 Taiwanese patients who spent more than 3 days in ICUs and who described their experiences after discharge. The patients revealed that social support is divided into three categories or levels of support. The first relates to family support given by regular visits, which provides them with a sense of togetherness. The second level of support is gained from friends and relatives who provide encouragement and cheer them up during visits and also take care of their children for them when they are in hospital; in addition, half of the patients mentioned that their religious beliefs and a belief in fate helped when they were admitted to the ICU.

The third level of support comes from the nurses and physicians in the ICU. Physicians' support includes proper diagnosis and help in the treatment regimen, even though the patients did not expect any emotional support from the physicians. However, the patients revealed that the nurses were of most help, especially in assisting with their physical needs, understanding their needs, providing information and explanations, and communicating with them. It seems that the Taiwanese community have strong families and social connections, and therefore the patients found their primary source of support came from being with their family.

These two studies (Chen et al, 1990; Barrio et al, 2004) suggest that the meaning of the critical illness may be shaped through social and religious contexts and the level of support that patients perceive they received from their family and from health care professionals. In contrast, Papathanassoglou and Patiraki (2003) explore the lived experience of 8 ICU patients in Greece with an emphasis on the patients' dreams. They reveal that the participants' meanings are based on the 'transformation' of perception, the 'lived body', time and space, and the transformation of life and death (Papathanassoglou and Patiraki, 2003:15). The Greek patients in this latter study report that the ICU was unfamiliar and unknown, which affects how they interpret their experiences with their bodies. They describe that they could not do their basic activities as before their critical illness. The second theme stresses social isolation, with patients reporting feelings of loneliness and strangeness because they had limited contact with their family and friends. A sense of separation from their social system, with the experience of uncertainty about their health condition, was described by many of them as 'death was near' and was associated with a sense that they could not guess whether they would live or die at any time while in the ICU. Papathanassoglou and Patiraki's analysis is based firstly on Parse's transcendence theory, which considers that people create a sense of meaning about their lives through freedom of choice, and therefore the meaning can grow with time, and secondly on the Heideggerian philosophy, with its notion that human have separate body and mind/soul, and that language is an important aid to interpret the human existence (Heidegger, 1976; Parse, 1981, cited in Papathanassoglou and Patiraki,

2003). The basic Greek philosophy, which assumes a mind and body split, provides a primary meaning for Greek patients' experiences in ICUs (Aristotle (384-322 BCE))⁸

Other studies concern the phenomenon of social support for patients in the ICU (Cutler and Garner, 1995; Kolleff et al, 1997; Bergbom and Askwall, 2000; Hupcey, 2001; McKinney and Deeny, 2002; Strahan and Brown, 2005; Samuleson et al, 2007). The emphasis of these studies is related to how nurses and family can help in reduce negative experiences of the patients in the ICU. Hupcey (2001) describes the meaning of social support for 30 American ICU patients during their stay in the hospital ward, with the primary meaning during their time in the ICU connected to the presence of close family members, such as a spouse or close friend, who stays with patients during their time in the ICU. The patients described how family members provide them with a sense of happiness, although they give excuses for those family members who could not visit them. Some patients said that they felt happy when they knew that their family members prayed for them at home. Hupcey suggests that the presence of close family member who stays with the patients during the critical illness is crucial. However, she did not give a clear definition of the 'social support' as this could vary between each individual patient.

Similar findings are discussed by Bergbom and Askwall (2000) who explore the meaning of 'nearest', which reflects the intimacy of social relationships; whilst 'dearest' reflects the social identity and individuality the patients feel when close family members are present (Bergbom and Askwall, 2000: 388). Bergbom and Askwall suggest that the meaning of 'nearest' for the patients is connected to the presence of their close family members, such as their husband and children, who provide them with a sense of safety, love, and being alive. The family connections seems important to 'get on with life' during their stressful time in the ICU. The patients also appreciate their family's physical help and care. Bergbom and Askwall base their interpretation on Eriksson's theory of suffering, which assumes that suffering is a continuum between two poles: the 'good' and the 'evil' (Eriksson, 1994 cited in Bergbom and Askwall, 2000). This study shows that patients'

⁸ Aristotle general introduction [online] from <http://www.iep.utm.edu/a/aristotl.htm>. Accessed in [March, 22nd, 2008].

experiences of suffering can be palliated by keeping them close to their family and close confidants with whom they wish to share their feelings.

The above body of work, although conducted in different countries, shows that the meaning of illness varies according to personal, cultural, social, and spiritual beliefs. The shared element among these studies is that the family provides a primary meaning for the patients' positive experiences in an ICU.

Uncovering the meaning of illness among patients who were on mechanical ventilation or who are unconscious is more complicated. Johnson (2004) explores the experience of 9 patients spent more than 7 days in the ICU and were connected to mechanical ventilation in the UK. One of the themes related to this study is that the patient tries to reclaim their everyday world. The participants reveal that when they were separated from their family and close friends due to the presence of the ventilator, they felt that they lost control of the environment around them. This made them frustrated and led them to question why they were present in an unknown place (the ICU). Physical pain was an integral part of their experience of suffering, with the pain described as severe enough to disturb their sleep at night. The presence of machines around them and being connected to their bodies left them with a feeling of loss of bodily control. These experiences affected them even after they left the ICU to the wards, where they suffered from the consequences of the psychological effect of the presence of the ventilator machine.

2.4.3 Patient-Nurse communication

Patients admitted to the ICU are usually experiencing life threatening illnesses. The majority of these patients are unable to communicate due to different causes; some lose consciousness on their way to the ICU; others could be sedated and/or intubated. These conditions mostly affect their ability to speak and verbally communicate with the nurses or physicians. Travelbee (1971:7) defined nurse-patient communication as:

the process which can enable the nurse to establish a human to human relationship, and thereby fulfil the purpose of nursing, namely, to assist individuals and families to cope with the experience of illness and suffering, and, if necessary, to assist them to find meaning in these experiences (cited in Hagland, 1995, p.111).

This definition provides an explanation that communication between the nurses and patients is not only a two way process (Alasad and Ahmed, 2005), but also one of shared feelings and emotions (Finch, 2004). The focus of this section will be on the patients' experiences of their verbal communication with the ICU nurses, from their point of view, however, there is only one study relating to the patient's perception of non-verbal communication (Menzel and Milwaukee, 1998). In addition, the nurses' viewpoint and experiences of communication are as important as the patients' experiences, and this aspect will be discussed in section 8.2.

The studies reviewed relating to verbal communication from the patient's perspective draw attention to two main issues: the feelings that patients experience when they are unable to communicate verbally, and patients' description of their experiences when they perceive that the ICU nurses did not meet their needs or/and could not understand them (Elpern et al, 1992; Lawrence, 1995; Menzel and Milwaukee, 1998; Johnson et al, 1999; Odell, 2000; Gonzalez et al, 2004). The majority of these studies have been conducted retrospectively with patients who had been on mechanical ventilation, or those who had lost consciousness in the ICU (Thomas, 2003; Shattell, 2004).

Several studies report that the lack of interaction between the nurses and patients in the ICU leaves some patients feeling frustrated and overwhelmed, with most highlighting the need for nursing care that values and respects patients' individuality, and meets their social needs (Hupcey, 2001; Gonzalez et al, 2004; Shattell, 2004). These issues are particularly clear in an autobiographical account from 1989, by Ann Douglas, a nurse who spent more than a month in the ICU after she had a car accident. Douglas reflects on her experience with the ICU nurses, pointing out the essential issues in the relationship between the nurses and herself as a patient:

...As I look back, it seems to me that collaboration (between the nurses and herself) is the major mechanism. This collaboration is not uniform. It is essential to remember that one member of the team, the patient, cannot exercise the same level of emotional control, intellectual judgment, nor the same degree of motor activity. ... In the intensive care unit, the major responsibility for collaboration rests with the staff. They initiate it. They cultivate it. The patient's successful recovery depends heavily on the staff's ability to engineer collaborative relationships, to accomplish the expectations designed for restoration (Douglas, 1989, p.234).

As Douglas describes her own feeling of dependence and vulnerability in the ICU, she stresses the role of the nurses in helping patients to recover physically. The recovery includes not only the healing of wounds or maintaining the body integrity, but also psychological recovery.

A number of studies show that patients feel frustrated when they cannot communicate effectively in the ICU. McKinley et al (2002) and Russell (1999) found that Australian patients reported that they felt vulnerable, and depended on the nurses' physical and psychological support and help. This support was mainly experienced when the nurses shared the patients' feelings and concerns, and helped the patients to overcome their worries and fears. Russell (1999) conducted a mixed method study with a total of 298 Australian patients; of those, 212 patients completed a self-reported questionnaire, and 86 were interviewed by telephone at their homes. The patients reported that their communication with the nurses was interconnected with their feelings of safety and reassurance. When the nurses explained the treatment regimen, the patients felt that they knew what to expect in the progress of their illness. However, poor communication caused anxiety and uncertainty which left patients feeling that their recovery was unmanageable. Russell suggests that effective communication between the patients and nurses in the ICU could help in decreasing the psychological problems following discharge. Similarly, McKinney and Deeny (2002) describe the experiences of six Australian patients who spent more than four days in the ICU. The patients were interviewed twice, once prior to their transfer from the ICU, and then within approximately 48 hours after they had been transferred from the ICU to the ward. The participants stated that they had developed a positive relationship with the ICU staff, and appreciated the advice, explanations, and support received from the nurses during their time in the ICU. On their transfer to the ward, the patients felt that they had lost the relationship which

they had developed with the nurses. McKinney and Deeny point out that patient's live with the positive empathetic relationship with their ICU nurses, even after they left the unit.

Many studies support the view that patients who cannot communicate verbally report feelings of being overwhelmed, anxious, and losing their sense of self (Elpern et al, 1992; Lawrence, 1995; Menzel and Milwaukee, 1998; Johnson et al, 1999; Odell, 2000). For example, Menzel and Milwaukee (1998) investigate the relationship between the intensity of the intubated patient's negative emotional response to being unable to speak, and their physical, emotional, and intellectual response. They interviewed 48 patients after they spent more than 24 hours on mechanical ventilation. The findings show that most patients had feelings of anger and fear at being unable to speak. Many factors were related to the patients' feelings of anger and fear, such as their inability to express their feelings verbally, the severity of their illness and their feeling of low self-esteem.

Many studies reported that communication is an important way for patients to convey their needs and emotions to the nurses in the ICU, but many patients could not express their thoughts verbally, due to the presence of the ventilator. A recent study conducted in Denmark shows that communication is fundamental for the patient who had open heart surgery (Schou et al, In Press). The patients in this study revealed that they felt socially isolated and distressed when they have been weaned from the ventilator, one patient said:

‘The ventilator bothered me, I could not talk to anyone. It was a relief to be rid of the tube, but for days my voice and ability to swallow didn't come back, but I didn't feel actual pain’ (Shou et al., In press).

The patients also noted feelings of unhappiness and embarrassment when they could not explain the operation to their family members and friends. The findings of Schou and Egerod reflect those from an earlier study conducted among patients in Netherlands: Hafsteindottir (1996) discussed the experiences of communication on eight mechanically ventilated patients and highlights that patients felt anxious and perceived the nurses to not be very helpful when they did not provide explanations or give any information about the progress of their illness. Similarly, Holland (1997) finds that patients who undergone cardiac surgery in the UK reported limited

communication with the ICU nurses, the only interaction they perceived was when the nurses did the clinical procedures. On the other hand, (Carroll, 2007) discusses the very long term experiences of nineteen American patients who had difficulty communicating verbally due to the presence of the ventilator. The time of being connected to a ventilator varied between a week and 19 years. The patients expressed that their loss of verbal communication made them feel powerless, and they lost their integrity as a whole person. The patients said that their life was restricted, and felt frustrated when they could not express their feelings in words. Some patients felt angry and resentful, as they thought that the people around them could not understand them, and were unaware of their needs. Because some patients were dependent on other people for their care, they felt powerless, and were not in control of their individual care. The patients in this study were interviewed within different times after their experiences. Some were interviewed after one week of their recovery, and another one who had lived 19 years with mechanical ventilation. The patients' experiences could vary and change in time. The patients who had ventilation for only one week, and then recovered, might have different interpretation of their experiences than those who live with mechanical ventilation for the rest of their lives. As Charmaz (1990) argues, patients who live for a long time with their illness could change their perception of self and identity.

Although many studies purport to have an emphasis on the role of the nurses to develop a therapeutic relationship with their patients, based on mutual understanding, many studies tend to relate nurse-patient communication in the ICU as solely related to carrying out patient care 'tasks', rather than caring for the patients in any wider sense (Hagland, 1995; Alasad and Ahmed, 2005). Patients, on the other hand, believe that their relationship with the nurses is more important than performing nursing 'tasks', or monitoring machines (Mann, 1992). Many studies describe the patients' view of nursing communication in the intensive care units, with the emphasis on developing a better collaboration between the patients and the nurses (Ashworth, 1992, Mann, 1992, Wilkinson, 1992, Barnard and Sandelowski, 2001, Wojnicki-Johansson, 2001, Shattell, 2004). For example, Wojnicki-Johansson (2001) explores the experience of 22 Swedish patients, using a series of three interviews over a period of two months with the aim of determining the communication difficulties experienced during mechanical ventilation. Wojnicki-Johnson reports that the

majority of the patients found the nurses were understanding of their needs, and willing to share their feelings and worries with them. However, most of the patients reported that nurses' communication and support was related to performing the nursing procedures, with limited information provided by nurses about the progress of their diseases, and a tendency for nurses not to include them in treatment plans. Wojnicki-Johnson suggests that care should be planned as far as possible by involving both the nurses and the patients, based on transparent communication and interaction between both of them. The findings of this study are supported by many studies conducted with patients on mechanical ventilation; the researchers in these studies point out that communication from the patients' perspective is based on sharing the emotional feelings between the nurses and their patients, rather than constructing patients as a set of tasks or procedures (Bergbom-Engberg & Haljamae, 1989; Hafstteindottir, 1996 Cutler et al., 2003).

A recent study, conducted in the UK, gives an explanation of how the patients experience different types of communication between themselves and the nurses. McCabe (2004) explores how five British patients interpret nurses' communication in the ICU. Based on the hermeneutic phenomenological approach, McCabe identified four main themes: lack of communication, attention, empathy, and being friendly. The lack of communication for most of these patients refers to the nurses' concern for doing tasks rather than talking to them, with most of the patients reporting feelings of being frustrated, and assuming that the nurses did not care for them as individuals. The attention theme suggests that the patients acknowledged that, when the nurses listen to their requests, and give them time to express themselves, they feel reassured and cared for. The empathy theme describes more emotional involvement and interaction between the nurses and the patients. The patients revealed that when the nurses show that they understand their needs and share their feelings they felt relaxed and happy with the communication with those nurses. Moreover, the patients accepted the nurses as friends when nurses employed humour during their care. This made the patients feel happy and relaxed in communicating with the nurses. McCabe suggests that nurses are able to communicate effectively, and meet their patients' needs, especially when they accept that adapting to patients' individuality is part of their aim when providing nursing care.

2.4.4 ICU delirium (syndrome)

The term 'ICU syndrome' was developed by the psychologist, McKegney, who argued that ICU syndrome involves an impairment of 'psychological make-up and brain dysfunction', mainly caused by severe illness conditions, sedative drugs and lack of windows in the recovery rooms or ICU setting (McKegney, 1966:634). In an attempt to define the 'ICU syndrome' concept, (Granger et al., 1996) reviewed 20 studies published between the years 1954-1990 related to ICU delirium or syndrome. They found that no specific sign and symptoms of this phenomenon are described in these studies, but that depression, fear, loss of memory, unconsciousness, sensory overload, lack of sleep, use of sedation, and severe physical pain all contribute to the development of the phenomenon. The researchers conclude that the ICU syndrome involves:

'an altered emotional state, occurring in a highly stressful environment, which may manifest itself in various forms, such as delirium, confusion, crazy dreams, or unreal experiences' (Granger et al., 1996, p.19).

Many researchers explore patients' unreal experiences in the ICU, using the title 'ICU syndrome', 'crazy dreams', 'unreal experiences', 'ICU psychosis', or 'ICU delirium'. Different explanations are used to account for this phenomenon but, in essence, are related to patients feeling lonely and isolated, which together with the lack of their ability to communicate, lack of family support, and bright lights and noise from the environment, causes them to experience unreal events, such as hallucinations, delusions, and nightmares (Laitinen, 1996; Granberg et al 1998; Dyson, 1999; Justice, 2000; Rundshagen et al., 2002; Roberts and Chaboyer, 2004). The emphasis of these studies is divided between understanding why this phenomenon happens to patients or/and how to decrease such phenomenon by providing psychological support.

In her attempt to explain why ICU syndrome happens to patients in the UK, Dyer (1995a) argues that environmental stressors are the main cause of ICU syndrome. Dyer uses both concepts of 'psychological torture' and 'brain washing' developed by Edward and Hunter (1950) in a study of American prisoners who were 'tortured' during the Korean War (Edward and Hunter, 1950 cited in Dyer, 1995a). The feeling

of isolation and unfamiliarity with the ICU environment is accompanied by the patients' loss of the ability to eat or sleep, as well as the noise from the machines and the negative behaviour of nurses all potentially leading to the development of ICU psychosis. Nursing care, as Dyer suggests, should be based on the 'humane' nursing care to decrease such phenomenon (Dyer, 1995b). These findings are supported by (Dyson, 1999) who claims that the lack of nurse interaction with patients, who are in an unfamiliar and hostile ICU environment, is connected with the development of ICU psychosis. Dyson's analysis (1999) is based on (Peplau, 1952) behavioural interaction model, which assumes that the lack of individual interaction with the environment and the social context leads to the development of mental and behavioural problems (Peplau, 1952 cited in Dyson, 1999). Dyson suggests many situations where nurse-patient communication and interaction may be constrained. These include the patients' presence in an unfamiliar environment which disturbs their every day life events, the severity of their illness that hinders verbal communication and the loss of consciousness for many patients. According to Peplau (1952) all these combine together to lead to the development of psychosis. However, the lack of nursing interaction and the environment are not the only factors that lead to the development of psychological problems; there are other elements that help in the development of this phenomenon such as medication, the severity of the disease, and how the person copes with the illness (Lazarus and Hagens, 1968). Justice, a psychiatric consultant nurse, observes that many elderly patients develop ICU syndrome during their admission to ICUs. She points out that there are many factors that may lead to the development of ICU delirium in elderly patients, with some of these factors being poor nutrition, use of catheterisation, the severity of the patient's illness, and the use of sedation (Justice, 2000), also suggests that providing care for the patient as an individual is important to decrease the incidence of the phenomenon.

An alternative way of understanding this phenomenon is by examining patients' accounts of their experiences of ICU delirium. In a study conducted within a Swedish community, (Granberg et al., 1998) describe the experience of 19 patients who spent more than 36 hours in an ICU, with the aim of identifying the causes of ICU syndrome. Patients reported that there were many factors connected with their experiences of unreal events, such as their feeling of 'bodily emptiness', or not

knowing what had happened during unconsciousness, witnessing severely ill patients in the same unit, difficulty in sleeping, and the presence of ICU machines connected to their bodies. A year later, (Granberg et al., 1999) found that some patients reported that the experience of unreal events, and ICU delirium, were related in many ways to their fear of falling into a deep sleep and losing their ability to communicate verbally with the health team.

The phenomenon is also discussed in relation to the patients' experiences of confusion and nightmares. Laitinen (1996) describes the experience of ten patients who had an open heart surgery in Finland, finding that the majority of patients experienced confusion and nightmares. Followed this, Axell (2001) uses an interpretive phenomenological approach to explore the experience of ten Swedish patients who were on mechanical ventilation and diagnosed with the ICU delirium. Axel, observed the patients in the ICU and then followed them up through an in-depth interview after they had been discharged to the ward. Data analysis revealed many themes including the main cause of the ICU syndrome as related to fear and chaos. Axel found that patients when have extreme experience of fear and interlinked with uncertainty and chaos may develop unreal experiences of confusion and delirium.

Although there is no current definitive interpretation of this phenomenon, the emphasis of all the studies is on the need to find better approach to care for this group of patients. A second shared point is that patients frequently do not share their experiences of unreal events with ICU nurses: this may be because they are worried that the nurses will judge them negatively and think of them as mad.

2.4.5 The long term impact of ICU experiences

Previous studies have reported that the experience in the ICU is traumatic for the majority of the patients. These experiences can also impact on the patients' life after they have been discharged home. Physical problems take many forms, some of which include physical pain, difficulty in sleeping, loss of appetite, and tiredness (Green, 1996; Saarmann, 1993; Daffurn et al., 1994; Hall-Smith et al., 1997; Russell, 1999; Chaboyer et al., 2002; Granja et al., 2002). For example, Daffurn et al (1995) report that while many ICU patients regain near normal general health just three

months after their discharge from the ICU many tend to report persistent physical and psychological complaints which include pain, difficulty in sleeping, tiredness, breathlessness, and feelings of loneliness and depression. The researchers in this study did not describe what the patients perceived as causing these complaints; rather this depended on the researchers' clinical judgment. In addition, the word 'normal' may have a different meaning from the patients' view point, which could differ from the researchers' view point.

Physical recovery for many patients is described as slow, and as characterised by feelings of tiredness and weakness (Griffiths and Jones, 1998, 1999, 2002; Jones et al., 2001; Papathanassoglou and Patiraki, 2003). One study, for example, explores the impact of long ICU treatment on muscle mass, Griffiths and Jones (2002) are two physicians in the UK, conducted a structured interview with 148 patients who visited their follow up clinic two months after their discharge from the ICU. They found that the majority of their patients lost much of their muscle mass (about 2% of muscle mass a day) during their stay in the ICU. The loss of muscle mass was related to many factors such as lack of mobility, loss of protein as a response of the catabolic effect of the stress, insufficient nutrition, and the use of some medication such as corticosteroids or the neuromuscular blockade which helps to increase the muscle weakness. Griffiths and Jones (2002) report that after patients are discharged from the hospital, they start to recognize the effect of the muscle weakness on their bodies with 44% reporting difficulties in climbing stairs, and 29% using wheelchairs to move outside their homes. In addition, some patients develop neurological problems, such as polyneuropathy⁹, which is manifested by slow motor movements and loss of sensation in the limbs. The recovery process may be slow and depend on patients' age, the length of time spent in the ICU, and the severity of their illness. At the same time, many patients experience psychological problems, and some of these problems are related to the phenomenon of PTSD. A similar observation is reported by (Linos et al., 2007) a group of ICU specialists who have worked in the ICU for many years. They highlight that patients who spend more than one week in the ICU, or had sepsis, are at high risk of many neurological and muscle problems including the heart

⁹ Damage to the nerve endings of the motor axons due to sepsis, malnutrition, and change in osmolality.

muscle and use the term ‘polyneuropathy’ to classify all patients with the same symptoms.

2.4.5.1 The relocation stress and/or PTSD

The patient’s recall of unpleasant experiences and stressful events in the ICU has been reported to adversely affect their psychological recovery and to be interlinked with the development of PTSD (Jones et al., 2001; Löf et al, 2006). Studies published in the last decade place emphasis on the physiological experiences in the ICU, showing that patients may experience panic, nightmares, flashbacks, or delusions when revisiting their time in the ICU (Scragg et al., 2001; Jones et al., 2001). In a recent study in the UK, one patient who recalled her nightmares after discharge from the ICU said:

‘When I moved out of Intensive Care, the first day that I spent on the Ear, Nose and Throat ward, High Dependency ward, there was somebody there that I could hear crying in their bed and being talked to by a doctor, telling her that, she kept saying that she had a brain injury and that, she said, ‘I know I’ve been in an accident and I’ve lost half my brain’...I would say that that lasted three weeks, before I got a proper, what I call a settled night's sleep, where I slept through without waking up, without waking up because of a dream, because of a nightmare. That was when, that was when I came home (DIPEX, 2007).

The phenomenon of PTSD is experienced by some patients to last for weeks and up to 12 months after discharge from the ICU (Griffiths and Jones, 2002). The NHS encyclopaedia defines the PTSD as:

a psychological and physical condition, which can be caused by extremely frightening or distressing events, when somebody witnesses traumatic events and then feels extreme fear, horror, or helplessness (NHS, 2008)¹⁰.

A large number of studies use a longitudinal quantitative approach to investigate the phenomenon of PTSD, and the effect of the delirium on the patients’ quality of life after discharge (Stoll et al., 2000; Jones et al., 2001; Schelling et al., 2003; Capuzzo et al., 2000, 2004; Granja et al., 2005; Griffiths et al., 2006; Löf et al., 2006; Pattison et al., 2007). For example, Jones et al (2001) compared between memories of the ICU and the level of anxiety among 45 patients the UK, classifying patients’

¹⁰ (Direct quote from <http://www.nhsdirect.nhs.uk/articles/article.aspx> . [Accessed in Jan, 2008].

accounts in relation to the memories of nightmares and delusions after one week of their discharge from the ICU, and then 8 weeks after discharge. The findings show that 33 of the patients had delusional memories 2 weeks after their discharge, while they recalled factual unpleasant memories 8 weeks after discharge. Jones group highlight that the development of PTSD may be related to the recall of delusions alone, but not to the recall of the factual stressful events. Similar findings are reported by (Roberts and Chaboyer, 2004), who interviewed 31 Australian patients 12-18 months after their discharge from the ICU, finding that some patients report that they had had unreal dreams, such as seeing a savage dog, or a robot coming out of a cupboard, and thought that the nurses were attempting to kill them. Similarly, a recent study conducted in Sweden by Löf et al (2006) who describe the emotional experiences of mechanically ventilated patients, at 3 and then 12 months after their discharge from the ICU. At 3 months, some patients recall vivid dreams and stressful events during their admissions in the ICU. One patient had an experience of hallucination, in which snakes and humans were crawling toward her as she was lying in bed. The patients were not able to distinguish the real events from the unreal events, which made them feel frustrated and scared. After 12 months, the patients recalled these experiences with the same complexity and details, but recognised that the events were unreal. This study shows that patients were able to recall the stressful events even 12 months after they had been discharged from the ICU.

The findings discussed in these studies, although providing one window into patients' experiences, have limitations: the research methods were mainly quantitative approaches using structured questions or questionnaires, thus insufficient attention may be given to fully understanding the meaning for individual patients of these physical and psychological symptoms. A limited number of studies have used qualitative methods to explore patients' recollections of their experiences in the ICU a long time after their discharge. (Maddox et al., 2001) describe the psychological needs of Australian patients and their significant others during their recovery from the ICU. A total of five patients and four significant others were interviewed 6-15 weeks following discharge from the ICU. The patients revealed that their physical recovery was based on their adaptation to their new health condition and their attempt to maintain their previous routine work and activities, in spite of feelings of weakness and tiredness most of the time and some difficulties in sleeping. (Adamson

et al., 2004) explored the impact of critical illness on 6 Australian patients six months after their discharge from the ICU, showing that most patients did not recall all their events in the ICU, but they instead emphasised how the slow recovery process affected their life after discharge. Some patients felt powerless and unable to continue with life as before, while others said that they experienced pain and discomfort hindering their sleep. A recent study conducted in Norway by (Storlu et al., 2008) used a hermeneutic approach to explore the meaning of living with memories in the ICU. Ten patients were interviewed 10 years after their discharge from the ICU. The first theme 'looking back to their past memories' reveals that the patients narrated their ICU experiences as past traumatic events in the 'old time'. Patients said:

'I remember a taste of soup; it was so delicious'... 'I had the feeling that people were dying all around me... I sort of saw them in front of me...just like they were...autopsied' (Storlu et al., 2008, p.89).

Ten years after their discharge from the ICU, those patients connect their past experiences to the present time when they have been interviewed. Many patients describe how their experiences in the ICU. One patient said:

...if someone or something touches my throat, everything gets constricted in me...you get a feeling that you might die! It is that feeling which comes back as well, and the feeling of suffocation, it really stays with you. I don't think, in any way, I will ever be rid of it. But now I can live (Storlu et al., 2008, p.91).

The patient, in this account, challenges her existential being and feels uncertain about her life. Her fear of suffocation is interlinked with past memories from the ETT tube in the ICU, with these experiences present in her life some ten years after the ICU discharge. Although this study analyses the patients' stories to gain depth and an individual view of patients' memories of the ICU, it needs to be acknowledged that the experiences of these patients could be changed as the interview time was far a way from their experiences; the patients may not recall most of the events. In addition, the factors such as the context of the interview, and the severity of the patient's illness were not discussed in this study.

2.5 Illness and stories

During the last decade many studies in the wider field of health and illness emphasise on how stories can be seen as a way to share the illness experience

between the patients themselves and their health care providers and engage the patient as an active contributor to healthcare organisation (DIPEX, 2007). The focus of this section is on studies that are conducted in the ICU; there will be a more depth discussion in the methodology chapter.

There are a very small number of 'auto-narratives' by sociologists and nurses who write about their own experiences in the ICU (Douglas, 1989; Smith, 1987; Frank, 1991, Richman, 1996; Rier, 2001). Ann Douglas is a nurse who spent more than 42 days in the ICU, and recounts her experience of loss and the change in her body during the ICU (see Douglas account in sections 2.3 and 6.2). Rier (2001), a sociologist, reflects on his own loss of 'personhood', with the emphasis on patient autonomy and 'self- determination'. On his reflection initially after he was admitted to the hospital, Rier said:

'By the time I woke up sick the first morning, I was already so weak that I could not think clearly. I had a very high fever, chills, and difficulty in breathing. The day I entered the hospital, I deteriorated rapidly, to the point that the struggle to breathe consumed nearly all of my attention. This led to a second characteristic of my illness, immediacy (sic): the focus on the next breath, or the next painful procedure. ... my authority and responsibilities of home and work quickly and decisively fell away' (Rier, 2000, p.72).

As seen from his account he remarks that the loss of a patient's autonomy starts with the concentration of the present illness, and the rapid change of his role from an independent person at home or at work, into the dependent patient role. A recent study, conducted in the USA, describes the meaning of the ICU nursing care from the patient's perspective (Gramling, 2004). Gramling uses the narrative inquiry approach with 10 patients. The findings were analysed qualitatively, using the Van Manen approach (Van Manen, 1990). Two themes were related to the present study: 'the perpetual presence', and 'honouring the body'. The 'perpetual presence' describes the patients' stories relating to psychological help and support from the nurses in the ICU. The patients maintained that nurses were willing and available for help at any time, and this helped them to feel secure. One patient revealed:

One night I did not sleep at all because I was so afraid. I kept thinking that my breathing could stop again, you know, that's something that happens... Well he (the nurse) kept talking to me, I mean he says that you are monitored and we are watching you every minute. We know everything that happens, even with monitors. (Gramling, 2004, p.388)

The other theme, 'honouring the body', describes the way the patients make sense of the nursing bodily care. They revealed that they wanted care which acknowledged their needs and treat them with dignity. One woman expressed her feeling of embarrassment when she had vaginal bleeding:

I felt that it was a huge loss of dignity (using the bedpan), you know, but at the same time my nurse was very good in making me feel that it was not anything disgusting, or no big deal in the way she performed. She was like, 'Aw', I have seen much worse (Gramling, 2004, p.392).

This study, however, has several limitations; the interviews were conducted in two ICUs where the nurses' care in each ICU could vary -- the story of a nurse describe by one participant in one of the ICUs will differ from the story generated in the other ICU. Secondly, the researcher mentioned that she conducted two interviews with each participant but did not offer any explanation about the context of the interviews.

Recently in the UK, the Personal Experiences of Health and Illness (DIPEX) project, and the patients' voices project, launched a web-site (late 2006), as a means of sharing patient stories. The project is run by the DIPEX charity, and located at Oxford University. The project is considered unique in the UK because it describes both the patients' experiences and the practitioners' viewpoints (Yaphe et al, 2000). The overall aim of this project is to identify issues which people face when they are ill. It is intended to help other patients who may have the same illness whilst also helping to develop health care professional's knowledge about patient needs. Importantly, this project acknowledges the central role of the patients in the health care settings.

The DIPEX project involves a collection and analysis of interviews with people about their experiences of illness, the effect of the treatments, and the support available from other resources in their lives (Herxheimer and Zeibland, 2004). The project used open-ended interviews, and asked the participant to reflect about everything that had happened to them since their illness began. This is followed up by a semi-structured interview where participants are asked specific questions related to their illness, and the treatment regime. About 25 different topics, which were important to the ill people, were identified and discussed. This discussion is supported by illustrations from patients' video or audio clips (Herxheimer and Zeibland, 2004).

In late 2006, the project interviewed forty people who had been admitted to ICUs in England, asking about their experiences, and the health issues they faced after their discharge from the ICU (DIPEX, 2007). The stories of 40 people were discussed, and classified in two ways: by the age of the patient interviewed¹¹ and also into three main topics. These accounts provide a source of rich and vivid data. One example is given below:

Experiences in the ICU: Case number 13 (I will call her Mrs. A) is a 43-year-old female single woman, from white-British background, worked as a trainer and researcher. She was admitted in 1998 after she had planned surgery to remove her kidney. She stayed in the ICU for 2 days and five weeks in the hospital ward.

Mrs. A. described her first time when she woke up in the ICU and felt that she was drowning:

... woke up in Intensive care and, as I say, I was in a lot of pain from the chest drain. But they dealt with that very, very quickly, I have to say. But I woke up with them actually trying to clean my teeth. I was on a ventilator. And it's hard because I know they were trying to do it because they were trying to make me feel more comfortable, you know, to make my mouth more sort of fresher and so on. But because obviously I had a breathing tube in, I couldn't swallow. So they had to take the fluid out and I thought I was drowning... obviously I'd come round before and not remembered. So that was actually quite, really frightening, of the whole experience was the most frightening experience. Even though the pain was horrible, I knew it was going to happen and I knew that something could be done about it. This, not being able to speak and sort of trying to say, you know, I think I'm, I feel like I'm drowning, was actually very frightening. And it was actually a nursing thing rather than a medical, a sort of doctor-related thing (Case 13).

Mrs. A. describes the pain after the operation as severe and overwhelming:

...and particularly because of the spinal condition, it would be more likely that it would be more painful for me because the ribs are so close together. And I'm so, so glad that he told me that because actually when I woke up, it was incredibly painful. And if I'd woken up like that, I would have been so scared that, you know, somebody had chopped my arm off or something, because every time I breathed, it was incredibly painful (Case 13).

¹¹ The patient individual stories are divided by age (30 and under, 31-40, 41-50, 51-60, 61-70, then 70 and above) and then the same accounts are classified into topics (the patients' experiences in the ICUs, their experiences on the hospital wards, and their recovery period at home).

Mrs. A described how the nurses and physicians gave little attention to her needs after discharge from the ICU:

nurses and doctors not being aware about disability is that the Associate Consultant did come to see me about, you know, coming out of hospital and he said, "Oh well, people are up after surgery, after two or three days of having this surgery." I mean, usually it's not quite such a big operation as I'd had because, to start off, but the other thing is, they'd stand up, whereas I would, in fact the whole of my bottom half would be just dragging on the thing because I don't have any movement at all in my legs. So it would be absolutely agony, it would be just, you know, it would just be like being torn in half when you've had a major, major thing like that then there is no way you can have a dead weight dangling off [laughs]. So again I think that lack of knowledge, and awareness of, I mean obviously they can't know about every single sort of disability that people have, but just to be more aware, just another understanding is definitely needed. (Case,13).

The second project developed in the NHS in 2006, is based on stories from 23 patients (expanded now to 100) who had different diseases, and from people of different ages and cultural backgrounds. The aim of the project is to provide a database for the professional development of NHS health-care staff, based on the subjective experiences of those patients, and from their stories (Pilgrim Project, 2007)¹². The project was developed at the Royal College of Nursing, with collaboration with the NHS team, and the stories provided by using the video digital records information, with illustrations from patients on specific areas of care. The project is still under the development stage, and the stories are limited to specific areas of care (Hardy, 2007).

The patients' experiences reported in the DIPEX project provide a rich in-depth account of those who suffer from critical illness. These stories could help the health-care professionals, especially the nurses, to improve the quality of their care. Based on the patients' stories the health-care professionals can help other patients to recover from their illnesses in a humanistic and dignified environment.

Findings from the reviewed studies in this chapter provide different ways of understanding the patients' experiences in the ICU, after their discharge home. However, some notable gaps exist. First, most of these studies were conducted with

¹² For more information please see the website www.patientvoices.org.uk .

people in the western countries such as the UK, USA, Canada, or Sweden. Studies which explore patients' experiences of their illness in the Muslim countries, such as Jordan are scarce. Second, to date, no published study exists which explores the Muslim women's experiences in the ICU. Third, recent research, related to patients' experience of critical illness, neglects to address the cultural differences of those patients. Fourth, empowering nurses to support the patients according to patients' needs, is not well developed in some countries, including Jordan. My study aims to address some of these gaps in knowledge. This is a qualitative longitudinal study which explores how Muslim women in Jordan regard their critical illness at different points in time. Interviews were carried out within two to three weeks after their transfer from the ICU to the hospital wards, then at home, within one to six months after their discharge. The study also aims to address how Jordanian nurses can provide support to help this client group to recover. The following chapter provides a comprehensive view about the qualitative longitudinal methodology applied in this study.

Chapter 3

Making sense of qualitative data: the research methodology and methods

3.1 Introduction

This chapter discusses the philosophical perspectives that underpin the study and the use of narrative as an approach to data collection and analysis. The chapter also discusses my reflections on undertaking a narrative approach in the field. After stating the research aim and questions, I discuss the philosophical thoughts that influenced the way in which I undertook the study, I then outline the use of narrative from different schools and point out the strengths and limitations of applying a narrative approach to the study.

In the second part of the chapter, I reflect on the interview process; in particular, the challenges posed by conducting open-ended interviews with the women in the study. I discuss my experiences of conducting open-ended interviews, the opening question, the use of silence, recording the interview, and practical considerations. I then reflect on the issues raised during my interactions with the women. These issues are: building rapport, recalling distressing stories, and ending the interview. Finally, I reflect on the process of translating, transcribing, and analysing the interviews.

The third section discusses the process of conducting focus groups with the nurses in two Intensive care Units (ICUs). The section includes a description of the nurse population and the sample, the recruitment process and the process of data analysis.

3.2 Research aim and research questions

My aim is to describe women's experiences of critical illness in Jordanian ICUs with a view to informing the development of supportive care strategies for this client group. To achieve this aim I have four research questions:

- ◆ How do women recall their experiences of intensive care in Jordan following recovery from a critical illness?

- ◆ How do woman narrate their experience of critical illness in Jordan in the context of their wider lives?
- ◆ How do women who have been patients in the Jordanian ICUs recall nursing care?
- ◆ What recommendations to improve the care and support of women facing critical illness in Jordan can be identified?

The study comprises two interlinked phases with the main focus on the first phase of the study. The first phase involved interviewing women between one and three times within a period of six months. The first interview took place in the ward within three weeks of the women's discharge from the ICU to the wards. Following discharge from the wards, interviews took place in the women's homes. The second phase of the study involved two focus group discussions with nurses who provided the care to the women in the ICUs in which women were recruited. Applying the two phases was influenced by the philosophical perspectives and thoughts that underpinned the study. These will be discussed in the following section.

3.3 The philosophical perspectives underpinning the study

Before setting out my research questions and choosing my methodology, I consulted the literature. Mason (2002: 14-17) recommends that the researcher should ask herself about the essence and purpose of the research under study. Mason suggests five important questions that may help the researcher to understand the essence of the research study. These are:

- What is the nature of the phenomena or entities that are to be studied?
- What might represent knowledge or evidence of the phenomena or entities?
- What is the research topic or with what substantive area is the research concerned?
- What is 'the intellectual puzzle' that is to be explored?
- What are the purposes of the research and the research questions?

The starting point of my doctoral thesis was that I wanted to know more about how women patients made sense of their experiences in the ICU, how these women interpreted their experiences in the context of the Jordanian culture, and how this could be achieved within a framework that gave them a voice. Exploring the women experience in the ICU based on the meaning that these women share during the

interview. My aim is to understand meanings within the women's narratives and the ways in which these women made sense of their experiences in the ICU. Mead (1934) points out that understanding people's experiences is positioned within the meaning that they share in the context of their interaction (cited in Cook, 1993). Mead's philosophy discusses how people understand each others through their interactions and within any given socio-cultural context (see also Denzin, 1989; Dilthey, 1911 cited in Crotty, 1998).

Applying Mead's philosophy to my study, the researcher (myself) began with certain pre-assumptions and expectations about the phenomenon under investigation. Then, through my interaction with participants, I evaluated the new experiences that we shared, and accordingly, modified my old assumptions or thought of new ways of understanding the women's lived experience based on our shared meanings. A student of Mead, Herbert Blumer points out that that people share meanings of their experiences through their interaction with others, and these meanings are modified according to the context of the interaction, and the interpretation of each person (Maines and Morrione, 1990). I was also inspired by Dewey's (1968) arguments who emphasized that analysis of meaning cannot be understood without referral to the context that the interactions occur; in simple words, the meaning has reference to the situation and the condition in which the interaction occurs (Crotty, 1998) .

This philosophical perspective helped me to gain a fuller understanding of the nature of my study; I used reflexivity as a means to understand the women's experiences of critical illness. The use of reflexivity is based on an active acknowledgement of my own actions and decisions that will impact on the meaning of the experiences under investigation (Koch and Harrington, 1998, Freshwater, 2005, Ingleton and Seymour, 2001). Thus, I employ a definition of reflexivity as 'showing awareness that, the findings are inevitably influenced by the researcher's values and assumptions, and the 'subjective' nature of research should be acknowledged and even celebrated (Spencer et al., 2003:46). I sought to undertake a process of self-examination which admits the influence of my experiences, beliefs and values on the stories that I constructed with the women and my interpretation of their stories (Ingleton and Seymour, 2001, Finlay, 2003). I also aimed to clearly identify my potential impact on the data collection, data analysis, and presentation of the findings (Finlay, 2003,

Cough and Finlay, 2003, Mason, 2002, Carolan, 2003, Freshwater, 2005, Gough, 2003), and to acknowledge that other researchers within different social contexts might develop different interpretations (Gough, 2003).

My beliefs are also influenced by feminist methodological debates; in particular, the issues that concern the relationship between the researcher and the researched. Feminist researchers assert that there can be a power relationship between the interviewer (the researcher) and the interviewee (the women in the study) during their interaction (Oakley 1981; Finch 1984; Maynard and Purvis 1994; Phoenix 1994). It is argued that the balance of this power may shift over the course of the study. In the recruitment stage the interviewees may have the ultimate power to share or refuse the interaction, as the interview takes place (Oakley, 1981). During the interview process; the shift of power may depend, to some extent, on how the interviewer builds a rapport with the interviewee (this is discussed in more detail below), whilst during the data analysis and writing-up of the study, the researcher relatively has more power than the interviewee (Oakley 1981; Finch 1984; Phoenix 1994). Oakley (1981) argues that formal, survey-type interviewing is inappropriate for feminist research, especially when women interview other women – such a relationship is inappropriate for the feminist researcher, because it means that we are ‘objectifying our sisters’. She prefers an unstructured research strategy which avoids creating a hierarchical relationship between the interviewer and the interviewee (Oakley, 1981:41). Oakley stresses that the relationship should be reciprocal, which depends on the extent to which the interviewer is willing to share her personal identity in the research relationship (Oakley, 1981).

Building rapport with interviewees may encourage interviewees to talk freely about different aspects of their lives in-depth and share some of their private experiences (Phoenix, 1994; Holland and Ramazanoglu, 1994; Ribbens and Edwards, 1998). However, as Finch (1984) points out, this may leave participants feeling vulnerable and exploited in the research process. She suggests that the researcher should give careful thought to the issues that may rise during the interview process, and handle these issues sensitively. Clarke (2006) reflecting on using a biographical approach to explore older people’s perceptions and experiences of aging, points out that for research undertaken in health care settings using a longitudinal in-depth interviews,

the researcher should be mindful of the potential exploitative or even harmful effect of in-depth interviews on participants. She suggests using a reflexive approach to minimise the harmful effects of the questioning process.

The philosophical perspectives discussed above helped to inform my choice of methodology. The following section discusses how I chose my methodology and the limitation of using this particular methodology.

3.4 Methodology

After developing some understanding of the ontological and epistemological stance of the study, I sought to find a methodology that would help me to achieve the following:

- ◆ To provide a rich account that reflects the Jordanian women's experiences of critical illness within the context of the interaction between myself as a researcher and the women.
- ◆ To explain the meaning of the critical experiences within the context of Jordanian culture.
- ◆ To explore the changes of the critical illness experiences after a period of time and when the women were back in their homes.

Generally, storytelling is one of the oldest and most basic of human activities; we tell stories during our interaction with others, when chatting, gossiping, or discussing events in everyday life (Rubenstein, 1995). Stories are used to define who we are, and reflect our ability to show our biographical details and give meaning to our experiences in life (White, 1987; Polkinghorne, 1988). The history of storytelling hails from literary science when Aristotle mentioned in his *Poetics* that a story has to have a beginning, middle, and an end (Thornborrow and Coates, 2005).

The word narrative¹³ is derived from the Indo-European word “gna”, which means “to know” and “to tell” (Hinchman and Hinchman, 1997, xvi). Shared elements in the narrative are that the narrative is related to time (chronology), the time in the

¹³ In this study I use the term ‘story’ and ‘narrative’ interchangeably. I acknowledged that scholars have debated about the differences between them. See for example Polkinghorne (1988) and Abbott (2002).

narrative is related to events which start from the present then move backwards to the past (for example, life history books), or move backwards and then forwards to the future (for example, a life story¹⁴), or even related to a specific time, when the person faced challenging experiences or illnesses (Greenhalgh and Calman, 2006). The 'genres' of the narrative reflect how people interlink the events of the stories in a thoughtful way to show how these stories unfolded through time, and convey a message from these stories (Abbott, 1992, Elliot, 2005). For example, the Holocaust narratives show the tragedy of the Jewish people, who were killed and tortured during the Nazi movement (Rittner and Roth, 1993). The 'coherence' of the narrative reflects how the summation of all parts of the story makes the whole story (Greenhalgh and Calman, 2006).

The narrative is also about morals; people do not tell their story in a vacuum, or convey a set of coherent sentences, but they want to persuade the listener about their own perspective (Greenhalgh and Calman, 2006). For example, when patients tell stories to their physicians, they not only to seek physical treatment, but also to confirm that they suffer from the illness, and want a witness to their illness experiences (Baruch, 1981; Frank, 1997). A recent study shows that stories can be used as to educate people:

'Stories are one of the most ancient of teaching – and learning – techniques, and are effective within and across cultures. The use of stories as an educational resource acknowledges that behavioural and systemic change often stems from a felt understanding of the implications of decisions rather than from a purely abstract or theoretical one. Stories can be used to communicate visions and needs in a powerful way; they offer a compelling and practical means of exploring issues and experiences from different perspectives, while promoting reflection and stimulating dialogue and debate' (Pip Hardy, May, 2007).

During the last two decades, the use of narrative as related to illness experiences, has been widely explored in many areas of research, specifically in the sociology of health and illness. The American medical sociologist and anthropologist Arthur Kleinman (1988) uses patients' stories to differentiate between illness and disease, and points out that disease reflects what practitioners learned in their schools, and the theoretical background in the medical school, which classifies patients in relation to

¹⁴ See for example *The Life Story Interview*, edited by Atkinson (1998).

symptoms, each of which are addressed separately. On the other hand, illness reflects the subjective meaning of these symptoms for the person who experiences them. According to the Kleinman theory, the meanings of illness develop through cultural beliefs, norms, and behaviour which shape the people's reaction to illness (Kleinman, 1998). In simple words, the meaning of illness is gained through learning from cultural norms. However, the illness not only reflects the cultural values and behaviour, but there are other elements which interfere with the meaning of illness; for example, the severity of the illness, and the level of social support are both important in the interpretation of illness.

The development of medical sociology enhances the use of narrative as a method of research to support people who suffer from chronic illness. Many studies explore the experiences of chronically ill people through interpreting their stories (Bury, 1982; Williams, 1984; Charmaz, 1983, 1990; Hyden, 1997; Seymour, 1998). Charmaz (1983; 1991; 1999), as an example, points out that the stories of chronically ill women in the USA provide a means of expressing how they experience the change and loss related to their illness experiences in their everyday lives (see section 7.2 for details).

Following the Chicago school, Arthur Frank, a medical sociologist (1991), wrote about his own experience of heart failure and cancer through the use of narrative. In his book, 'At the will of the body', Frank reflects on his experience of heart disease and cancer. The moral of his story is divided between the differences in meaning between the lay people (himself), and the physicians or nurses, together with the changes of his body as lived within the illness (Frank, 1991). Four years later, Frank (1995) develops four types of narrative used by ill people when narrating their experiences of illness. These are: the restitution narrative, the chaos narrative, the quest narrative, and the testimony narrative. The first is a story told by people who have recently fallen ill. The restitution story reflects the ill person's desire to get well and stay well after the illness experience. These stories follow a linear sequence; Frank describes this as "Yesterday I was healthy, today I'm sick, but tomorrow I will be healthy again" (Frank, 1995:77). The second type of narrative is the chaos story, which is communicated by people who suffer from their illness, and imagine life as 'never getting better again' (Frank, 1995: 97). The chaos story is fragmented, disorganised, and lacking in narrative order. The stories reflect how the sufferers

lived through their illness but found difficulty in expressing their experiences in words. The third type of narrative is the quest narrative, which is a story told by people who accept their illness and search for a cure for it. These people find that they have gained something through their experience of illness. The fourth type of narrative is the 'testimony' story, which is told by people who organise their stories around a particular meaning, which people find within the illness or the healing. They pass on a unique message to others, that the experience has a moral or emotional meaning.

The use of narrative in research is underpinned by different schools of narrative. These schools share the assumption that storytelling is a means of gaining an insight into some aspects of a person's life. However, each school takes a particular stance to narrative, with overlapping assumptions and philosophical backgrounds within these schools. Table 3:1 below summarizes these different schools of narrative.

In this study, the narrative interview is used as an approach to qualitative research in order to elicit and analyse the women's accounts as stories and to allow the women to use their own words to describe their subjective experiences of critical illness (Elliott, 2005).

I invited the women to tell me about their illness in general, and then probed to elicit more depth about their stories. I take the view that there is no 'whole story' to tell but rather participants will relate partial stories that are important to them (Greenhalgh and Calman, 2006). In her study, Amanda Clarke used narrative as an approach to explore how older people experience later life. Clarke (2001) conducted two or three open-ended interviews with each participant, and found that using a narrative approach helped participants to reflect on their life experiences as they moved forwards and backwards in telling their life stories. Clarke found that conducting follow-up interviews provided rich, in-depth data that could not be achieved by using other approaches.

Secondly, it has been suggested that engaging in a narrative interview may help provide people with an opportunity to talk about what is important to them (Frank, 1995). Participants arrange their illness experiences according to their understanding

and from their own perspective (Elliot, 2005). Participants actively construct the features of their experience want to share (Kleinman, 1988; Frank, 1991; Hurwitz et al 2005). At the same time, researchers can participate in shaping the narrative accounts through active listening, and by asking questions to clarify or specify about these experiences (Kvale, 1996; Elliott, 2005).

Table 3.1 The use of narrative as a method within different schools of narrative. [The table is modified from table 5.1 from Greenhalgh and Calman (2006) Approaches to the use of narrative in research.

THE USE OF NARRATIVE	DEFINITION	ANALYTIC APPROACH	EXAMPLE
Narrative interview	Researcher collects and studies ill stories from patients or stories of professional practice from healthcare staff.	Individual narrative, analysis for structure, coherence and meaning in a particular social context	DIPEX project, 2007 Murray et al, 2002
Naturalistic story- gathering	Researcher becomes a fieldworker immersed in organisation or group so as to collect 'real' stories in informal space and interpret them in context	Organizational subgroup. Analysed for subtleties in individuals and groups different interpretations of the same event/action over time	Timmons, 2001
Discourse analysis	Researcher studies a range of data (e.g transcripts of conversations) to identify the prevailing ideologies and power relationships which shape and constrain the use of language by individual	The text is embedded in a set of interpersonal power relationships and a macro-level social organisation. Micro- analysis of text in context.	Mishler, 1986 Thornborrow and Coates, 2005
organizational case study	Researcher presents an account of an organisational change initiative in the form of a detailed story	The 'case' (organisation or props) analysis using of qualitative and quantitative methods	Muller, 1999
Action research	Researcher works with participants to develop a shared perspective on the problem and its causes, and to plan and implement action	Group of participants, analysed for development and enactment of shared meanings/purpose. Use cycle of participation and reflection	Bate, 2004
Meta-narrative approach to systematic review	Researcher studies published papers to identify the overarching 'storylines' of how different research traditions unfolded	Research tradition, analysis of concepts, theories, methods, and instruments how it unfolded over time.	Griffith et al., 2007

Thirdly, using narrative reflects not only individual experiences but also some cultural aspect of the person's life (Kleinman, 1988; Muller, 1999). People tend to tell their stories according to their cultural values and beliefs, culture affects the way people tell their stories, and what kinds of story they wish to share (Overcash, 2003). Narrative accounts thus represent a shared cultural understanding (Muller, 1999). Frank (1995), as an example, identifies four main types of narrative stories which

reflected the North American culture. These experiences, however, could be transferable to other ill people.

Fourthly, using narrative may improve the nurses' quality of care, since patients, through telling their stories, can provide different perspectives on how they experience nursing care (Frid et al., 2000). Patients arrange the priorities of care according to their needs, which could be different than those perceived by the nurses (Bailey and Tilley, 2002; Overcash, 2004). Through listening to patients' stories, nurses may develop an interpersonal awareness of the patients' needs. This may represent a new way of caring, based on seeing patients' needs as central to the care provider, rather than focusing on 'curing' the patients' symptoms (Newman, 1999; Rashotte, 2005). In other words, storytelling may give a voice to patients and may also provide an opportunity for nurses and physicians to hear and use these stories as an integral part of their care (Frank, 1995; Fred et al, 2000; MacCance et al, 2001).

Fifthly, through using a narrative approach, patients may have the opportunity to explore aspects of their identity in the context of the researcher/narrator interaction. By telling their stories, people not only recall their illness experiences, but they may also use it as an opportunity to gain something from these experiences (Frank, 1995; Younger, 1995; Hurwitz et al 2005). Frank (1991) suggests that disease cannot be separated from a person's identity, and that patients' lives will be changed after facing life-threatening illnesses. These changes can be shared by exploring how people understand themselves as they live through time (Ricoeur, 1988, Charmaz, 1991).

Lastly, it has been suggested that using narrative could be therapeutic, both for the narrator and for the listener. By telling their stories the narrator may feel relieved from traumatic experiences (Charon, 2004, Bakhtin, 1984, Elliott, 2005) [this is critiqued later under the section 'distressing stories']. Listening to patients' stories may offer other patients who have similar circumstances strategies to help cope with their illnesses (Greenhalgh and Calman, 2006; DIPEX, 2007). For example, the DIPEX (2007) project shows that people with different illnesses, such as cancer, mental diseases, heart diseases and critical illness, as well as screening examinations, sharing their experiences through a voice recorder or videotape, and discussing some

aspects of their care and struggles when they have been admitted to the ICU (see section 2.3).

In summary, the use of a narrative approach may provide rich accounts to help in understanding the people's experiences of some aspect of their lives (Coffey and Atkinson, 1996). However, there are limitations to using this approach. These will be discussed in the following section.

3.4.1 Limitations of using the narrative methodology

Although the use of narrative provides a different perspective for the women's experiences in this study, there are many elements that could limit the use of narrative in qualitative research. These elements are: the truthfulness of the narrative accounts, the issue of representation, and the ethical issues of using narrative.

3.4.1.1 The truthfulness of the narrative

The first aspect of using narrative as a method is the issue of the truthfulness of the narrator's story. It is argued that people tell part of their life events and sometimes they tell of unreal and imagined events (Atkinson, 1998). This could be assumed to be a kind of fiction (Denzin, 1989). This raises a question about the truthfulness of stories and the extent to which they represent the experiences of the narrators.

My reflection on this is that the women told stories which reflected their understandings of the events as they had experienced them. These stories, whether real or not, are real to the narrator, representing how they interpret their experiences. In agreement with Kohli (1981), telling stories represents how people see the world from their point of view. In other words, the authenticity of telling narrative stories is high, because people tell what they believe, and how they see the world (Denzin, 1989). As Bogdan and Taylor (1998:9) pointed out, one person may describe their experience in one way, whilst another person describes the same experience in quite another way, but both are telling 'the truth' according to their own perspectives and interpretation.

People interpret their experiences as good, bad or indifferent, depending on how they understand their illness condition, and their cultural, social, and educational

background (Kleinman, 1988; Atkinson, 1998). Allowing participants to tell their stories without any structured questions should encourage them to present their experiences as they live it and without fragmentation (Mishler, 1986). Susan Smith (1996) provides an example of how the participants in her study, through telling their stories, were encouraged to tell the truth of their experiences. She explores the experiences of women students who returned to study after some time and stresses that the participants were encouraged to provide specific details about their experiences using their own words. She comments that:

By enabling women to tell their stories, and creating a context in which they felt comfortable exploring their feelings and experiences, I was able to learn more about those aspects of their lives which crucially affect their chance of success when they return to study (Smith, 1996, p.71).

Similarly, Cox (2003) suggests that narrative allows participants to talk about what they feel is important to them and this may be considered as evidence to enhance the truth of narrative accounts.

The question of truthfulness leads to another question concerning whether individual stories can be extended to cover a wider population. This will be discussed in the following sub-section.

3.4.1.2 Representing the narratives

The second issue concerning the narrative approach is whether stories are general to other members of the population or settings: can these stories be extended to cover a large number of people? This could be seen as a limitation of the use of narrative as a method because it does not cover a large number of participants. However, the use of narrative can be understood in a different way; stories can have shared elements which reflect the experiences of the wider population. One example is the use of narratives in the DIPEX project (DIPEX, 2007), wherein the participants provided their personal accounts that reflected their experiences, which were shared by many patients who had the same diagnosis. People with heart disease, for example, provided rich accounts concerning how they experienced their illness; this provided a bridge by which other ill people who were diagnosed with heart disease could share some elements of their experiences. In other words, these experiences are transferable to other patients who may share some of the illness experiences (Taylor

and Bogdan, 1998; Frank, 1995). As Frank states, ‘people tell stories not just to work out their own changing identities, but also to guide others who follow them’ (1995:17).

The role of the researcher in facilitating the transferability of the stories to others may be better achieved through providing a clear and rich description of how the stories were generated, the context of the research, and making clear to the reader how the themes and the interpretation of the stories emerged (Denzin, 1989; Riessman, 2008). Chase (1995) asserts that narratives do not simply provide a description of individual stories, but rather, are a means to understand more about the broader culture shared by those with the same experience:

Life stories themselves embody what we need to study: the relationship between this interaction and the social world the narrator shares with others; the way in which culture marks shapes and/or constrains this narrative, and the way in which this narrator makes use of cultural resources and struggles with cultural constraints (Chase, 1995, p.20).

As seen from the above, it is argued that the story is the main element in representing people’s experiences, but not every person is able to tell a story. This will be the focus of the next sub-section. There is another important element in the shared stories: the stories are rhetorical, and have a moral tale; the stories convey messages to the reader (Baruch, 1981). People who read these stories believe that the stories are about them and/or similar to their experiences (Frank, 1997, Greenhalgh and Calman, 2006).

3.4.1.3 Can all people tell a story?

The third issue of using narrative as a method of data collection is that not all of people are able to tell stories to describe the events of their lives. This issue was apparent in many studies which have explored patients’ experiences in the ICU. Studies show that patients recovering from a critical illness may have temporary loss of concentration, or loss of memory, and may have been unable to comprehend their experiences (Russell, 1999, Rotondi and et al, 2002, Jones et al., 2001). Frank (1995) points out that some people told ‘chaos’ stories; these stories are disorganized and their speech tends to decline into fragmented sentences, or a run of sentences, with sentences moving from past to present and vice versa. Frank (1995) argues that although people who tell chaos stories could not describe their experiences in words,

they reflect on how they lived their life experiences, and the researcher cannot ignore such stories.

My reflection on the above argument is that although some people cannot tell stories in words, the researcher should be transparent in presenting these cases, and discuss the context in which these people found it difficult to share their stories. This could provide a clearer view to the reader on how the deviant cases could provide a different meaning to the findings of the study.

Adopting a narrative approach also raises some ethical issues, such as those related to building rapport, and distressing stories, which I will explore in the second part of the method chapter [see conducting interviews with Jordanian women].

3.5 Applying the narrative approach within the Jordanian context: the fieldwork

This section is divided into two main parts: the first part describes the setting, ethical issues, recruitment, population, and sample. The second part is a reflexive account of the data generation process.

3.5.1 The setting

The study was conducted in two hospitals in a major Jordanian city. For ease of identifying each hospital in the discussion, these will be named Hospital A and Hospital B. Hospital A is located in the north of a major Jordanian city. The hospital has 540 beds with a highly specialised section for intensive care. The hospital contains 26 specialised units, and 12 medical and surgical wards. The funding for the hospital is half governmental and half private. The hospital covers all of the insured patients from different companies and the local citizens living nearby.

The intensive care unit is an open area with eight beds, and the patients are separated from one another by curtains. The unit admits patients from the operation room, paediatric units, medical and surgical wards, and the accident and emergency unit. On their recovery, patients are transferred from the ICU to the general wards. The wards are divided into two medical and two surgical floors. On each side of the floor

there is a male section and a female section, with the women in the female section being attended only by female nurses.

Hospital B is governmental hospital, located within a major Jordanian city. The hospital has 700 in-patients beds and more than 120 day case beds. The hospital is maintained by the Ministry of Health, and accepts patients from all over the country, including the rural areas. The hospital departments are divided into separate buildings; the surgical building includes an intensive care unit, an emergency unit, two medical and surgical female wards, and two male medical and surgical wards. The medical building includes the coronary care unit, the endoscopy unit, one medical female section, and one medical male section.

The intensive care unit has ten beds in an open area, with a nursing station in the centre. Patients are separated by curtains, with two private rooms for patients who need isolation. The unit admits patients from the accident and emergency unit, the operation theatre, and patients who are transferred from other governmental hospitals in the rural areas.

3.5.2 The process of gaining access

Within the early months of my study, I sought to discuss my overall plan of the study with the nurses in critical care in both hospitals. Two copies of a summary research proposal, with a covering letter were informally sent to the managers of the two hospitals, asking if I could discuss the research proposal with the critical care staff in each unit.

The manager in hospital A welcomed the idea of asking the patients about their experiences in the ICU. Similarly, the manager in hospital B, showed willingness to share the study findings with the nurses and his desire to improve the nursing care in his hospital. He replied:

...uhh, yes. I think there is a need to know more about patients, this is a new way of data collection to me. I hope that your results can help the nurses to improve the way of caring in our hospital¹⁵.

The process of gaining ethical approval to my study comprised three phases: First, I followed the ethical approval procedure adopted by the University Research Ethics

¹⁵ Telephone conversation.

Committee (UREC) at the University of Sheffield¹⁶. Ethical approval was gained from the ethical committee at the University of Sheffield. [See Appendix A for the ethical approval letter from the University of Sheffield].

Second, because there is no national ethical approval system in Jordan, ethical approval had to be gained separately from each proposed hospital. A formal letter attached with the research proposal, covering letters, information sheets and consent forms, both in English and translated into Arabic, was sent to the ethical committee in hospital A, where they discussed my overall plan, and then gave approval to conduct the study with no further comments [See Appendix B for the formal letter sent to the hospital and the approval letter].

Third, the ethical approval at hospital B involved two processes; a formal letter was sent to the director of the Ministry of Health asking for permission to access the hospital. Then, after gaining permission, a formal letter, attached to the research proposal, covering letters, information sheets and consent forms, was sent to the ethical committee in hospital B. The process took about seven months to gain access permission [See Appendix B for the ethical letter and forms]. The process of gaining access permission took more than nine months. The time waiting for ethical approval was stressful and caused some delay in carrying out my study within the planned time for data collection.

The reason behind choosing two ICUs was related to the women's social class. Hospital B serves citizens from the middle and lower-classes and from rural areas, whilst hospital A serves citizens from the higher and educated classes. I thought that by choosing two different hospitals, I would access women with different backgrounds. However, I explained to the ethical committee in the proposal that the research design was flexible and depended on the women's willingness to participate in the study.

3.5.2.1 Contact with the ICU departments

The ICU in hospital B was familiar to me as I had worked there as a staff nurse. My relationship with the hospital manager and with the director of nursing helped me to

¹⁶ The University of Sheffield adopts the COREC Ethical Approval Forms. Please see <http://www.corec.org>. Accessed in July, 2005.

gain access to the heads of the department in the ICU and in the medical and surgical wards. I reflected on their help and support in my research diary:

Today, I had meeting with Miss A. the director of nursing. She was one of my colleagues in the past, and she welcomed me warmly and invited me to share with her a cup of coffee. When I discussed about the research, she welcomed the idea of conducting a study with women patients in the ICU. She said "well R. as you know me from before, I always encourage researchers to do more research related to our care. I hope that the ICU nurses will benefit from your results. [Smiling] It seems to me that you will collect some very interesting data, and I am looking forward to seeing the findings of the study.' Then she rang the head of the research department and clarified about my study, and encouraged him to facilitate my duty (Research diary: 3rd March/2006).

In contrast to Hospital B, the manager and the senior staff in hospital A regarded me as an 'outsider'. When I arranged to meet the Dean of Nursing, she was busy and it was two weeks before I was able to meet her. During the meeting, she read the ethical approval letter without making any comment, and asked me to contact the head of the ICU department.

On the first meeting with the head of the ICU department, he was anxious and asked many questions such as what are you going to do with the data from the women? How you will meet the nurses here? He seemed worried about the findings of the study and feared that the application could have a negative effect on the reputation of his department. He clearly revealed his worries when I started to apply the second phase of my study and met the ICU nurses. He explained that he was worried about the negative experiences that might be described by the women, and the possibility that the findings could provide negative feedback to the hospital manager. I reflected on his comments in my research diary:

... I have difficulty in persuading Mr. A, the head of the ICU department, about the second phase of my study. Mr. A was worried about the women's accounts, which might describe the negative experiences of the nursing care in the ICU. He mentioned to me that there could be negative experiences from the women's accounts, and that if I were to discuss it with the nurses, or if any nurse mentioned it to the director of nursing at the hospital, they would take it as a negative point against his department. I assured him that all information from the nurses would be kept strictly confidential, and only the recommendations of the nursing care would be shared with the managers. I mentioned also that I would appreciate the possibility of discussing any issue with the director of nursing beforehand. Then I agreed with him on a date to conduct the focus group discussion with the nurses (Research diary: 29th June, 2006).

In contrast, during my regular visit to the units, I started to develop a relationship with the bedside nurses in the ICU. Some nurses started to ask about my study and why I wanted to interview the women. In the coffee room, we had discussions about how I wanted to follow-up the patients in their homes, and about qualitative research in general. Others asked me: “I see you regularly, so could you tell us more about your study?”, and I spoke to them about my study and the interviews with the nurses. They were curious to know what the women said about their care and their willingness to share their experiences in the study. It seemed to me from their questions and discussions, that the ICU nurses had limited background about the nature of focus group discussions, but I could only guess at this because I did not ask the nurses if they had attended a focus group discussion before. Later, I found out from a colleague of mine¹⁷ who was undertaking a study in the same units, that the ICU nurses mentioned my name in relation to their first experience of participating in a focus group discussion.

3.5.3 Addressing ethical issues

Applying a narrative approach involves obtaining and reflecting on the participants’ lived experiences (Coffey and Atkinson, 1996). This interconnects with the ethics of the researcher relationship with these participants. The narrative researcher has an ethical duty to protect the privacy and the dignity of those who share their experiences (Clandinin and Connelly, 2000). The ethical codes emphasize assuring the free consent of the participant to participate, assuring the confidentiality of the data, and protecting the participants from harm that may arise from their participation in the study is fundamental in any research (WMA Declaration of Helsinki, 2002¹⁸). Early in developing the proposal, I sought to take into consideration these ethical issues and to ensure that I had a means to protect the privacy and dignity of the women in the study.

3.5.3.1 Privacy

To protect the privacy of participants, I sought to conduct the first interview in the women’s private rooms where they could feel free to share their stories. In practice,

¹⁷ My colleague is a PhD student at the University of Sheffield. She conducted her study ‘the development of evidence practice in Jordan’ in many hospitals in Jordan including hospital A and B. and interviewed ICU nurses at different levels.

¹⁸ Accessed online from <http://www.brookes.ac.uk/res/ethics/helsinki>. Accessed in [December, 21st 2007].

in the hospital setting, I found that some women had shared rooms, therefore I had to seek their permission to conduct the interview in a private room on the ward, this applied in both hospitals.

During the interview process, I noticed that the women seemed reluctant to share their accounts when any of the nurses or the physicians interrupted our conversation. For example, when I had the first interview with Um-Bashar (all participants' names are pseudonyms), one of the nurses came to check her blood pressure and I had to turn off the recorder and wait until she had finished her duty. With the women's agreement, I decided to stop the interview when any of the health team members were undertaking their duties and then resume the interview when they left.

I planned to conduct the follow-up interviews in the women's own homes where they gave me permission to do this. I anticipated that they would wish to have the interview in a private room. However, when I visited some of the women to conduct the follow up interview, they invited me to take a seat in the common room¹⁹ and I found that there was a limited option to choose a private room for our interview.

There was some interruption during the interviews, especially when family members served us tea or coffee and I had to stop the recorder and have a general conversation with them before resuming the interview. For example, when I met Um-Sami at home, she asked her daughter to leave the room. A few minutes later, the daughter prepared tea for both of us, and then she sat with us and asked me many questions about my family and what I was going to do after finishing my PhD. After ten minutes, she prepared a fruit juice, and again she spent about fifteen minutes chatting about her life and experiences with her mother.

I also found that some women lived in poor housing conditions where they had neither a common nor private room. For example, when I met Um-Ahmed at her home, I found that she had a bedroom, a kitchen, and a living room and she was living with five children. There was nowhere for the children to play, so they stayed with us, and sometimes they disturbed our conversation asking her for help, so she had to leave our conversation and serve the children. I learned then that achieving

¹⁹ The room called 'Madafah' or the visitors' room.

privacy for participants is dependent on the situation. My role was to prepare a convenient place for the women, where they felt happy to share their accounts.

3.5.3.2 Gaining informed consent

Participation was based on gaining an informed consent. Each participant received two copies of an invitation card from the Head of the Department in the ward, and those who indicated that they would like to share in the study sent back the second copy of the invitation card with their contact details or called me. I then contacted the Head of the Department to obtain the card and called the participant to arrange a meeting and discuss the information sheet. I asked for participants' consent to conduct more than one interview, to use a tape recorder and to transcribe and translate the interview before conducting the first interview (please see Appendix A, a sample of the informed consent form). At the same time, I assured the participants' that they could withdraw at any time during the research study or the interview.

I planned to use a process of consent which involved gaining written consent before conducting each interview with the participant. Thus, women who had three interviews would sign three consent forms. However, in practice, I found that the women were unfamiliar with the process of informed consent and most of the women tended to say that they had already signed a consent form. One woman said: 'I already signed one before'. Another woman made it clear that she was happy with the first consent form and she was reluctant to sign a new one:

...ohh, R. we already agreed on the interview, don't worry, I know that you will keep my information to yourself. I think that there is no need for more papers before each visit, [laughing]' (Um-Mahmoud, social conversation before the second interview).

It appeared then that process consent was unfamiliar to the participants in this study and I had to adjust my plan. Therefore, I sought to gain written consent prior to the first interview and verbal consent prior to the following interviews. The application of the process of consent is discussed in the section on recruitment (see section 3.5.6). Mason (2002) suggests that gaining informed consent is a complex process and raises many issues - such as what the participant is consenting to or whether the participant is familiar with the data analysis process. However, my aim was to clearly present to the participants the process of conducting the study and clearly stating their right to ask if they did not want their account to be included in the research (see for example Um-Bashar's account who refused to include part of her account in the

research). I also answered all their questions about participation in the study. However, I could not fully explain how I would interpret the data at this stage, since during the early stage of my analysis; I was not clear in my own mind about the analytical intention of my data.

3.5.3.3 Anonymity and confidentiality

To protect the participant's anonymity, no names or personal details were transcribed. Each participant was given an identification code and a pseudonym. To assure confidentiality, I kept all the records and the transcribed data on my personal computer, which is password-protected. In addition, all of the research diaries and notes, and the translated papers, were kept in a locked cupboard, to be destroyed at the end of the study. The anonymous transcriptions will be kept for 5-7 years and then destroyed. Despite these safeguards, I acknowledged what Geiger (1986) maintained, that in using storytelling, the researcher cannot be absolutely confident of assuring anonymity just by changing names and places, as participants may share details which are unique to them and might be identified through their stories. However, I kept in mind what Moody (1993) said: that negotiation with participants for their consent was vital if I wished to include some of their accounts.

3.5.3.4 Not to do harm

Considering the importance of the beneficence of the patient in the interview process (WMA Declaration of Helsinki, 2002), I assured the local ethics committee that my aim was "not to do harm" to participants. However, I was mindful that as the participants had recently been discharged from intensive care, they might recall experiences that could distress them. Unfortunately, there was no support mechanism for patients who had been discharged from the ICU in the proposed hospitals; therefore, I had to provide them with one-to-one social support²⁰. Some women described the extremely upsetting experiences of their critical illness, as discussed in detail, in the next part of the method chapter [see section 3.6.7 for further discussion].

3.5.3.5 Safety and respectful researcher-participant relationship

One of the important features in developing a trusting relationship with the participant is to show them respect [see section 3.6.6 Building Rapport for details]. I

²⁰ The social support includes listening to women's concerns, giving them a hug, or touching their hands, showing emotional feelings and verbal acknowledgement of their traumatic experiences.

tended to use special words for naming the women whom I interviewed. For example, it is culturally unacceptable to call married women directly by their first name; therefore, when I started conversations with the women, I used the word 'Um...' which means the mother of, then the name of her eldest son. Sometimes, I used words such as 'aunt' or 'sister' before addressing them by name and, with the older women I used the word 'hajjah²¹', which is a term of respect. Using these words encouraged the women to tell me more about their time in the ICU.

When visiting the women in their homes, I brought a present [a box of sweets or chocolates], which is a Jordanian cultural norm used to express that I shared my feelings with them, and I was glad that they were getting better after their critical illness. The women tended to thank me warmly for the present, and served coffee to welcome me on my arrival. I would drink a cup of plain Arabic coffee, which culturally means 'welcome'. Most of the women invited me to share a meal or a drink [tea or juice] with them. I accepted in order to show them that I appreciated their generosity and hospitality. On leaving the interview, I would drink another cup of sweet coffee²², which means 'goodbye'.

Before doing the follow-up interviews, I took some safety precautions to maintain my personal safety such as: a) using a temporary telephone during the period of data collection, for the purpose of the study only. During the follow-up interviews, I kept the mobile phone with me; b) leaving my address and my mobile number with one of my colleagues before going to the interviews at the women's homes. Then I called her back on leaving the interview.

3.5.6 Recruitment

In order to organize the recruitment process, I developed a plan for recruiting and gaining consent from participants (Figure 3.1). The Figure summarises how the participants were identified, approached, recruited, together with the process of gaining informed consent.

²¹ The term 'hajjah' is culturally used when addressing older women to show them respect.

²² It is a common cultural norm in Jordan that when the visitor arrived they have plain Arabic coffee, and when they leave the house they have a cup of sweet coffee.

3.5.7 The population and the sample

My intention was to involve all the women who were transferred from the ICU to the wards. A full description of the population of the study is provided in Appendix C. The sample is derived from a population of forty two female patients discharged from the ICU in hospital A, and thirty three female patients discharged from the ICU in hospital B. The following table describes the number of the participants and the number of interviews in the study (Table 3.2).

A purposive sample of sixteen women was recruited over a period of six months. The women who had spent more than 48 hours in the ICU were invited to participate in the study. The inclusion criteria were that the women should be: above 18 years old, able to speak, comprehending, able to give an informed consent, and willing to invite me to their home²³. The women's age varied between 19-82 years, the average days where the women stayed in the ICU was 10 days, and the time where the women stayed in the ward varied between 2 weeks to 6 weeks.

The attrition in the sample size was due to a variety of reasons: first, it was difficult to estimate the number of female patients transferred from the ICU to the ward who would be able to share in the study. There were some women who were diagnosed as brain-dead, or in a vegetative state, women who were admitted from prison and women who were diagnosed as mentally ill. All of these women were excluded from the study because either they could not sign the informed consent or were legally unable to share in the study (the women in the prison). In addition, women who had been admitted to the units for only 6-24 hours for close observation were excluded from the sample.

Secondly, as I planned to conduct follow-up interviews (using a longitudinal research design) I had difficulties in following-up all the cases in the study. Sixteen women shared in the first interview. Eleven women of the sixteen agreed to take part in second interviews, and welcomed me to their homes.

²³ In Jordan, the cultural norm is that women invite visitors to their home.

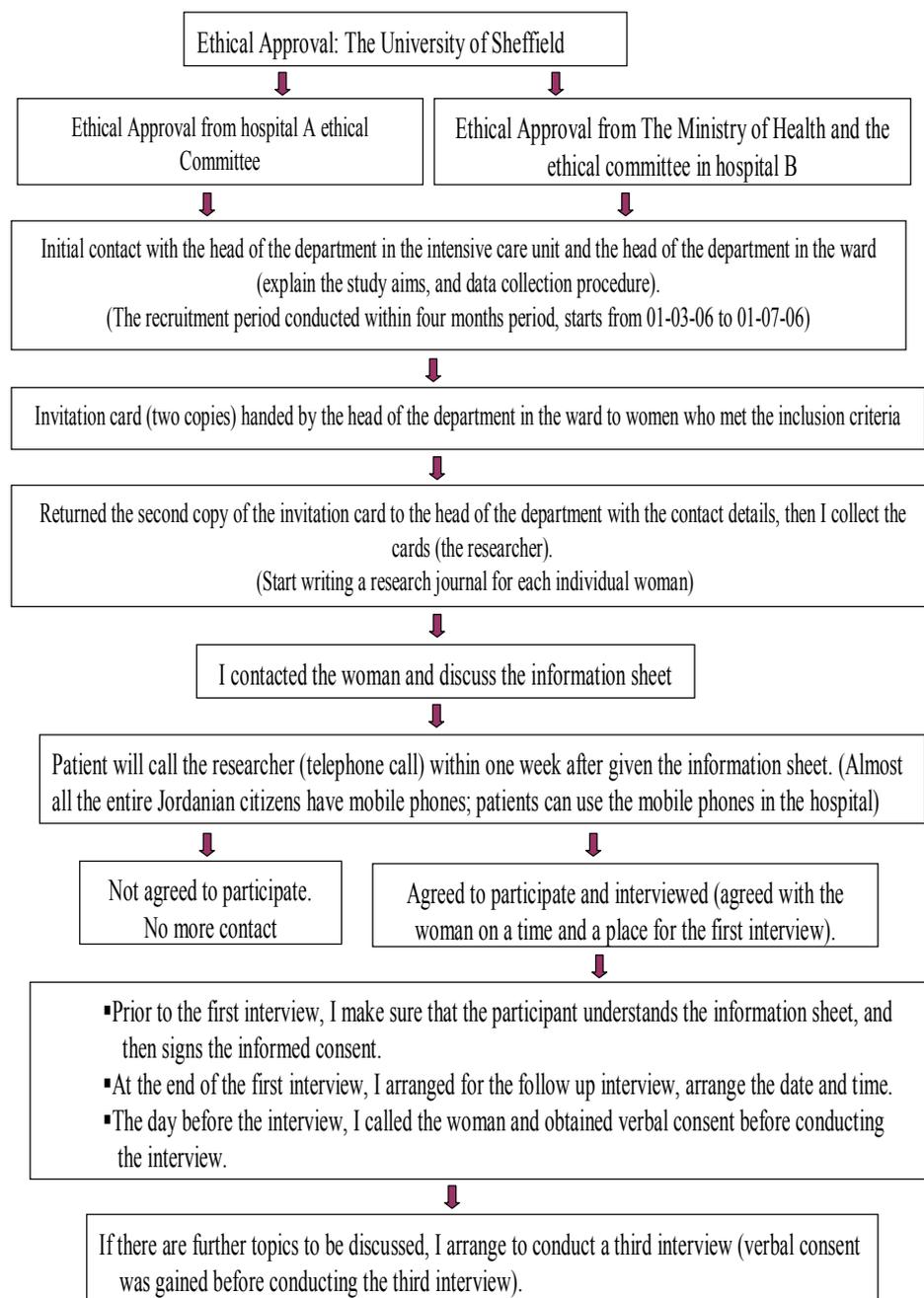


Figure 3.1 The recruitment process.

Table 3.2 The number of the participants involved in the study and the number of the interviews.

DESCRIPTION	HOSPITAL A	HOSPITAL B
patients admitted to the ICU	112	99
Women discharged from the ICU (the women population)	42	33
Women met the inclusion criteria	22	15
Women consented to participate in the study	10	6
Women interviewed (1 st interview)	10	6
Women interviewed (2 nd interview)	5	6
Women interviewed (3 rd interview)	0	2
Total number of interviews (29)	15	14

Two women after their first interview refused to conduct a further interview, two women travelled with their families outside the country and I lost any further contact with them. One woman died shortly after she was discharged home. As the third interview was optional and depended on the women's willingness to share in a further discussion, only two women agreed to participate in a third interview.

Thirdly, during the first month of data collection, I discovered that my overall plan of recruitment needed to be adjusted. This was because from thirty women who transferred from the ICU to the wards, only three sent back the invitation card. I recognized that the heads of the department in the wards were too busy, and most of them forgot to approach the women. I decided then to be available in the hospital most of the time, and visited the unit every day. I also kept reminding the head of the department in the wards to give the women the invitation cards. I recorded all the decisions that I made, and the adjusted plans, in my research diary. This helped me to organize the number of participants excluded and included in the study [see supplementary document for all the cases discharged from the ICU]. Table (3.3) provides a summary of each case participating in the study; I also provide a descriptive account of all the participants in chapter 4.

Table 3.3 Description of the participants included in the study, their age, medical diagnosis, days in the ICU, days

NO	CODE PSEUDONYM	HOSPITAL	AGE	MARITAL STATUS/ EDUCATION	NUMBER OF DAYS IN THE ICU	NUMBER OF DAYS IN THE HOSPITAL	NUMBER OF FOLLOW UP INTERVIEWS
1	US03070306 Eman	A	21 yrs	Single/ student	17 days	8 wks.	one
2	UN04150306 Um- Anas	A	36 yrs	Married/ Diploma in teaching	23 days	4 wks	Travelled outside the country.
3	UA02140406 Abeer	A	21 yrs	Single/ BSc student	3 wks	5 wks.	Refused to conduct follow up interviews.
4	UZ05200406 Um- Mahmoud	A	62 yrs	Married/ housemaid Primary school	2wks	5 wks	one
5	UL09010606 Um- Bashar	A	59 yrs	Married/ Housewife Secondary school	two wks	1 week	one
6	UF12130606 Um- Fadi	A	37 yrs	Married/ BSc Maths	3 wks	3 days	One
7	UF13170606 Um- Mohammed	A	75 yrs	Married/BSc Arabic	3 wks	1 week	Died on her discharge to the home.
8	US 14120606 Amal	A	19 yrs	Single/ student	2 days	1 week	One
9	UB15080706 Um- Adam	A	82 yrs	Married/ grandmother housewife	2 wks	1 week	Refused to conduct follow up interviews
10	UK120706 Um- Sami	A	72 yrs	Married/ grandmother secondary school	2 wks	4 wks	Travelled outside the country.
11	BH01010306 Um-Ahmed	B	35 yrs	Married/ housewife. Diploma in education.	17 days	45 days	two
12	BJ06120506 Um- Essa	B	68 yrs	Widow/ grandmother Primary school	42 days	8 wks	two
13	BN07050506 Um- Ali	B	56 yrs	Married/ widow/ grandmother. BSc Islamic studies	7 days	2 wks	one
14	BF08180506 Um- Saber	B	60 yrs	Married/ housewife secondary school	21 days	4 wks	one
15	BK10040606 Um- Malak	B	28 yrs	Married/ housewife Diploma in education	2 wks	3 wks	one
16	BH11110606 Um- Nader	B	35 yrs	Widow/housewife Secondary school	1 week	Three weeks	one

3.6 Reflexive account of interviewing women in Jordan

In the following discussion, I reflect upon the interview process; in particular, the challenges posed by conducting an open ended interview within the Jordanian community and the difficulty in conducting a narrative approach. First, I discuss my growing experiences in conducting the open ended interviews. This includes:

conducting an open ended interview, the opening question in the interview, using silence in the interview, the use of a tape recorder, and practical considerations. Second, I discuss the issues I encountered during the data collection which include, building rapport, recalling distressing stories, and ending the interview. Third, I reflect on issues of translating the interviews and the data analysis process.

3.6.1 Conducting open ended interviews

The current study focuses on how the women told stories about part of their lives – their experiences in the ICU and the long-term effect of the ICU experiences on the women’s everyday lives. A total of 29 interviews were conducted with 16 women participating in the study. Of these, 11 interviews were conducted in a second follow up interview and 2 third interviews were conducted - all at the women’s homes. The interview length varied between one hour to three hours; some including a break where I had coffee or tea with the participant.

Using an open ended interview was appropriate for this study for the following reasons: first, using open ended interviewing allowed the participants to talk freely about their experiences; helping to understand how they made sense of their experiences and the stories they wanted to share (Kvale, 1996). Second, the open ended interview encouraged the women to be active participants in the research process and to tell their stories in a flexible and dynamic manner. The flexibility of open ended interviewing assists the uncovering of new areas or ideas that are not anticipated at the outset of the research (Murphy et al 1998; Taylor and Bogdan, 1998). Third, by giving participants the opportunity to talk about their experiences, they may be able to share their feelings and emotions (Patton, 1990).

With the understanding that the interview is a two-way interaction, I acknowledged that my role in eliciting the stories from the participants is important (Wenrich and Curtis, 2006). Wengraf (2001) points out that the researcher, through the interview, can generate discussion such as explanation, and clarification. In contrast, Mishler (1986) argues that participants in the interview have a natural tendency to tell stories and the researcher has to sit and wait for the participants to start their stories. However, in this study I found that preparing for the interviews was important in order to focus on my research topic. Developing the aide-mémoire (see Table 3.4)

before conducting the interviews helped the interview process in two ways; it provided a wide range of alternatives when the interviewee kept silent or wanted me to initiate the discussion and, as a reference for the follow-up interviews, especially when the interviewee focused on one topic of their experiences. The questions in the aide-mémorie were developed according to my early reflections on the interviews; for example, in the first interview with Um-Ahmad, who was the first women I had interviewed, I asked questions that did not encourage her to tell me more about such as "What happened to you when you admitted to the hospital?" and "What happened after you had been transferred to the ward?". On reflection, I found that my questions were too focused and did not allow her to tell me about her story in the ICU. I learned from her interview to probe further and ask open ended question such as: 'tell me about your time in the ICU', 'can you explain more about...?' And also how these experiences had affected her, and what these experiences meant to her. The modified questions are listed in Table 3.4 below:

Table 3.4 The aid-mémorie and the modified questions

<p><u>The main questions to cover:</u> Can you tell me about your experiences in the ICU? Can you tell me about your experience in ICU from beginning to the end? Can you tell me about the nursing care in the ICU? Can you tell me about your life after you have been discharged from the ICU?</p>
<p><u>Modified questions:</u> Can you tell me about your self? Can you tell me about your illness? Would you, please tell me about [an event], that you mentioned earlier? You mentioned [an event], Can you explain to me how that [event] affect you? Can you give me an example of the nursing care...., then how did that....affect you? What happened after you've been discharged home? What did you think then? What does this ... meant to you? Repeat some of the participants' words and waited for their response to continue the conversation. Use of silence</p>
<p><u>Clarification Questions:</u> What happened then? Tell me more about...? Can you give me an example of...?</p>
<p><u>Questions that relate to obtaining the participant's permission for the next interview:</u> Is there any thing else you would like to say? (if there is issue that need more exploration) Can we meet later (in a convenient time to you) to discuss this issue?</p>

3.6.2 Opening question in the interview

My opening question was 'can you tell me about your experiences in the ICU?' Starting with a broad general question is important to give the participants the chance

to recall the chronology of events (OliFFE and Mróz, 2005), and to allow the participants to present their stories using their own words and style (Overcash, 2004; Holloway and Jefferson, 2000). I felt that my question was wide enough to elaborate more about the women's experiences in the ICU. However, I found that their stories started with personal experiences before their ICU admission. This seemed to help them to recall the events in ICU. Accordingly, I adjusted my question to be 'can you tell me about yourself?' or 'can you tell me about your illness in general?'

Most of the women started to talk freely about themselves and their illness, while two women could not understand how my question related to the study's aim. For example, when I asked Eman to tell me about herself, she looked confused and replied

"..Oh!! (Pause)²⁴, what you want me to tell you about my self?". Similarly, Um-Nader talked freely about her self then she asked "...That's it... but what is the relation of this question with the interview?". Holloway and Jefferson (2000) described how they could not elicit narratives from their participants by asking general open-ended questions and concluded that not all open-ended interviews help the participant to tell their stories. As they stated:

...our opening question to Ann, what's the crime you most fear? Is open but in a narrow way, which may account for its failure to elicit much from her.... To learn more about the meaning of fear to Ann a more open question such as "what do you most fear? Would be necessary (Holloway and Jefferson, 2000, p.34).

My experience of conducting open-ended interviews developed over time. During the first interviews, I reflected that I tended to ask specific or leading questions. For example, I asked Eman "tell me about your illness?" but in another interview, I asked Um-Ahmed 'what made you feel sick in that unit?' The latter type of question reflects how my earlier background as nurse affected the way I posed the research questions. When reflecting on my first and second interviews, I found that my questions did not encourage the women to tell more stories about their experiences in the ICU. Accordingly, I learned to ask questions that helped the women to tell me more about their experiences and used the silences in the discussion (I will discuss this in the next subsection) to encourage the women to provide more detail about their experiences. I also learned how to pose further questions to clarify and explain

more about the women's experiences. Some of these questions such as: 'tell me more about...', 'how did this [event] affect you', 'what this [event or experience] meant to you' are helpful to gain more in-depth knowledge about the women's experiences.

Kvale (1996) asserts that posing the questions are the important part of the interview discussion; open questions are needed to encourage the participant to provide detailed stories of their experiences, the researcher can then listen carefully to their response and then ask more in-depth questions. Using closed questions or questions that elicit short answers may suppress the storytelling process and should be avoided (Mishler, 1986, Riessman, 1990, Elliott, 2005, Chase, 1995). Chase (1995) conducted open-ended interviews with women to explore their experiences within the male-dominated profession of public school superintendents. Early in her study, she asked the women what it was like to be a woman in a male-dominated profession, but the women tended to reply with short, specific answers. Further on in her research, she found that asking the women to tell stories about their professional lives helped them to elaborate about their experiences and encouraged them to describe in more depth accounts of their professional lives (Chase, 1995). The use of non-verbal communication is also helpful to let the women talk freely about their experiences; this will be discussed in the next sub section.

3.6.3 Using silence in the interview

In my first and second interviews, I tended to interrupt the women and ask questions which prevented the flow of their stories. As I became more experienced with more interviews, I found that asking fewer questions and using silence helped the women to tell more stories and helped me to concentrate on what further questions I needed to ask to obtain more depth to their accounts. Sometimes, when the women started to talk freely about their experiences, I used some uttering words such as 'Ahhh', 'Aywah', and 'Tayeb' and maintained eye-to-eye contact that showed them that I was actively listening to their stories and wanted to hear more about their experiences. These Arabic utterings are used to encourage people to say more during the conversation. I found that participants broke the silence themselves and then continued to tell me more. Most of the women talked spontaneously about their experiences. However, I felt that with one woman using silence was ineffective. This

²⁴ Pause means silence for about 10-20sec. Silence means more than 30 second.

woman was blind. She talked very briefly about her experiences, and I tried to encourage her to tell me more, but each time she told me *'I don't know, I cannot remember'*. When I attempted to use silence with her, she started to look around as if searching for me. I felt that I failed to find a way to encourage her to engage in a two-way discussion.

Kvale (1996) points out that using silence in the interview provides time for the participants to relate and reflect on what they have on their minds. Booth and Booth (1996) argue that the use of silence is as important as the telling; silence can help the participant to remember events and arrange them before sharing their experiences with the researcher, whilst the researcher should take into consideration what the silence means to the interviewee and must learn to read the spaces between words. Interrupting participants while they are telling their stories may cause them to forget some elements of the story, thus keeping the questions to a minimum may encourage participants to say more about their experiences (Mishler, 1986). My experience showed that using silence depends on the participant; some participants have the ability to freely communicate their experiences, leaving the researcher to ask few questions, whilst other participants may feel lost and need more direct questioning.

3.6.4 Using the tape recorder

With all of the interviews I sought the participant's permission to use the tape recorder before conducting the interview, since I felt that this would help to keep note-taking to a minimum and would allow me to follow-up issues raised by the participant and to maintain my attention on what I was being told (Clarke, 2001; Elliot, 2005).

Active listening during open-ended interviews may help the researcher to probe further and explore topics that are of interest (Ritchie and Lewis, 2003). I prepared the tape recorder and had extra batteries with me before starting each interview. However, in my first interview with Um-Ahmad, the recorder stopped and I didn't recognize that it was run out of charge. When I went home to transcribe the interview, I was shocked that nothing was recorded and I had to try to remember all of the conversation. I found it difficult to remember what was said, the way the participant had responded and how silence or pauses were used during the interview.

I decided then to have an extra recorder with me, as a back-up in case the first one did not work.

Using the tape recorder sometimes appeared to affect the women's conversation; for example, when I conducted the interview with Um-Bashar, when I showed her the recorder, she held it and said, "it looks nice and small", but during our conversation, I noticed that she started to look at the recorder and seemed worried. I asked her if she would like me to turn off the recorder and she replied "Ok, when I want to put it off, I will tell you." After about half-an-hour of our conversation, she mentioned that she would like to share with me her account without recording, so I turned off the recorder. I use her account as unrecorded data and reflect on her wish not to share part of her account.

Halabi (2005) interviewed Palestinian women refugees and found it difficult to gain permission from the participants to use the tape recorder. Halabi provided explanations for not using the recorder due to unfamiliarity of the subjects with research and their anxiety about recording their accounts, in spite of assurances from the interviewer of confidentiality. In contrast, Clarke (2001) found that using the tape recorder helped her to focus on the interaction with her participants and to remember the details of the interview process when transcribing the interviews.

3.6.5 Practical considerations

The first interviews took place in the ward at a point when the women were well enough to take part in an interview. However, establishing when the women felt well enough to participate was not without difficulty. Some women, although they had transferred from the ICU to the ward, still felt weak and were unwilling to engage in conversation. For example, I had agreed with Amal on a time and date to conduct the first interview but when I met her, I found that she was coughing and sneezing and found it difficult to talk to me. I asked her permission to set another date when she would feel more comfortable to talk with me, and she welcomed my suggestion, and we agreed on another date for the interview. Similarly, Um-Ali agreed to conduct the interview the day after we had discussed the information sheet. When I met her at the agreed time, I found her with an oxygen mask on her face, breathing forcefully. She

mentioned that she had 'bad breathing' and made it clear that she would like me to interview her. She said:

Yesterday, I had chesty cough. I had bad breathing and I felt suffocated, but today after I had the oxygen I feel much better-coughing. I told my sister that you will come today to meet me and I am very happy to meet you Ruqayya- smiling (Um-Ali, social conversation before the first interview).

I was concerned that if she removed the oxygen mask, her health status would be at risk, so I acknowledged her wish to be interviewed and sought her permission to conduct the interview at another time when she could talk freely without the mask. She agreed and we arranged a new date for the meeting.

One of the practical considerations I had to take concerned not interviewing during family visiting hours. I noticed that the women preferred not to talk when there was a family member around them; it seemed that they would like to spend most of their time with their family. Therefore I decided not to conduct the interviews outside of the family visiting hours.

3.6.6 Building rapport

Gaining access to the women's narratives was an ongoing evolving process rather than a one off event. It involved a process of multiple interactions in shared conversations over a period of time. I felt that building rapport with the women would help in developing a trust relationship and allow a relaxed atmosphere to develop (Booth and Booth, 1996, Overcash, 2003). Therefore, I conducted a visit with each woman prior to the interview where I had a social conversation and I would discuss the information sheet. I found that this was an opportunity to introduce myself and discuss the aims of the study. The initial interaction helped to develop a relaxed atmosphere during the first interview. My availability and willingness to answer their questions seemed to help them to reciprocate by sharing their personal accounts with me in the subsequent interviews. For example, when I interviewed Um-Saber, she asked me who I was, which family I was from and where I lived. Then she asked about my qualifications and professional background. My personal account seemed important to her in order to develop a trusting relationship with me.

My relationship with most of the women was developed throughout the hospital stay and at their homes. When I visited the hospital wards, I said 'hello' or 'hi'²⁵ to the women who stayed in the hospital after the first interview. I felt satisfied when the women responded to my invitation to do a follow-up interview. Women used many words to show their willingness to invite me to their homes; such words include 'Ahlan wa sahan'²⁶ which means, 'you are very welcomed' and 'ya marhaba'²⁷, which means, 'welcome at any time at home'. One example is when I mentioned to Um-Ahmed that I would visit her at home and she replied:

'It is a pleasure to invite you to my house; we could have a meal together, if you don't mind' (Um-Ahmed, telephone conversation before the second interview).

Most of the women invited me to their homes as part of the Jordanian cultural norm. Guests are usually invited to the home to share drinks or meals with family members; this is one way to show generosity and hospitality to visitors (Halabi, 2005). They welcomed me and invited me to share tea or coffee and sometimes lunch. This reflected on the way the women interacted in the second and the third interviews; some women started to tell more about their experiences and explained some of their past stories. Others shared some of their emotional feelings. At the same time, I felt that my understanding of their experiences took on more depth. I started to be sensitive to their personal issues and began to understand more fully their experiences. My way of thinking developed to think about and with them and feel their struggle and suffering. In my research diary, I reflected on how some of the women's accounts affected me as a researcher (see chapter four for reflections on my interactions with each participant).

Developing a trusting relationship between the researcher and the participant may help to develop reciprocity in the relationship; reciprocity involves a process of communication in which the researcher both gathers and gives information to the participant (Booth and Booth, 1996, Clarke, 2001). The research interview is a collaborative process, where the researcher and the participant work together to generate the research data (Oakley, 1981). The relationship of trust helps to develop a relaxed environment in which the participants feel free to share their accounts (Carolan, 2003). A sense of equality also enables the free flow of communication and

²⁵ I used Arabic words such as Marhaba which means 'hello'.

²⁶ Welcome at home.

helps the researcher to ‘get inside’ the participants’ experiences (Taylor and Bogdan, 1998, Grbich, 1999).

Conducting follow-up interviews is important in order to explore the change in individual stories over a time period (McAdams, 1989; King, 2001; Burns, 2005). People may find it difficult to discuss all the events in the first interview, particularly if they are ill. Therefore, over time the researcher becomes more involved with participants then they may feel more confident to share their accounts about their experiences (Booth and Booth, 1996). For example, Aranda and Street (2001) describe narrative accounts of close relationships from nurses who had friendships with their patients. In the first interviews, the researchers elicit descriptive stories from the nurses, while in subsequent interviews, the researchers began to engage in the experiences and share their personal experiences with the participants; the reciprocal relationship helping the nurses to tell more about their experiences.

3.6.7 Recalling distressing experiences

Considering the importance of the beneficence of the patient in the interview process, I had assured the local ethics committee that my aim was ‘not to do harm’ to the participants. When I conducted the interviews, I found that the women expressed stressful events in the ICU and used different coping mechanisms to deal with their stress. Some women started to cry and weep; for example, when I asked Abeer about time in the ICU, she remembered her family and started to cry and requested to end the interview:

...the most terrible things that I felt so sad for being away from my family. When I was there all of my life has passed through my memory, I remembered the beautiful days when me and the whole family were sitting together, talking, laughing, telling jokes, oh!! How much I missed these days, how awful – she started to cry-(Abeer, first interview).²⁸

She had tears in her eyes and was very anxious. Although I tried to provide her with one-to-one social support, I felt that my support was not enough because I had no experiences in supporting blind women and it was clear from her response that she

²⁷ Means you are very welcomed.

²⁸ I held her hands and tried to support her but she was very sad and weepy. I asked her if she wanted to continue the interview later and asked her permission to arrange a meeting with her physician to discuss the possibility for her to meet her family in the hospital, but the physician did not agree on my request.

required some specialist support. This in contrast to Um-Adam who expressed her distressing experience differently, after she told part of her story, she refused to tell me about her time in the ICU, she said:

...I am not at the torture section now, not any more!! Would you please stop talking about the torture section and that awful experience I had passed through there. I am happy now, I don't like to talk more about it, and I am fed up, khalas – enough- (Um- Adam, first interview).

From these experiences, I learned that the women recalling the distressing experiences needed social support. As many women in this study express their emotions through crying, other felt unwilling to revisit their experiences. Unfortunately, there are no support mechanisms for patients who are transferred from ICU or discharged home in Jordan; therefore I could only offer some personal support to share their feelings.

Dealing with distressing stories is one of the issues discussed by social researchers. Although some researchers argue that telling stories can provide the narrator with some distance from whatever threatens them (Frank, 1995, Plumer, 1983, Plumer, 1995), and could help the participant to feel relieved when sharing some of the distress with others including the researcher (Atkinson, 1998, Frank, 1997). This study found that engaging in the interview could be distressing to some participants because they remembered some of their traumatic experiences through telling their stories. I agree with Clarke who recommends that using reflection may limit the impact of the traumatic experiences in the interview (Clarke, 2006). Clarke, gave an example of one of her participant, when she was with her terminally ill husband, after his death and during the interview process, the participant recalled her time while crying.

In addition, the women in this study expressed their emotions by crying, weeping, or by avoiding talking about traumatic experiences. This could help them to feel relieved when sharing their feelings. It could be that the women accepted caring from my side; therefore, they shared their deep emotional feelings and even cried in front of me. Kleinman (1988) suggests that feelings not only affect the research but are also part of the process. This sharing of their emotions also had an impact on me and I developed a greater sensitivity to the women's feelings. Pellatt (2003) reflects upon her experiences when sharing the emotional feelings of injured patients. She found

that her emotional interactions with the participants had an impact on her values, perceptions and on the research process as a whole. Atkinson (1998) points out that field work is about emotions; sharing participants' happiness, sadness, and anger may strengthen the reciprocal relationship between each party and that this should help the researcher to be more honest about the data generated.

The other aspect that I noticed from the women's accounts, especially during the first interview, was that none of these women discussed medical facts such as blood tests, blood pressure, or temperature charts. Also, none of the women described how the nurses applied the monitors or what medication they had. It seemed that most of the women connected the events they experienced to their feelings and emotions. The accounts might have been different if I had interviewed male patients. I had made such an observation when I conducted a pilot interview with a male patient, as part of module requirement course at the University of Sheffield, and reflected on the data collection process. I found that the male patient tended to give facts about his condition such as asking about his blood pressure and describing blood tests, but did not share any emotional accounts.

Feminist researchers have raised this issue and assert that there are differences between male and female experiences (Harding, 1989, Phoenix, 1994, Maynard and Purvis, 1994). Oakley (1981) for example, reported that women participants in her study tried to explore emotional experiences more than the men; men being more concerned with describing facts. (Woods et al., 2003) explored the experiences of men with cardiovascular diseases using in-depth interviews and found that men tended to separate themselves from their illness and had difficulties integrating disease into their lives.

3.6.8 Ending the interview

The time taken to conduct the interviews varied between one to three hours. During the interviews I did not feel the time pass and I enjoyed listening to the stories that the women told me. However, the closure of the interview is important. Abbott (2002) asserts that each story has a closure and the researcher should seek to achieve closure in order to understand the whole story. However, how this is achieved, raises an ethical consideration, especially when the interviewee is vulnerable and/or if they

have exposed significant aspects of their lives, or have developed a level of friendship with the researcher (Jesselson, 2005).

During the first interviews I found that ending the interview depended on the individual situation – the participant’s condition and her willingness to continue the conversation – in the knowledge that further issues could be explored in follow-up interviews. For example, when I interviewed Um-Sami, after we had talked for about one and half hours, she started to take a deep breath and checked the watch on her arm. I felt that she might feel too tired to continue our conversation so I asked her if there was any other topic she would like to discuss, and she replied:

Oh, I feel tired and I think I need to take a break, can we arrange another meeting for our conversation (Um- Sami, first interview).

Follow-up interviews were conducted at the women’s homes. The aim was to obtain in-depth descriptions of their experiences mentioned in the first interview and the changes in the women’s perceptions and experiences over time. As I discussed in the two sections above (see section 3.6.5 and 3.6.6), we developed a rapport over a time period, and the women shared many aspects of their lives with me, including their emotional experiences. Most of the women appeared to enjoy the conversation and the interview took two or three hours. Ending the interview was entirely the women’s choice. The women at the end of each visit prepared a sweet Arabic coffee²⁹ which is the culturally accepted means to end a visit in Jordan.

Ending the relationship with these women was difficult for both me and the women in the study. Although I sought to use some of the sentences and questions to prepare the women emotionally for ending our relationship. Some of these sentences included: ‘I feel that I learned a lot from you and this will help in my work’, ‘I highly appreciate your openness and honesty in sharing your experiences’; ‘I do appreciate your willingness to share your experiences with me’; ‘Would you please tell me about how you feel about our relationship now the interviews have finished?’ Some women reflected that they felt happy to share their accounts and they were looking forward to seeing how the study had an impact on the way critically ill women received care in the ICU. However, some women wished to continue our relationship, especially those whom I had interviewed three times. I also found it an

²⁹ In Jordan we call it the goodbye coffee.

opportunity to develop new friendships with these women. For example, Um-Ahmed invited me to visit her after finishing my PhD, Amal wished to meet me at the university where she was to continue her study, while Um-Saber mentioned that she would pray for me to achieve my PhD.

The length of the interviews varied; the length of the first interview varied between one to two hours. While the time of the follow up interviews varied between two to three hours [sometimes I had a break or lunch]. The length of the open-ended interview is debatable. Some researchers recommend that ninety minutes is sufficient for qualitative research interviewing (Seidman, 1998 cited in Elliot, 2005). While others have found that participants find it hard to tolerate long interviews, and feel reluctant to continue the interview when they perceive that there is no new information to share or the conversation become repetitive (Elliott, 2005, Oliffe and Mróz, 2005). Elliot recommended that if the interview lasts more than two hours, then permission should be sought to conduct a further interview (Elliot, 2005). I found that ending the interview depends on the situation and on the participant's condition.

In summary, I have reflected on how I conducted the research within the Jordanian context. I have discussed my growing experiences of conducting open-ended interviews and reflected on the data collection process. In the third section, I reflect on the translation and the analysis of the data.

3.7 Analysing the data

I consider the processes of analysis include in all stages of the research project, from planning the research design into the final interpretations of stories. For example, when conducting the interviews, I point out how my reflections and interpretation of my interactions with the participants informed the development of further questions in the later interviews. However, in this section, I will reflect on my struggles relating to the analysis of my data. The section is divided into three subsections: in the first sub-section, I reflect on the translation, then on transcribing the interviews. Finally, I discuss my journey to analyse the data.

3.7.1 Reflection on translation

I agreed with Denzin's (1989) point that translating the text from one language to another is by itself is an analytic act and decided to translate the interview transcript based on the meaning of the stories. Here, I aimed to take each sentence in the Arabic transcript and translate it into the English language without losing the meaning of the sentences.

I spent more than one week translating the first interview with my first participant. I learnt that the translation process is laborious and time consuming and can result in many grammatical errors. The difficulty in translation is two fold; first, I had to literally translate the meaning of the Arabic words into the English words and then check if the translation made sense within the English context. Secondly, there are many Arabic words that have cultural meanings but lose their meaning when turned into the English translation. For example, when I translate the word sentence 'Bitfalsafo' the literal translation is 'philosophical rubbish' which has no meaning within the English context. Therefore I have to search for the alternative word in English that has the same meaning in Arabic.

Using a translator is one of the alternative options that I used; I hired a translator who had excellent Arabic and English language backgrounds. I gave her a sample of the first interview that I had already translated. I found then that there were some differences between my translation and hers. For example, she translated the word 'nafsity' as the 'psychological status' while in the slang Arabic words this term is used to express social and emotional feelings. I could not think of any way to handle this issue and I sought help from my supervisor who suggested that I could meet with the translator and check the translation transcript at the same time of translation. In doing this, I managed to keep the translations errors to the minimum by developing many strategies for translation, these are: a) I chose a bilingual translator who had an excellent English and Arabic language background. b) I checked with the translator the meaning of the translated transcripts during verbatim with the translation. c) I decided to keep the Arabic words such as 'nafsity', 'Musakkinat', 'Hamdolellah Alaalsalameh', 'hathayan' which could lose their cultural meaning in translation, and then explained the meanings in a footnote. d) I used a sample of the translated

accounts and sent it back to another translator for back translation [see a sample of this two way translation in the supplement documents].

There is a scarcity of literature that reflects on the translation process in qualitative studies. In an exploratory study which examined the influence that translation had on the validity of the findings from in-depth interviews of non-English-speaking Chinese women, Twinn (1997) compared the translation of the analyzed English version with the same data analysed by another researcher in its original Chinese. Although Twinn found that there were no significant differences in the data analysed, there are some words in the Chinese language which have no true equivalent in English. In another study, Esposito (2001) translated the data from a focus group discussion from Spanish to English. She found that the language barrier is a significant challenge for people for whom English is not their first language. The researcher encouraged the use of meaning based translation from Spanish to English and recruited an interpreter to check the validity of the translation. Translating the context from one language to another can be very complex because there are differences in the cultural meaning between the words; (Kapborg and Bertero, 2002, Temple, 2002). In this study, I aimed to use the meaning of the context of the discussion as the basic principle in the translation, This is part of the interpretation process which I will discuss later in this chapter (Patricia, 2001).

3.7.2 Reflection on transcribing the interviews

The analysis process starts with transcribing the interviews during the data collection time. After I had transcribed each woman's interview, I transcribed the interview in the Arabic language, at the same time, wrote down all my reflections and the key issues I found in that interview. This helped me to explore these issues further in the follow-up interviews and provided me with some notes later when analysing the data.

Transcribing the interviews involved the following. First, I transcribed the Arabic interviews the same day after the interview were held, which I considered an easy task because that the language was familiar to me. It also gave me the opportunity to reflect on the interviews. I was careful to transcribe the accounts word-by-word and to record the use of silence and pauses. Secondly, I checked the transcribed interviews with the English translation. I found the process of transcribing to be

laborious and time consuming, and an hour of interviewing took me more than eighteen hours to transcribe and a similar time for the second level transcribing.

I decided to be consistent in transcribing all the interviews; therefore I developed a plan for transcribing each interview: 1) I listened to the whole interview from start to finish - my aim was to get an overall idea about the women's account. I concentrated on the narrative in the story and the paragraphs of each story. I wrote my reflection on the interview process in general and commented about my feelings and my responses during the interview. 2) I listened again to the recording in details and transcribed each interview fully. I wrote also the uttering, silences, and non-verbal responses - my aim was to write the interview as it was and to prepare a transcript for English translation. 3) After the interview was translated, I read the translated interview and I listened to the women's Arabic accounts, then I made comparisons between the Arabic and English accounts.

3.7.3 Reflection on the analysis process

My approach to analysis was the result of a long consideration of several bodies of literature: case study analysis, grounded theory, and narrative analysis. I initially used a mix of these approaches in my analysis. The preliminary analysis of the interview data started after I had interviewed ten women and I decided to prepare for the group discussion with the nurses. My aim was to provide a content analysis of the stories and find commonalities amongst the interview data. The preliminary analysis was dependent on the thematic method (one sheet of paper method), which is developed at the DIPEX project at the University of Oxford (Ziebland and McPherson, 2006). This analysis starts with coding or grouping the accounts that have the same topic under one code, these codes are interlinked with the ID of the participants who share their accounts. Then, one sheet of paper is used to write down all the codes and break the data into main headings. The common words or notes that are repeated many times by the participants are also noted. When this has been completed, the researcher groups these codes and headings into larger themes and writes reflections about the relationship between these themes and headings. Finally, the researcher provides a depth analysis of individual cases (Ziebland and McPherson, 2006). When using this method in practice, I managed to have themes to present in the focus group discussions, however, I felt overwhelmed with more than

two hundred themes and struggled to find the interlink between the themes [see Appendix D]. This method initially influenced my early analysis and helped me to use the case analysis for each individual woman.

In order to deal with the data, I drew on a number of influences that helped me to analyse the data. The use of case study analysis mainly focuses on the systematic analysis of multiple forms of data that enhance understanding of a given context and those who live that context (Gangeness, 2006). Yin points out that descriptive case study present a complete description of the case within its context (Yin, 2003b). Stake (1998) supports that the case could be used as a unit under study; here, the case may be used as an ‘instrument’ to provide insight or refinement of more depth analysis (Stake, 1998:88). I assumed each woman in the study to be a case and wrote a descriptive account of the 16 cases, followed by reflections on each individual case. The use of the cases provided a thick description for further interpretation.

I started a deeper analysis by initially adopting a grounded theory analysis developed by (Glaser and Strauss, 1967). I thought that Axial coding might help to generate interpretation of the findings. However, I found that grounded theory (characterised by developing a theoretical framework based on close and continuous relationship between the data collected and the theoretical framework (Strauss and Corbin, 1990) and the use on line-by-line coding) lost the coherence of the individual stories of participants. However, the use of a more recent grounded theory approach (as explained by Charmaz, 2006) did influence the way I developed concepts from my data. Charmaz’s (1999, 2006) view of grounded theory places an emphasis on the data as a joint product between the researcher and the participant (Charmaz, 2006); data is socially constructed (Charmaz, 2006).

As I engaged more with the data and felt more familiar with it, I found that data could not be divided into lines but rather plots of the many stories. I became aware of different layers of stories or stories within the main story. Additionally, I felt that the changes of the events over time can be connected by using narrative analysis. Riessman (1993) points out that one advantage of using narrative analysis is that the researcher can explore not only what the participant said (the content of the story) but also how the participants tell their story (the structure). As Denzin asserts,

narrative analysis is highly interpretive but also subjective in nature; it is the researcher who mainly impacts on the interpreting process. Coffey and Atkinson (1996) support Riessman's point and argue that thinking about the stories in an analysis can enable the researcher to think creatively about the sort of data collected and how to interpret the data. They suggest that researchers think of narratives as a social construction within a certain context. They state:

The analysis of the narratives can focus on social action implies in the text. This can involve taking a slightly less systematic and structured approach to narrative analysis, deriving more context dependent infrastructure and focus to explain the effect of the story or tale. This emphasizes the idea that individual narratives are situated within particular interactions and within specific social, cultural, and institutional discourses (Coffey and Atkinson, 1996, p.62).

Riessman (2008) emphasises that narrative analysis has many meanings and methods. One of method she explores is the use of case method to analyse narrative. She states:

Narrative analysis relies on extended accounts that are presented and treated analytically as units, rather than fragmented into thematic categories...long accounts are distilled into coding units by taking bits and pieces- snippets of the account often edited out of text. While useful for making general statements across many subjects, category centred approaches eliminate the sequential and structural feature of narrative (Riessman, 2008, p. 12).

The work of Coffey and Atkinson (1996) and Riessman (1993, 2008) supported my approach to analysing data. After writing descriptive accounts of the 16 cases in the study and reflecting on each individual case, I moved to examining each woman's story as a whole and the interconnectedness between the first, second and third account. This helped me to understand the changes of each individual woman's experiences over time. Then, I moved to compare and contrast the individual's story with other women's stories. I identified coding words based on Charmaz's (2006) coding analytic approach and identified concepts in the study (see for example, the concept of body work in Chapter 6). At a second level of analysis, after I identified the codes and concepts, I went back to each individual case and compared and contrasted how each applied to the women's accounts. Figure 3.2 provides a map of how I analysed the data.

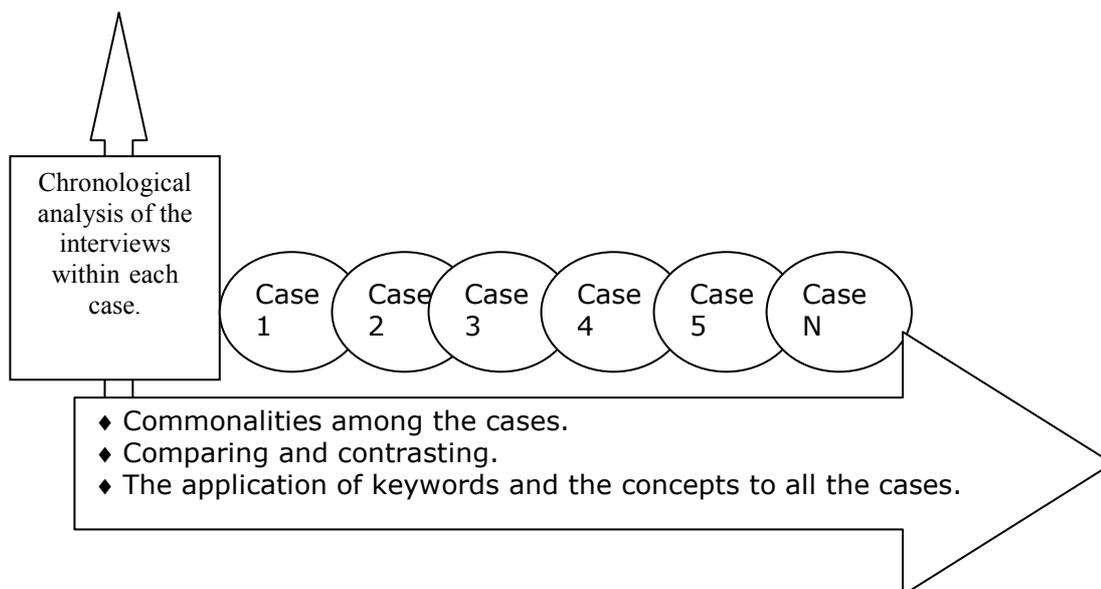


Figure 3.2 The overall map for analysing the data.

3.8 Phase II: Nurses (group discussion).

This phase is related to my final aim in the study: that is, what areas of ways to develop care can be identified from the women's accounts. My aim of conducting the focus group discussion was two fold: 1) I wished to share part of the findings with the ICU nurses to know more about their reflections on women's accounts and 2) I wished to develop supportive care strategies for women admitted to the ICU based on the nurses' suggestions. In the following section, I discuss my plan of the focus group discussion and then reflect on how I applied this to my study. I describe the setting, the population, the sample and recruitment, data collection and analysis.

Kitzinger (1994:103-104) describes how the focus group involves a carefully planned discussion designed to obtain perceptions on a defined area of interest in a friendly, collaborative environment. According to Morgan (1997) the focus group discussion involves an interaction between the participants to produce insights and generate data through the group interaction. The participants, through their interaction, help each other to overcome the embarrassment and mutually support each other to express their feelings and common concerns (Kitzinger, 1994). The use of focus group discussions to collect research data has received considerable attention in health care research from qualitative perspectives (Higginbottom, 1998; Sim, 1998; Lane, 2001; Webb, 2002; Mclafferty, 2004). For example, Mclafferty (2004) undertook focus group discussions with registered nurses, student nurses, and

nursing lecturers in order to explore their beliefs and attitudes toward caring for older people. McLafferty found that the use of focus group discussions generated rich information that helped the researcher to understand the attitudes and beliefs of the nurses. She points out that using a smaller group number is more manageable for the coordinators; however, a larger group results in more interaction within the focus group and generates more data (Kitzinger, 1995). Kitzinger (1994) asserts that the researcher's main role in the focus group discussion is to encourage the participants to get more involved in the interaction, thus encouraging them to elaborate on the topic under investigation (Kitzinger, 1994).

3.8.1 The settings

My plan was to conduct two focus group discussions: one in each hospital. I also planned for the possibility of conducting more than two focus group discussions in order to facilitate the nurses' attendance. In practice, I found it difficult to arrange a place for the focus group discussion in Hospital A. In part this was because the director of nursing objected to the idea that I would conduct the focus group in the conference room in the hospital. Her rationale was that the medical doctors used the room for their discussions. She suggested conducting the focus group in the meeting room in the ICU. I felt unhappy about her decision because there is limited facilities for the presentation in the meeting room, and there is possibility that this would disturb nurses who needed to write their reports. However, I felt that there was no other choice available and I arranged the meeting with the head of the department who was on holiday for two weeks and waited for his approval. After further discussion with the head of the department, we agreed on the date and time for the focus group discussion.

My experiences with the head of the department in Hospital B differed to those at Hospital A: she helped me to book a nurses' meeting room, where the nurses attended courses and discussed case reports. Then, she provided me with all the nurses' addresses in order to send them the invitation cards. The common room was quiet and all the facilities were provided for my power point presentations. The meeting room was also convenient for the nurses as they could move easily to the unit. This, however, did not appear to influence the number of the ICU nurses who

attended the focus group discussion: 7 nurses in hospital A and 6 nurses in hospital B attended the focus group discussions.

3.8.2 Ethical considerations

Before conducting the nurses' focus group discussions, a covering letter, information sheet, and a reply slip were sent to all the nurses who worked in intensive care during the data collection time. Participation in the study is based on signing an informed consent. This will be discussed in the section below.

3.8.3 Recruitment and Data Collection

As I discussed in the previous section, during my visits to the unit to ask for the patients' names that had transferred from the unit, some of the nurses started to ask about my study and I explained my aims and discussed the second stage of data collection. By the end of the first stage of data collection, I wrote an advertisement about my study and the focus group discussion on the nurses' communication board.

The recruitment took more time than I anticipated. After I contacted the heads of the departments and obtained full addresses of all the registered nurses in the unit, I sent a package containing an invitation letter, information sheet and a reply slip to each nurse working during the data collection period, I used the local mail and received a reply slip from 15 nurses in hospital A and 13 nurses from hospital B. Within one week, I contacted each nurse and signed the consent form. I also provided more information about the study and clarified any questions about the study). Prior to the meeting, I called the nurses to confirm the date and the time of the focus group meeting and I sent an invitation letter to all the nurses through the local mail in the hospital, once I had gained access permission to the hospitals (see appendices for the ethical approval protocol).

3.8.3.1 The discussion process

In this study, I used (Finch and Lewis, 2003) method of discussion, consisting of five main stages as discussed in the following chart, together with my reflections concerning how I undertook the focus group discussions. I also developed my agenda for the discussion process which I summarise in the Table 3.5

Table 3.5 Focus group discussions

<p><u>Part I: Scene setting and ground rules:</u> I prepared the meeting room (the chairs, table, the light, the temperature, the flip charts, the plain papers, the data show and the material for presentation) I welcomed the participants, thanked them warmly for their attendance, and introduce myself to them. Then provided. a short view about the study (the aim, outlines of the focus group discussion). I outlined the confidentiality and anonymity of the group information. and explained about how their accounts would be reported.</p>	Group A. time	Group B time
<p>10 min</p>	10 min	5 min
<p><u>Part II: Individual introduction:</u> I asked the group to introduce themselves (by saying their names and give simple background information). At the same time I distributed plain papers and pens to the participants (if they wish to take notes).</p>	5-10 min	10 min
<p><u>Part III: The opening topic:</u> I asked the participants to explore their feelings and expectations about women's experiences and participating in the study.</p>	10 min	5-10 min
<p><u>Part IV: Discussion:</u> During the interaction I presented some of the women's accounts using PowerPoint presentation (please see reflections chapter 8). I attempted to involve all participants in the discussion and encouraged them to explore their ideas.</p>	40 min	30 min
<p>Coffee break and refreshments</p>	5 min	10 min
<p><u>Part V: Ending the discussion:</u> I thanked the entire group for their participation and stressed how helpful the discussion has been. I asked the participants for any other suggestions. I left my address and contact number if they have further suggestions.</p>	5 min	6 min
<p>Time for the focus group discussion</p>	80 min	70 min

3.8.4 The population

I intended to invite all the ICU nurses registered nurses who had a minimum of one-year experience in critical care (I did not include student nurses who had less than one year's experience). These criteria are applied to all nurses working in the intensive care unit in both hospitals before they apply to the work in the ICU³⁰. The total numbers of ICU nurses are 35 nurses in hospital A and 25 nurses in hospital B. I also estimated that some nurses would be on duty (35% of the nurses) or on vacation (5%) and would not be able to share in the discussion.

3.8.5 The sample

15 nurses from hospital A and 13 nurses from hospital B responded to my invitation letter and signed the consent form. However, at the time of the group discussion, on the day of the focus group discussion, 7 nurses from Hospital A and 6 nurses from hospital B attended the focus group discussion. All the nurses in Group A were

³⁰ This information gained through telephone conversation between the researcher and the head of the department in each hospital.

registered nurses: their experiences varied between 1 year to 25 years of experience in the ICU. All the nurses held Bachelor degrees in general nursing; the group had 3 female nurses and 4 male nurses. The nurses in group B were all registered nurses, their experiences varied between 3-5 years on ICU, with only one nurse having 18 years experience in the ICU. The majority of the nurses held bachelor degrees in general nursing and two nurses held master degree in clinical nursing, the group had 2 female nurses and 4 male nurses.

3.8.6 Data analysis

Analysing the focus group discussion was a very laborious activity, although I enjoyed the focus group discussions. I applied Morgan's (1997) focus group analyses to the data. Morgan (1997) discusses three main elements of analysing focus groups: coding the data, interpreting the data and reporting the data. Morgan (1997) asserts that the findings of the focus group depends on the aim of the discussion; if the researcher use the discussion as a supplementary data, then the content analysis of the focus group is enough. Coding include identifying the topics that are discussed in the focus group, listing the accounts with the ID of each participant under each code and then comparing and contrasting between the groups interactions. Interpreting the data includes distinguishing between what the participants find interesting and what they find important to them. Reporting includes writing up all the elements of the focus group discussion that answer the research questions (Morgan, 1997).

As my aim of analysing the data was to develop a supportive care strategy, I felt that the focus of my research question was on the content of the focus group discussion; however, after further reading and re-reading the nurses' accounts, I found that the group interaction could not be separated from its context, I sought then to write reflections on participating in the focus group discussion and then summarised principles for the development of supportive care strategies (as I will discuss in chapter 8 and 9). I acknowledge that the focus group discussion in this study is limited. Firstly, the topics were specific and I had limited experience in encouraging the group to get more involved in the discussion. Secondly, I did not notice that I was leading the group rather than giving the participants freedom to express their feelings and interpretations. I discovered this when I transcribed the focus group discussions.

Finally, the length of the discussion (1:30 min) was not sufficient to raise all the issues in the focus group discussion.

In summary, this chapter discussed the philosophical perspectives that underpin the study and the use of narrative as an approach to data collection and analysis. The chapter aims to provide a reflective account of the application of a narrative approach in the field work. I reflected on the interview process; in particular, the challenges posed by conducting open-ended interviews with the women in this study, then I considered the process of translating, transcribing, and analysing the interviews. In the third section, I discussed the ways in which I undertook the nurses' focus group discussions. The following chapters [chapters 4-8] discuss how I analysed and interpreted the findings of my study.

Chapter 4

Introducing the participants of the study

This chapter provides a preliminary introduction to the findings chapter. The aim is to give the reader some more detail about the participants in the study, and the context of each woman's story. I reflect on each woman's interview, and how the interviews have enriched my understanding of the women's experiences.

4.1 Eman

Eman is a 21-year-old woman, the youngest in her family, who left school early whilst still at the age of ten. She was born with a congenital anomaly of an obstructed bowel, and a small bladder, which left her with a permanent abdominal stoma and urinary incontinency. She also had a sensory and motor deficiency in her left arm and leg, due to an unknown congenital reason. Eman developed massive bleeding after cystoplasty³¹ surgery. She was then transferred unconscious to the ICU and stayed for seventeen days on continuous cardiac and respiratory monitoring. She was then transferred to the surgical ward. I interviewed Eman twice: the first time was three weeks after her transfer to the surgical ward, and the second interview was two months after being discharged.

In the first interview, Eman, who was a very quiet woman who took her time in answering each question. I tried not to ask her direct questions, in order to encourage her to tell more about her experiences, but it needed a lot of effort to encourage her to continue talking about her experience in the ICU. There were a lot of silent moments during the interview.

In the second interview, she was more relaxed and spontaneously talked about her time after she had been transferred from the ICU. She explained that in our first interview, she considered that I might be one of the medical staff who worked in the ICU. This was in spite of my continuous explanations of my position as a researcher, and my explanations about the purpose of the study. My understanding of this was

³¹ Plastic surgery to enlarge the bladder.

that she considered the health-care staff as those who aimed to gain particular type of information from their patients in order to write reports. In the second interview, however, she mentioned that she was happy to tell more about her experience at home as she felt relaxed. This was reflected in the way she told her stories. She explained more, and clarified some of the topics we discussed in the first interview. For example, I raised a question about her relationship with her family; she was reticent in the first interview, whilst in the second interview, she freely started to tell about her relationship with her family and friends. I was interested in knowing more about the gradual changes in her identity, especially in relation to her disability.

4. 2 Um- Anas

Um- Anas is a thirty six-year old mother, living with her husband and two sons. She was born with a congenital heart defect of Aortic stenosis³². She had three operations when she was five, nineteen and twenty five years old to widen the valve³³. She developed valve stenosis again three months before her admission to the ICU and planned to do Aortic valve replacement surgery. After the surgery, she was transferred from the theatre to the ICU for the weaning process³⁴, and for close monitoring. She spent twenty three days in the ICU.

In her first interview, Um- Anas was relaxed and calm, and talked about the events in the ICU in a factual way [she only described what happened to her], and this could be due to her background as a history teacher. Um- Anas was the second woman I interviewed in my study with whom I felt that my experiences as a nurse affected the way I posed my questions. I asked her questions, such as “Tell me about your illness.” I felt that my questions were narrow and specific, and posed little opportunities for conversations, and did not give Um- Anas a chance to tell me about her experiences. On reflection, I decided to ask more general questions, and give her the chance to express her experiences and feelings. Unfortunately, when I tried to contact her at home³⁵ to conduct a follow up interview, her neighbour reported that

³² Narrowing of the Aortic valve of the heart.

³³ She had three surgeries in one of the countries near Jordan.

³⁴ The process of removing the mechanical ventilation machine gradually from the patients until they can breathe effectively with out using the machine.

³⁵ I used a telephone call.

she had moved with her family to another country. I learned from her first interview how to ask fewer questions, and to allow the participant to tell more stories.

4.3 Abeer

Abeer is a 21- year-old woman, a university student, studying psychology. Abeer is the youngest in her family, and she lived with her mother and two brothers. Abeer has been blind since birth, and in the interview I had a feeling that she totally depended on her mother, even for her basic needs, such as toileting and bathing, and this was obvious when I asked her about her personal life, and how she managed to take care of herself. Abeer was admitted unconscious to the ICU, via the emergency department, after she was involved in a car accident. She spent three weeks there, with multiple fractures and injuries, and then was transferred to the surgical ward.

My first experience with her was challenging, especially within 15 minutes of the initial interview. This was because I have no experience in interviewing blind women. At the beginning she showed very limited response, answering with brief phrases. She was cautious, giving little information, and short answers, which made me wonder if I would be unsuccessful in gaining her trust, and would be unable to encourage her to tell me about her experiences. I also felt hesitant in asking her about her blindness, because I thought this could be a sensitive topic. As the interview proceeded she became more relaxed, and more responsive. It seemed to me that she accepted me and was less reluctant to share some of her experiences. This in turn influenced the line of my questioning. I started to ask more precise questions, and used my aide mémoire to probe with more questions. Part of the difficulty I faced was connected to her use of silences. Because she could not see me, when I kept silent in order to allow her to tell me more, she looked around to try to find where I was. I felt that using silence was ineffective during our conversation.

I felt dissatisfied with my interview with Abeer, and could not think of a way of encouraging her to tell me more about her experiences. I sought help from my supervisors, who suggested delaying the follow-up interview for a relatively longer time, to allow her to recover from her illness, and perhaps then share her experiences. Three months after her discharge from hospital I contacted Abeer, in order to conduct the follow-up interview. Unfortunately, when I requested another interview,

she apologised, but showed her unwillingness to take part in any follow-up interviews.

Abeer's story, although short, affected my understanding of the women's experiences in the ICU. I started to challenge my prior assumptions, as a nurse, about the patient's experiences in the ICU, and took into consideration that there are many disabled women who suffer during their stay in the ICU, and who have special needs as individuals.

4.4 Um- Mahmoud

Um Mahmoud is a 62-year-old widow, who lives with her five daughters and two sons. She was admitted to hospital A for hysterectomy surgery, stayed in the surgical ward for two weeks, and was then discharged home. At home her wound became infected but she delayed seeking medical treatment. Her condition gradually deteriorated into septic shock, and she was admitted to the ICU via the Accident and Emergency unit.

Um- Mahmoud was a calm and quiet woman; she talked slowly, and gave a deep sigh after each sentence. In the first interview, I invited her to tell me about herself. After an initial hesitation she started to describe her events in the ICU in a relatively disorganised way. She moved backwards to the time before her illness, then moved to her time in the ICU, and compared the conditions there with the conditions in the ward. At the end of her story, I had the feeling that she gave a descriptive list of the issues she faced in the ICU, and I was unsuccessful in getting any depth to our conversation, despite my asking clarifying questions, and probing for more explanations. I felt that by conducting a second interview it would help me to ask more in-depth questions, and to clarify more about her life.

In the second interview, she welcomed me warmly into her home, and invited me to share a cup of coffee. She then spontaneously started to tell me about her time in the ICU, and about the time after she had been discharged home. This reflected on my questioning. I asked a few questions and repeated some of her words in order to encourage her to continue the conversation. After she had told me her story, she admitted that she felt reluctant to share her experiences in the first interview because

she was exhausted, and felt that she had nothing to tell, but in the second meeting she felt relieved when sharing her experiences with me.

4.5 Um- Bashar

Um Bashar is a 60-year-old widow, and a housewife. Her husband died five years before she became ill. She lives with her daughter and son; both are university students. She works at home doing embroidery to financially support her family. Eight months before she was admitted to the ICU, she complained of severe abdominal pain, and was referred to the out-patient clinic for an ultrasound. Her private physician confirmed that she had a fibroid in the uterus, and advised her to have a hysterectomy. She planned to be admitted for hysterectomy surgery two months after that. After the operation, she became severely hypotensive³⁶ and lost consciousness. One day later, the doctors decided to re-operate on the surgical site, because she had developed internal bleeding. She spent three weeks in the ICU, and one week in the gynaecology ward.

In her first interview, she was anxious about using the tape-recorder. As the interview went on, she became more relaxed, and shared part of her experiences. It seems that she was anxious when recalling her experiences in the ICU, and felt reluctant to share parts of them, which she considered as a 'private experience'. Her tension was reflected in the interview process, as I could not ask more in-depth questions, especially about the traumatic experiences in the ICU.

In the second interview, three months later, I was welcomed at her home, and she mentioned that she was very happy to see me again. She talked freely about life after her discharge from hospital, and then she moved back in time, and told me about her experiences in the ICU. I had the chance to ask for more clarification, and probed with more questions about her experiences. As we developed a trustful relationship, she was happy to tell me in more depth about part of her private experiences. I also felt that I had been privileged to live her experiences, and to share her feelings, especially the aspects related to the covering of the body, and the care received from a male health-care giver.

³⁶ Low blood pressure, while hypertension means high blood pressure.

She highlighted aspects of the nurses' care which I took for granted; I started to challenge my own thinking, and thought about how Muslim women experienced male nurses' care in the ICU. This reflected on the analysis part of the study, as I developed a theme related to the nurses' care as related to their gender.

4.6 Um- Fadi

Um- Fadi is a 37-year-old mother. She was living with her husband and her 2-year-old daughter. She had developed hypertension and gestational diabetes during her pregnancy, and had a caesarean delivery. Her premature son developed aspiration pneumonia, and was admitted to the neonatal ICU. Um- Fadi was admitted to the maternal ward a few days after her delivery, due to uncontrolled hypertension and severe shortness of breath. Two days later, she had severe hypertension, and lost consciousness, and was admitted to the ICU for cardiac and pulmonary monitoring. She spent three weeks in the ICU, and was then transferred to the maternal ward.

In her first interview she seemed sad and depressed. Although she welcomed me warmly, and mentioned that she was happy to share her experience with me, she was anxious and worried, especially when she recalled her children. She cried when she narrated her loss of her ability to care for her children. I felt sympathy with her, and tried to support her psychologically. When transcribing the interview, I felt unhappy with the limited depth questions that I asked. I had not paid attention to her story relating her loss and change in identity as a mother who could not care for her children. I felt that my questions were general, and did not probe deeply about her role as a mother. I sought then to conduct a further interview, in order to get more 'inside' more ideas about her experience as a mother in the ICU.

In the second interview, three months after her discharge from the hospital, she was relaxed and willing to talk freely; this provided me with the courage to further discuss her experiences as a mother, and her changed identity over time. I learned from her interviews to actively listen to the women's accounts, and to probe with questions which revealed more in-depth accounts, relating to the research topic.

4.7 Um-Mohammed

Um- Mohammed is a 75-year-old grandmother. She lives with her elder brother and her daughter-in-law, and three grandchildren. She was admitted to hospital for a total abdominal hysterectomy, and stayed for three weeks in the surgical ward. Later, she developed a pulmonary embolism, and was transferred to the ICU, where she spent five days. Because of her age, she has difficulty in walking, and needed assistance in some of the daily living activities, such as bathing and grooming.

During the first interview, three weeks after her transfer, she was weak, and could barely talk. She responded to the interview questions in a low tone of voice, and a slow rhythm of speech. She apologised that she could not remember each detail of her experience in the ICU. After about an hour's conversation, I felt that she was tired, and wanted to have a rest, as she could not follow the discussion, and her eyes closed many times. I asked her permission to meet her again for a second interview. Sadly, when I wanted to conduct the second interview, I was informed by her daughter that her mother had died one week ago. I felt sad about her, and sent my condolences to her family.

4.8 Amal

Amal is a 19 years-old high school student, living with her mother, three sisters, and four brothers. Her mother worked at a school in order to secure the family's financial position. Amal was admitted to the surgical ward as a case of hyperthyroidism, underwent surgical removal of the thyroid, and was then transferred to the ICU because of her unstable haemodynamic³⁷ status, and her severe hypotension. She was unconscious for three hours, and was on continuous cardiac monitoring. She stayed for two days in the ICU and was then transferred to the surgical ward, where she spent three weeks.

The first interview was carried out in her third week in the surgical ward. Although Amal had to talk slowly because of surgical intervention, she was happy to answer my questions. She spontaneously started to tell me about herself and her time in the ICU. Her initial response was positively reflected in the way the interview preceded.

³⁷ is a medical term for the dynamic regulation of the blood flow in the brain

I was relaxed, and felt no qualms in asking for detailed information, which was gained, mainly by repeating some of her phrases, or by asking for clarification. She was happy for me to arrange a follow-up interview, which was conducted two months after her discharge from hospital. In the second interview she related more detailed stories about her experiences in the ICU, and her feelings when meeting her family, after the transfer to the surgical ward. I felt the interview had gone well and I particularly noted how she related ways in which she had learned from her experiences in the ICU to apply in her future.

4.9 Um- Adam

Um- Adam is an 82 year-old grandmother, living with her eldest son, his wife, and their five sons and a daughter. Um- Adam is the oldest person in her family; she had five sons and three daughters, all of whom are married. She has a history of hypertension, diabetes, asthma, and heart failure. She is physically dependent on her sister-in-law to help with some of her daily living activities, such as bathing, and toileting. Before her admission to the ICU, she developed severe shortness of breath and chest pains in her left side. She was seen by a respiratory consultant, who advised her to be admitted to the hospital for respiratory investigations. The lung CT scan showed that she had left lung fibrosis, and the consultant decided to perform a lobectomy³⁸. During the surgery, she developed hemodynamic instability, and was transferred while unconscious to the ICU. She spent two weeks there, with three days on a ventilator.

She was unhappy about the nurses' care in the ICU, and transferred herself from the ICU to the surgical ward where I met her. She was one of the women with whom I felt unable to build a trusting relationship. She perceived me as a young nurse with limited experience of life in general. Although I explained my role many times to her, she maintained some barriers of communication between us. She had a short temper, and spoke in a loud voice. She showed a lot of anger while she was talking about her experience in the ICU, and smiled ironically. This influenced my interaction with her. I felt reluctant to ask in-depth questions about her experiences in the ICU, and I could not find any way of building a two-way discussion. It seemed to

³⁸ Removal of the lower lobe of the lung.

me that she transferred her anger on me, as I was a passive listener. Um- Adam's perspective may differ from mine but I found it was difficult to develop rapport with her.

When I called her to arrange for the follow up interview she refused to reply to the telephone, and told her daughter-in-law that she was unwilling to talk to anybody. I felt rejected at that time, and tried to understand her feelings of anger. I think she considered me as one of the health-care staff who she was trying to forget. The ICU experience was painful for her, and she was trying to adapt by forgetting. Her answers in the first interview were brief, but I felt that her suffering was mixed with her wariness. I would have liked to explore issues with her in more depth in a second interview but this was not possible.

4.10 Um- Sami

Um Sami is a 72 years-old-grandmother. She lives with her daughter in a large city in Jordan. She has three sons and a daughter, all of whom are married. She worked as an Arabic teacher for seventeen years before retirement.

Um- Sami was admitted to the ICU with deterioration of the level of consciousness, related to massive upper gastrointestinal bleeding. A few days later, she developed respiratory failure, and was connected to a ventilator. She also had close cardiac monitoring, and drug support. She stayed fifteen days in the ICU, before she was transferred to the ward. During the first interview, she was very polite, using a lot of compliments, and tried to keep a smile on her face throughout the interview. She dealt with me in a professional way, and was conservative when mentioning the nurses' behaviour in the ICU. I felt that she was trying to hide her feelings, but her smile covered a lot of pain. It seems that she believed I was a member of the health-care staff, and was reluctant to share her feelings. I tried to encourage her to tell me more about her experiences, and explained my role as a researcher to her, but it seems that I could not win her trust. Unfortunately, I was unable to conduct a further interview, because she moved outside of the country with her family, and could not be contacted.

4.11 Um-Ahmed

Um- Ahmed is a 35-year-old mother, and a housewife. She lives with her husband and five children in one of the Palestinian refugee camps. Eight months after the delivery of her last child, she had severe pain in her joints and tightness in her chest. After she had visited her specialist, she was diagnosed with Systemic Lupus Erythematosus (SLE)³⁹, and was advised to be admitted to hospital. A few months later, she was admitted to the general medical ward in hospital B, where she was diagnosed as having Pulmonary Embolism (PE)⁴⁰. In the hospital she developed severe shortness of breath, lost consciousness, and was admitted to the ICU. She spent three days unconscious, and on mechanical ventilation, before she awoke. She was transferred to the respiratory ward after fourteen days, and spent 45 days in hospital. I interviewed her three times, the first time in the respiratory ward, the second time at home, three months after her discharge, and finally six months after her discharge.

Um- Ahmed was the first woman whom I interviewed for this study. This interview was a valuable experience, which I used as a guide to the other interviews and interaction. Initially, I used closed questions, which reflected my limited experience in conducting open-ended interviews. I felt dissatisfied with this particular interview, and asked for some help from my supervisors about how I could encourage the women to tell me more about their experiences. I learned then how to ask clarification questions, and to probe with further questions to initiate discussion.

In the second interview, however, she welcomed me warmly, and talked freely about her experiences. This encouraged me to ask further detailed questions about her experiences in the ICU, and afterwards. I was affected mostly by her account relating to missing her children during her time in the ICU. At the end of the interview she had a visitor, and asked my permission to arrange another meeting.

³⁹ Systemic lupus Erythematosus is a disease in which effects the body's immune system starts attacking the body instead of defending it. Lupus affect many different parts of the body, mainly the joints.

⁴⁰ Is solid or semi-solid particle travelling in bleed stream and cause blockage in the lung arteries

My aim in the third interview was to get an in-depth account about the effect of her critical illness on her relationship with her family and the changes to her role as a mother.

4.12 Um-Essa

Um- Essa is a 68-year-old grandmother, who lives with her six sons, her daughters-in-law, and twenty-two grandchildren. She was admitted to the ICU in hospital B after she fell down from her balcony, while she was having coffee with her son. She was admitted to the ICU with multiple fractures, and was placed on complete respiratory and cardiac support. I had three interviews with Um- Essa, the first one three weeks after her transfer to the orthopaedic ward. The second interview three months after her discharge and the third interview one month later.

She described herself as a grandmother, who lived happily with her sons and grandchildren, and she talked about her time when she was enjoying herself with the family, and talking to her daughters-in-law. She went further, and described her everyday activities and routines; she used to listen to the news in the morning, helped in preparing the meals for the family, and listened to the music in the afternoon. To her, Friday was the day of the family gathering; she used to invite all the family members to share breakfast, and enjoy family conversation. She relied on her daughters-in-law to run errands, and do the bulk shopping.

During the first interview, Um- Essa appeared changeable – she was happy one minute, and hostile the next. At the beginning of the interview, she was cooperative, and talked freely about her life with her children. When she recalled her time in the ICU, she started to become anxious and lost the ability to comprehend what had happened to her. It seemed to me that she was agitated, and could not express her feelings in words but she vividly communicated her experiences with the ICU nurses. Towards the end of the interview, she mentioned that she felt tired and preferred to end the interview.

In the second interview, she mentioned that she was happy to see me at her home, and invited me to share her lunch. She kept referring to me as her (M) daughter, I suppose because of her age. She smiled whilst she talked about her suffering. She

was thankful to be alive after her critical illness, and thanked Allah many times for saving her life. She mentioned that she had strong religious beliefs. In the third interview, she was relaxed, and smiled most of the time. She was relaxed and spoke freely about her time at home. She repeated many of her experiences in the ICU and stressed on the power of Allah in supporting the people after surviving critical illness.

4.13 Um- Ali

Um- Ali is a 56-year-old grandmother, who lives with her son and two daughters in a large city in Jordan. She was dependent on her unmarried son for financial support. After nine months of continuous visits to the out patient clinics, she was diagnosed with an intestinal obstruction, and was admitted to hospital B for an intestinal resection⁴¹. Shortly after her surgery, she developed massive bleeding, lost consciousness, and, was transferred from the surgical ward to the ICU. She spent three days there on respiratory and cardiac support, and another two weeks on cardiac monitoring. She had a past medical history of diabetes and hypertension.

I met her twice. In the first interview she was calm and quiet, and talked slowly. She mentioned that she had severe pain which disturbed her sleep, and other activities, and she used to utter words such as ‘uhh’ and ‘ay’ to show her feelings. This gave me an indication that she could be in pain, and I asked if she would be able to continue the discussion, but she insisted that she would like to tell me about her experiences.

In the second interview, she was relaxed, and talked freely about her experiences. During the interview, I asked a few clarification questions, and summarised what she had said. This influenced her responses, as she started to tell more deeply about her experiences. I felt happy with her interview, and she provided a rich account about her time in hospital, and after her discharge home.

⁴¹ Remove parts of the gut in a surgery.

4.14 Um- Saber

Um- Saber is a 59-year-old grandmother, who lives with her two sons, and daughters-in-law. She has nine daughters, and forty grandchildren. She was admitted to the ICU after a car accident when she was with her husband, going to visit her cousin. She was in the ICU for four weeks, spending the first week unconscious, and was on respiratory and cardiac monitoring. She had multiple fractures, and plaster casts on the left femur and arm.

In the first interview Um- Saber wore an oxygen mask, and had difficulty in breathing, I asked her permission to conduct the interview later, when she was able to talk without the oxygen mask. Two days later she was very forthcoming, and communicating with me. She was kidding and smiling most of the time. This was reflected in my rapport with her, I liked the interview, and felt easy when asking clarifying questions, and able to probe with more topics for discussion. She mentioned that she was a religious woman, and frequently wished to visit Mecca⁴². Praying five times a day and reading the Qur'an⁴³ was part of her everyday activities.

In the second interview, she looked tired, and had limited mobility, due to the plaster cast, and this was evident from her appearance. However, she welcomed me, and mentioned that she was happy to tell me about her experiences. During the interview she invited me to share tea, coffee and lunch. I enjoyed her hospitality and generosity, and I felt that I had developed a friendly relationship with her. She invited me to visit her home after my graduation.

4.15 Um- Malak

Um- Malak is a 28-year- old mother, who lives with her husband and mother-in-law, and her four young daughters. Her illness history dates back to three weeks after she had delivered her fourth daughter. She complained of a severe pain in her left ear before she suddenly lost consciousness. Her husband sent her to the accident and emergency unit, from where she was transferred to the ICU. She was diagnosed with meningitis, and spent two weeks in an isolated room in the ICU. She then was transferred to a medical ward, where she stayed for two weeks.

⁴² The holy place in Saudi Arabia for Muslim pilgrimages.

⁴³ The Islamic holy book

The first interview was conducted in the medical ward; she was cooperative, open, and responded to all my questions. She seemed to like to communicate with me, and I felt comfortable interviewing her. I felt satisfied with the amount and quality of the data gained. I recognised that I felt more confident in my ability to interview women who are closer to my age; possibly this commonality assisted the development of rapport.

The second interview was conducted at home, three months following her discharge from the hospital. She was quite and cooperative but the interview was interrupted by the visit of her neighbour, who stayed for one hour. Because she insisted that she wanted to share the lunch with me, I continued with the interview after the lunch. I shared with her part of my personal life but I felt privileged when she shared part of her experience as a mother, who lives with four young daughters. I empathised with her experience of motherhood, although I am a single woman and have no experience as a mother.

4.16 Um- Nader

Um- Nader is a 35-year-old woman, living with her five children in a Palestinian refugee camp. Her husband died after a car accident six months before she gave birth. She had twins, and was admitted to the hospital for post partum hypertension, and spent four weeks in the gynaecological ward in hospital B. Two months later she developed severe chest pains and shortness of breath, and was admitted unconscious to the ICU. She was diagnosed with a pulmonary embolism, and spent one week on cardiac monitoring, where she had cardioversion⁴⁴ shock treatment, and was then transferred to the maternity ward.

In the first interview, she was sad and depressed. She was quite cooperative, and spent time in responding to each question. When I asked her questions about her illness, she responded by smiling but I felt her suffering behind her words. This was evident when I asked her to tell me about her time before the illness. She started to

44 the process by which an abnormally fast heart rate or cardiac arrhythmia is terminated by the delivery of a therapeutic dose of electrical current to the heart at a specific moment in the cardiac cycle.

cry, and left me feeling guilty at asking such a question. I was deeply affected by her story, which still lives with me.

The second interview was similar to the first. She welcomed me warmly, and mentioned that she was happy to share her experiences with me. Initially she put on a front and give an appearance of coping with her loses. She told her stories in a calm way and smiled most of the time but as the interview progressed the extent of her suffering revealed and she started to express her sadness. I felt sympathy with the losses and changes in her life before and after her critical illness and I reflect on her story in detail in chapter seven.

Chapter 5

Women's experiences of pain and suffering

5.1 Introduction

I had no previous idea about what was happening, I couldn't hear or see anything, I was unconscious, you know when you stay for long, without knowing what was happening, you lost too many things...when I woke up there, my body was covered in plaster cast. Erm I was stunned. I never imagined in my life that this would happen to me, yeah, it was horrible!!. Yeah. I was full of pain(s); my legs hurt a lot...I remember that I was connected to that big machine; I couldn't breathe and there were tubes all over my body, Oh!! I felt the oxygen blows, yeah, the oxygen was entering my lungs, and I couldn't breath. I felt suffocated, and I wished that I could remove that tube from my mouth, but I couldn't; I was covered in plaster cast. It was horrible!! I felt very strange, hearing different voices. I couldn't speak or even shout to anybody. Oh, I couldn't call anybody from my family, I lost them, and I don't know where my husband was. I was totally broken (Um- Saber, first interview).

The above quotation, by Um- Saber, illustrates the main focus of this chapter. Um-Saber was admitted to the ICU after a car accident. She describes her state of shock on learning that she had been admitted unconscious to the ICU and regaining consciousness to find herself connected to a respirator, unable to move or perform any activity. She describes her physical pain as part of her suffering as she had severe pain from broken limbs. The sudden loss of her previous good health led her to think about her family; she describes her feeling of strangeness and loss when she could not communicate with her family. With all of these critical events suddenly crashing in on her life, she had lost her sense of self and felt a 'totally broken' woman.

Critical illness is sudden and unexpected and is often life threatening. The admission to the ICU is accompanied with physical pain, psychological distress, family loss, and the harmful affect of medical procedures which may all cause critically ill people varying degrees of suffering. A small number of existing studies shed light on the experience of ill women within Western cultures (Charmaz 1983; DIPEX 2007). However; the experiences of suffering among critically ill Muslim women have been neglected within published health research. This chapter focuses on Jordanian Muslim's women's experiences of suffering shortly after their transfer from the ICU to the hospital wards. The chapter is interlinked with chapter six which examines the

women's experiences of their bodies, and chapter seven which examines the changes of their experiences over a period of time and at their homes. However, for clarity, I have divided my findings into these three chapters.

Women in my study fell into three categories: First, women like Um- Saber who was suddenly admitted after an accident. Second, women who had unexpected post-operative complications, and were moved whilst unconscious from the operating theatre to the ICU. Third, women who were transferred from hospital wards when their conditions suddenly worsened. From examining the women's narratives after their transfer from the ICU to the wards, it emerged that there were multiple and overlapping experiences of suffering.

The chapter starts with the background about the experience of suffering as documented in the wider literature and is followed by an overview of the data analysis and a concise summary of each section in the chapter. The findings reveal three main categories, these are: the multi-dimensions of suffering, the experience of vicarious death, and the temporal element of suffering which will be the heading of each section in the chapter. Both Um- Essa's and Um- Saber's accounts are used as a guide when comparing and contrasting other cases. Um- Essa's account demonstrates the experience of suffering as connected to the physical pain, social suffering, and negative experiences of nursing care. Um- Saber's account demonstrates the experience of suffering as connected to the experience of vicarious death and the temporal element of suffering. Finally, I discuss the findings within the context of the wider literature.

5.2 Background

The experiences of pain and suffering as narrated by the women in this study are very complex with overlapping themes and issues, but there are a number of perspectives which can assist in the interpretation of these narratives. Kleinman's (1988) illness experiences theory discussed the personal and cultural meanings of pain and suffering among chronically ill people. Kleinman highlighted that people accept their suffering as part of every day living. Kleinman elaborates that the

cultural meanings of illness are vital in shaping the pain and suffering that ill people experience:

The cultural meanings of illness shape suffering as a distinctive moral or spiritual form of distress. Whether suffering is cast as the ritual enactment of despair, as paradigmatic moral exemplars of how pain should be borne (as in the book of Job), or as the ultimately existential human dilemma of being alone in a meaningless world, local cultural systems provide both the theoretical framework of myth and established script for ritual behaviour that transform an individual's affliction into a sanctioned symbolic form for the group (Kleinman, 1988, p.26).

In this statement, Kleinman argues that whatever the personal beliefs about suffering, people give meaning to their suffering and respond to their illness experiences in relation to their cultural background. This also reflects the moral and spiritual suffering among some religious believers.

Williams (1984) analysed the stories of people who suffered from rheumatoid arthritis. Williams revealed that when his participants related their biography, they reorganised their accounts to compensate for the changes brought by their illness and their relationships within the world in which they lived. In contrast, Bury (1982) found that the sudden onset of arthritis was communicated by the people with rheumatoid arthritis as a complete interruption in their lives. To this extent, illness was considered a discontinuation of their ongoing lives and led the arthritis sufferers to re-think and question previously taken for granted assumptions about their every day lives. For both Williams and Bury, the meaning of illness was fundamentally related to the participants' viewpoint, based on shared cultural beliefs for those who experienced arthritis. This chapter asserts that the shared cultural beliefs affect the participant's interpretations of their experiences.

There are similarities amongst those experiencing chronic illness and those with critical illness; suffering is evident when the illness disturbs the integrity of the whole person and leads people to re-evaluate their past experiences and re-connected it to their present illness (Kleinman, 1988; Williams, 1984; Bury, 1982). Nevertheless, the experience of women in the present study is associated with the sudden onset of illness, the unpredictability of the illness conditions, and a period of

unconsciousness in which the ill people were unable to comprehend all the events of their experiences. These experiences could provide different meaning to those who suffer critical illness compared to those with chronic illness.

The experience of suffering for people who receive palliative and end of life care has been examined in the research literature. The founder of hospice and palliative care, Cicely Saunders (1960s), described one way of understanding suffering among people who may be at high risk of dying. Saunders coined the concept of ‘total pain’ to alert health care providers that pain cannot be understood as purely a physical phenomenon but in relation to the personal social, psychological, emotional, and spiritual context. She used the patients’ narratives and biographies as a means to understand their experiences of pain and suffering and argued that the best way to understand and unfold the problems encountered during terminal care is by analysing the patient’s accounts of their experiences (Saunders and Sykes, 1993, Saunders and 1990, Clark, 1999). Listening to the person’s fears and concerns in a sympathetic manner is also a means of addressing the emotional pain of dying, which in turn influences an individual’s perceptions of their physical pain. The social pain described by Saunders includes the distress of the dying person’s family and friends. However, Saunders did not mention the cultural aspect of pain. The present study found culture to have a major role in the women’s interpretation of their illness and suffering.

Despite the strong association between suffering and disease, Cassell (2004) notes that there is a lack of discussion of suffering in the medical literature. Cassell explained three integral points to suffering: first, suffering affects the person as a whole. The person has a past, present and future, a cultural background, family, different roles, social relationships, and a private life. Therefore, the person cannot be divided into parts. Second, suffering occurs when

The state of severe distress associated with events that threaten[s] the intactness of the person (Cassell, 2004, p.32).

This distress can be experienced as real or perceived and stays with the person until the threat diminished or the integrity of the person is restored. Third, as the suffering affects the whole person, there is no separation between the mind and the body. Medicine tends to focus only on the body; the lack of understanding of

suffering stemmed from medicine's adoption of the Cartesian dualism with its notion of a mind body split.

Frank (1995) draws upon Cassell's definition of suffering and points out that suffering could be experienced when the person tries to resist the threat to himself or the change of his identity. The suffering is incorporated inside the self and body, and the person's reluctance to share their stories of suffering could increase their suffering. He also explained that suffering has a social nature and social context. The personal experience of suffering reflects a cultural explanation. As discussed in the method chapter (see section 3.3), Frank used three types of narrative that ill people narrated when experienced their illness: the restitution narrative, the chaos narrative, and the quest narrative. He explained that people who suffer an illness and imagine life never getting better again, told a chaos stories; the stories are fragmented, disorganised and absence of it is narrative order. The stories reflect how the sufferers lived through their illness but found difficulty expressing their experiences in words. Frank (2001) asserts that:

Suffering is loss, present or anticipated, and loss is another instance of nothing, an absence. We suffer the absence of what was missed and now is no longer recoverable and the absence of what we fear will never be. At the core of suffering is the sense that something is irreparably wrong with our lives, and wrong is the negation of what could have been right. Anyone who suffers knows the reality of suffering, but this reality is what you cannot 'come to grips with'. To suffer is to lose your grip. Suffering is expressed in Myths as the wound that does not kill but cannot be healed. (Frank, 2001, p.355).

There are some elements that suffering shared with physical pain. Cassell (2004) points out that suffering and pain could be interlinked for people with illness, especially when the physical pain is overwhelming, continuous, and non manageable, but to remove pain does not lead to the removal of suffering.

Intensive care patients are one group who suffer from their illness. Many studies have described how ICU patients recall the stress and discomfort they experience when they are initially admitted to the ICU (Elpern et al 1992; Turner, Messervy and Davies 1992; Soehren 1995; Rotondi et al 2002; Hweidi 2005). Some of these experiences include: the experience of physical pain (Pasero and McCaffery, 2002), lack of sleep (Cooper, 2000), difficulty in communication (Hafsteindottir, 1996),

lack of control (Soehren, 1995), and difficulty in breathing due to ventilator (Bergbom- Engberg and Haljamäe, 1989; Rotondi et al, 2002; Hweidi, 2005). The ICU environment is considered by most patients as unfamiliar, stressful and noisy (Johnson and Sexton, 1990; Dyer, 1995; Topf, 2000). Other studies found that the traumatic experiences in the ICU affected critically ill people psychologically and left them with negative feelings of fear, frustration, depression and anxiety (Mandy, 2000; Whittaker and Ball, 2000, MacKinney and Melby, 2001; MacKinney and Deeny, 2002). In addition, some critically ill people who had extreme negative experiences described that they experienced unreal events of hallucination, deliriums, and nightmares (Granberg et al, 1999; Dyson, 1999; Justice, 2000; Rundshagen et al, 2002; Roberts and Chaboyer, 2004). These studies provide an explanation of how critically ill people experience their illness. However, none of these studies discussed the ways in which people from different cultures might give different meanings to their experiences. The women who lived in the eastern Jordanian culture could have a different meaning of their experiences in the intensive care than those women in the Western countries.

In the United Kingdom, the voices of critically ill people have been examined through their narratives. The database for Personal Experiences of Health and Illness (DIPEX, 2007), (discussed in chapter two) describes the lived experiences of people with critical illness from their stories. The DIPEX database classified the patient's interview into topics and each topic is divided into different categories. Critically ill people describe their experiences of critical illness and the affect of these experiences on their lives after discharge.

The present study used the participants' stories to explore the experiences of critically ill Muslim women who lived in a Jordanian eastern culture. In the next section, I will provide an overview of these experiences which are related to the women's suffering.

5.3 Chapter overview

To identify the themes and to understand the issues raised by the women's narratives, I created the table 5.1. This shows the connection between the narrative elements and how the themes and the categories have been developed.

The first category identified within the women's stories is related to their suffering from physical pain. The experience of physical pain was evident in many women's accounts, especially those who were admitted to the ICU after a major surgery or after an accident. The physical pain is also interlinked with the loss of their families and children. This brought a new theme which is related to the women's social suffering, I noticed that most of the women used the word 'nafsi' interchangeably to describe many aspects of their social and emotional suffering. Some women used the term to describe their emotional distress and the feeling of insecurity, while others used the 'nafsi' to describe the loss of the family support. I used then the concept 'nafsi' as a heading for the second theme.

The words 'vicarious death'⁴⁵ in the second category reflects extreme experiences of loss and change in the ICU where the women described how they believed their life could come to the end at any time. Some women felt insecure and unsafe, mostly during their initial time in the ICU. The first theme identified here is related to the uncertainty of their illness condition; participants' stories showed that women felt worried and thought that their condition may deteriorate any time in the ICU and they started to connect themselves to God to seek help and support. The second theme relates to women's accounts of witnessing the death of other ill people in the ICU. Women said that they were worried that they might have similar experiences as those who died in the same unit. The third theme is related to the participants' accounts of living in limbo and ambiguity. Women described their experiences of unreal events in the ICU and used the word 'hathayan'⁴⁶ to describe all the unreal events, the dreams, the hallucinations and the delirium experiences in the ICU.

The third category I discuss is related to time. Here, time has two main elements; 'lost time' describes women's stories when they described their initial time in the ICU, most of them were unconscious or lost their consciousness due to the sedations. The second element is 'suffering time' - the temporal dimension of women's accounts of living their suffering through time. Some women experienced their time in ICU as being a longer period than it was; they experienced it as a long period of suffering. It was clear also that the stories related to the period in the ICU are disorganised,

⁴⁵ The term 'vicarious death' has been drawn from my own experiences; it is not something that has been deconstructed in the relevant literature.

Table 5.1 The main codes, themes, and categories of suffering.

CODES	THEMES	CATEGORIES	
My body hurts	Physical pain and suffering	Multiple- dimensions of suffering	
Horrible pain			
Nail digging in my leg			
Alarm [physical pain]			
Full of pain(s)			
My pain was 'Nafsi'	Nafsi pain		
Family cheers me up	Psychological pain		
My life totally changed [at home]	Social suffering		
my life come to me a gain [with the family]			
Nurses are caring	Angels of mercy		
Angels of mercy- the ICU nurses			
so happy with their care- nurses			
Helpful nurses			
Nothing certain there [in the ICU]	Uncertainty	Experience of vicarious death	
all of sudden something happened to me			
Fast sudden events			
I may pass away at any time.	Allah's will		
I cannot guess what will happen			
ICU is a place of death			
I am under Allah's will			
People there [in the ICU] are near to death.	Witnessed other ill people dying		
Scared of death			
Allah helps the young men dying.			
See children before, dying.	Praising Allah		
Praying to Allah			
Thank Allah, if I was still alive.			
Alhamdoedllah [thanks God] I pass it [the critical time in the ICU].			
Allah won't let me be alone	Hathayan		
I have 'hathayan' there...			
I had awful dreams and night mares- hathayan.			
I was in a mosque praying to Allah	Lost time		Temporal element of suffering
Cannot remember anything			
Nothing to recall	Suffering time		
I was in a coma			
Nights passed slowly			
I stayed for long			
Years of suffering			

⁴⁶ The word hathayan in Arabic dictionary means unreal events (Al-Muheet Dictionary, p. 1019)

fragmented, and lack chronological order, these are discussed in the last section of the chapter.

In the first section, extracts from Um- Essa's narrative have been chosen to illuminate the multi-dimensional aspects of suffering. I use her account as a framework within which to compare and contrast the other women's accounts. In so doing, I highlight how the experiences of physical pain contribute to the women's suffering. I discuss the meaning of 'Nafsi' from the women's view point and how they interlinked this term to their experiences of emotional and social dimension of suffering. The loss of family support is also connected to the nurses' support in the ICU. I use the phrase 'angels of mercy' to discuss the women's accounts that describe their experiences with the ICU nurses.

In the second section, I use extracts from Um- Saber's account to illustrate the experience of extreme suffering as connected to the experience of vicarious death. Her account is used as a guide for other women's accounts, which are then compared and contrasted. Here, I discuss the experiences of uncertainty and fear, then the experience of witnessing the death of other patients, and the way in which the women use the term 'hathayan' to describe their nightmares and dreams.

In the final section, I explore the temporal element of suffering. I use both Um-Essa's and Um- Saber's accounts as a guide for other cases. I discuss the themes of 'lost time' and 'suffering time'. Finally, the experience of suffering are summarised and the findings in the context of the wider literature are discussed.

5.4 The multiple dimensions of suffering

The experience of physical pain as seen from the women's accounts has two main contexts; the first context shows that the experience of physical pain contributes to the women's suffering. In contrast, the second context shows that the physical pain is a minor element in the women's suffering. Both contexts are described fully in the physical pain sub-section. Then I discuss the 'nafsi' to illustrate the social and emotional dimension of the women's suffering. This includes the loss or change of the family and social support and the effect of these losses on the women's emotional

experiences. In the third part of this section, I discuss how these women experience the nursing care in the ICU.

5.4.1 Physical pain

...After I had a shower, I went to my son's flat. We sat on the balcony and we had a wonderful coffee together, then Oh! God's help, oh, still I couldn't imagine what was happening, oh dear! it was panic to me; the balcony fell down with us, and we all fell down shouting. Oh, God...I didn't wake up, I stayed in coma about a week, and you know I cannot remember any thing when I was unconscious, nothing at all but I felt my legs hurt me a lot. You know dear, I was all broken!! Extremely tired, very sick!! How can I describe that pain to you? It is horrible, horrible, OH!! God, a human being is very weak; I wish I died because of that pain!! I imagine that something like a nail digging on my body (Um- Essa, first interview).

This extract from Um- Essa's account reflects her individual experience of pain and suffering in the ICU. Um- Essa was admitted unconscious to the ICU after an accident. Um- Essa described how her physical pain was overwhelming. The experience of physical pain is interlinked with her sense of general weakness and tiredness. Her words 'a nail digging in my body', and 'horrible', and the utterance⁴⁷ "oh", which is culturally used when somebody has severe pain, indicate the way in which she describe the severity of her physical pain. Suffering was evident when the physical pain was severe and overwhelming and is interlinked with her loss of memory, loss of her body strength and her inability to comprehend all the sudden events that happened during her first time in the ICU. All these events left her to think that she was a 'broken' woman.

For some critically ill women, the experience of physical pain is the main element of their suffering, especially when the pain is severe, overwhelming, and disturbs their sleep. While for other women physical pain is considered as part of their illness before their admission to the ICU, and they have to endure pain to recover from their illness. Similar to Um- Essa's experience, Um- Saber, Um- Anas, Um- Ali, and Abeer described their physical pain as overwhelming and intolerable. Um- Ali, after she had been diagnosed with intestinal obstruction, she planned to have abdominal surgery. In the operation theatre she developed massive bleeding and was transferred to the ICU. She described how the wound from the operation site was extremely painful and disturbed her sleeping:

⁴⁷ Utter means to emit something as vocal sound.

It started when I had this severe abdominal pain; it was so painful, yeah. Still I can remember. That pain made me unable to sleep, and it has continued for about four days, and yeah, they were very awful days in my life (Um- Ali, first interview).

Similarly, Um- Anas, transferred to the ICU after open heart surgery, described that she had severe and overwhelming pain from the operation site; she used the sentence 'every cell in my body hurts' to describe the severity of her physical pain:

Oh, after the operation, I had pain all over my body. These pains were not tolerable; you see, when somebody feels that every cell in her body hurts, that is what I felt, every cell in my body hurts me. (silence) Nobody felt that pain, only me. I couldn't imagine myself like that; it was horrible (Um- Anas, first interview).

Um- Anas, as seen from her account, points out that the experience of physical pain is subjective and when the pain is overwhelming the pain affected her whole body.

In contrast to Um- Essa's experience, Um- Adam, Amal, and Um- Ahmed described their pain as part of their suffering before admission to the ICU. Um- Adam described her long history of pain, as she had a fibroid tissue in her lung. She said that before her admission to the hospital, the pain disturbed her sleep:

I was coughing all the time and I had severe pain during the coughing.... It was awful, and I used to wake up in the middle of the night unable to sleep because of the cough and the pain. I wanted that to end (Um Adam, first interview).

Um- Adam, after lobectomy surgery, described her physical pain as part of the healing process, which she had to endure. This lent quite a different tone to her account:

Well. Sometimes I feel pain all over my body, especially when I move or cough, but I think it's a matter of time. The wounds need time to heal (Um- Adam, first interview).

Similarly, Um- Ahmed had experienced severe joint pain before her admission to the hospital. She described how the pain affected her every day life; the pain limited her physical mobility and she found difficulty in doing the housework:

...my illness started a long time ago; I think many years ago, when I had an awful pain in my joints. The pain was all over my body; in my knees, in my ankles, and I found it difficult to stand for long, it became worse after doing the housework. It was frequent. I visited Dr....and Dr....They gave me Musakkinat. Actually, I felt that these drugs helped me a lot. The pain decreased for a short period but, you know, as soon as the effect of the drug finished, I had my pain again (Um-Ahmed, first interview).

The experience of pain for Um- Ahmed is a continuum of her suffering before her admission to the ICU. The use of analgesic medication did not help in decreasing her

suffering; she suffered continual pain which affected her mobility. When Um-Ahmed was admitted to the ICU and had lost her consciousness, she described that she felt very weak and could not control her body, but the physical pain was apparently a fairly minor part of her experience. She described that she had some pain in her joints, but that her suffering was primarily connected to the loss of her independence and family support:

...I had some pain in my shoulders, especially when I moved my hands but I felt that without my family and husband's help, I could not face all of these critical changes alone. He gives me a strong push in life, and he tried to decrease my "nafsi" pains (Um- Ahmed, first interview).

As can be seen above, Um- Ahmed used the term 'nafsi' to describe her pain which is related to the loss of her family support. This type of suffering will be discussed in the following section.

5.4.2 Nafsi⁴⁸:

All the women used the word 'Nafsi' to describe the loss and change of their family support. They identified the presence of family as vital for their emotional wellbeing. For some of them, family support is considered an essential element of life, to the extent that life involves being with their family, while death is connected to the feeling of loneliness and strangeness. Um- Essa perceived the ICU as a very strange place, unlike her everyday world. There was nothing familiar to provide a way for her to make sense of the ICU environment:

I was so scared by that place [the ICU] - it was very lonely. I did not know anybody there. None of my family was there. Yeah, I think I found that horrible, because you just feel so strange ... when I first came here [in the ward], I felt my life coming back again, yeah, I felt as if I was getting out of my tomb, and I was alive on the floor, and I saw all my sons here [in the ward]. I didn't want to go there [the ICU], never. Here all my daughters-in-law helped me, they bathed me, they fed me, and they changed my dress, they helped me, God bless them all (Um- Essa, first interview).

Um- Essa described how the continuity of her life is interlinked with the presence of her family in the hospital. Part of her suffering in the ICU was connected to the separation from her family. To her, the meaning of life was connected to her presence with the family, and her experience of loneliness was connected to the fear of dying. She explained that gathering together with her family was considered as regaining her life.

All of the women in this study described how they felt lonely and socially isolated during their time in the ICU. Similar to Um- Essa, older women such as Um- Saber, Um- Adam, and Um- Ali described their families as part of their essential being. Life was connected to being present with their family. Um- Adam and Um- Saber connected their life with the presence of their family. Um- Adam used the word 'nafsity' to describe her emotional pain when she was separated from her husband and lost his support in the ICU:

Time was very long, oh, months of suffering. I wished I was at home with my husband, I missed him, you know, he was the only one left with me, how could he live alone now without me? Erm, my 'nafsi' was very bad, I felt sad having to leave him alone...A lonely old man! I missed him, you know. It is a matter of life! You won't be able to understand, you need to have the experience of living with someone for more than 40 years, seeing each other every day, every day! - (showing a bitter smile)- I missed him, you are young. Erm, you need time to understand... oh, He cheered me up! Trying to hide his own tears, but he couldn't deceive me, his tears were betraying him all the time. He couldn't hide his deep feelings towards me. Always saying that he missed me, and he wished I could come out of the torture section as soon as possible, and he was so happy when I was out. I felt happy too and regained my life (Um- Adam, first interview).

Um Adam freely shared with me her subjective experience of the deep emotional life with her husband. She had lived for forty years with her husband and suddenly she was admitted to the ICU and lost this daily contact with him. She described that the suffering time turned into 'months of suffering', she felt isolated and missed his support in the ICU. When she was moved to the hospital ward, she was re-united with him, both felt happy, and her suffering slowly diminished. (The temporal element of suffering will be discussed in the third section of this chapter).

Similarly, Um- Ali recalled a negative experience in the ICU when she felt anxious and sad. She narrated that when she asked the nurse if she could see her daughter, the nurse did not respond to her request. She insisted that her comfort was connected to the presence of her daughter:

I felt down. Uhh... I asked a male nurse to phone my daughter, I told him that I need to talk to her right now, I need her very urgently, I felt that I wanted to die and needed to talk to her. Yeah, he ignored my request said that no visitors were allowed at that time, then he closed the door and I burst into tears, I cried a lot, yeah a lot, I mean what would it matter to them if my daughter visited me for five minutes, they were telling me that they wanted me to feel comfortable well, my comfort was with my daughter and family (Um- Ali, first interview).

⁴⁸ The word is culturally used to express any psychological and emotional status of the person.

As seen from this account, when Um- Ali felt sad and depressed, she asked to communicate with her daughter. Her daughter is considered as a source of comfort and she could not separate herself from her children.

Some women stressed that the presence of their family was crucial in improving their psychological and emotional experiences in the ICU. The family cheered them up and helped them to recover. Amal, for example, was admitted to the ICU after a thyroidectomy⁴⁹, and had lost consciousness in the operating theatre. She described her suffering as being connected to her loss of family members. She used the ‘nafsi’ to describe that her emotional status was improved by visits from her family:

...I felt very relieved, I felt happy because I could see my sisters and my mother again. It is great to see your family around you. They give you a support, a sense of happiness, and even I forgot my pains with them. They cheer you up all the time, ha ha (laughing) and some times they were kidding with me, reminding me about the old days when I was nervous all the time... my nafsi is much much better now(Amal, first interview).

Amal used the ‘nafsi’ as opposed to her physical pain; she described how she felt happy and forgot her physical pain when meeting her mother and sisters, her family decreased her sadness and cheered her. In contrast, Um- Anas described her feelings of sadness and depression when she was admitted to hospital; part of her suffering connected to the loss of her children:

My ‘nafsi’ was very bad; I lost the contact with all my children, they are too young and I could not see them in the hospital, I was very sad and depressed and I felt that part of me is missed (Um- Anas, first interview).

As seen from this quote, she used the term ‘nafsi’ to describe her emotional loss and her feelings of sadness when she was separated from her children.

When the women described their experiences of social suffering they expressed their relationship with the ICU nurses. Their accounts are classified into two main groups, the first group experienced the ICU nurses as unhelpful and unsupportive. The second group described the nurses as supportive. This will be the focus of the following section.

⁴⁹ Surgery to remove all or part of the thyroid gland.

5.4.3 The angels of mercy: the women's experiences of nursing care

The experience of nursing care and support played a crucial element in decreasing or increasing the women's suffering. Some women described the nursing care in the ICU as dehumanising and undignified, although most of the women considered nursing care as a source of comfort, and nurses were the 'angels of mercy'. Here, I use the phrase 'angels of mercy' which was a term used by two women who experienced the nurses' care as positive and supportive. Most of the women described the ICU nurses as very caring and supportive, and they helped them to recover from their critical illness. Um- Mohammed described how the nurses worked hard to provide comfort for the ill people:

I saw nurses working very hard with ill people. Yes, they do their best to care for them [the ill people], and support them...erm, sometimes they almost never leave their beds... the nurses work hard, they do their best to make the ill people comfortable, they do that because they seek the 'Ajer'-(reward) (Um-Mohammed, first interview).

Um- Mohammed states that she found the ICU nurses supportive and hard working; they were a source of support and help. Her interpretation of the nurses' care is connected to her Islamic religious belief. To her, the nurses helped the patients in order to have a reward from Allah, which she called the Ajer⁵⁰. The Ajer is a fundamental Islamic belief where most Muslims help other Muslims in need in order to seek a reward from Allah. Um- Sami's experience was similar to Um- Mahmoud:

Nurses were very kind, they came to me every day asking about my health, they treated me so kindly, that is very important. They reassured me every day, and you know, my aunt – talking to me- reassuring the sick people and telling them about the improvements in their health is so important (Um-Sami, first interview).

As seen from her account, Um- Sami found the ICU nurses to be helpful and kind and their communications were reassuring. She also considered the nurses' explanations of the progress of her health condition as vital during her time in the ICU.

Um- Bashar had a different understanding of nursing care; she accepted the ICU nurses as part of her family, and liked them to call her mother; she described them as the 'angels of mercy':

⁵⁰ Means: reward from Allah.

I see, erm, I see that nurses were very, very kind to me, they did care about me, they responded to all my calls. They talk to sick people patiently, they called me Mum. You know I was very pleased when they called me Mum. I liked their way, and I liked them.

Q: would you tell me what this care meant to you?

Uhh, I felt that they were like my children; they were helpful, co-operative, and nice. They know what ill people need, and they respond accordingly. I think that a good nurse needs to be patient, and a good listener, because ill people have many needs, and need to explain them to the nurses. Nurses are 'angels of mercy', and without their efforts the sick cannot survive (Um-Bashar, first interview).

Um- Bashar sought to live peacefully with her family. To her, nurses became a surrogate family who helped her to survive and regain her health during the critical time in the ICU. For most of the women the ICU nurses helped them to perform some of their basic bodily care such as bathing or grooming which is discussed in the section of 'the dependent body' in chapter five.

Six women in this study linked the nursing care they received in the ICU as part of their suffering, especially when they perceived that nurses did not communicate effectively with them, or did not meet their needs. These women are Um- Essa, Um- Ali, Um- Adam, Um- Anas, Eman, and Abeer. Um- Essa described how, during her first experiences in the ICU, the ICU nurses did not communicate with her and did not respond to her question when she asked for water:

...I mean nurses there [in the ICU], Erm, I was shouting all the time Oh!! For the sake of God, I wanted water, I wanted only a sip of water, Erm, they were all bad, they didn't give me any, any water, they were with no emotions, they never helped me (Um- Essa, first interview).

Her first experiences provided her with a negative impression about the nurses in the unit. Later when she described one of the nurses perform the dressing procedure she said:

They [the nurses] came every day to do the dressings for the wound; it was painful, especially when they touched it. They added a solution,⁵¹ and wrapped it in a white sheet⁵². I felt the pain move from my leg to my head, I could not tolerate it [the pain] (Um- Essa, first interview).

The anticipation of pain significantly contributed to her suffering. The nurses unwittingly increased her suffering, when performing the dressing procedure. Further

⁵¹ Normal saline and povidine.

⁵² Dressing gauze.

on in our discussion, she mentioned that that nurses did not give her “Musakkinat.”⁵³ She connected pain medication to her past experiences of analgesic medication; she used to take Ibuprofen⁵⁴, one tablet daily to relieve her chronic back pain, and the tablets were pink in colour:

...I was in pain and they didn't give me injections in my muscles, I mean, they didn't give me any injections at all. When I asked them for injections, they told me 'you have pain-killers and medicine in the bag above your head', and that was going into the veins, and then they showed me a big needle with fluids. They told me that it was 'Musakkinat' but no, no, I didn't think that was 'Musakkinat'...I know, I know 'Musakkinat' very well. When I had back pain in the past, the doctors gave me pink pills, yeah; they were pink in colour, not liquid. I was sure that 'Musakkinat' was pink pills, not liquids (Um-Essa, first interview).

Um-Essa thus relates how she experienced the attitude of the ICU nurses towards her as uncaring while she expected to provide support and help. These perceptions led her to lack trust in their explanations; she did not believe the nurses explanations, and insisted that she did not have enough analgesia in the ICU.

For Um- Adam, Um- Ali, and Um- Essa the nurses were considered as 'alien'. Um- Adam labelled the ICU as a 'torture' unit and the nurses as unsupportive and uncaring. When she described her events in the ICU, she mentioned that her suffering was connected to her loss of her husband [as mentioned in the 'nafsi' section] and she expected the nurses to communicate with her:

It was called the ICU, but I think it was the section for torture and suffering. I was in a coma, and then I woke up in that section [the ICU]. When I first entered, I saw people wearing blue, they all wore masks, and nobody talked to me, I talked to nobody, either. Nobody asked me about my feelings at this time! I was very, very tired, erm, scared, dying, lonely, how can describe my condition then? It was the most difficult time in my life, being alive but wishing for death because of my suffering! What a feeling! (Um-Adam, first interview).

The apparent lack of communication between the ICU nurses and Um- Adam, as described by Um- Adam, led her to describe the ICU as a torture unit, in which she felt lonely and frightened. In her account, she did not mention the word nurses and considered them only as people wearing blue dresses [the ICU uniform]. This could reflect her feelings of anger towards the ICU nurses. She connected her subsequent feelings of isolation and loneliness to the experience of dying.

⁵³ This word is used for any medication to relieve the pain and includes analgesics and painkillers.

⁵⁴ Analgesic, or a medicine to relieve the pain.

Eman and Abeer described how they felt the nurses objectified them, treating them as a machine with no emotions. Eman for example, stated that the nurses did not give attention to her individual needs as a disabled woman [this will be discussed in chapter five], she wished that the nurses would treat her as an individual:

All of them [ICU nurses] ask the same questions to all of the "ills" [ill people] around here, they treat us as one person having the same problems and the same complaints. Don't they know that every ill has his own problems and conditions that are differing from others (Eman, first interview).

Abeer, a blind woman admitted after an accident, similarly described how nurses inserted a 'painful' needle in her arm without asking about her feelings:

...they put a needle in my hand, it was very painful, I shouted and shouted, but nobody heard me!! I felt very sad, they treated me so badly, and they knew that this needle hurt but they didn't care about my pain as if I were a machine with no sensations (Abeer, first interview).

Um- Anas had mixed feelings; she felt happy with some of the nurses in the ICU, but she felt that most of the nurses were not supportive. She clearly said that from her perspective the ICU is intensive in terms of the technology used but not in terms of providing intensive nursing care:

...I felt that the intensive care is intensive in the machines and the monitors not in the care provided. I saw many high-tech monitors and well developed machines but I could not see any nurse ask me how are you today, how you feel today, they only observe the monitors and the machines then they wrote on their papers. None of them look at me as a human they treat me as part of these machines (Um- Anas, first interview).

Here, Um- Anas described the ways in which she felt that the ICU nurses objectified her and treated her as part of the machines. It seems that the shared element of the six women who felt unhappy with the nurses' care in the ICU was due to lack of communication between themselves and the nurses. This in turn was interpreted by the women as the nurses being unsupportive.

This section explored the multi-dimensional experiences of suffering. Physical pain is the main contribution to the women's suffering, especially when it is accompanied by the loss of body control, and being in a strange environment. The nafsi pain is part of the women's suffering when they lost their contact with their family and, for some women; life is interlinked with the presence of their family. Nurses have a crucial role in decreasing or increasing the women's suffering: lack of communication

between the women and the ICU nurses led some women to describe nurses as unsupportive or uncaring. The interrelationship between the experience of suffering and the fear of dying will be discussed in the next section.

5.5 The experience of ‘vicarious death’

The women’s narratives are to some extent pervaded by the experience of uncertainty and fear, with fear of death communicated as a major threat to their sense of self. The women feared that their health could deteriorate into a life-threatening condition at any time during their stay in the ICU, or even that they would die. With the women witnessing the death of other ill people in the ICU, they vicariously started to think about death and began comparing their illness conditions with the dead patients.

The term ‘vicarious⁵⁵’ death is used to discuss how women experienced the fear of dying when their illness conditions were uncertain and having witnessed the death of others. It also includes how the women experienced the death through their dreams and the experience of unreal events (this will be discussed in the ‘hathayan’ subsection). I used the extract from Um- Saber’s account to illustrate the experience of extreme suffering connected to the experiences of vicarious death. Um- Saber connected her ‘critical time’ to the fear of dying, and reflected that the extreme suffering was linked to her connection with to Allah. I will discuss the experience of vicarious death in three main subsections: the feeling of uncertainty, witnessing the death of other ill people, and hathayan.

5.5.1 Feeling of uncertainty

All of the women in this study connected themselves to Allah when they felt that their life was threatened and their future was uncertain. They described how Allah is the source of power and support and could help them to face their critical conditions. Um- Saber, as presented in the first page of this chapter, is one of the women who had a sudden illness when she was admitted unconscious to the ICU after a car accident. She described her loss when she woke up and found herself connected to

⁵⁵ The meaning of vicarious is experienced in the imagination through the feelings or actions of another person (Oxford online dictionary, 2007). The term has been drawn from my own experience and has not been deconstructed in the relevant literature.

the respirator where she could not move or perform any activity and was covered with a plaster cast.

Um- Saber's story has similar elements to Um- Essa's story; she had a car accident, and was admitted unconscious to the ICU and connected to the ventilator⁵⁶. Um- Saber had a sudden change in her health condition; she moved from her familiar environment, into the ICU where she found difficulty in breathing, and was unable to move her body due to a plaster cast. She also lost the support from her family. She said that these events were a shock to her, but connected herself to Allah for help and support:

... When I woke up again I said: my Allah had decided that this is for me, I was only to be patient. I believe in Allah, and Allah is the one who cures the ill people...Umm, you know it was just to stay there and wait for what would happen to you, nothing definite there [in the ICU], my condition, I mean my health would get worse at any time and I cannot guess what would happen to me the next day, everything was going fast. I just contacted myself with Allah; all the supports are from Allah, and it is entirely Allah's will (Um- Saber, first interview).

As seen from her account, Um- Saber described how all the events suddenly happened and she could not make sense of them at that time. She considered her critical condition as a test from Allah to see how she could tolerate her experience of suffering, the meaning of her suffering is to be close to Allah by accepting her illness and to endure her suffering. Her Islamic belief provided a primary meaning of her suffering⁵⁷. She went further to explain that her condition was uncertain and could deteriorate at any time in the ICU. Although she did not use the word death to describe her fears of dying, she used the sentence 'entirely Allah's will' which is culturally used when somebody fears that he/ she may die at any time.

Many women like Um- Saber entered the ICU with a fear of dying and were uncertain about their health status. Their accounts showed that they feared they might die at any time, or that their health might suddenly deteriorate and they suffered more when they could not explicitly speak of their fear or express their complaints. Um- Sami's account is another example; she was transferred from the medical ward to the ICU after her illness condition deteriorated. She described that part of her previous

⁵⁶A machine which delivers oxygen-rich air through a tube inserted into the mouth, down to the throat and the lungs.

⁵⁷ A central Islamic belief is that people are not responsible for their illness, but they are tested and purified from sins, and, if they accept the will of Allah and bear their suffering patiently, they will be rewarded.

assumption about the ICU was that the ICU is a place of the ‘near death’ people. When she found herself in the ICU, she said that she was scared and terrified and, for a period of time, she lived in a limbo and ambiguity. During the first interview she praised Allah for rescuing her from her critical illness:

In the ICU, people are near death, they seek help from Allah, then the help from doctors and nurses. Allah placed them in a critical situation to see how patient they are. I mean myself, Allah wanted to see if I could tolerate all those critical days or not, erm, and Al-hamdolellah [All praise to Allah], I passed it , I get well again as you see, my condition is getting well now (Um- Sami, first interview).

For Um Sami, the primary meaning of critical illness was considered a test from Allah to ensure that she could accept her illness. She could not tell anybody in the ICU about her suffering; she did not share her fears and worries with anybody in the ICU. She lived in fear but could not express her fears in words. It was only when she moved from the place of her fear [the ICU] that she could describe her experiences. Um- Adam had similar feelings to Um- Sami. She said that on her admission to the hospital for lobectomy surgery, she felt that she could lose her life during or after the surgery, and therefore she said ‘goodbye’ to her husband and asked her children to pray for her before the surgery:

I thought of the pain after the operation if I was still alive. I said goodbye to my husband, asking him to forgive me if I had committed any earlier mistakes with him. I talked to my children...I asked them to pray for me... I was scared of death (Um- Adam, first interview).

As seen from her account, Um- Adam was worried about dying and asked her husband to forgive her. She believed that praying was another way that could help her during this critical time and so she asked her children to pray for her.

It seems that praying is a means for some women to be close to Allah. Eman’s account is one example. Eman, a young woman, was admitted to the ICU after massive bleeding from abdominal surgery. She lost consciousness and suffered loss of her bodily control, and family support. She described how her condition in the ICU drove her to think that death was inevitable, but she started to pray to Allah to save her life:

I think once I just accepted that I will stay there[in the ICU], I was just going to be ill for that amount of time, and I stopped thinking about anything else just to live and get well enough to go outside that unit. And there were really low moments; I was so ill and tired, I just couldn't imagine ever feeling normal again... Erm, actually I prayed to Allah to let me out of the ICU, I prayed many times thanking God for everything. I felt that I would never get better any more but AL hamdolellah⁵⁸ that I am still alive and (laughing) as you see I am here now (Eman, first interview).

Eman described how, when she felt very ill, and lost hope, she connected herself to Allah. Prayer is the spiritual behaviour she used to face the uncertainty of her condition and possible death. To her, prayer is a means of communication with Allah to seek help and support during her extreme suffering.

As seen from the four accounts above, the women communicated how their experience of uncertainty about their health condition, accompanied with their fear of dying, provided a revelation that they had to be closer to the mercy of Allah, and this was the primary meaning of their experiences; Allah is the only source of life and death, so they sought Allah's help and support to survive and recover from their critical illness. Their interpretation is described in two ways: two of the women considered the illness as a test of Allah to see how they endured their critical illness, while the others used prayer as a means to keep close to the mercy of Allah. Another aspect of the vicarious death was communicated when the women witnessed the death of other ill patients. This will be the focus of the next sub-section.

5.5.2 Witnessing death of other ill people

For many women, the fear of dying was heightened when they witnessed other ill people dying in the same unit. This challenged the continuity of their lives and their essential wellbeing. Some women stated that they felt scared and felt that they were close to the death. When they moved from the ICU, they thanked Allah for keeping them alive. Um- Saber recalled her experience when she witnessed the admission of some people after a car accident:

Oh dear! That place [the ICU] was full of very ill people, every night while I was in, I saw the results of accidents, two or three ill people entered the unit, some of them died, and others, erm, were in a coma. When I saw them, I said to myself (al hamdolellah) [All praise to Allah] I have been saved. Erm, my accident was easier than theirs. (Pauses and deeply sighs) - Allah helps them (Um- Saber, second interview).

⁵⁸ Means 'all praise to Allah'.

When Um- Saber observed other critically ill people, she started to compare her condition with theirs; she felt that her condition was much better than theirs. Um-Saber, three months after her discharge from the ICU, described her fear of dying when she witnessed the death of critically ill people. She thanked Allah for helping her to survive in the ICU and regain her health. It seems that she vicariously experienced the fear of dying when she observed the death of critically ill people around her, but found it difficult to express her experiences. After she had been discharged home, she recalled her events and expressed her suffering.

Many other women shared Um- Saber's fundamental Islamic belief that death is inevitable and every soul will taste it. Witnessing the death of others led them to re-evaluate their life's continuity. The only way they could make sense of their extreme suffering was to connect themselves to Allah, who has the most power for life and death. Um- Ali communicated that when she observed the death of a woman in the ICU, she was afraid of dying, and had nightmares:

...you know last Sunday I saw a sick woman. She was very, very ill and couldn't breathe well, and suddenly her heart stopped pumping, yeah, I saw her monitor go off and the machine peep loudly. After that many nurses came around her, and then they closed the curtains, after that she died. Yeah, I saw a dead body very near me, she died. I felt very scared at that time, oh, I knew that all of us would die one day but she was very near, I felt very ill and I did not want to see the other sick people (Um- Ali, first interview).

As seen from Ali's account, she was scared of dying and wished to be separated from the dead body close to her bed. Similarly, Um- Mohammed when witnessing the death of the other people in the ICU, reconnected herself to the mercy of Allah.

...Erm it was a horrible place...the ill [the ill people] themselves they were lying with no motions, I saw them in their beds they cannot move their bodies, and then they died. I considered that the ill people there [the ICU] were under 'Allah's mercy'. Nobody can decide their Ajal⁵⁹. But we can pray to Allah to help us to recover from our critical condition (Um-Mohammed, first interview).

Although Um- Mohammed did not clearly state that she was afraid of dying when she observed the death of other ill people, she used her basic Islamic belief to give meaning to her suffering. Um- Mohammed considered that the time for death (the Ajal) is entirely at Allah's mercy and is inevitable. She considered prayer could help her to avoid death and to recover.

⁵⁹ The time when the person faces the death.

By contrast to all of the other women in this study, Amal's account can be considered a deviant case from all those who witnessed the death of other critically ill people. Amal was admitted to the ICU for close monitoring after she had severe bleeding from thyroidectomy surgery. She was the only woman that did not consider the death of other ill people a major threat to herself. She described how she observed a young girl dying next to her bed and felt sympathy for her:

... Ummm, and I was also affected by other ill people, some times I looked at the bed next to me, seeing a very little girl, she was very ill, she couldn't breathe without machines. The next day she was dying, erm, I felt very sorry for her...yeah, that was really sad (Amal, first interview).

Amal described that she was affected by the death of the young girl but did not consider the death as part of her suffering. It is possible that fear of death is connected to the women's age. Amal, a twenty-one-year old woman, considered death as a sad experience but not a major threat to herself.

The experience of vicarious death is also described by women through their dreams and nightmares. The women used the word 'hathayan', which culturally means hallucinations and nightmares, to describe their events. This will be discussed in the next sub-section.

5.5.3 Hathayan: the women's experience of unreal events

Some women, after they had spent a period of time in the ICU, experienced an extreme loss of self, living in limbo and ambiguity. The experience of their suffering was manifested through their dreams and nightmares which they called 'hathayan'. Um- Saber is one example, she described one of the events that she had experienced during her ICU stay and named it as 'hathayan':

Erm! I still remember, one night I had 'hathayan', I was in a place where I was praying, I entered a mosque and a holy place, I saw a lot of people, while I was asleep, I was talking to myself, saying that wherever I prayed it made no difference to Allah, yeah, I talked to them [the people in her sleep] they told me to pray more so I can go out of that place (Um- Saber, first interview).

Um- Saber used the word 'hathayan' to describe her experience when she was praying in a mosque and talked to religious people there. She considered these experiences as real to her during the time in the ICU. These experiences helped her

to give spiritual meaning to her suffering and to survive. It was not until she shared her story that she recognised these events as unreal. It seems that she experienced an extreme loss of self but connected herself to Allah through experiencing the unreal events.

Similarly, Um- Essa described how she saw angels in the ICU. These angels supported her to recover from her critical illness:

Ummm any way, all the time, I was in a coma or, umm, all the time I had 'hathayan'- (hallucinations and nightmares). I was dreaming, dreaming of my sons, dreaming of the angels around me, horrible dreams, I didn't realise that I had these dreams, you know, when I closed my eyes, I saw the angels, yeah , they were dressed in white clothes. I thought that I was talking to them, they told me you should go out of that place, I mean the ICU, or you would sleep for ever, yeah for ever... they came to me from the window in that unit [the ICU], they spoke to me at night. Some times I felt that they were real, not dreams.

Q: Umm and how did those dreams affect you?

You know, I felt very, very scared in the beginning, you know, I couldn't sleep well, but after some time I felt that it was a message, yeah it was a message from Allah to keep me alive, yeah, it was a message for me to get out and to live again, yeah, it was like a dream, but it gave me the power to live. I felt that I could survive with all these fractures and pains (Um-Essa, first interview).

As seen from her account, she said that these dreams were real to her during her time in the ICU, but she recognised that these experiences were unreal after she had been transferred. The angels through her dream provided a tool for her to be connected to Allah, who then provided her with the power to survive and recover from her illness.

Um- Bashar is a third woman who experienced the unreal events in the ICU. She described that she had 'hathayan' in which she imagined herself at home with her children, she was praying to Allah and asked him to forgive her and help her to recover from her illness. During the interview, she was reluctant to share her account and asked for the recorder to be turned off. This could be part of her private account and she did not wish to share her private experiences with others.

One explanation of the 'hathayan' experiences could be that when the women lived in limbo and ambiguity, they lost their sense of self. Therefore they experienced the unreal events as being real to them and so gave these experiences meaning. They lived these experiences and they gave meaning to their suffering through dreams.

Although these dreams were not 'real' events to me as a researcher, they helped the women connect to the meaning of their suffering, and were a means to survive in the ICU.

In this section, I have discussed the experience of suffering as connected to the experience of vicarious death. I discussed the women's experience of uncertainty with the fear of dying. Then the primary meaning of their experiences is related to their Islamic beliefs which is described through enduring their suffering and praying to Allah. When witnessing the death of other ill people, the women vicariously experienced the death and became frightened of dying. As they had transferred to the ward, the women started to re-evaluate their life and thanked Allah for being rescued from their critical conditions. The women, who lived in limbo and ambiguity, lived the experience of vicarious death through their 'hathayan'. The meaning of their 'hathayan' helped them to endure their suffering.

The experience of suffering not only affected the women's perception of life and death, but also changed their experience of time. The temporal element of the women's accounts will be discussed in the following section.

5.6 The temporality of pain and suffering

This section discusses the women's experience of suffering as related to time. Here, time is considered in two different contexts. First, the sequence of events of their stories which are related to the clock time and the calendar days; the plot⁶⁰ of the story starts in the past, moves to the present and then into the future. However, the women's stories when they described extreme suffering were disorganised and lost their temporal sequence or chronological order. Events were described according to how these women suffered in the ICU not according to a sequence of time. Second, time is discussed in relation to how these women described their stay in the ICU. It is clearly noticed that the women experienced some time as lost from their memories. This time is related to their experiences when they were unconscious or under sedation. The time in the ICU was also described as long. To present these experiences, I have divided this section into two sub-sections: lost time, and suffering time.

⁶⁰ The plot of the story describes how the narrator when telling the story moved from past events into the present time then to future time in chronological order.

5.6.1 Lost time

For most of the women in this study, the initial time in the ICU was considered unknown or lost. The lost time was experienced when the women were either admitted unconscious to the ICU or lost their consciousness due to sedation. Um-Essa, for example, described how she could not recall any events during her unconsciousness:

I didn't wake up; I stayed in a coma... I cannot remember anything when I was unconscious, nothing at all, but I felt my legs hurt me a lot (Um- Essa, first interview).

Um- Essa stated that past time in the ICU was lost to her; she could not recall the events of her experiences. Similar to Um- Essa, many women who were admitted unconscious to the ICU described that the time was lost or unknown. The women described that when they lived in limbo and ambiguity they could not recognise that they were asleep or unconscious and their perceptions of time were lost during these days. Some of them such as Um- Ali and Um-Fadi described how they lost consciousness after they had received sedation.

...when they admitted me to the ICU, I found myself in a place full of machines, (silence) it was the first experience for me of the ICU...then they gave me medicine to make me sleep. I slept for a long time, and I did not know what was happened (Um- Ali, first interview).

Um- Fadi was unsure if she was unconscious or asleep; her account shows that she did not know how long she was unconscious:

...I was drowsy or I don't know, maybe unconscious, I knew nothing after that, I knew that they gave me medicine, trying to help me so that I didn't go into a coma, but in fact I did not woke up (Um- Fadi, the second interview).

Malak had different experience than Um- Ali, she describes that she could not recall her admission to the ICU:

...oh, at that day, I thought exactly at that night, I did not know what happened. I felt very tired and my husband told me that they sent me to the hospital, to the emergency room. I was in a coma, yes, I could not see or hear anything. Yeah, anything, I stayed for long time there [in the ICU] (Um- Malak, first interview).

The lost time as seen from these women's accounts is strongly interlinked with their memory. Loss of memory was part of the women's suffering. They said that during the lost time they could not comprehend all of their experiences in ICU but they

wanted to know what had happened to them during the lost time. Um- Ali, for example, described how she wanted to know what had happened to her during her unconscious time:

My health was critical and I wanted to know about my situation. Yeah, I should know. Erm, actually I needed to know everything happening there [in the ICU]. You know, when you come to a strange place, you just want to know what was going on, what the nurses, and doctors did to me. I am in their place, the hospital, and they know what was happening very well, so they can answer all my questions (Um- Ali, second interview).

Similarly, Um- Sami communicated that she lost her memory of her initial time in the ICU, and asked her family to explain about what the past events in the ICU:

At first, I was not awake, maybe I lost consciousness because of the big amount of bleeding, but I asked my family, what happened to me. Erm, as my family told me, I was totally unconscious, they told me that my condition was very bad, I couldn't recognize them, I lost my memory for a short time, then I woke up again (Um- Sami, first interview).

As seen from her account, time is lost during her unconsciousness but her family helped her to recall some of the events. Her experiences in the ICU started when she regained her consciousness after lost time in the ICU.

In this sub-section, I have highlighted the women's experiences of their lost time. Women described how they lost their experiences of time when they were unconscious or sedated in the ICU. The women suffered when they could not recall any events during their lost time and wanted to know what had happened to them. The experience of time is also related to the way the women narrated their sufferance, which will be discussed in the next sub-section.

5.6.2 Suffering time

Suffering time is the term I used to describe the women's narratives when the time they spent in the ICU was described as long but, at the same time the plot of their narratives do not follow a chronological order. These experiences are discussed in this section.

As seen in the multi dimensional experiences of suffering (section 5.4) in Um- Essa's first interview, her narrative is focused on what happened to her in the ICU. She described her time in the ICU as long:

Oh, dear, In the ICU, I stayed there very long, yeah; I felt it was more than a year there, yeah, years of suffering. When you are ill, you lose the sensation of time, you think that it [time] passes very slowly. I felt that when I was in the ICU. They told me that I spent only a month there, but alas! I don't believe them, it had been years! Years of pain, suffering, sleeplessness!! How dare they tell me that it was only a week? I am the one who spent that time there, not them, and I can tell now that I had been there for a long, a very long time (Um- Essa, first interview).

Um- Essa's account describes how the time during the extreme suffering in the ICU is considered long, and 'years of suffering'. The time was connected to her experience of physical pain and connected to other elements such as difficulty in sleeping, loss of family support, and what she perceived as the lack of nurses' support. Although in calendar time she spent only forty two days in ICU, she experienced her time as years.

Amal experienced time differently. She described time as interlinked with her lack of sleep and loss of her family. She felt that the nights were very long:

I felt that, Ummm I was so tired in the ICU, I couldn't concentrate well, I felt that I needed a complete week-long sleep to get well, and what can I tell you about the night time, when everybody was sleeping except for me, just gazing at the ceiling and the walls? I was thinking of everything, thinking of my family, my sisters, and my school. How bad it is when you were alone at night, when you are supposed to enjoy dreams and comfort. I can't tell you how long were the nights! Those nights are stuck to something big, very big! Those nights couldn't move. They couldn't pass (Amal, first interview).

Amal clearly described her time in relation to her loss of family and sisters. To her, the time moved slowly and was thus experienced as a longer time, especially when she was thinking of her family.

Similarly, Um- Adam considered the time in the ICU as drawn out but related it to her experience of physical pain. Um- Adam could not sleep because of pain from the operation:

Yeah, days moving very slow, I was awake all the night, looking at the ceiling, oh! It made me very tired, unable to focus or concentrate, always sleepy, and what can I tell you about the nights? Umm, the time was very long, full of pains. It is difficult to describe those days (Um- Adam, first interview).

Um- Adam said the nights moved slowly during her experience of pain.

As seen from these three accounts, when the women recalled their experiences in the ICU, they considered their time in the ICU as long and drawn out. This time is connected to the events they experienced in the ICU.

On examining the plot of the women's narratives, I found that a common theme in all of the women's stories was the notion that when narrating their experiences in the ICU, the women did not recall events in a temporal sequence or chronological order. In other words, the plot of their stories does not move from the past into the present then into the future.

In their first interview, the women narrated their present time as they looked back to the past. It is obvious that none of these narratives describe the future. Um- Saber, account is one example (see section 5.5). Um- Saber's account moved to described her past events during her initial time in the ICU where she lost her consciousness, then she compared the past time with the present when she said 'I never imagined in my life that this would happen to me' then she moved back to describe the past events of her experiences in the ICU. There perception of the future is missed from her first interview. Similarly, when I interviewed Um- Malak she looked back to her time in the ICU and described her experiences of suffering in the ICU:

Yeah, I opened my eyes in a very strange place, I have never been in the ICU, Erm, and I did not see anybody around me. At first, I didn't know where I was, you know, I was scared , very scared, I was watching machines over my head, it was my first experience, Ummm, I had never been to hospital before, machines every where (Um- Malak, first interview).

Um- Malak looked back to her experiences in the ICU from her present time, all through her account she did not mention any events connected to the future. This was in contrast to her second interview when she started to talk about the future and how she was looking forward to it:

...I think that my attitude towards life has been changed, Yes. My experience in the ICU was very critical; it makes you realize that life is precious. My outlook on life is so different and, like I said, I was very nervous, I cannot put up with my daughters, or husband complaints. But now I learnt, I learnt to be patient with myself and with all the people around me, yeah, life is nothing without my children and husband around me, I learn not to be angry with my daughters any more, any more (Um- Malak, second interview).

As seen from the above quote, she started to re-construct her account in relation to her past experiences in the ICU and looked forward to her future.

All the women's first interviews looked backward to their experiences in the ICU, then to their present narration time and then moved back to the ICU time. None of these accounts described the women's future or how they were looking forward to their future. However, in the second interviews most of the women recalled their past events in the ICU and were looking forward to their future.

5.7 Summary and Discussion

Data from this chapter suggests that the experiences of pain and suffering, as narrated by the women in this study, had many overlapping themes and issues. Three main categories have been identified from the data: the multiple dimensions that constituted the experiences of pain and suffering for the women, their experience of vicarious death, and the importance of temporality in their narratives of pain and suffering.

For some critically ill women, the experience of physical pain is the main element of their suffering, especially when the pain is severe, overwhelming, and disturbs their sleep; while for other women, pain is considered as part of their illness process and they have to endure pain to recover from their illness. Alongside the experience of physical pain, all the women used the word 'nafsi' to describe their emotional and social suffering as being connected to the loss of their family. The presence of their family is vital for their psychological and emotional wellbeing. For some of them, family support is considered as an essential element of life, to the extent that life involves being with their family, while death is connected to the feeling of loneliness and strangeness.

The findings in this study supported the previous findings, that pain is a main source of stress among critically ill patients (Hweidi, 2007, Adamson et al., 2004, Rotondi and et al, 2002, Turner et al., 1990), and could affect the sleep of ill people, (Cornock, 1998), however, the experience of physical pain could not be separated from the whole of personal experience. Women described how physical pain is

accompanied by lack of sleep, fear of dying, loss of their family support, and loss of control over their bodies, which made the physical pain severe and intolerable.

Most of the women expressed an immediate preference for being with their family during the critical illness. The findings particularly showed that Jordanian women would favour to stay with their family to enhance their 'nafsi' which is reflected on their emotional, and social and psychological support. These expectations were formed in the context of the cultural norms and values and mean that togetherness with the family is regarded as vitally important. The literature suggests that family support is crucial for the critically ill patients in western countries (Bergbom and Askwall, 2000, Papathanassoglou and Patiraki, 2003). Some women described that although they felt some changes in their appearance in the ICU, they preferred to have closer contact with the family (Cooper et al., 1999, DIPEX, 2007). The present study supported the findings of these studies and emphasised that for some Muslim Jordanian women, the presence of the family was considered an essential part of life and that the women found it difficult to separate themselves from their families.

The experience of vicarious death is described by the critically ill women through three different themes: the experience of uncertainty and fear, witnessing the death of other ill people, the experience of 'hathayan'. The women's narratives are to some extent marked by the experience of uncertainty and fear. The women feared that their health could deteriorate into a life-threatening condition at any time during their stay in the ICU, or even that they could die. The Islamic religious belief provided a primary meaning to their experiences; the women connected themselves to Allah, who gave them the power and support to face their critical conditions. Women described how their suffering is a means of being closer to the mercy of Allah and. For some of them, prayer was the communication between themselves and Allah. Witnessing the death of other ill people was considered a threat to the women's sense of life. The women started to compare their health conditions with those who were dying. Some women thanked Allah for rescuing their life and for regaining their health. A particular group of women experienced their vicarious death through their dreams and nightmares, which they described as 'hathayan'. The events were seen as real to them and provided a meaning to their extreme suffering.

These findings support the fact that some religious people, when faced with uncertainties about their health condition, connect themselves to God. Hawley (1998) conducted a study in Australia to describe how Christian patients experienced the uncertainty of their conditions. Thirteen participants were interviewed, between four and twenty four weeks after they had coronary artery bypass graft surgery. The participants stated that when they faced the uncertainty about their health, and were afraid of dying, they made peace with God. For most of them, prayer was one way to maintain their relationship with God. For those who could not pray, they read the Bible and asked for God's mercy to feel safe. Their Christian faith helped them to make sense of their suffering and uncertainty. Another example is provided by the account of the Catholic woman who spent more than twenty days in the ICU. Douglas (1989, p.229) is a nurse who was admitted to the ICU after an accident. She reported her feeling when she woke up and found herself in a strange unfamiliar environment (the ICU) with multiple injuries and fractures. One challenge was to understand where she was:

...when I returned to consciousness, I did not have to ask; I new immediately where I was. With that knowledge was awareness of my specific injuries, but rather that I was in danger of death (Douglas 1989, p.229).

Fear of death was one of her main challenges, when she faced uncertainty about her condition, she asked God for help and support. She connected herself to God, asking for help and support. She also described that when witnessing other peoples' dying in the ICU, she felt anxious and stressed. The present study also found that Islamic beliefs provided a central meaning to the Muslim women when they experienced uncertainty about their health and fear of death.

The experience of suffering is not always accompanied by physical pain but has a 'moral status'. A moral status confers relative human worth and deserved values or devaluation (1999). The experience of suffering as connected to life threatening illnesses can harm the integrity of the existential wellbeing of the person (Mount et al., 2007). For example, for people who have recently been diagnosed with cancer, their suffering is evident at the thought that they might die in the near future (Ohlen et al., 2002). Some cancer patients when faced with the threat of death re-evaluate their existential being and connect themselves to the God for their support and

healing (Mount et al., 2007, Rasmussen and Elverdam, 2007). Religious beliefs can help some people to make sense of their suffering or accept the uncertainty of their illness conditions (Puchalski and O'Donnell, 2005).

The extremely stressful experiences in the ICU may lead some patients to experience unreal events. Previous studies have shown that some patients experience hallucinations, delirium, and nightmares during their time in the ICU (Dyer, 1995 a, Dyer, 1995 b, Green, 1996, Dyson, 1999, Axell, 2001, Granberg et al., 1999). Granberg et al (1999) explore how the alteration of the emotional state of the patients, accompanied by being in a highly stressful environment, can lead to experiences of delirium, confusion, or hallucinations, which is classified under general terms as 'the ICU Syndrome' or the ICU delirium. Patients described their experiences as nightmares, crazy dreams, and fantasies, and said that they were 'real' events during their time in the ICU. However, none of these studies revealed what these dreams meant to the patients themselves. The present study shows that the unreal events could be experienced as real when the ICU women lived in limbo and ambiguity. These dreams helped the women to find a meaning to their suffering. Richman (2000) described his own experiences in the ICU, states that the 'crazy' dreams were real to him during the critical time and helped to him to endure his suffering. Richman is a sociologist who spent more than a month in the ICU where he experienced the ICU delirium and hallucinations. A year later, he reflects on these experiences as a kind of dream, describing how he felt vulnerable and experienced a loss of control over his body. He had experienced his dreams as part of his real world in the ICU and found this helped him to endure the suffering.

Women in this study communicated their stories in relation to time. Time was divided into 'lost time' and 'suffering time'. The lost time described the women's experiences when they lost their memories as they were unconscious or they had received sedation in the ICU. The women started to think about the missing parts of their experiences. Time was also described as long, especially when the women lacked sleep due to physical pain or loss of their family. The women's narratives did not follow a temporal sequence or chronological order. Women narrated their experiences as they looked back to their past time in the ICU and moved backward

and forward to their present, the future was missed from their first accounts. As they moved home, they started to reconstruct their time in relation to their future.

Corbin and Strauss (1987) described the experience of chronically ill people; they used the concept 'biographical time' to illustrate how chronically ill people described their time in relation to their lived experiences. They argued that the concept of time could be understood in two different ways: 'clock time' in which chronically ill people described the element of their stories as they moved from the past into the present and then to the future over the course of life; this reflects how people told their stories in relation to the calendar days or weeks. The 'biographical time' reflects the stories which include clock time, plus the person's perceptions of time at any moment within the life course. This time did not reflect the calendar days, but rather, experienced events.

Charmaz (1991) also found that time had different contexts and illness gave a new way of experiencing time. In her discussion of the experiences of chronically ill women she observes:

Living with serious illness and disability can catapult people into a separate reality-with its own rules, rhythm, and tempo. Time changes-dramatically...good days and bad days lend new meaning to the present and future and shade memories of the past'. (Charmaz, 1991, p.5).

In another study, people who have had a stroke (Hjelmblick and Holmstrom, 2006) described that the uncertainty of their condition disturbed their awareness of time. To them, time is divided into three dimensions; the cycle time when they repeated the same events continuously, the exchange of time where they valued the time when they lived with others including their family, and the exclusion time when they excluded time from their accounts because they did not want the stroke to influence their every day routines. Similarly, a study exploring the experiences of sportsmen after they had developed spinal cord injuries experienced the time differently (Sparkes and Smith, 2003). Immediately after their spinal cord injuries, Sparkes and Smith identify how their participants' time is experienced as disruption of the whole life and body in which they could not comprehend the events of their experiences. After they had spent long period in the rehabilitation unit, the men started to re-evaluate their present conditions with their future time.

Rasmussen and Elverdam (2007) described the experience of twenty-three men and women (10 men and 13 women) who were survivors of cancer. The cancer diagnosis affected their perception of time; time was divided between their experiences before the cancer diagnosis and after their recovery. Participants described how they would like to spend their remaining time after the cancer diagnosis as they could live their life at a time; they wanted to live every moment of their remaining time.

This chapter described the experience of suffering as overlapping and complex. The experience of physical pain overlapped with the feeling of strangeness, fear, and loss of the family support, the experiences are also mixed with the feeling of uncertainty and witnessing the death of other ill people. These experiences led some women to think about death. The extreme suffering is also connected to the loss of the women's perception of time and the chronology of narrating their events in the ICU. These experiences are also interlinked with the women's experiences of their bodies which will be discussed in the next chapter.

The women's experiences of their bodies

6.1 Introduction

A key issue for all the women who took part in this study is the experience they had in relation to their bodies during their critical illness. This theme emerged as I analysed my interviews; I was struck by how many women were telling stories about their bodies, and how they interpreted nursing care in relation to their experiences of their bodies. The women reported that, as they moved from their homes to the ICU, they lost their ability to work independently, and some of them lost control over their bodies. Some women described how they felt paralysed and completely dependent on others, including their family members and nurses. Others reported that they felt exposed when wearing the ICU gown. For most of the women, family support and help was crucial that helped them to recover during their 'critical' time in the ICU.

My experience as a nurse in an intensive care unit informed me that providing care for critically ill patients involves difficult and distressing bodywork. Yet, to some extent, I assumed that body care was a routine nursing activity in which I had to meet the patients' needs, such as nutrition, movement, bathing, and elimination and in which I also had to manage technical aspects of care connected to monitoring and the use of machinery. I had little insight about how the patients experienced my care, especially as related to their bodies. After analysing my data, I recognised that nursing bodily care could have a different meaning for the women who went through this experience. This encouraged me to explore further how these women interpreted nursing care, and how they perceived the care in relation to the gender of the nurse.

This chapter starts with an overview about experiences of the body as reported in the wider literature. This is followed by an overview of the data analysis process and of the different sections of the chapter. Four sub-concepts are identified from the data: the dependent body, the social body, the cultural body, and the mechanical body. This conceptual analysis adds to the theoretical understandings of 'bodywork' first

described by Lawler (1991)⁶¹ and Twigg (2000), and is applied in this study as a means to gain insight into the women's experiences of their own bodies, and their interpretation of the nursing care which is related to the body care. Finally, I will reflect on the women's experiences of their body in the context of the wider literature.

6.2 Background

Every person has a body. The relation with one's body may vary from identification with it to admiration, loathing, or constant fear... Disease can so alter the relationship that a person's body is no longer seen as a friend but an untrustworthy enemy. This is intensified if the illness occurs without warning, so that the person comes to distrust his or her perceptions of the body; as illness deepens, the person may feel increasingly vulnerable or damaged (Cassell, 2004, p.40).

This quotation from Cassell provides an insight into the personal experience of the body. Cassell asserts that although the body is the identification of the person's self and identity, the person during illness could lose the trust of his/her body and feel weak and broken. Frank (1991) has described the changes of his relationship with his own body when he suffered from heart disease and cancer. He said that pain is the body's response to illness but, when his pain became severe and overwhelming, he lost his sense of coherence and felt isolated within his body. His main concern was to endure the pain and live peacefully with his body; the loss of his hair left him feeling stigmatised and ashamed. Frank, after a period of time, started to appreciate his relationship with his wife and close friends; he learned to be more dependent and live his life differently. Four years later, Frank (1995) asserts that

...The ill body is certainly not mute, it speaks eloquently in pains and symptoms, but it is inarticulate. We must speak for the body and such speech is quickly frustrated: speech presents itself as being about the body rather than of it. The body is often alienated, literally "made strange"(sic), as it is told in stories that are instigated by a need to make it familiar (Frank, 1995, p.2).

The body exists in and through everyday life. Foucault was one of the theorists who argued that the body has no existence in the world but is rather generated through the

⁶¹ See the background section for the discussion about bodywork concept.

process of discourse (Foucault, 1977). Here, the body is seen as a general concept representing the identity of all people who share the same discourse. Medical staff and some nurses follow the same principle when diagnosing patients. Patients are classified as ‘asthmatic’, ‘cancer’, or ‘heart disease’ patients. However, this diagnosis does not represent the experience of how each person lives with asthma or cancer; the medical diagnosis misses the individual experience of illness (Lawton, 2000).

People in everyday life tend to pay little attention to their body functions, but as they become ill they start to be more aware of their body’s routine functions, such as breathing or moving (Leder, 1990; Shilling, 1993). Similarly, Madjar (1997) asserts that people in everyday life take their body for granted while during illness they become more aware of their body since it becomes unfamiliar, or feels different. For example, people who suffer from chronic obstructive pulmonary disease become more aware of their breathing difficulties, and learn how to use their extra chest muscles to breathe more effectively (Lomborg et al, 2005). Similarly, women who live with multiple sclerosis describe how their illness affects their sexual identity. They have difficulties in adjusting and experiencing their changed body; some of them feel a burden on their partners or family, while others become socially isolated, and feel unhappy with the changes enforced on their lives (Kralik et al., 2003, Olsson et al., 2004).

There are many concepts applied to exploring the bodily experiences of illness. Williams (1996) used the concept of ‘absent body’ to describe the living experiences of people who have chronic illnesses. People with chronic illness give little attention to their illness conditions when their body works with just a minimal limitation; but when their illness limits their mobility or disturbs their lives, they tend to re-evaluate their past condition, and compare their past and present experiences of their own bodies. They start to reconstruct a new narrative to express their emergent illness conditions. Seymour (1998) applied the same concept to make sense of the accounts of twenty four men and women who experienced permanent paralysis. The participants described how permanent paralysis changed their physical appearance and disturbed their everyday life. Seymour revealed that the paralysed men and women focused on adapting to their bodies, and accordingly, reshaped their worlds.

Some disabled women said that they changed the type of clothes they wore to feel happier with their new appearance, and others felt that their disabled body was different and inadequate for their needs. They started to use make up and took more care of their hair and body. The men stated that they started strict rehabilitation training to improve their body posture.

Nursing care and interaction of nurses with patients' bodies has been described as 'bodywork' (Lawler, 1991; Twigg, 2000; Shakespeare, 2003). Lawler describes the embodying experience of the newly graduated nurses when performing body care, as they physically help the patients in bathing, manipulation and dressing. She reveals that nurses consider bodywork as problematic, and feel embarrassed when being watched whilst doing basic bodywork. For some nurses, bodywork is considered as part of managing the patients' signs and symptoms; what Lawler calls the 'objective body', whilst other nurses, become aware of how the patients cope with their own body through illness: the 'subjective body' (Lawler, 1991: 40). The subjective body includes the nurses sharing their feelings and showing their willingness to help their patients. Lawler's theories is based on the somological approach to nursing care, which argues that nurses who practice somology perform their bodywork through understanding, and integrates the body as an object, or a set of symptoms and feel and help the patients to share their feelings (Lawler, 1991). Along the same line, Twigg (2000) discusses bodywork as part of the carework which involves:

... working directly on the bodies of others ... it involves touching, manipulating and assessing the bodies of others, which thus became the object of the worker's labour (Twigg, 2000, p.137).

Nurses, according to Twigg, have tended to move away from the direct body care, such as providing a bedpan, or doing sponge bathing, into more technical skills such as monitoring or writing nursing notes. Doing basic bodywork is considered to be on a lower level, or as 'dirty' work. Lawler's and Twigg's discussions of bodywork, however, give little attention to how the patients who receive this care may experience the nurses' body care. Patient may experience the nurses' carework differently; this study aims to explore the nurses' carework from the patients' perspectives.

There are many factors which influence the way that people interpret their experiences with their bodies. Culture has an impact on how the people perceive

their bodies, or how they accept and perceive bodily care provided by others (Kleinman, 1988; Lawler, 1991; Twigg, 2000). Cassell (2004) argues that:

Culture defines what is meant by masculine or feminine, what clothes are worn, attitudes toward the dying and the sick, mating behaviour, attitudes toward odours and excreta...how the aged and disabled are treated...Cultural norms and social rules regulate whether someone can be among others or will be isolated, whether the sick will be considered foul or acceptable, and whether they are to be pitied or censured (Cassell, 2004, p.38).

Cultural norms, for example, influence the perception of health among the Jordanians, as some women feel it is shameful to be examined by a male medical doctor (Omran and Al- Hassan, 2006), and most Jordanian women cover their head as part of their cultural identity (Majali, 2001). In addition, many Jordanian women used to cover their whole body and wear Abaya⁶² in public areas (Sonbol, 2003). Religion has another impetus on the women's perception of their body. Muslim women in many western countries consider the hijab⁶³ as part of their Muslim identity (Ruby, 2005). Iranian Muslim women used to cover themselves completely in public, with none but the closest family members such as the husband or father seeing her uncovered (Karami, 1982).

Bodywork in the intensive care settings is central to nursing care. Many patients are admitted to the ICU in a state of unconsciousness or are completely dependent on nurses due to the severity of illness. Nurses are responsible for helping them to perform some of their basic needs such as bathing, eating, and moving (Smith, 1987). Seymour (2001) uses both the concepts of bodywork and emotional work to discuss the nursing work of the dying people in the intensive care unit:

...far from nurses using bodily care as an escape from the demands of emotional engagement, in this environment it is an integral part of their emotional engagement not only with dying persons themselves but also with their companions...It is through these twin activities (bodywork and emotional work) that nurses create 'whole person work' and invest the process of dying with meaning, purpose and intimacy. For some nurses, the compulsion to reproduce the subjectivity or 'person hood' of their patients is experienced as intensely painful (Seymour, 200, p.125).

⁶² A long black dress which covers the whole body.

⁶³ A special dress which covers the whole women's body.

Thus, bodywork is more than what nurses do with their own bodies to provide care. It is also the way in which nurses share their emotional and psychological effort to communicate with their patients during the care (Alasad, 2002; Shakespeare, 2003). Some literature has explored patients' bodily experiences in the intensive care units. Smith (1989) provided evidence on the mechanically ventilated patients' experiences of their bodies in the ICU, and found that most of the patients lost some of their body boundaries, and had what she called 'extended body image'. Her interpretation, however, was based on previous literature which did not reveal how patients themselves might describe their experiences of their bodies. Similarly, Platzer (1987) reviewed twenty two articles published during the 1960s and the 1980s. She found that the majority of the ICU patients experienced psychological disturbances due to the loss of their body images, and some did not recognise parts of their bodies. However, none of the studies reviewed shed light on how the patients might describe their experiences with their sick bodies, and how they experienced the nurses' care in relation to their body.

6.3 Chapter overview

This chapter focuses on how women interpreted their experiences of their own body, and the nursing care they had received in the ICU. My early data analysis started with the general sub themes related to the women's experiences of their bodies. For example, many sub themes were related to the cultural norms, such as covering the body, wearing a scarf, feeling exposed. As these were grouped together, they formed three main themes as seen in Table (6:1). This provides a summary of the main themes and sub- themes and the relationship with the sub-concepts in this chapter. Other sub-themes which were related to the physical performances such as inability to move and loss of body control are grouped under the independent and dependent physical performances. In further analysis I began connecting the themes and particular sub-concepts as noted. These concepts are: 'the dependent body', 'the social body', 'the cultural body', and 'the mechanical body'.

Table 6.1 Organizing the sub-themes in to sub-concepts.

Sub-themes	Themes	Sub-concepts
Care for children	Independent physical Performance	Dependent body
Care for others		
Depend on myself		
Dependent on nurses		
Where I am loss of body control		
Unfamiliar environment.	Dependent physical performance Strangeness	
My body hurts		
Body cannot carry me any more		
Cannot move my body		
Body is too weak	Loss of communication	
Loss of the ability to talk		
Nurses are too busy to talk		
Nobody cares		
Nobody to talk with	Social isolation	Social body
Family assistance in caring		
Need to chat with friends		
Miss the children		
Miss the family member	Social loss	
Miss the husband		
Short gown		
Feeling naked		
Uncovered all the time	Covering the body	
Feeling exposed		
No privacy		
Feeling "Aster"	Haram	Cultural body
Protect my body		
Male cannot touch the body		
Men and women in the same unit		
Exposed in front of men		
Preferring female nurses		
Male nurses providing care		
ICU full of machines	Machines controlling the body	Mechanical body
Machines everywhere.		
Machines do everything.		
Cannot live without machines	Physical malleability/ image	
Red marks all over my body		
Full of tubes and lines		

The sub-concept: 'dependent body', describes the changes of the women's physical performances when they moved from their home to the ICU, and are then transferred to the hospital wards. Here, I explain how the women felt about their bodies during their initial time in the ICU. I use Um-Ahmed's account as a means to illustrate this sub- concept, and then I compare and contrast it with other cases in the study.

The 'social body' discusses how the women experienced the body as a social entity, changes in social relationships, and the interactions between the women and their families. The discussion also includes changes in verbal communication between the women with their families. The concept is noticed to be relevant to all the women

who participated in this study. Both Abeer's and Eman's accounts provide vivid accounts of the experiences of disabled women who lived through the critical illness; Abeer is a blind woman who was admitted under a state of unconsciousness to the ICU, while Eman had congenital dysfunction of her urination and elimination. Both accounts will be used as a guide with which to compare other cases.

'The cultural body' describes the way in which cultural norms and religious beliefs affect the women's experiences of their bodies. It also refers to how the women interpret the nurses' body care in relation to the nurses' gender. Um- Bashar's account will be used to illustrate how cultural norms and Islamic religious beliefs shape the women's experiences of their bodies; then a comparison is presented between women who accepted the male nurses' care but preferred to receive care from female nurses, and those who did not accept the male nurses' care. Some cultural norms and Islamic religious aspects are also elaborated.

The 'mechanical body' describes the way in which the women perceive the ICU as a highly technological area, and describe the ICU machines as an integral part of their bodies that control their physical mobility. I use the accounts from many cases to illustrate this sub-concept. Table (6.1) is the summary of the main themes and the way how they are organised into sub-concepts.

Following a detailed final analysis of the data, I concluded that the concept of 'bodywork' could be used to gain insight to the women's experiences of their bodies in the Jordanian ICUs. After I have formed the 'bodywork' concept, I went back to all of the cases in my study and compared and contrasted each of the concepts. The concept of bodywork is described in the following Table 6.2 which summarises all of the cases in relation to each concept:

Table 6.2 The concept bodywork and the cases in the study

Bodywork	Hospital and Cases
Dependent body	Hospital A: Amal, Um-Bashar, Um-Mahmoud, Um-Nader. Hospital B: Um-Saber, Um-Ahmed, Um-Essa, Um-Malak.
Social body	Hospital A: Abeer, Eman, Amal, Um- Sami, Um-Adam, Um-Bashar. Hospital B: Um-Ahmed, Um-Ali, Um-Essa, Um-Malak, Um-Fadi.
Cultural body	Hospital A: Eman, Um-Bashar, Um-Adam. Um- =Mohammed, Um-Nader. Hospital B: Um- Ahmed, Um-Ali, Um- Saber, Um-Essa.
Mechanical body	Hospital A: Eman, Um-Mahmoud. Hospital B: Um-Ahmed, Um-Saber, Um-Ali.

6.4 The dependent body

Yeah... I felt like a paralyzed person. I felt sorry for myself, because beforehand everybody was depending on me, I used to take care of my husband and my kids, erm, ... Yes. I was really paralyzed during the intensive care, I was totally dependent on others, I mean, nurses and doctors did everything for me, all the 'Ejra'at⁶⁴ Oh, I cannot imagine how weak I was, I needed help in everything I did, even in using the toilet-- I could not control my bladder. I used to wet my bed so they would use incontinence nappies (pads) to keep me dry and every time the nurses wanted to change the bed and cleaned me. I felt so embarrassed and shy. I really wanted that to end (Um-Ahmed, first interview).

With these few words Um-Ahmed, first introduced in chapter 4, described her first experience in the ICU. Um-Ahmed suffered Systemic Lupus Erythematosus several months before her admission to the ICU; she had chronic joint pain and visited the hospital several times before. She described how her pain increased during housework but she tended to tolerate the pain and cared for her children. Child care is the fundamental bodywork which she had to do every day at home. Before her admission to the hospital, she felt that her mother could take care of her children when she was in the hospital.

...I felt a little anxious, especially when I thought about my children. I was thinking who will take care of them; I have to prepare their meals every day, dress them well, um, and send them to school. I asked my mother, please could you take care of the children, uh, I also asked my sister-in-law for help. It is difficult to leave them alone, they are young. All of them are at school; they need a lot of care (Um-Ahmed, first interview).

Admission to the ICU was a major challenge to her. After she had spent five days in the medical ward, her health condition suddenly deteriorated and she was admitted unconsciously to the ICU. Um-Ahmed described that she woke up after seven days in the ICU which was a very strange place, and found herself connected to machines and monitors.

⁶⁴ procedures

As seen from her first account, the first challenge to her was to move away from her formerly independent bodywork, and from being a mother who provided care for her children and husband, into a completely dependent woman who received care from nurses, even in performing her basic needs. She described herself as a paralysed woman who could not move or do anything by herself. She moved backwards with her story to offer a comparison between her status before her critical illness and her condition in the ICU, where she felt shame and embarrassment when the nurses changed her incontinence pad. She could not comprehend that she was unable to do any activities in the ICU. Further in her interview, she explained that the sudden events accompanied by the unfamiliar place were part of her experiences.

You can imagine that all my life I had good health; the only complaint was joint pain and slight tightness in my chest. Then all of a sudden I found myself in a place where only very ill people were kept. This was the first time I was in intensive care. It was a totally strange environment to me, I did not know anybody there, and no one from my family was with me to support me, or at least to ease my worries (Um-Ahmed, first interview).

For her, the unfamiliar place led to a new bodily experience which she could not comprehend. The change caused her to feel strange and ask for support from her family, people who were familiar to her.

Like Um-Ahmed, many women who were admitted to the ICU suffered from the loss of their physical strength and body control. The women in this study moved from their familiar environment, where they lived with their family and relatives, into a new place which was unknown to them. The events were sudden and unexpected. when the women were first admitted to the ICU they lost their familiar environment, which added significant meaning to their daily lives. The ICU was described as completely unfamiliar and scary. They connected the unfamiliar place [the ICU] to their experiences of their bodies, which they knew well. Some described how they lost their bodily control; other reported that they temporarily became unaware of their bodies. For all of the women, their awareness of their bodies increased, and they started to think on how they could survive with their new dependent body. Um-Saber, introduced in chapter 4, is a grandmother who accepted some help from her sons and daughters when she felt tired at home. When she was admitted

unconsciously to the ICU after a car accident, she stated that she felt paralysed, unable to control her body's movement:

I had no previous idea about what happened, I couldn't hear or see anything, I was unconscious...I was covered in casts, all over my body, I was surprised, I never imagined in my life that this would happen to me, yeah, it was horrible !!. ... Erm, Dear, I was very, very scared, I felt that I would never get well, I was completely paralyzed, yeah with all those machines and monitors, I couldn't move or do anything, I was shocked. Yeah everything was strange to me; I had never been in that unit before. It all happened to me, all of a sudden. All of the events came together very fast and I couldn't piece all the events together, yeah they was fast and sudden events (Um-Saber, first interview).

Um-Saber described that she felt shocked and could not comprehend all the events of her experiences which made her unfamiliar with her body, which she thought she knew so well. She started to be aware of her limited physical mobility when she was connected to the ICU machines and wearing the plaster cast. Nurses were part of the dependent body experiences; she described that she accepted the nurses as part of her family who provided help and support during her critical illness.

I consider them all like my children [the ICU nurses]. One of them was a very good nurse, she always came to me, massaged my back, and brought me water any time. Erm, and she changed the sheets, whenever she saw me, she asked me to pray for her. You know, some times I felt too shy to press the button every hour for help. They worked hard, and I tried not to be a burden (Um-Saber, first interview).

Um-Saber accepted the nurses' care partly as a compensation for the loss of her 'old' body before her admission. She accepted the nurses as part of her family who provided help and support when she was tired. Nurses accepted the nurses as helper and supporter to her, nurses helped her in doing her basic needs and to cope with her new illness condition. However, she implicitly mentioned that she felt like a burden to the ICU nurses and was reluctant to ask the nurses for help too frequently. Similarly, Um-Malak, who was admitted unconscious to the ICU after she had developed septic shock, reported that she could not move or do anything because she was surrounded by machines and connected to many tubes:

I opened my eyes in a very, very strange place. I have never been in the ICU before. I did not see anybody around me. At first, I didn't know where I was, you know I was scared, very scared, I was watching machines over my head. One over my head, the other connected to my hands and around my arm, oh, so many of them. I could not do anything; my body was full of tubes and connected to the monitors. Erm, I had no energy to hold my body or even to pull my hand, I was very weak. Nurses did everything for me, and I had to wait for them to feed and clean me all the time. It was very embarrassing (Um-Malak, first interview).

Um-Malak linked the strange environment to the presence of the ICU machines, loss her ability to do her basic needs and dependence on the ICU nurses to perform her needs as part of her suffering.

When the women were discharged home, they faced difficulties resuming their daily activities and regaining their familiar bodies. In her follow-up interview, Um-Ahmed described her struggle to cope with her new life after her recovery, and she felt weak and unable to resume her daily routines. Caring for her children and doing the housework were also difficult. This will be discussed in chapter 7.

Bodywork is not only related to the changes in physical performances, but also includes changes in social relationships. Um-Ahmed's story represents the change of the woman's' body work as they moved from their independent status at home into a completely dependent condition. She felt shame and was embarrassed to receive care from the ICU nurses, but did accept their help and care. Similarly, Um-Saber and Um- Malak felt strange and completely dependent on the nurses. Um-Saber accepted the nurses as part of her dependent body while Um-Mahmoud felt embarrassed when the nurses tended to some of her basic needs.

Two women in this study had a relatively different experience of their dependent body to the women's as described above. Abeer and Eman already had a permanent disability which left them partially dependent on their family for help and support. Both cases will be the main focus of the following section.

6.5 The social body

Support from family and relatives are part of Jordanian cultural norms. These norms stem from the Islamic religious perspective. For most of Jordanian Muslims, illness is a family issue. All family members try to provide help and support to the ill person. The family-social relationships become stronger when any of the family members is admitted to the hospital, or is struck by a critical illness.

As part of the Jordanian community, the women in this study described their relationships with their family and relatives as very important, especially when they

were admitted to the ICU and lost control over their bodies. Abeer, introduced in chapter 4, is one of the disabled women who has been blind since birth. She said that she was dependent on her mother to perform some of her daily activities. The mother helped her in dressing, bathing, and studying. When she was admitted to the ICU, she described how she felt isolated, and missed her mother's familiar voice:

I don't know, I can't remember, I can't see anything around me, you know, - pause- I am blind...I only felt that my body was moving up and down, and I was hearing doors opening and shutting, ah. Pains all over my body, every cell in my body hurts, Umm, and I don't know what was going on around me, being blind is so difficult in such situations... I shouted 'please, call my mum, I need mum' I wanted her badly to tell me what was going on, I was very scared, I felt very strange, I couldn't concentrate (Abeer, first interview).

Abeer considered her blindness as part of her suffering during her time in the ICU; she could not see or know what was happening to her. She said that she lived in limbo and ambiguity when nobody explained to her what was going on in the ICU. For her, her mother's social support was crucial in order to understand what was happening around her, and when she heard her mother's voice she felt relaxed:

... I felt relaxed when I heard my mum's voice, you know I lived with Mum all of my life; she is both my mother and friend. She never bothered me. I never gave her my attention and she did whatever I asked her to do. You know, Mum understands me well and she can explain to me what is happening here. Mum can take care of me (Abeer, first interview).

The mother's support formed part of her social body and dependent body. Abeer, when recalling her experience during the intensive care, started to appreciate her relationship with her mother.

Further in the interview, Abeer recalled her brothers and sisters. Her voice was hesitant and she burst into tears. She was unable to continue her interview:

...all of these things [events in the ICU] made me so sad, but the most terrible thing was that I felt so sad at being away from my family. When I was there, all my life passed through my memory, I remembered the beautiful days when the whole family and I were sitting together, talking, laughing, telling jokes, oh!! How much I missed those days, how awful – (she started to cry) (Abeer, first interview).

Abeer expressed her loss in tears; her tears reflected on how much she had suffered during her time in the ICU. Abeer felt socially isolated and missed her family in the ICU. Abeer ended her interview with few sentences describing her events in the ICU:

... I woke up lying down in bed, I think, well, I was in a coma, and I heard many voices around me, saying 'she had a terrible accident' and ...Yeah... 'Many fractures'. Pains were all over my body, every cell in my body hurt, Umm, and I didn't know what was going on around me...Yeah, I couldn't tell in the beginning, voices everywhere, I didn't know what was going on, and being blind makes things much more difficult to understand, I was suffering a lot, many pains, my legs hurt, my hands, my chest, my whole body, I couldn't move, every thing was happening too fast, I was not given even a glance to think of what was up!! You know how things seem, when the tape of your whole life passes in front of your eyes in a second, but I don't even have the eyes to see what was going on (Abeer, first interview).

Abeer ended her interview with some sentences about the ICU. I cried when I heard Abeer's last few words describing all the events of her illness. She left me wondering how it must feel to be a blind lady living in the experience of a critical illness, where she could not see anything in the ICU; she lost her bodily strength, accompanied with severe pain, and the inability to see anything around her.

The second case, involves Eman, who has a congenital anomaly in an obstructed bowel and a very small bladder. This leaves her with a permanent abdominal stoma and urinary incontinence. She also has a sensory and motor deficit in her left arm and leg due to unknown congenital reasons. When I asked her to tell me about herself, she described her disability as part of her identity; disability has long since changed the way of how she accepted herself, although she felt sad at having to live as a dependent woman. A feeling of shame was also evident because she was dependent on her family:

My illness started years ago when I felt that I could not control my bladder, and I have to wet myself. Umm, my mother sent me to a nerve specialist to see what was wrong with me, he told her that this is a very rare disease and I have a 'Tashouh Khalki' [congenital anomaly]. This problem leads to laziness in my bowel and bladder, and so they do not function well. Yeah, I have suffered from these problems for many years, and the doctors say that there is no chance of recovery from this disease in Jordan.

R: Oh dear, how did this affect you?

(Laughs) It affects me a lot, yeah a lot, umm, I feel sorry for myself, I live my life dependent on others, and you can imagine that a woman of my age, yeah, nineteen years old who cannot control herself. (pause) You know it is very painful to be like this all your life, I mean I could not control my bladder and sometimes my bowel (Eman, first interview).

On her admission to the ICU, Eman felt shocked and confused. She described how she found herself in a strange place where she could not move or breathe because of the ventilator machine. She connected her feelings of alienation with the loss of her family, on whom she was dependent:

Oh, (silence) and because you haven't got anybody near you. I couldn't ask anybody to help me, I was very scared... I was crying a bit when I saw my brother, in a hurry I asked him to take me home. Umm, my family helped me. They supported me, uh. Nobody helped me in that unit [the ICU] and I felt very lonely, yeah, very (Eman, first interview).

It seems that her experience in the ICU was a continuum of her dependent body which she experienced before her admission. Family loss was part of her suffering in the ICU. When Eman was re-united with her family members, she felt happy and relieved. She considered her family as an integral part of herself which she could not live without

... this made me feel happy to share with others , umm, we had a shared feeling, and after some time we used to sit together and have our lunch or dinner (Eman, first interview).

Eman, in her follow-up interview three months later, started to think differently about her disability, when I asked her about how she felt about herself at that time, she replied

...Oh, I'd like to be able to behave as any ordinary woman would, I would like to go everywhere, I would like to visit my friends and have a chat with them. I would just like to be normal and enjoy my life. I would like to go shopping. I don't know if I can go shopping on my own, but I wanted to be like any ordinary lady (Eman, second interview).

It seems that Eman's experiences in the ICU provided her a chance to re-evaluate her experience of her body and her relationship with the family. She accepted her disability and wanted to live her social life as any other ordinary woman. She decided to be sociable, and to communicate with her friends.

Family support was important for all the women in this study during the time they were in ICU. They maintained that social support was crucial in helping them cope with their dependent bodies and to improve their psychological wellbeing. Um-Ahmed, discussed in the dependent body section, felt embarrassed when the ICU nurses helped her basic needs, but she felt happy to ask her husband to help her when performing physical needs, such as bathing or grooming:

...When I was in the intensive care unit, he helped me in many procedures. He helped me in bathing and grooming; he sat near my bed and reminded me about the wonderful time we spent together; he encouraged me to recover... When I felt very frustrated I told him that I may die, he replied no, you will recover and come home with me to see your children, you know, these words made me very happy and cheered me up (Um-Ahmed, second interview).

As seen from Um-Ahmed's account, she considered her husband's help and support a means to her recovery in the ICU. It also seems that verbal communication with her husband expanded her happiness.

Verbal communication with the family is important. The women said that they felt happy to talk and discuss their feelings with their families. They felt anxious when the family left them which caused in their feelings of loneliness. Um-Ali explained that she felt unhappy about staying alone, and wanted some of her family to stay with her. She wanted her daughter to explain the progress of her illness condition and to share her feelings. Loss of her family members was considered a painful experience:

You see that if women are on their own, with no one from the family around, it is very difficult. I mean, in the special unit [the ICU], visits are limited; erm, and I wanted to talk to my children, and asked them what happened to me. I can share my worries with them. I felt my condition getting worse all of a sudden, and then I was in the strange unit, and I did not know anybody there. It was painful - very painful. (Um-Ali, first interview).

On the other hand, loss of verbal communication with the family was distressing to the women. They explained how they suffered when they lost their ability to communicate verbally with their families. Amal, admitted to the ICU after a thyroidectomy surgery, described that she was worried over losing her voice after the operation and felt happy to re-unite and talk with her family:

Erm, I was worried that I could have lost my voice after the operation, and I might not be able to talk with my family and friends, but I felt happy when my voice steadily returned (Amal, first interview).

Similarly, Um-Mohammed described that she felt dumb when she lost the verbal communication with her family. She said that the use of pen and paper is not enough to express her feelings:

Yeah, they had taken out the tube from my throat a day before they sent me to the floor. I was struggling with that tube, I asked them [the nurses] to take it out many times, yeah, many times because I couldn't speak with my family. Though they [the nurses] helped me with pen and paper, it was difficult. It was very difficult to stay without talking; you cannot express your worries. I felt that I was dumb (Um-Mohammed, first interview).

The women not only interpreted their experiences in relation to their dependent or social body, but they also narrated these experiences in the context of the Jordanian culture. Women within the Jordanian culture are used to covering their body, and

wearing a scarf. The women described their desire to cover their bodies and to keep their cultural norms. This will be discussed in the next section.

6.6 The cultural body

This section discusses the cultural aspect of the body in two ways. The first is the effect of cultural norms, or the Islamic religious beliefs of the women's interpretations of their experiences. Caring from the women's perspectives are divided into male and female nurses' care. The women said that they preferred to receive nursing care from female nurses, although some women accepted having to have some help from the male nurses. I use the concept of 'Haram', which was narrated by the most of the women discussed in this section. Secondly, most of the women cover their body as part of the Jordanian culture. I discuss the women's desire to cover their bodies and acquire privacy.

6.6.1 Haram⁶⁵

In both the ICUs where I conducted my study, I found that the head of the department allocated the nurses according to the severity of the patients' conditions. The head nurse did not consider the patient's gender when allocating a care team. When asked for the reason, they explained that they had a shortage of nurses. After I had analysed my data, I found that a majority of the women raised this issue. Fifteen women in this study mentioned that they preferred to receive care from female nurses. For them, only the nurses of the same gender are allowed to perform body care. Um-Bashar, introduced in chapter 4, was the first women who showed her disagreement in receiving care from a male nurse in the ICU.

... anyway, I remember that on last Thursday, nurses came to me, they lifted my head and they cleaned my hair, a a, and wrapped all of my body, I felt cool and refreshed, Um, what I like very much is the idea of having women like you, caring about you. I don't like to be helped by men. But you know dear, in that unit [the ICU] all the health team are mixed, they work together, I don't like to be cared for by men, I don't like the men to touch my body, this is 'haram' in Islam even if they are doing their job. There are women nurses there [in the ICU]. Why should the men care for ill women! I didn't accept that a man might take care of me, Erm!! I will never allow him to bath me, (ha ha ha: laughing) I will tell him, go away from my bed and see another sick man, I will never accept it (Um- Bashar, first interview).

Although she was happy with the nursing care in the ICU, she explained that she would never allow a male care worker (either a nurse or a doctor) to touch her body,

or to give her a bath. Um-Bashar felt surprised when male nurses provided care to the female patients in the ICU; her interpretation of the nurses' care is based on her cultural norms and religious beliefs; nurses from the same gender are preferred to provide the care. She is a religious woman too; when I met her in the gynaecology ward, she was wearing a long dress covering her entire body except for her face and hands. She mentioned that on her transfer to the ward, she asked the ICU nurse to transfer her to the gynaecology ward where she could be with female patients. Um-Bashar used the ward 'haram' to explain why she did not agree to receive care from male nurses; this concept is used by many women in this study. The Arabic word 'haram' means forbidden, here in this context Um-Bashar used this concept to explain her disagreement in receiving care from male nurses.

Women who have Islamic religious beliefs consider any man who is not a close family member, such as the father, brothers, uncles, or grandfather, as a 'strange'⁶⁶ man. Islamic belief is a main determinant of the cultural norms and attitudes in Jordan (Hasna, 2003). In Islam, non-relative men are not allowed to touch a female body or see any part of the woman's body except her face and her hands. Therefore a male nurse is considered as a 'strange' man and is not allowed to touch the woman's body. Women such as Um-Bashar do not accept male nurses performing body care, or to touch her body, and they request the care from a female nurse. Similarly, Um-Ahmed, introduced in the dependent body section, acknowledged that male nurses helped her to recover, but asserted that she would not allow a male nurse to touch her body:

... although male nurses did their best to help me, they treat me as their sister, but I prefer to be cared for by a female nurse.

Q: Why?

Because I don't like any man to touch my body. The only man who can touch me is my husband, you know we all live in this country and it is not acceptable that a male touches a female. Yeah I think also because I am a Muslim and I wear hijab and cover my body, in Islam it is not allowed for a strange man to touch my body, it is mine, I mean my body is mine and I will not allow any man to touch it (Um-Ahmed, second interview).

⁶⁵ Means forbidden, the English word taboo could have close meaning, but does not have the same cultural context.

⁶⁶ In the context of the Jordanian culture, the Arabic adjective 'Gareeb' is used to describe any man who is not a close family member. The English meaning of this word in the dictionary is 'strange'. I acknowledged that this word could have different meaning within western culture.

It seems from her account that she did not accept receiving care from male nurses for two reasons: firstly, because of her religious beliefs she explained that men were not allowed to touch the women's body. Secondly, as a female patient, she did not want any male care worker (a male nurse or a doctor) to touch her body but her husband.

Um-Adam, on the other hand, connected her experiences of the body with her sense of honour and respect. Um-Adam is an eighty-two-year-old woman who considered the cultural norms and religious beliefs as part of her identity and everyday life. When she was admitted to the ICU, she felt exposed wearing the ICU gown; she described one of her traumatic experiences in the ICU with anger.

..."oh yea, yea, - silence- I remembered an incident I would never forget. The nurse's name was A. I politely called her many times, telling her that my back hurts. I asked her to look at my back, so she might see what was wrong with it. You know what she did? Of course you don't, and won't be able to imagine, - smiling ironically- she called for a guy, a young man, to look at my back!! I mean a male nurse, how could she?! How did she dare to do that? I didn't know, I started to shout as loud as possible, blaming her for calling a male nurse to see me from behind.- silence- imagine, dear, can you imagine what happened to me, I , who was very old in that section became a sightseeing attraction for everybody to look at !! And at what?! At my back! God won't forgive them! It is Haram, they had no shame, no honour, no feelings, how could she dare to do that, how could she allow a strange man to see me from behind, you know because of shyness, I felt that my face was exactly as a small bit- a proverb in Arabic to show an exaggeration of shyness. I decided to leave that unit; I didn't need them anymore (Um-Adam, first interview).

Um-Adam interpreted the male nurse's care when he tried to help her in back massage as both traumatic and disrespectful. She used phrases such as 'no honour' and 'haram' to express her anger and dissatisfaction. Her interpretation of the nurse's behaviour is related to her cultural perspective and religious belief of her body; men are not allowed to touch the women's bodies. Similarly, Um-Saber, a fifty-nine year old grandmother, told me that she is a respected woman within her family. She described one day in the ICU where there were no female nurses in that unit.

I was uncovered most of the time, I mean with that little gown, what a gown! My legs lay bare and my back opened. I was unable to serve myself, the male nurses had to change the sheets under me, yeah, it was very embarrassing, you know I refused to take a shower because I didn't want any man to see me, you know it is haram... I would never allow them to change my clothes or to wash me, or (ha ha) to change my underwear, never ever. I would not allow them. Even if I was in a critical situation (Um-Saber, first interview).

Um-Saber, as seen from this account, felt exposed and ashamed of her uncovered body in front of the male nurses. She refused to receive a bath that day because she would not allow the male nurses to see her body; her religious haram was the cause of her refusal for such care from any male nurse.

One woman, whom can be considered as a deviant case, agreed to be cared by a male nurse, and said that the male nurses' care was more supportive than the female's. Um-Essa, as described in chapter four, lived through the experience of vicarious death, when she felt that she would die at any time in the ICU. These events could have affected her interpretation of the nurses' care:

Ummm, to be honest, no, not all of them, you know I remember the nurse X, he was wonderful, God bless him all the time, he was very supportive, you know, he moved me when I asked, he fed me, (ha ha) you know dear he used to bring the food and gave it to me by spoon slowly, slowly. Even if I could eat alone, he fed me, I was very happy with him, he was a great nurse. But the female nurses were complaining all the time, they didn't want to respond to any of the ill people's requests; they were lazy (Um-Essa, first interview).

By her description of the male nurses as supportive and caring, it is obvious that she only agreed to let them feed her as part of her fundamental needs. For her, nurses who provide basic needs such as feeding were considered to be good nurses. In her follow-up interview, however, she narrated her experience with the male and female nurses using different a form; Um-Essa acknowledged the male nurses' care, but made it clear that she would not accept body care from a male. She connected her interpretation with her religious beliefs and cultural norms.

...there was a very gentle nurse, he was so kind, whenever I told him that I need an injection to relieve my pain, he gave me one at once, here on my left shoulder, but you know, I couldn't ask him for everything, I am a woman, I couldn't for example ask him to change my diaper!! Haram...Yeah, some of them, men and women, but men were better than women. Erm. But you know dear? It was better to have good female nurses to take care of the ill women at the ICU, but there were few there. It is not our traditions that a woman can uncover herself in front of men, so women are preferable. Having men in the unit embarrassed me (Um-Essa, second interview).

It seems that Um-Essa accepted the men's care when she felt that her life was threatened, but when she went back home, she re-interpreted her experiences according to her religious beliefs.

As noticed in Um-Saber's and Um-Essa's accounts, both women said that they wanted to cover their body. Covering the body is an integral part of the Jordanian women's culture. This will be discussed in the next sub-section.

6.6.2 Covering the body

All the women in this study described their desire to cover their bodies in the ICU. They said that covering the body is part of their Jordanian women's identity. Women usually wear the long dress [called Thoub or Abaya] at home. Um-Mahmoud makes one of the examples. She told me that she used to wear the Thoub⁶⁷ at home with her children. When she was admitted to the ICU she had to change her dress and wear the ICU gown, which she described as follow:

No, I didn't like it [the gown], it was short and exposed my legs, and also it had an opening in the back. To me it was something that I didn't wear, yeah, not even in front of my kids. I felt embarrassed (Um-Mahmoud, first interview).

Um-Mahmoud felt embarrassed to wear the gown and expressed her dissatisfaction with her physical appearance. In her follow-up interview, Um-Mahmoud explained more about the ICU gown.

I was without clothes dear, I mean that this gown was very short, and I couldn't cover my body, I felt ashamed because I would never be that way, you know dear, when you grow up you will feel that you need to behave in a decent manner. It is the culture my dear, we need to cover our body, I couldn't imagine that my children would look at me with that bad gown. I couldn't remove my scarf, I needed to put on the blanket to hide myself in front of my children and my visitors. It was difficult to be like this all the time, you know, it is summer time, and nobody can stay under the blanket for long –laughing- (Um-Mahmoud, second interview).

As seen from her account, Um-Mahmoud lost part of her cultural identity when she wore that ICU gown; she felt exposed and lost her modesty. She could not show her exposed body to her children or relatives.

Loss of cultural norms was not only expressed by Um-Mahmoud, but also by all the other women in this study. Um-Ali, for example, connected her experience with the Islamic religious beliefs. She explained that she had to cover her body and wear a scarf all the time in the ICU. This is because of the presence of male nurses and other male patients. She also suggested that it would be preferable to have a separate section for female patients and male patients.

⁶⁷ A long black dress which covers the whole body.

... I couldn't feel comfort and I couldn't even remove my scarf in front of them [the male nurses in the ICU], I felt very hot in that room[in the ICU] but I couldn't remove my scarf because there were many sick males around me. I think it is better to separate between sick males and sick females.

Q: So you like to be separated from the males?--

Yeah, I felt more comfortable with other women, I could remove my scarf, and you know, it is "Aster" (to be protected). You know, when the relatives came to visit their sick they will see the women with that gown. It was very short and open at the back, and it didn't cover the body (Um-Ali, first interview).

Um-Ali used the word 'aster' to express her desire to cover her body and her shame when wearing the ICU gown. She suggested having a separate section for the male patients. Similarly, Um-Sami described that when she was admitted to the ICU, she used to cover her body all the time and wear scarf.

...actually I wished that there were separate sections for the women and for the men, as you know, all of the men and women are mixed together, well, this made me uncomfortable, yes I felt that. Um, it's just you feel that you need to be covered all the time. Some times I felt hot and wished to remove my scarf but I couldn't; [strange] men everywhere there [in the ICU] (Um-Sami, first interview).

Eman is one of the women who connected her desire to protect her privacy of the body with her need to be covered.

.... you know, you're a bit exposed. I had to put on a very light dress; it was very short and opened from the back. I felt very cold and ashamed of myself, every time I had to cover myself with the sheet...we are Muslims; we should have our own "Khososyeh" [privacy]. Men should be separated from women, and women need a special gown; that gown in the unit is very exposed and thin; it was open from the back and I think we need a good cover for our hair, our hair was also exposed - there were no scarves in the ICU and there was a cover which was transparent, why cannot we wear our scarf in the ICU! Why could we not use a long thick gown! You know I think these are the most basic needs of the women in the ICU (Eman, first interview).

Eman considered the head and body coverage as one of the priorities of the women in the ICU, she felt exposed when she wore the ICU gown and lost her privacy. She used the word 'privacy', it seems, to reflect her cultural identity.

6.7 The mechanical Body

In Chapter Five, I have discussed some aspects of the machinery on the women's experience of suffering. The ICU technology was vital for the women's lives, but also a source of their suffering and pain. Early in my data collection I noticed that

many women mentioned that the ICU machines were the first things they saw in the ICU. As I went further in my analysis, I found that the women experienced the ICU machines differently. I asked the women what these machines meant to them. This section discusses how the women interpreted the presence of the ICU machines in relation to their body. Here I will use many of the women's accounts to discuss the concept of the mechanical body. Eman, introduced in the social body section, described the ICU machines as distressing and frightening when seeing them for the first time. Further in the interview, she explained how she perceived the ICU machines:

... dear I felt that these machines control my life. I completely depend on these machines. They work automatically. Umm, I tried to move my body but there was a huge machine connected with a big tube to my mouth, it was very big and annoying, and I could not talk or breathe, it blew air in my lungs and I wish I could shout 'please can you remove this machine from me' but I cannot say anything. I was completely dependent on that machine and without it my life was at risk (Eman, first interview).

As seen from her account, Eman considered the respirator as an external device which provided her with oxygen. The ICU machines were considered distressing and troublesome, but she tolerated them in order to survive in the ICU.

Um-Mahmoud had a different perspective about the ICU machine, and she described her time in the ICU with memories of limbo and ambiguity.

I was very scared; machines controlled my body, everything was working by machines. I felt that I couldn't get out of these machines. If I did so then the nurses would put it on me again. It was a must dear, I was living with all these machines, and some times I heard peeps from the machine and I started to shout 'please see what was wrong with me'. Yeah, you know, when the machine peeps, there is a problem in my body, and nurses come to handle the problem. It was the machine which saves the life of the sick people in the ICU. It saved my life. (Um-Mahmoud, first interview).

Here, Um-Mahmoud considered the ICU machine as an integral part of her body, as the machine is the source of life. She trusted that machine more than her body, and when she heard the noise of the monitor she felt that her body was not working properly. In contrast to the other women, Um-Ali felt happy to see the ICU machines and described the ICU machines as a source of her safety.

When they let me into the ICU, I found myself in a place full of machines, (silence) it was the first experience for me in the ICU. Uhh. They put many tubes on my body, in my nose, in my arms and here (she pointed to her abdomen), I felt, I felt that I was full of tubes, full of holes all over my body... You know, everything was done by machines, many machines, one for the heart, another machine for the blood pressure and one for the temperature, every thing was controlled by computers.

Q: I see..., and what do these machines mean to you?

(smiling) Well, I like it, not because it is comfortable for me to have them connected to my body but it is good for keeping me under their eyes. Yeah I felt safe somehow, but at the same time it kept me anxious and alert all the time, every time the machines or computer gave a noise I felt scared, because it meant that something was wrong with me (Um-Ali, first interview).

As seen from her account, she found her vitality was totally dependent on the machines. She felt secured when she was strictly monitored. It seems that she experienced extreme limbo and ambiguity that she could not trust her body, and found that the ICU machine could help her to re-gain some control over her body not her own will.

In this sub-section I have given three different interpretations of the ICU machines. Eman considered that the ICU machines separated her from her body, but were vital for her to survive in the ICU. Um-Mahmoud lived in limbo and ambiguity and considered the ICU machines as distressing, but trusted them more than her body. Um-Ali considered the ICU machines as a source of safety and security.

6.8 Discussion and Conclusion

This chapter has focused on the Jordanian women's experiences of their bodies in the ICU. Here I have tried to give voice to the women through their stories. I used the concept of 'bodywork' to gain insight into their experiences. The concept of 'bodywork' consists of four sub-concepts: 'the dependent body', 'the social body', 'the cultural body' and 'the mechanical body'.

The dependent body concept describes the way how the women narrated their experiences as they moved from their homes, where they worked independently, into the dependent status in the ICU. The case examples of Um-Ahmed, Um-Saber, and Um-Essa illustrate the women's loss of their body control when they were first admitted to the ICU. The women connected their experiences with distressfulness

and frightfulness. After the women had spent some time in the ICU, some of them lost their physical capabilities to perform their basic needs, such as bathing or washing. The women described themselves as being temporarily disabled or 'paralysed'. The temporary disabilities were connected to feelings of shame, when the women felt that they were totally dependent on the ICU nurses to perform some of their basic needs. After they had been discharged to their homes, the women faced the challenge of regaining their independent body. They said that they felt weak and could not cope with the changes in their bodies after discharge. However, family and close relatives' support helped them to get through these challenges.

This description reflects on what Madjar (1997:57) writes in a discussion about how health status is connected to the presence of 'the habitual' body, or the body that we are familiar with, whose functions are taken for granted. During life-threatening events, such as critical illness, the experience of unfamiliar places with the loss of the control over the body alters the perception of the body. The description also reflects what Frank (1991) asserts that through telling stories about the body, the ill people can make sense of their illness; the body becomes more familiar to the ill rather than the ill accepts the body as different from his/her identity. However, this study emphasises that the ill women usually can neither make sense of their illness nor tell a coherent stories, for the ill women live through the traumatic effect of their illness and can not comprehend most of the sudden events happening to them. In addition, this study asserts that family support helps the women to make sense of some of the events in the ICU and physically and psychologically assists the women to recover from their illness.

The findings of this study support the earlier findings discussed by Papathanassoglou and Patiraki (2003) who explore the survival experiences of 8 ICU patients in Greece. Their studies reveal that the 'lived body' is related to the patients' loss of a familiar residential environment and their presence in an unknown place, which affects how they interpret their experiences with their bodies; they describe that they could not do their basic activities as before their critical illness. In addition, the patients' feelings of social isolation stem from the lack of contact with their family which causes them to feel lonely and strange, and uncertain about their illness condition. Granberg (2001), who investigated the experiences of the ICU patients in

relation to the ICU delirium within the context of Sweden culture, finds that the patients reported loss of their body control, and felt that their bodies were empty during their ICU presence; these are related to the loss of their daily routines and activities. Granberg argues that these feelings can be connected to their loss of control over their bodies early in the ICU; however, the researchers did not mention how those patients interpreted their loss of body control. This study adds to the previous findings with the observation that the women felt temporally disabled when they loss the control over their bodies and longed to have some control back. Thomas (1998), in her attempt to define disability based on studies conducted in the UK, argues that the experience of disability cannot be solely understood through the impairment or the restriction of the disabled person's activities, but also in the effects on the social relationship with the others, and the emotional status of that person. However, within the classification of disabled for all the people who have a similar symptoms under the medical model of care, these people are seen as 'victims' who are dependent on the health care staff for support and care (Thomas, 1998:137). Seymour (1998) reveals that the disabled people's feelings of paralysis change their physical appearances and disturb their everyday life, and they merely focus on adapting to their physical changes and reshaping their worlds accordingly. One difference between the present study and the above studies is that the women in this study, although feeling disabled, mentioned that their disability is not permanent and their health condition would change to a better one after they are through with their critical illness.

The dependent body is also a social body. The social body is the concept which I use to describe the changes of social relationships as the women moved from an independent into a dependent body, and also after they had been discharged home. Family support, as part of the Jordanian culture, is considered crucial for the health and wellbeing of the women. Women who are disabled, or experienced temporary disability, sought social support and family help during their time in the ICU. Loss of social support during critical illness is connected to the feeling of strangeness and loneliness. Loss of verbal communication with the family is also considered as distressing and frustrating experiences. When the women were transferred from the ICU to the ward, they were reconnected to their families and friends. The women described their experiences as positive and felt happy to rejoin the family. Some

women argued that being with their family helped them to decrease their suffering and pain. Similar findings are discussed by Johnson (2004), who explores the experience of 9 patients over 7 days in the ICU in the UK, who were connected to mechanical ventilation. Johnson highlights on loss of verbal communication which made the patient feel frustrated as they could not convey their needs verbally. The mechanical ventilation also made those patients feel that they could not control their bodies. This study suggests that the lack of verbal communication is not the only frustrating experience.

Cultural norms and Islamic religious beliefs affect how the women perceived the care in the ICU. The concept of 'the cultural body' is used to describe the effect of cultural norms and Islamic religious beliefs on their experiences. The women preferred to be cared for by female nurses in the ICU; the nurses' care is connected to the women's cultural norms and religious beliefs; and some women connected their experiences with their cultural norms, where the women tended to be with other women in their everyday life. Other women connected the male nursing care to their Islamic religious beliefs, in which a [strange] male, such as the ICU male nurse, is not allowed to touch the women's bodies or provide bodily care. Cultural body care is also related to the women's desire to cover their body. Covering the body is part of the Jordanian women's cultural norms; the women considered that wearing a long dress and scarf is part of their identity; the women felt exposed when they wore the ICU gown. When they were admitted to the ICU they lost their cultural norms and accordingly their cultural body. A similar finding discussed by Karami (1979) investigates the behavioural responses of the patients in the ICU within the context of the Iranian culture. Forty patients were interviewed in the hospital wards, and were asked to tell about their experiences at the hospital. Female patients reported that they wished to cover their bodies all the time. Their wishes were connected to their desire to achieve their privacy; the perception of privacy is an integral part of the cultural norms for the Iranian women. This study supports the cultural norms in the way how women perceive their bodies and interpret the nurses' care.

The mechanical body is the concept which I use to describe the way how the women interpreted the ICU machines as an integral part of their bodies. The women described the meaning of the ICU machines in three forms. The first group of women

said that the ICU machines were distressing and frightening, and also controlling their bodies. The second group considered the ICU machines as part of their bodies, and trusted these machines more than their bodies. The third group considered the ICU machines were vital devices to keep their bodies in control. These findings supported Smith (1989), who argues that patients, during their time in the ICU, can lose their physical boundaries, and consider the ICU machines as part of their bodies. She provides an example of patients who are on mechanical ventilation, and describe how these patients lose their body boundaries, which is connected to their loss of body image. Similarly, Johansson and Fjellman-Wiklund (2005) conducted a qualitative study with seven patients who were on mechanical ventilation; the study explores the patients' experiences of their physical awareness in the ICU. Participants reported that they lost trust in their bodies, and felt that their bodies were without boundaries. These experiences were linked to their continuous connection to the mechanical ventilation, which was considered as an integral part of the body.

What this chapter demonstrates clearly is that the women's experiences of their body in the ICU are connected to their level of dependency and the social support of their family and close relatives. Jordanian women interpret their body experiences through the lenses of their cultural norms and Islamic religious beliefs. The main focus of this chapter, however, is on the women's experiences of their bodies after a short time of their transfer to the ICU, whilst within the hospital settings. The impact of the ICU experiences after the women had been discharged home will be the focus of the next chapter.

Looking back on critical illness: the women's experiences at home

7.1 Introduction

This chapter focuses on the impact of the ICU experiences on the women's every day life, and the meaning of their critical illness after they had been discharged home. These experiences were explored in their follow up interviews two to six months after their discharge home. From the sixteen women who shared their experiences in the first interview, eleven women agreed to take part in a second interview, and welcomed me to their homes. Two women did not give consent for a further interview, two women travelled overseas with their family and I lost any further contact with them, and one woman died shortly after she was discharged home. Participating subsequently in a third interview depended on the women's willingness to share in further discussion about their experiences. Two women agreed to participate in a third interview.

The analysis of the follow up accounts indicates that the women experienced a range of physical, psychological and emotional difficulties in the period following their critical illness. These difficulties included an inability to sleep, severe pain, difficulty in physical movement, inability to walk, the need for family help at home, difficulty in doing housework, loss of appetite, and self-doubts about good motherhood. Other concerns related to their health after they faced the experience of suffering, and the change in their 'bodywork' experiences, which were noted in the two previous chapters.

Four main patterns among the women's accounts were identified. The first pattern describes the change of the body experiences and includes changes in body performance, the feeling of weakness and tiredness. It also connects to the women's difficulties in eating and sleeping, and having to change the home environment in order to adapt as they recuperate from their critical illness. This pattern is interlinked with the feeling of emotional difficulties, which reflects the women's feelings of frustration and fear, and some women felt like a burden to their family.

The second pattern, Tall'eh⁶⁸, is a continuum of the women's experiences of the 'social suffering' and the 'social body' which was discussed in chapters 5 and 6. Here, I reflect on the way how these experiences provided the women with new meanings to their family relationships. It was also apparent that for some women, relationships with their neighbours and relatives developed differently after the critical illness.

The third pattern, 'good motherhood', emerged from five women's descriptions of their roles as mothers. When the women were admitted to the ICU they described how they felt worried and anxious about their children. Taking care of their children had been an important task before their illness. In their follow-up interviews, the women spoke about the change of their role and identity as mothers at home.

The final pattern, the meaning of critical illness, discusses the changes in the women's experiences after their suffering. The women felt that they owed their survival from critical illness to Allah. Most of the elderly women said that they praised Allah through prayers and/or plans to visit Mecca to show their thanking for Allah who gave them their lives. Young women, on the other hand, felt that their critical illness had taught them to look forward to their future.

This chapter starts with a review of the research relating to illness experiences in the wider literature, and then is followed by discussions of the findings within two sections. Section 1, 'looking back on critical illnesses', discusses the change in the body experiences as related to difficulties in eating and sleeping, and the change in the residential environment; this section also includes the emotional experiences that the women faced at home. Section 2, the meaning of critical illnesses, includes resuming a social life, being a good mother, and surviving the critical illness. The final section includes a summary and discussion of the findings in the context of the wider literature.

⁶⁸ 'Talleh' is a colloquial Arabic word, used to describe visits made to people who were ill and residing in their homes.

7.2 Background

Experiencing everyday life after critical illness gives rise to many challenges and struggles for the critically ill patients. These experiences have physical, emotional, and social impacts on the patients' lives (Green, 1996; Sarnamann, 1993; Daffurans et al, 1995; Hall- Smith, 1997). Studies report that the physical and psychological impact of the critical illness for some patients varies between the time periods of six months to two years (Russell, 1999; Chaboyer et al, 2002; Granja et al, 2002), with some patients developing PTSD (Jones et al, 2002; Löf et al, 2007). These experiences may change the patients' relationship with their bodies, or provide them with new ways to think about their future (Corbin, 2003).

As mentioned in section 2.2.5.1, physical and psychological recovery for many patients is described as slow and characterised by feelings of tiredness and weakness, these experiences physically impede the women's ability to undertake every day activities (Jones et al, 1998, Jones and Griffiths, 2001, Papathanassoglou and Patiraki, 2003). In addition, I discussed the way how the traumatic experiences in the ICU may lead to the development of PTSD (Scragg et al, 2001; Stoll, 2000; Griffiths and Jones, 2001; Jones et al, 2003; Schelling, 2003; Capuzzo, 2000; Granja et al, 2005; Griffiths, 2006; Löf et al, 2006; Pattison et al, 2007). In section 2.2.5, I provide in-depth accounts of the patients' description of their experiences in the ICU after 6 to 18 months after their discharger from the ICU (Maddox et al, 2001; Papathanassoglou and Patiraki; 2003; Adamson et al, 2004). I also highlighted a study of the experience of Norwegian patients which showed that the traumatic experiences in the ICU may impact on patients more than 10 years after they are discharged home (Storlu et al, 2008).

The experience of loss and change when moving from good health to being chronically ill may change the way how people interpret their life events. Some studies conducted with chronically ill people show that chronic illness changes the way how those people interpret their relationship with their bodies (Olsson et al, 2005). Others demonstrate that people's relationship with their self and identities is changed (Charmaz, 1983, 1991; Bury, 1982; Carricaburu and Pierret, 1995). For example, Charmaz (1983) suggests that people who are chronically ill suffer from

physical pain and psychological distress. After a period of time, chronically ill people start to recognise that they cannot participate in the activities they previously valued or enjoyed. The activities that they took for granted become excluded from their everyday life, and this may lead some chronically ill people to lose their perception of the self. For other people the experience of limited mobility decreases their social interactions with their friends and families, and these experiences can leave people feeling lonely and socially isolated.

Being chronically ill may present people with new understandings and meaning which can impact on their future. These experiences are shared when the ill people tell stories about their illness (Frank, 1991, 1995). Many studies describe that people who live through life-threatening illnesses re-evaluate their life and begin to develop different interpretations to their previously taken-for-granted life events (Muzzin et al 1994; Aziz and Rowland 2003; Kirsten-Prydes, Sive, and Kerstin 2000; Radley and Bell 2007). For example, the women who survive breast cancer report that living with cancer helps them to reconsider the value of life (Radley and Bell, 2007). Frank (1991), in his reflection on his own experience of cancer, explained how cancer changed his relationship with his body. Frank felt ashamed and stigmatised by the changes in his body, and this reflected on his perceptions of his own identity. However, during his recovery period, he discovered that cancer provided him with an opportunity to perceive life differently; he started to become more independent again, and to enjoy the positive aspects of his life. The DIPEX project, as I have discussed in the Background Chapter, provides a wide number of cases where patients reflect on their experiences long after being discharged from the ICU. Another example is provided in section 2:3 (DIPEX, 2007).

7.3 Looking back on critical illness experiences

This section discusses two main issues: the women's experiences of the changes in their bodies, and their emotional difficulties. Here I use Um-Nader's account to begin the discussion.

...Uh, I don't know from where to start Ruqayya. Everything has changed in my life. I cannot imagine how I can handle all of these changes now. You know that I lost my husband, (Uhh) and with him I lost part of my life; he gave me all the support in the past... my admission to the intensive unit left me with many, many struggles. I could neither do my work as before, nor help my children at home. Erm, life is very difficult, my dear, and children need a lot of care... (Um-Nader, second interview).

The above extract is part of Um-Nader's story three months after she was discharged home. Um-Nader is the thirty-seven-year-old mother, who lost her husband in an accident. Shortly after her husband's death, she gave birth to twins and had to take care of the two infants in her family. In chapter 6, I have discussed part of Um-Nader's first interview that is related to her desire to cover her body, and receiving care from a male health care worker. Um-Nader also mentioned that she could not understand the meaning of 'pulmonary embolism', but she knew that she was suffering from severe shortness of breath and irregular heart beats. Her feelings in the ICU were connected to her wish to see her children and to talk to them.

In her second interview, three months after her discharge from the hospital, Um-Nader looked pale and tired, and she sighed when recalling events. As seen from her account, she experienced difficulties in performing her daily activities. Taking care of her children had once been part of her everyday routine. After her discharge from hospital, she could not take care of her elder children as well as the two infant twins who urgently needed her help and support. She mentioned that her body was unable to perform as well as it used to and therefore she felt too tired and weak to meet her children's needs. Her story reflects the multiple losses and changes that most of the critically ill women would experience after they are discharged from the hospital to their homes; and these changes affect the women's relationship with their bodies.

7.3.1 Changes in the body

The experiences in the ICU have a physical impact on the women's bodies after they had been discharged home. The majority of the women described feeling frail and tired, unable to do their every day activities that they used to do. As mentioned above from Um-Nader's account, she could not resume her physical activities at home, particularly the care of her children which she described as demanding and requiring much effort. She felt too weak to meet their needs. Many women, like Um-Nader, mentioned that they experienced loss of body strength, and felt weak and tired at

home. These feelings impacted on their ability to carry out physical tasks such as attending to their personal hygiene and toileting; some said that they could not move and lacked the confidence in doing many activities such as housework or cleaning. In my second interview with Um-Ali, three months after her discharge, she described her time at home as follows:

... still I think that, erm, I am too weak to do anything. Ya, I still cannot do the housework, my daughter feels that, she helps me in cleaning the house and washing-up. She sometimes observes me when I go to the toilet. You know, I feel that my body is too fragile, and I am too exhausted (Um- Ali, second interview).

Um-Ali indicated that after her discharge she could not move or stand steadily, and she felt weak most of the time. Doing the housework or taking care of herself was considered as a difficult task, and she was dependent on her daughter for most of her daily activities. Similarly, Um-Mahmoud said that although her condition had improved and she could resume some of her daily activities, she was dependent on her daughter to do the housework.

... I feel much better now. But when I started to work at home, I felt so tired, and I asked my daughter to continue what I had begun, I felt embarrassed with my daughters, I could not help them any longer, I was very tired and weak. Erm, poor daughters, they all work away from home, and when they returned home, they are also very tired, but they have to work at home too (Um-Mahmoud, second interview).

Although Um-Mahmoud realised that her health condition had improved after being discharged from the hospital, she said that she was unable to do the housework, which was part of her routine activities in the past. It is also clear that she felt a burden on her daughter when asking for help.

7.3.1.1 Difficulty in eating

The loss of body strength and feelings of weakness are also connected to the women's loss of ability to eat and to the change in their eating habits. Um-Nader did not mention the changes in her eating habits, as this might not be a primary issue in her experience. However it was an issue for many women after they were discharged home. Um-Ali said that she lost weight during hospitalisation, and she could not eat properly at home.

... yeah, I lost weight and I felt tired sometimes because I did not have a balanced diet, I had to eat only soft food, no meat nor fibres in the food. But you know, I couldn't taste the food, Erm, there was no taste of the food in my mouth, I just ate to fill my hunger, not because I needed food. I don't know why, I don't know (Um- Ali, second interview).

The changes in her body include changes in her ability to taste food. She had lost some sensory faculty, which had affected her eating habits at home. She also described that she no longer ate the food which she had eaten in the past. The diet regimen that she had to follow after her illness restricted her from eating foods from her former diet. Similarly, Um-Bashar described that she had difficulties in following the diet regiment that she had after she had developed a pulmonary oedema in the ICU. She had to decrease the amount of fluid in her diet.

I don't have the appetite to eat. I feel that I can't swallow food. The food is tasteless; ... In the past, I used to eat whatever I liked, and drink whatever I wanted, too. But now, I cannot drink liquids in the amount I like. For me, I follow the instructions of the doctors. I find it difficult to change the habit of drinking coffee in the morning. I thought it would be easy for me not to drink coffee, but I cannot (Um- Bashar, second interview).

Um-Bashar found it difficult to change her eating habits and restrict her fluid intake. It seems that she found it difficult to accept the new changes in her body after her illness and in changing her routines, such as drinking coffee in the morning.

In contrast to most of the women in this study, Amal, who had hyperthyroidism before her admission to the hospital, had been experiencing difficulties in eating prior to her admission to ICU. After having thyroidectomy surgery, she felt relieved from the 'lump in her neck', and said that she now ate much better than before.

I feel a little better, before that [at home] I had no desire to eat. Well, they [nurses] encouraged me to eat liquid food... After the nurses explained to me about the operation, they kept telling me 'you should try to eat, you need food'. Erm, I feel better now, I can eat Jelly... and Ya, when they had taken out the tube from my throat, there is a scar, I am worried that this scar would stay here (pointed on her neck) and it has an unattractive look (Amal, second interview).

Amal found that the nurses' encouragement helped her with her eating habits, which actually improved after her surgery. However, her main concern was to protect her physical image in front of her family and friends, and this seems to be a part of the changes she experienced after being discharged from the hospital.

7.3.1.2 Difficulty in Sleeping

Some women suffered from the consequence of the traumatic experiences in the ICU for up to two months after their discharge. Um-Ahmed, for example, mentioned that she remembered traumatic events in the ICU, which appeared to have affected her

sleeping. Um-Ahmed said that sometimes she recalled her traumatic experiences at night, and felt worried and scared.

As I told you before, I woke up at 5 a.m. Sometimes I woke up in the middle of the night remembering the hospital, erm [smile] my husband told me that I was screaming sometimes at night, saying "please remove the lines from my mouth". You know dear, it seems that I am still influenced by it. It was a dreadful experience, awful (Um-Ahmed, second interview).

It seems that recalling the traumatic events in the ICU has a negative effect on Um-Ahmed's ability to sleep. Some women, like Um-Ahmed, interlinked the difficulty of sleeping with recalling the unpleasant time in the ICU. The flashback of some stressful experiences seems to disturb the women's sleep. Um-Malak, for example, said that she often woke up at night, remembering them.

I had a very difficult experience there [in the ICU], yeah it was unforgettable. Sometimes I woke up and felt scared, I was scared that my condition might get worse again, yeah, I felt that I might have to go back to the hospital and the ICU again, and even my husband woke up many times in the night, he heard me shouting, 'please I am very worried, please let me out of the hospital', yeah I had bad dreams after I went home, my husband reassured me, he told me 'don't worry, depend on Allah, there is nothing wrong with you (Um-Malak, second interview).

As seen from her account, Um-Malak was afraid of any return to the ICU and felt insecure about her health condition. This seems to be hindering her ability to sleep. In addition, the difficulty of sleeping is connected to having nightmares when she does sleep. This woman is perhaps showing signs of PTSD.

It is also important to consider whether her difficulty in sleeping could have been due to other reasons. The women who were discharged from hospital after their surgery faced difficulties in sleeping because of pain. Um-Ali recalled that she had severe pain from the operation site, which in turn made her sleep difficult.

Pain! Erm, In the middle of the night, I felt something hurt in my tummy, it struck me throughout the night. Uh!! How painful it was. I could not sleep, I was tired, but it hurt (Um-Ali, second interview).

Similarly, Um-Essa said that she could not sleep because of the severe pain she had, but she used sleeping pills to get over her difficulty in sleeping.

I didn't sleep at night, unless I had medicine, the pain was very strong. Today I took four pills to help me sleep, but even then I couldn't, and I am an old woman, I need some time for my bones to recover. We need time to heal (Um-Essa, second interview).

The sleeping difficulty for Um-Essa was caused mainly by the pain. This still affected her six months after she went home.

7.3.1.3 Changing the home environment

For some women, their loss of physical strength and performance requires some modification of their home environment in order to help them cope upon their return home.

Um-Nader decided to move with her children to stay in a house close to her family. When I asked her about the reason for moving, she explained that she needed help in many aspects in her life; she could not go shopping, and she needed help in taking care of her children. She found that moving close to her mother was one of the solutions to the 'critical' changes which developed after the illness.

As I was living away from my family, I had nobody around to help me, therefore, I decided to move with my children to live close to my family's house in [the name of the Avenue] ... I used to go to the market every week, and bought all the fruit and vegetables to my house, but now (erm) no more, I feel my hands are too weak. I cannot move or carry heavy bags... I have to visit the physician every month. Erm, I have to leave the children with my mother and you know how difficult the waiting in the out-patient clinic is, and sometimes I spend the whole day waiting to see the physician (Um- Nader, second interview).

As seen from her account, the decision to move from her house was linked to her inability to perform many activities independently, and she sought help from her mother, who would take responsibility for her children when she went to visit the out-patient clinic. Many women, like Um-Nader, found that changing their residential environment was necessary in order to adapt to the new changes in their lives following illness. Some women said that they made changes so that they found it easier to cope their post-illness condition. For example, they put the telephone near their bed, and they asked family members to rearrange the furniture in the house, so that it was easier for them to reach things. Um-Saber, for example, said that she moved her bed to the ground floor, as she found it difficult to get up and down the stairs.

I get used to my new condition. As I lived on the second floor, it was very difficult for me to move up and down the stairs. I asked my sons to move my bed to the ground floor, so I can easily reach the kitchen and the bathroom; and I asked them to put the telephone near my bed. I have to get on with these changes even, sometimes, I feel unhappy at having to sleep away from my husband, but what can I do? (Um-Saber, second interview)

Um-Saber accepted her new environment as a temporary solution for her condition, although she felt unhappy about not being with her husband. Similarly, Um-Malak agreed to live with her mother-in-law for a short time after she was discharged from the hospital, but then she decided to stay with her daughters.

My husband said 'maybe it is a good idea to send you to my mother, and she will take care of you'. Um, in the beginning I agreed because I really needed to get out of my house, but after two days I started to feel uncomfortable. Erm, I feel more comfortable at home. I asked my husband to move all the beds, because I could not move up and down the stairs. I used to sit on a chair to do the house work, and ask my sister-in-law for some help. It is difficult, and I feel that life is full of struggles (Um-Malak, second interview).

As seen from her account, Um-Malak found it too difficult to live away from her home, and she longed to have support from her husband and sister-in-law, in order to cope with the changes in her health.

For many women their inability to do basic activities had an emotional impact, for example feeling guilty about being a burden. As seen from the accounts of Um-Malak, Um-Ali and Um-Mahmoud, the difficulties that they faced during their everyday activities led them to ask for help from family members or relatives. The emotional feelings which accompanied their limited physical difficulties will be the focus of the next section.

7.3.2 Emotional difficulties

The loss of physical strength and the feelings of weakness and tiredness had led some women to experience emotions of fear, frustration, and of being a burden on family members. Um-Nader stated that after she could not take care of her children, she felt frustrated, and her identity as a mother was challenged.

My children will suffer if I get ill again. I cannot give them proper care. I feel very frustrated. I could not imagine that this would happen. I will do my best to help them (Um-Nader, second interview).

It seems that Um-Nader's concerns included feeling frustrated because she would not be able to care for her children as before, and she was also worried that she might become ill again, which would leave her children without the care of their mother.. Many women like Um-Nader feared a return of critical illness. For example, Um-Mahmoud was concerned that she may die and leave her unmarried daughter behind, and when recalling this she started to cry.

But the most difficult thing for me now is my children. I think about my children all the time, especially my daughters, how they are going to live if I die, what will happen to them, especially those unmarried daughters. If God remembers to take me to him, what would happen to my daughters [crying] I wish I wouldn't die before they get married, because when they get married I don't care if I die (Um-Mahmoud, second interview).

This reflects that the suffering experiences were affecting her in everyday life. She was worried most of the time, and wished not to lose her children. Um-Ahmed experienced her relationship with her children differently. She felt sad and frustrated when her children did not accept her care at home (see section 7.4.2).

This section has discussed the changes in the women's physical experiences and the feelings of weakness and tiredness. These changes affected the women's every day life. The impacts include the loss of the ability to do their every day activities such as attending to their personal hygiene and toileting, difficulties in eating and sleeping. Some of the women decided to change their residential environment or moved to live with their families where they could have support and help. These experiences together contributed further to feeling frustrated and burdensome to their family. For some, they also felt that their health was fragile but they did not want to be readmitted to the ICU. The long term meaning of the women's experiences will be discussed in the next section.

7.4 The meaning of critical illness

This section focuses on the meaning of critical illness, as narrated by the women according to their follow-up experiences. The women's experiences of suffering and the changes made to their bodies during their time in the ICU have many meanings in their lives. For some women, critical care experiences provide them with the chance to re-evaluate previous assumptions about life and to seek a different meaning to their lives after the critical illness. Three main patterns are identified according to their accounts. Firstly, 'resuming social life' describes the way that all of the women re-evaluate their relationship with their family and how they appreciate their family unity and support, as well as their social relationships with their neighbours and relatives. Secondly, 'being a good mother' describes the experience of five women who took care of their young children at home. The final section, 'surviving a critical illness', describes how the women looked forward to their futures after their illness.

Here, I re-visit some of the women's accounts presented in Chapter 5 and 6 by discussing each of the patterns. These are then compared and contrasted with other cases in the study.

7.4.1 Resuming social life

The experiences in the ICU impacted on the women not only physically and emotionally, as described in the beginning of this chapter, but also in terms of having an impact on the relationship with their families and their social lives. In Chapter Four I discussed Um-Saber's story to illustrate the women's experiences of social isolation and loneliness. Here I draw upon her second interview to discuss the changes in her social relationships after she returned home

Um-Saber, in her first interview, considered the family as the important part of her life and she talked about her 'nafsi' suffering in ICU, which reflected on her feeling of social isolation and loneliness (see section 5.4.2). In her follow-up interview two months after she was discharged home, Um-Saber looked back to her experiences in the ICU and clearly mentioned that she had learned from her experiences to value her family's support and help.

...Now I am home again with my family, the dearest to my heart. I told you that I have forty grandsons and granddaughters. They all care, they all come to my bed, asking about me, kissing my hand, saying 'Grandma, how are you today, God keeps you healthy'. I felt that my life came back to me again when I saw them all around me. They were responsible for my happiness (Um-Saber, second interview).

As her account shows, she connects her happiness with the presence of her family around her. She considered family unity as a sign of re-birth during the recovery period. Um-Saber, through this account, maintained that the family is part of her social identity, from which she cannot be separated. Her experience was shared by many other women in the study; Um-Essa, Um-Ali, and Um-Bashar were all dependent on their family for most of their personal care during illness. The family members helped them bathe and dress, as well as providing help with the housework and the cooking. For example, Um-Ali, after being discharged home, said that her children were most helpful:

I was very happy to see all my family around me, home is much better than the hospital. All of my children were around me, and helped me in eating, dressing, and even going to the toilet... You know, they are all my life, they support me now, they give me whatever I need. You know, dear, when you become old like me, your children are the only ones who will take care of you... yeah, no one can tolerate parents better than their children, God bless them all (Um-Ali, second interview).

Um-Ali describes how the unity of the family provided her with a means for enduring her illness after her discharge. Um-Ali could accept herself as a sick woman who needed help and support from her children. She felt happy when her children took the role of the carer at home. This is in contrast to what Um-Essa said in her account. Um-Essa recalled that her daughters-in-law cared for her at home, feeling that she was completely dependent on her family:

... Yesterday I was with my family, I mean with all my sons and their children and daughters-in-law. My family is a blessing... I depend on my daughters-in-law, uhh, all of the time they woke up early, to change my diaper under me. I can't go to the bathroom! It is embarrassing, but what can I do? In the past, I was able to depend on myself, but, you know, all my life has changed, I need someone to hand me a cup of water; my daughter-in-law keeps cooking, and serves me soup. I am completely broken; I mean, I cannot do anything by myself (Um-Essa, second interview).

In the beginning of her interview, Um-Essa stated that her family provided her with happiness, but later in the interview she clarified that she felt embarrassed by having to depend on her family. She considered herself as a 'broken woman', who must seek help from her daughters-in-law. It seems that Um-Essa felt happy to re-unite with her family, but she felt like a burden to her family. She longed to regain her old identity before the critical illness.

Family support was not always available to all the women in this study. Some women lived in their own houses and cared for their young children. These women asked for help and support from their mothers and relatives. Um-Nader and Um-Malak decided to move with their children, closer to their family home. Similarly, Um-Ahmed asked her mother to help her in caring for her eight-month-old infant and asked her sisters and sister-in-law to help in cleaning and tidying the house.

...I still can't do the housework. My family help, especially my sisters and my sister-in-law... she comes daily to help me and to clean the house and do the washing up. You know, I still feel that my body is too weak and that I am too exhausted (Um-Ahmed, second interview).

It seems that family unity and cooperation helped Um-Ahmed and the other women during the recovery period. Um-Ahmed, in her third interview, stated that her family provided a vital contribution to her life after the illness.

Oh!! I cannot forget how my family made my life easier. I felt that I could not handle it alone. I mean my life was critical and without my family I would have faced all these struggles alone (Um- Ahmed, third interview).

As her account shows, she describes how she appreciated the help from her family and relatives, and valued family unity during her recovery highly.

Family support was not totally separated from social relationships with neighbours and relatives. In the next section the word ‘Tall’eh’ will be used to discuss how illness strengthens the social relationships between the women and their neighbours.

7.4.1.1 Tall’eh (the neighbours’ and relatives’ visits)

A common Jordanian custom is that neighbours and relatives visit ill people after they are discharged from hospital, bringing them fruit, candy, or flowers. The word ‘Tall’eh’ is a colloquial Arabic word, used to describe visits made to people who were ill and residing at home. As part of my respect to these women, I observed this cultural norm, and brought a box of candies when visiting each woman at home. All the women mentioned that their neighbours and relatives visited them at home. Um-Ali said that she was happy to see her neighbours at her home.

My neighbours visited me many times, you know, all of my neighbours and friends around performing ‘Tall’eh’. It is the tradition, my dear, I felt happy to tell them what was happening to me in the hospital, and you know they went through and felt my experience with me all the time (Um- Ali, second interview).

Um-Ali was happy to share part of her experiences with both her neighbours and friends, who may help her during the recovery period. Many women like um-Ali consider ‘Tall’eh’ as a mean of sharing feelings and receiving sympathy, which makes them feel less alone and psychologically supported. For example, Um-Ahmed indirectly expressed her happiness when she saw so many neighbours visiting her at home.

They came for ‘Tall’eh’. Umm, I have too many guests. Oh dear, (smiling) you know how neighbours and relatives are coming all day to visit me. I felt that I should stay at home and wait for them (Um-Ahmed, third interview).

Although Um-Ahmed did not say that she was happy about her neighbours’ and relatives’ visits, she mentioned that she would prefer to stay at home and wait for the

visitors. Um-Bashar also expressed this kind of happiness of receiving visits from her neighbours at home:

They kept doing 'Tall'eh' many times; Mrs. X and Mrs. Y visited me every time, and brought gifts with them. I felt relieved, and said 'Alhamdulillah⁶⁹'; I can see how people share the pain with me (Um- Bashar, second interview).

Um-Bashar said that the neighbours' visits are considered as sharing the illness with others, which positively reflected on her life after her discharge.

As seen in this sub-section, the women consider the family as a source of unity in their lives and valued highly the family support and help received at home. The support is also connected with the women's social identities. The women also appreciated the 'Tall'eh' from the neighbours and friends and considered it as a way to share their feelings.

One important part of the family is the children. Five of the women in this study took care of their children at home, and they described some of their experiences with their children. This is the focus of the next section.

7.4.2 Being a good mother

Five women, who were mothers and looked after their children at home, said that their relationship with their children had changed. When they were asked to tell about themselves all of them said the word 'Um', which means 'mother' in Arabic, followed by the name of their eldest child. This is part of their cultural identity. For example, when I asked Um-Ahmed to tell me more about herself, she said '*I am Um*', and then gave the name of her eldest son (this anonymous name is Ahmed). The women who were grandmothers also used the word 'Um', followed by the name of the eldest son. Here, I use the accounts of Um-Nader, Um-Malak, Um-Ahmed, and Um-Fadi to illustrate this pattern. However, I did not use Um-Anas' account because I was unable to conduct a follow-up interview with her (see section 3.5.7 for details).

⁶⁹ Thanks and praise to Allah

Um-Nader, in her first interview, described how she felt sad at having to leave her children at home; she made it clear during her hospitalisation that she missed her children.

..I could not see my children. You know, the mother's feelings. I used to think about them all the time, how they were, what they ate, who would help them in their studies. It is difficult, my dear, to leave your children and stay in the hospital. Children need a mother, to love and care for them (Um-Nader, First interview).

During the interview, Um-Nader could not hide her emotions and cried when recalling her children. It was clear from her account that being unable to care for her children made her suffer in the ICU. However, in her follow-up interview, Um-Nader describes her struggle to meet the needs of her children and how guilty she was when unable to help them.

...I neither could do my work as before, nor help my children at home. Erm, life is very difficult, my dear, and children need a lot of care... Well I am too tired to take care of them, and this makes me feel sad, and, Erm, guilty. Uhh, they are the nearest to my heart. When you have children, in the future –inshallah-, you will see how your children are the closest to your heart; they are a part of me (Um-Nader, second interview).

It seems that Um-Nader felt that part of her identity as a mother is lost, which made her feel both guilty and sad. Um-Ahmed shared the same feeling, finding it difficult to accept that her relationship with her daughter had changed.

...my darling daughter, my little daughter, doesn't accept me as before, because of the long period I was away from her in the hospital...she is only five...she doesn't accept me any longer. When I want to get her dressed or wash her face, she refuses. She takes her clothes and goes to my sister-in-law, who bathes her and combs her. Erm, can you imagine the mother's feeling when she is abandoned by her little daughter – (about to cry)- it is unbelievable. No, I will never forget it (Um-Ahmed, second interview).

As seen in Um- Ahmed's account, she felt rejected by her daughter and blamed herself as a mother. She also felt guilty when she could not help her children do their homework because she was too tired and could not cope with their demands. Later in her interview she said

...I haven't been able to do anything because I am so tired and weak. I feel guilty that I am unable to help them, I blame myself; how can I be a good mother if I am not able to satisfy my children's needs (Um-Ahmed, second interview).

Um-Ahmed's inability to carry out many tasks she had previously undertaken challenged her identity as a good mother. However, the experience of motherhood

for Um-Malak and Um-Fadi gave a different meaning to their lives. Um- Malak describes how she learned from her critical illness to be a good mother.

I think that my attitude towards life has been changed, yes. My experience in the ICU was very critical; it makes you realise that 'life has taste' [an expression in Arabic used when somebody gives value to his/her life events]. My outlook on life is so different and, like I said, I was very nervous, I could not put up with my daughters. But now I've learned, I've learned to be patient with myself, and with all the people around me. Yeah, life is nothing without my children around me; I've learned not to be angry with my daughters anymore (Um-Malak, second interview).

Um-Malak learned from her past experiences to care for her daughters and felt this made her a better mother. Similarly, Um-Fadi said that she wanted to survive so that she could help her children

... I need to survive to help them...When I get out of the ICU all of these feelings go away. I feel that I should be with them, I must survive to help them, you know dear, children need their mother... you know my main aim was to get better and just be well to help my children, to be a good mother...I want to give my best to my children, you know I wish to see my daughter grow up and go to the university (laughing) (Um-Fadi, second interview).

Um-Fadi's identity as a good mother was closely connected to being there for her children. Um-Nader and some of the other mothers had become aware of their mortality through their time in ICU. All perceived the experience of critical illness as an opportunity to survive so that they could be there for their children. The experience of the women who considered themselves as survivors will be discussed in the next section.

7.4.3 Surviving the critical illness

In Chapter Five, I discuss the experience of 'vicarious death', where the women faced an extreme experience of suffering. These women described that surviving after their illness gave their lives a new meaning. Um-Essa is one of the examples, who valued the family relationship and unity. At the same time, she maintained that she learned from her experience to thank Allah for help and support. This is clear in her third account.

Ummm, my self, uhh, and after all of what I had, I will thank God for everything, yeah 'Al hamdolellah' for everything. I feel that I should look on the positive side of life, not the negative side. And Inshallah I will go to Mecca to visit Omreh⁷⁰ with my children as soon as I can (Um-Essa, third interview).

Um-Essa describes herself as a religious woman and connecting to Allah was part of her 'vicarious death' experience. At home, the first thing she did after her critical illness was ended was to thank Allah through prayer, and a visit to Omreh. Many women like Um-Essa confirmed that their priority after surviving their critical illness was to praise Allah for giving them back their lives, and they continued to do so after being discharged home. Um-Malak said that she started to pray after her illness.

...I mean that the time I spent in the ICU made me come back to Allah and pray. From that time, I started to pray every day. I thank Allah for giving me my health again (Um-Malak, second interview).

It seems that her vicarious experience of death gave her life a new meaning. She found prayers to be a means for surviving her illness, a means of thanking Allah for re-gaining her health. She continued to pray habitually after she was discharged home. Um-Mahmoud also gave a similar description of her 'vicarious death' experience and the loss of her body strength. This provided her with a new meaning of life after she was discharged home.

Well, I've changed. Totally! I can say that my life was totally changed... I prayed to Allah to ask him to give me my health again; he is the only one who can help me (Um-Mahmoud, second interview).

This illustrates how the Islamic belief has effected her interpretation of life and death. Her survival is connected to the mercy of Allah. Um-Bashar went further and advised survivors to commit themselves to Allah. When I asked her what she would like to tell the ICU patients, she said

...Um, I would like to say, be with Allah, always with God, God will help all of you, and uh, be positive all the time, don't feel despair, no, God will help you all ... Sometimes I think of myself a little bit, I am above 60 years old now, and I have never been to Mecca to visit Omreh. I wish I had time to go to Mecca on a pilgrimage. I wish I could go, even if it costs me one million Dinars⁷¹ (Um- Bashar, second interview).

Um-Bashar experienced the loss of her body strength and the loss of her family support during her time in the ICU (see section 6.5). She described the meaning of her losses and changes to her health as a means to gain hope in life and a chance to

⁷⁰ A religious rite where Muslims visit *Mecca* to worship Allah.

regain her faith in Allah. It seems that most of the elderly women found it a priority after their critical illness to praise and thank Allah for regaining their lives, but this was not the case with some of the younger women, like Amal and Eman.

Amal is a 19 year-old student at secondary school, who lives with her mother and seven sisters and brothers. She had thyroidectomy surgery and did not consider her experience in the ICU as a sign of suffering but that her operation was a continuity of her treatment regime. As mentioned in Chapter Four, Amal stressed that her ICU time was only a temporary period where she recovered slowly. In her second interview, Amal said that she learned from her critical illness experiences to be positive in life.

... my experience gave me the courage to challenge everything, to see things from a different point of view. I mean, to look at things in a positive way. I learned that everything has many alternatives. If I get ill I have two choices, one is sitting down and doing nothing, and then I will fail my exams. The other one is to study hard, and get what I want, yeah, I can manage to study after the illness, uhh. You know, when I was in the ICU, I promised myself that if I ever got out of that unit I would work hard at school, I mean, I would study hard. And yes, I did when I came back from the hospital. I worked very hard to study and go to university (Amal, second interview).

Amal has learned to look forward to her future and she studies hard, planning to continue her higher education. Similarly, Eman, in her first interview, felt partially dependent on her mother and guilty. At home, she mentioned that she wanted to be normal.

I started to learn how to move my legs, and I moved my shoulders and arms. It was difficult in the beginning, but, in time, I learned, and I could move my legs eventually. You know, I felt very happy to walk again, but it was a very slow progress... Oh, I'd like to be able to behave as any normal woman. I would like to go anywhere. I would like to visit my friends and have a chat with them. I just like to do the usual things as before. I feel that I am normal and that I can do it [care for herself] myself (Eman, second interview).

Eman's experiences positively affected her life after being discharged, with her past experiences giving a new meaning to her life. She said that she wanted to be an independent woman and be able to resume her everyday life.

⁷¹ The Dinar is the currency in Jordan. She used a million Dinars as a metaphor to express whatever the cost, that she is willing to visit Mecca.

7.5 Summary and Discussion

This chapter suggests that the women's experiences of critical illness after being discharged from the hospital are complex and surrounded by many physical and emotional, social and spiritual issues. These in turn affect the women's experience of their everyday lives after discharge. The women described how the loss of their body strength continued for three to six months after their discharge from the hospital. Most of them felt weak and tired and this, accompanied with their inability to eat, forced some women to change their residential environment. The bodily experiences left the women feeling fearful and frustrated. Some women, when recalling the traumatic experiences at home, found difficulties in sleeping.

The findings in this study confirm that the patients experience physical and emotional difficulties 2-6 months after their discharge from the hospital (Maddox et al 1994; Russell 1999; Griffiths and Jones 2001; Hewitt 2002; Jones et al 2003; Adamson and Elliott 2005). Additionally, this study suggests that the physical experiences of illness lead women to re-think about their bodies and find new ways to cope with their physical limitations. The changes in the women's eating habits, the difficulties in sleeping, and the changes in the residential environment reflect how these women begin to accept the help and support from their family on whom they are partially dependent. Some women were happy to accept this new identity, while others felt as a burden to their family members. Corbin (2003) points out that when people accept that they are no longer able to do their usual everyday activities, they start to think differently about their bodies. These observations can also be found in the findings of Olsson et al (2004) who examine the experiences of 10 women who suffer from multiple sclerosis. These women mentioned that feeling fatigued most of the time changed the ways in which they interacted with their family and performed daily activities. The women felt that they could not visit their relatives or take part in many social activities such as participating in sport clubs. This left them feel lonely and isolated. For other women, difficulties in undertaking personal daily activities meant they had to ask for help from the family members, especially their spouse to help them in managing the house work. The role of these women changed from being a care provider in the family to being a dependent member of the family who had to seek help from the other family members.

The experience of the body and of suffering in the ICU brought new meanings of life after the women were discharged home. The majority of the women described how illness provided them with the opportunity to value the family unity and support. The experience of critical illness also acted as a means of sharing their feelings with their neighbours and relatives. The findings in this study support previous findings that family support is crucial during the recovery period (Chin, 1990; Maddox et al, 2001; Papathanassoglou and Patiraki, 2003). This is in contrast to Charmaz's statement that the majority of chronically ill people feel socially isolated because of their restricted lives, and the multiple physical and psychological distresses (Charmaz 1983, 1991). Another explanation could be that the women in this study were interviewed within 2-6 months after their discharge from the hospital, while the experience of the chronically ill people usually lasts for years or is permanent.

The findings in this chapter also suggest that with the women who have young children at home, the experience of critical illness will change their relationship with their children. Two of the women felt guilty, and their identity as good mothers challenged, whilst other women learned from their illness to live for their children, and to strengthen their role as mothers. Similar findings reported by Ewan, et al (1991) describe the change in the role of the Australian women who had Repetitive Strain Injury (RSI), and experienced severe pain. The women found that they had to re-negotiate their roles and relationships with their families and partners. This led some women to feel frustrated and their identity as competent mothers and wives challenged. Another study conducted by Arab women (Nahas et al, 1999: 70) describes the experience of post partum depression of forty-five Arabic migrant women. For these women, the loss of their traditional role as mothers and wives made them feel helpless and depressed. They believed that caring for their children and keeping the family members healthy was part of their duties, and when they could not cope with this role they considered themselves as 'bad' mothers. These findings support the previous ones that the illness experiences may give the women a learning experience that strengthens their relationships with their children.

Surviving the experience of critical illness is seen as central by many. Some elderly religious women found that their illness was a survival experience and a sign of re-birth. The women prayed, and performed 'Omreh' as a means of thanking God for

regaining their lives for them. This contrasts with the younger women perceptions. Two young women looked to their future differently; they used their past experiences as a continuum of learning, which they planned to apply to their future life events.

The effect of critical illness may have an existential meaning, in addition to what the traumatic experiences have offered. This supports what Papathanassoglou and Patiraki (2003) find when interviewing eight Greece patients, who had survived from intensive care. The patients interpreted their experiences of dreams as a transformation of the self. The participants' experiences in the ICU changed their attitude toward death. The interpretation was based on the Greece model of death, as the findings of this chapter show that Muslim women give the meanings of their experiences from the Islamic model of life and death (Sarhill et al, 2001; Shaqrah, 2008, personal interview). As some of these women had experienced the 'vicarious death', these experiences are interpreted as survivorship (as reborn) after being discharged from the hospital, and the women felt that they had to thank God through praying and visiting Mecca who gave them lives. These experiences of the survivors, as related to the death-reborn assumption, are shared by many people with a religious faith. A study conducted in Spain describes how the ICU patients have found that part of their religious meanings is connected to their Christian beliefs and sensed that they were in need of God's support. This gave them a sense of peacefulness, and some patients mentioned that they prayed to God many times to help them to recover.

This chapter does not suggest that these meanings are static, but could be changed if the interview took place after a longer period, for example, after one or two years. However, this chapter tries to grasp the subjective experience of critical illness in the women's everyday lives, and the shared meaning they had from their illness. In doing so, I have tried to 'give these women voices'. I also tried to give them voices through sharing some of the research findings with the intensive care nurses in Jordan. This will be the focus of the next chapter.

Reflection on Women's Experiences: the Nurses' Viewpoint

8.1 Introduction

One of the aims in this study is to examine how the nurses can develop their practice to support the women patients in the ICU. The focus of this chapter is to report on an activity aimed at developing principles for improving the nursing care for critically ill women through sharing part of the findings with ICU nurses. Seven nurses from Hospital A and six nurses from Hospital B attended the focus group discussion. In addition, the focus group discussions serve as a learning experience for myself who, as a novice researcher, conducted a focus group for the first time. Early in the data collection process I conducted a preliminary analysis of 10 women's accounts with whom I had conducted a first interview. Three main themes clearly emerged during the analysis which informed the topics of the focus group discussions with the nurses. The topics are: nurse-women communication, the women's need to cover their bodies, and the women's need to see their children.

This chapter starts with the background literature and is then followed by three sections. Section 1 discusses the nurses' reflection on sharing their experiences in the focus group discussions; section 2 focuses on the three proposed topics that were presented using a PowerPoint presentation to illustrate the women's accounts. Section 3 discusses the nurses' thoughts after sharing in the focus group discussions. Finally I provide a brief summary of the findings and I reflect on my learning experience of conducting a focus group discussion.

8.2 Background

Supporting and helping the patient to recover from their critical illness is the basic goal of nursing care in ICU. The nurses invest physical effort to provide care for the patients' bodies: manipulating, bathing, cleaning, and feeding are part of the nurses 'bodywork' (Lawler, 1991), accompanied with emotional effort through their interactions with the patients and their families (Seymour, 2001). Listening and

communicating with the ICU patients is part of the nurses' daily practice. Some scholars argue that the progress of nurses is a career moving from a novice nurse who has limited technical skills into an expert nurse (Benner, 1989). The development of the nurses' experience depends to what extent the nurses feel adept and confident in their ability to provide safe care and their ability to employ their knowledge to develop a therapeutic relationship with their patients and thus to help them to reach the optimum level of recovery (Benner, 1989; Ransse and Arbon, 2008). However, there has been limited research exploring nurses' reflections on what they might learn from their communication with ICU patients and how they might apply this knowledge to support and help other patients (Wilkin and Slevin, 2004).

The majority of the published studies which have been conducted in the ICU focus on improving communication between the nurses and their patients (Turnock, 1989; Bergbom and Haljamae, 1993; Hagland, 1995; Baker and Melby, 1996; Trovo De and Pies Da Silva, 2004; Magnus and Tarkington, 2006; Sheldon et al, 2006; Coyer, 2007). The emphasis of these studies is to develop a nursing care based on meeting the patients' needs, rather than the technical aspects of work, such as monitoring the machines or doing the nursing procedures competently. Respecting the 'humanity' of the patient is the overarching theme. In an early study conducted in Sweden by Bergbom and Haljamae exploring the nurses' opinion about their communication with their patients (1993), the nurses revealed that there were many factors which hindered effective communication with the ICU patient, such as work overload, and the rapid change in the patient's condition. These had the effect of moving the nurses from communication into performing life-saving tasks, such as resuscitation. However, the nurses felt frustrated when they could not meet the patients' need for communication. On the other hand, Trovo De Arroyo and Pies Da Silva (2004) point out that the Brazilian nurses found difficulty in communicating with their patients, because they felt that they were not prepared for such interaction; some nurses revealed that they found it difficult to overcome their own emotional involvement with their patients. In a recent study that compares the health-care teams' views of communication with the views of the patients who were on mechanical ventilation in the ICU, Magnus and Tarkington (2006) point out that while the nurses felt frustrated at the patients' incapability to communicate verbally, the patients felt lonely and

isolated. Both groups, as Magnus and Tarkington mention, agreed that using communication aids, such as the alphabet charts or the board, were helpful for both groups. However, unconscious patients could not convey their needs using such techniques and needed special support.

Other studies focus on the nurses' reflection on their experiences and practice in the ICU with an attempt to link nursing care and the patients' needs on the one hand, and the improvement of the nursing practice on the other (Bush et al, 1997; Svedlund et al, 1999; Seymour, 2001; Wilkin and Slevin, 2004). For example, Wilkin and Slevin (2004) explore the meaning of caring by asking 12 ICU nurses to reflect on their experiences in the ICU. The nurses revealed that they found it difficult to define their caring in simple terms, as they considered caring as a process of interlinking elements. However, they revealed that the caring of patients in the ICU could be understood through a combination of 'feelings', 'knowledge', and 'skills'. Together, these provide what they called 'good care'. From the perspective of feeling, the nurses communicated how their care includes providing emotional support, interacting and communicating with the patients and their families, orienting the patients to the ICU environment, listening and giving the patient's time to express and talk about themselves, and using the therapeutic touch to show their empathy. The nurses' knowledge is achieved through providing care for an individual patient as a 'whole'. The nurses consider that the individuality of each patient is mainly achieved through meeting the patient's physical, psychological, social, and spiritual needs, followed by providing information and explanations according to the needs of the patient and the family. The nurses relate their skills in two ways. The skills which they need to communicate and interact effectively with their patients, including how they could provide emotional support and help; and the skills which they need to manage the ICU technological devices, in order to facilitate the treatment regime of their patients. Here, the meaning of care for the British nurses in ICUs emphasises the 'human' aspect of care, and considers the machines and other tasks in the ICU as helpful in facilitating individual patient care (Wilkin and Slevin, 2004).

Swedish ICU nurses, as discussed by Bertero (1999), find that caring is related to maintaining a helpful and trustworthy relationship with their patients, and they tend to interact with their patients through listening to their ideas and fears, rather than

trying to develop agreed goals with the patients. Caring, for these nurses, is an interactional process, and it involves two concepts of 'caring for', and 'caring about' when interacting with patients. Bertero (1999) reports how nurses' main aim is to relieve the patient's suffering through many activities, such as interacting with the person, helping the patient with his/her physical needs such as bathing or feeding, and touching the patient to provide comfort. Bertero (1999) highlights how the nurses consider that, through applying the two concepts of 'caring for' and 'caring about', they can better identify the needs of their patients, and provide a nursing action which makes a positive change in the patient's condition, and helps them to make knowledgeable decisions.

These two studies reported above show that nursing care is achieved through meeting the patients' needs and stressing on the 'human' needs of care. In addition to meeting the human needs, nurses have to use the technological devices in the ICU to facilitate the care provided in the ICU; and these devices take more time from the nurses to manage. Alasad (2002) points out that some Jordanian ICU nurses consider that ICU technology makes their job easier, and they psychologically feel safe and in control of the patients' conditions. Alasad (2002) gives an example of the ICU monitors, mentioning that the monitors provide the nurses with information about the patient's condition, such as the blood pressure or temperature. But these monitors need time to be managed and the nurses use part of the caring time to familiarise themselves with these equipments to facilitate the patient's care.

Different from the above studies, Seymour (2001) uses the two concepts of 'bodywork' (Lawler, 1991) and 'emotional labour' (James, 1992) to explain how the nurses could transfer nursing care for dying people in the ICU from the 'technological' and 'biomedical' frame into the frame of 'emotional' and 'familial intimacy' (Seymour, 2001:125). Based on her observational notes and follow-up interviews with the nurses, Seymour gives an example of four case studies, in which the nurses interlink their 'bodywork' and 'emotional labour' for the dying patients. The first case is related to this study; it concerns a patient who suffered from a head injury and was recognised as dying at an early stage of his treatment (Mr. Hart). Seymour observes that the nurse provided the body care through maintaining his body hygiene, and this was acknowledged by the family members (his wife and son),

who were pleased to see him clean, and with a good appearance. The nurse maintained the trust with the family members, and encouraged them to stay close to him, and showed them photographs of him. Seymour (2001) interprets the nurse's action as an integration of body work (through maintaining cleanliness), and emotional labour (through encouraging the family members to get involved with the care), which is one crucial element for constructing death with dignity, and a sense of 'whole person'. Seymour argues that It is through these twin activities that nurses create 'whole person work' and invest the process of dying with meaning, purpose, and intimacy. For some nurses, the compulsion to reproduce the subjectivity or 'personhood' of their patient is experienced as intensely painful (Seymour, 2001:126).

Nurses' experiences, when providing care in ICUs in Western countries such as the UK or Sweden, are quite different from that in the Middle East. The patients may have different needs and issues. Halligan (2006) discusses the experiences of six non-Muslim nurses working in an ICU in Saudi Arabia, finding that three main themes emerge from the data: family and kinship, cultural and religious influences, and nurse-patient inter-relationships. The participants revealed that it was the family that made the principle decisions about the patient's care and discussed the care plan with the physician, often without involving the patients; this made the nurses feel stressed and frustrated, as the patient had no autonomy to take decisions. Halligan (2006) reports how the nurses also related that family visits were unlimited and that sometimes over 20 people visited the patient at once, which made their job difficult. The nurses experienced emotional labour in meeting the religious and cultural aspects of the patients' needs; the nurses found that most of the patients had to face towards Mecca, or leave their beds for prayer. Many nurses noticed that these patients preferred to receive care from a nurse of the same gender; older male patients disliked the female nurses taking care of them, and the female patients requested to receive care from female nurses, asking the male carers to leave the room. Some nurses found it difficult to communicate because they did not speak the patients' language (Arabic).

The language barrier surely hinders an effective communication, but there are other elements that may affect the two-way communication. Alasad and Ahmed (2005)

discuss similar findings when they explored the Jordanian ICU nurses experiences in communicating with their patients. They interviewed 28 Jordanian ICU nurses, with 5-20 years' experience, in an attempt to identify the nurses' experiences of their communication with the unconscious patients in the ICU. The nurses revealed that verbal communication was essential with the ICU patients, but applying the two-way interaction in practice was difficult. As most of their patients were unconscious or sedated, the nurses felt frustrated when they could not have a two-way conversation with them, therefore most of them guessed the patients' needs according to their previous experiences. Other nurses stated that they forgot to communicate verbally with the unconscious patients. A third group preferred to work with the unconscious patients, because, as they understood it, unconscious patients who cannot communicate their needs are mentally less demanding, so they could better control the patients' condition.

Developing a strategy to support the patients' needs in the ICU is another way of helping the patients during their recovery process. In the UK, the Intensive Care National Audit and Research Centre (ICNARC) began in 1994, with the aim of improving the quality of care in the ICU for the patients and their families. Part of their aim is to develop care through the use of the patient's data as a resource for teaching and research (Harrison, Brady, and Rowan, 2004). The DIPEX project is one of the projects which are funded partially by the ICNARC. The Intensive Care Society (ICS) is another example of supporting ICU patients in the UK. The aim of the ICS is to provide the highest quality care for patients in the ICU. With the cooperation of the Royal College and the NHS, the ICS provides training for ICU nurses in many specialties. They have also developed a booklet for ICU patients and their relatives, to help them to understand the ICU environment and protocols. This booklet is available on the internet for free. The booklet includes information about what the ICU is, the common conditions requiring critical care and the levels of care, admission to the ICU, treatment in the ICU, patient transfer, and many other issues relating to death and bereavement in the ICU.

8.3 Nurses' reflections on participating in the study

As I mentioned in section (3.5.2.1) during my early visits to the intensive care units, the nurses who provided direct patient-care started to ask about my study, and showed their willingness to share in focus group discussions. This was supported by my advertisement on the nursing board in each unit of both hospitals. The first group discussion was conducted in Hospital A with seven nurses. I warmly welcomed the group, and asserted the importance of their contribution in the focus group discussion. Each nurse then introduced him/herself to the group. I asked a general question about their feelings and expectations about the women's experiences in the ICU. A nurse replied

This subject attracts me because it discusses the patient's views. I think it is very interesting to know how they see our care. We usually listen to different opinions about our care, you know, the doctors, the head nurse, but not the patients. I think it is very important to know more about the patients' perception of our care (female nurse 6, Hospital A).

This nurse highlighted that the patient's opinion tends to be missing within the health care system in her department, and she deduced that listening to the patient's viewpoint is important. Her response opened up the discussion for the other nurses to share their opinions. A second nurse agreed with her opinion, and added

...yeah, ya, I agree with you, for me I want to know more about how women see our care. I can see that most of the ICUs make men and women sleeping in the same department, mixing the two sexes together. I cannot guess how they experience our care (female nurse 2, Hospital A).

Here, the nurse is aware of the challenges which female patients may face when receiving care from male nurses, and the challenge of mixing the sexes in the ICU department, but found difficulty in getting 'inside' the women's experiences. The rest of the group supported the idea of sharing their experiences with others and showed their willingness to hear about the women's experiences in the ICU.

I applied a similar approach with the nurses in Hospital B. The head of the department mentioned that the unit had a shortage of the ICU nurses because three nurses were on maternity leave and four nurses were on a six month course at the same time of the focus group discussion. Still I felt relieved when six nurses attended the focus group discussion, with three of them coming from night shift duty. On their reflection on the study, the nurses voiced different opinions. They acknowledged that

critically ill women needed psychological support, and most of the nurses emphasised the physical aspects of the nurses' care. One male nurse said that he found the women fragile, and needed a lot of effort to help them to recover from their illness.

Honestly, I care about the way the women are treated, because they are sensitive, and they cry easily. I had one woman who was admitted to the unit after she had septic shock. The patient next to her died, and she felt frightened. My role was to provide her with psychological support, and to be comforting to her. She was very scared (male nurse 5, Hospital B).

This nurse shared his view that women were more sensitive and needed special care; this interpretation is connected to his masculine identity. At the same time he stressed that 'psychological support' is part of the nurse's duties in the ICU, and therefore he provided the woman with support. It seems that he stressed the caring aspect of the women in relation to the women's feelings, as well as the other needs of this particular woman. He used the phrase 'psychological support' as a means of communication that was help he tried to provide to women. When I asked about the psychological support, he mentioned that he showed his sympathy and explained the situation to the patient. His response indicates that ICU nurses look on the women patients as vulnerable and sensitive. He also raised a question that nurses may consider the caring for their patients as a set of tasks and roles, rather than as humans. Though being judgmental is at risk, a second nurse showed a similar response. She described her experience with one of the female patients admitted to the unit as follow

I have been working in the ICU for twenty years now. One patient was admitted from the A&E, she was conscious and oriented, and effectively responded to my questions. On her physical examination, she had a pain scale of eight over ten, and had a fracture in her left arm....I saw her lips turn blue, and felt that she was in need of oxygen. I provided her with an oxygen mask, and it worked well, but after an hour her condition started to gradually deteriorate. A day after that, she started to regain consciousness, but I felt that she needed to stay on oxygen for a couple of hours. I felt affected when her family visited her; she started to cry and wanted to remove the oxygen mask. I could not allow her to do so because I was worried that her oxygen saturation level would go down. But I also felt her need to talk to her family members (female nurse1, Hospital B).

The nurse's aim in this account was to share her experience with one of the patients, whom she considered one of her cases. What struck me from her account was the way she described the patients in terms of signs and symptoms. She described the medical and nursing intervention rather than the patient's feelings, and perhaps did

not consider the humanity aspect. I unintentionally responded to her by asking ‘but how did this woman feel about the care you provided?’ The other nurses in the group noticed my response and they started to be more involved in the discussion. Two nurses responded to my question. One said:

I feel it is difficult for the patients. They have too many losses. Erm, I never thought about their opinions before this discussion. I think I feel curious to hear more about how the women see our care (female nurse 6, Hospital B).

It seems that the nurse started to think about the women’s stories, and this helped her change the way she thought about nursing care. The second nurse agreed with her, and stressed that the patients’ opinion is important in nursing care.

Yes, I completely agree with you, A. I never asked any patient how they perceived my care. I feel that it is important to have their opinion, because we are all working to support them [patients] (male nurse 4, Hospital B).

As seen from the nurse’s account he started to challenge himself, and to think about different ways of nursing care concerning the patients’ opinion. The discussion proceeded with me presenting some anonymous accounts of the women as an introductory to the topics that I will discuss in the next section. Some of these accounts are:

Some nurses were very nice... oh very nice and supportive. So kind, I felt as if we were a family, yes, we were a big family with all of the nurses around me, supporting me and doing their best to help me to get well, I highly appreciate their help and support (Um-Anas, first interview).

I saw nurses working hard with the ill..., yes they do their best to care for them, and support them... umm some of them never leave the ill in bed... they do their work to ‘Reda Allah’- meaning asking rewards from Allah- they did not ask for the people’s money, they are very caring (Um-Mohammed, first interview).

Starting with the positive accounts about the nursing care provided in the ICU reflects on how the nurses responded to the discussion. Some nurses mentioned that they felt happy to hear that the patients appreciated their work, other showed non-verbal agreement. Then I presented the three topics in the discussion. These topics are discussed below.

8.4 Discussing the nurses' experiences of some of the women's accounts

The themes are: the nurse-woman communication, the women's need to cover their bodies, and the women's need to see their children. Although these were the main topics that I used to open the discussion with the nurses, more topics were generated through the discussion and interaction process, such as communicating with the patients who suffer from delirium.

After I mentioned the three topics, I presented the account on PowerPoint presentation, and then I distributed handouts of these accounts, in which two accounts were related to each topic. Then I asked the nurses about what they thought about these accounts ⁷².

8.4.1 The nurse-women communication

The first issue I noticed during my preliminary analysis was that of communication, which was raised by many women in the study. I presented the following accounts to the nurses in both hospitals:

It was Horrible!! I felt very strange, hearing different voices. I couldn't speak or even shout to any body. Oh, I couldn't call any body from my family, my sons or daughters; I don't know where my husband was. One of them was saying 'God help the old woman; she has a lot of broken areas' (Um-Saber, first interview).

I was so scared from that place it was very quiet and lonely. I do not know any body there. Yeah. I think I found that horrible because you just feel so strange. And I had days in coma, connected to the big machine; I don't know what was happening during time (Eman, first interview).

...they put a needle in my hand, it was very painful, I shouted and shouted, but nobody heard me!! I felt very sad, they treated me so badly, and they knew that this needle hurts but they didn't care about my pain as if I were a machine with no sensations (Abeer, first interview).

In Hospital A, I was surprised by the nurses' responses. A nurse started the discussion by telling his way of providing support to female patients:

Generally speaking, the hospital policy in the unit is to take the vital signs and assess the patient completely, the level of consciousness, and a physical examination. Then to make an orientation to them about the unit, introduce myself to them, and tell them that I am here to help them if they need any help (male nurse 3, Hospital A).

⁷² During the focus group discussion I labelled the accounts accordingly as Woman1, Women 2, but I refer here to the accounts of the anonymous names that I give each woman in this study.

From the account of this nurse, I felt that the nurses accepted the women patients as a consequence of their work. Starting with vital signs, they then moved to the other aspects of the patients' symptoms. It is also clear that this nurse considered the care as directed in part by the unit's policy. This is in contrast with what another nurse considered about communicating with the patients. She stressed effective communication with the patients upon their admission:

I think communication with patients is very important. I think also that dealing with patients depends a lot on their personality, too. Many patients, as you know, did not accept the nurses when they first entered the unit. Maybe because of their critical condition, they speak very little, and some of them avoid speaking to us. This is understandable, they need more care, and support, we need to be very kind to them. We need to explain everything around them, especially the monitors and machines. Because, as one of them said, she was worried about the machines, and I completely agreed with her. This is her first experience in the ICU, and everything is strange for her. But in time, and with our explanation, she would feel more comfortable, and cope with the unit routine (female nurse 5, Hospital A).

This nurse stressed the important aspects of the client feeling strange when entering a new environment. She used explanation about and orientation to the unit as a means to release the patient's stress. As the discussion proceeded, the other nurses emphasised the importance of explaining nursing procedures. One nurse mentioned that she explained the nursing procedure every time to her patients, and another nurse stressed this point, and added

We usually try to make them comfortable. We explain everything, every procedure, we help them any time they want our help... (female nurse 6, Hospital A).

... [interrupting] by not only explaining the procedures, but also by listening to them. Some of them, especially the older patients, need to talk with me, this is part of their needs, some of them couldn't understand the explanation the first time, we need to repeat the instructions over and over again, before they grasp the ideas that you want them to get (male nurse 3, Hospital A).

As seen from the nurses' accounts, one way of supporting the patients is through orienting them to the unit, and explaining to them the nurses' procedure. A senior nurse provided his own strategy in nurse communication.

I treat patients as friends, especially if they stay for a long time, you know, some of them stay for a week or more. I spend a lot of time with them, so our friendship develops automatically with time, it helps them to get well and improves their psychological status. Patients trust me and talk to me without fear, even about some of their personal life. They perceive me as someone who is there to help them to recover. They need a lot of help in the first few days in the ICU (male nurse 2, Hospital A).

Here he stressed the important issue of the nurse-patient communication. His is a trustful relationship; he used friendship to gain the patient's trust, and then he supported the patients. Nurse 2, who has had more than twenty years of experiences in the ICU, shared his personal strategy in developing nurse-patient communication. Developing a trustful relationship with the patients helped the patients to express their feelings and share their experiences. His point of view was accepted by many of the nurses during the discussion, and by nodding they showed their agreement with his opinion.

In Hospital B, the discussion about the nurses' communication started with one of the nurses describing her difficulty in communicating with one patient who had delirium. She said:

I remembered a patient who suffered from hallucinations and delusions; she thought that she was going home, so she removed the tubes from her body, got dressed, saying 'I am going home'... that women had unstable blood pressure and a stroke. I mean, she was in a dangerous condition. We were afraid that she might die if she went out. But she insisted on getting out, she was badly deluded. She described the monitor as her TV at home, and sat on the floor, thinking that she was in the garden of her home. I talked to her, but with no response. I called her mother, who came and sat with her, trying to convince her. I really struggled to communicate with her (female nurse 1, Hospital B).

Nurse 1 brought up the issue about the difficulty in communicating with deluded patients. Most of the group showed their agreement on the difficulty of communicating with such patients. One nurse suggested inviting the family to get involved in the nursing care of these clients. She said:

I believe that a sick woman needs her family, especially if she suffers from hallucination, because her family are the familiar people to her, she can talk to them. I understand this, and try to explain to the family that they could help us to communicate with these patients (female nurse 4, Hospital B).

This particular tactic could help some patients regain their grasps on reality. Another nurse suggested explaining the events to the patients, but he had found it difficult to explain everything to the patient, as time was limited:

For me, when I first saw the patient, I introduced myself to her, telling her that she was in the ICU, trying to explain what was going on around her, but you know, because of time, I couldn't explain everything. Try to imagine that usually I am responsible for two cases, and one of them might be on the MV machine and in danger, so I need to monitor this patient (male nurse 2, Hospital B).

What I noticed from her account was that she considered the patients as cases, not as clients. Although I did not notice this during the discussion, she did not mention the human part of her patients. She received the patients as cases, and provided her care. This seems that the nurse separated herself from the human aspects of the patients' care.

Nurses in Hospital A also raised the issue of communicating with patients who had delusions. One nurse described the difficulty she had when caring for a patient who had hallucinations and delusions:

I feel that there is a problem in communicating with patients who develop hallucinations or delirium in the ICU - the ICU psychosis. They are not aware of their acts. They are always pulling out the ETT and CVP lines, and you know it is not easy to put the lines back in every time. It is also hard for them. Yesterday, one of the confused women here pulled the naso-gastric tube from her nose. I was sitting in front of her, but she did it very quickly, she pulled the tube, and all the secretions came out. It was really hard, and even when I told her that the tube was very important for feeding, she couldn't understand me. What can I do for her? (female nurse 5, Hospital A).

The difficulty raised here was found common for most of the nurses. Some patients who had delusions and hallucinations were described to have removed their naso-gastric and ETT tubes, which forced the nurses to be alert when watching their movements. A second nurse discussed the difficulty she found when some of the patients started to remove the IV lines and disconnected themselves from the machines:

We are always watching their hands; they may remove any tube with their hands. But it is difficult (male nurse 2, Hospital A).

The second nurse asserted that she found difficulty in watching the patients all of the time, so that they did not harm themselves. A third nurse told a story from her experiences with a woman who worked as a tailor, and had an ICU delirium. The woman thought that the ICU curtains look like a dress or her embroidery at home. I found their accounts to be an opportunity to develop a principle to support the women who have delirium in the ICU and asked about the ways how we, as nurses, could help these women. The nurses agreed principally on five suggestions.

1. Keep observing the patient.
2. Explain all the procedures.
3. Accustom them to the environment.

4. Explain to the family.
5. Repeat the instructions all of the time.

The further the discussion proceeded in the focus group, the more the nurses started to get involved, sharing their personal experiences, and defining their own construction of the patients' experiences.

The second topic concerns the women's need to cover their bodies. This I took particular notice of, when earlier I interviewed the women shortly after their transfer from the ICU to the wards. This will be discussed in the next section.

8.4.2 The women's need to cover their bodies

The next topic I raised during the focus group discussion concerns the women's need to cover their bodies. Here, I present two of the women's accounts:

I was without clothes dear, I mean that thin gown was very short, and I couldn't cover my body, I felt ashamed for myself because I've never been in that way [with the gown] ...It is the culture my dear, we need to cover our body, I couldn't imagine that my children would look at me with that bad gown. I couldn't remove my scarf, I need to put on the blanket all the time to hide myself in front of my children and my visitors, it was difficult to be like this all the time (Um-Mahmoud, first interview).

...oh!! I remembered that I was wearing a gown, oh!!! How awful that gown, it was very short, too short to cover me, it wasn't fine, I felt as if I were without clothes, you know, I have never been dressed like that. Uhh, it was open in the back. I was bothered a lot. I didn't like my look (Amal, first interview).

The nurses in Hospital A acknowledged the women's need to cover their bodies. One male nurse said:

I completely agree with the female patients, we are all Muslims, and the females are used to covering themselves. I can imagine one of my family in the ICU. I would sympathise with her. It is hard. I think we should recognise this need. We need to keep them covered at all time, and keep the linen on all the time. Personally, I will be more careful about female privacy, and I will discuss it with the nurses on the B shift, at our meeting (male nurse 7, Hospital A).

It seems that he started to think more critically about the women's need, and imagined his family in their situation. This led him to pass the message on to the other nurses on the B Shift. Nurse 3 in the group supported his view, and added that:

The gowns that we have in the hospital are short, and expose the female patients' body, but what can we do? Maybe we can ask the stores to supply long gowns with long sleeves (male nurse 3, Hospital A).

The second suggestion was that he would ask if it is possible to have a long gown with long sleeves from the stores. The senior nurse also replied that he would ask the head of the department to request this type of gown:

Yes, we can request them; I will ask the head of the department (male nurse 1, Hospital A).

The other nurses had a more practical solution. Nurse 5 suggested her strategy for covering the women's body:

I used to give the women two gowns to wear, one with the opening in the back, and the other with the opening in the front, so they would feel covered. I do this all the time (female nurse 5, Hospital A).

Her suggestion, to use two gowns, one with a front opening and the other one opening at the back of the women patients, was accepted by other group members, and nurse 7 agreed with her ideas:

Really? Yes, yes, I think this is great idea (male nurse 7, Hospital A).

This is in contrast to what happened when I discussed the same topic with the nurses in Hospital B. The initial response of nurse 1 was that she could not change the hospital policy:

Actually, it is difficult to handle this issue, hospital can't afford to provide us with suitable gowns for the women patients, and we can't let them wear their ordinary clothes. Supposing that one of them has a relapse, how could we deal with her clothes? It is so difficult (female nurse 1, Hospital B).

It seems to me that the nurses were more concerned with following the hospital's policy, and did not take into account the needs of the individual patients. This is clearly evident when the majority of the group agreed that they could not help the women because of the hospital's policy. Another nurse said that:

Yes, there are some limits, which we can't control. It is something related to the policy of hospitals (male nurse 3, Hospital B).

Another nurse said that they could not separate males from females because of the complexity of the patients' condition:

It is so difficult to separate the men from the women in the ICU, because when the patients are in danger, whatever gender they are, we just need an available bed, wherever it is. In the ICU here we have some beds for men and others for women. If any critically ill man is admitted to the unit, and there is an empty bed in the female side, we will admit him. We can't leave empty beds when the patients need them (male nurse 5, Hospital B).

From their accounts I learned that there are some restrictions in the hospital policies which affected the nurses' care. But I offered them what I had learned from the first group discussion, about using two gowns on the women patients. The nurses in the group started to think about my suggestion, and immediately one nurse responded:

Oh, yes. I will allow the patient to wear two gowns, so she can cover her back, too. Sometimes, also, we ask for heavy gowns, because they are available in the operation theatre (female nurse 6, Hospital B).

A second nurse recommended making sure that the curtains were around the women patients during the nurses' procedure:

I think that the presence of curtains between patients is very important, especially when we perform nursing care, you know, the ECG or CVP line. I think we need to make sure that the curtains are around during the procedure (male nurse 5, Hospital B).

The group agreed upon using two gowns for the female patients admitted to the unit, so they could feel covered, and to make sure that the curtains were drawn during the nursing procedures:

After a short break, I led the discussion and started by thanking the nurses for their contribution; then moved to the third topic, which was to develop some support for the women who were mothers. This particular theme was noticed from the first woman I interviewed, where she showed her wish to see her young children. This will be discussed in the next section.

8.4.3 The women's need to see their children

As the discussion proceeded in both focus group discussions, I felt less anxious and more involved with the nurses; I presented the women's accounts that are related to the women's need to see their children. These accounts are:

... I felt very sad seeing them [her children] in this state, I mean I am a mother and a mother is caring for her children. Some times I cried when they left the room, especially when I saw the youngest son. He is now eight months old, and he hugged me and I felt that he needs my care , you know, I could not tolerate to see him away from me... (Um-Ahmed, first interview).

...but I kept remembering my daughters. I was wondering all the time how they were. You know how mothers feel about daughters especially when they are still young, even if everybody took care of them but still, I have to see them by myself...My daughters like to see me every day, nurses allowed them to see me once, I missed them a lot, [crying] (Um-Malak, first interview).

The nurses in Hospital A showed their empathy, and one of the female nurses shared her experience as a mother:

I can feel how they struggle in the ICU, because I am a mother, and I could not imagine my self away from my children for long. It is a very hard time for them, yes, very hard (female nurse 5, Hospital A).

Another female nurse in the group supported this, but she suggested that it would be risky to allow children to visit their mothers in the ICU:

Yeah, but to tell you the truth, the rules here do not allow any children to visit the ICU, you know, because of the infection control (female nurse 6, Hospital A).

A third nurse felt the children may have psychological problems, and added:

...and their visit may affect them psychologically, they are children. I cannot imagine what will happen to them when they see the monitors and machines; they will be shocked (female nurse 7, Hospital A).

We could not find any agreement in helping the women to see their children. One nurse suggested allowing the women to have telephone calls with their children that could help them at least to talk to their children:

The least we can do is to let the women call their children, and speak to them on the telephone. This would decrease their worries (male nurse 1, Hospital A).

All the group members agreed with this suggestion. The nurses in Hospital B raised the same issue about infection control, and asserted that children were not allowed to visit their mothers because of the hospital's policy:

Frankly, the policy of the hospital will never allow children to come in, because of the risk of infections, as you know, even if the mothers are badly in need of their children (female nurse 1, Hospital B).

Two nurses disagreed with this opinion, and pointed out that this was a basic need for these women:

Well, I disagree with you, S. A mother cares more about her children, and I think it is her utmost need, which we should not neglect (female nurse 4, Hospital B).

Yes, you are right [nurse 4]. But I think we can let the patient phone her children (male nurse 5, Hospital B).

Nurse 5 suggested that the women could use the telephone to call their children, and chat with them. This helped the other nurses to think about more ways to handle the women's needs. One nurse said:

...she can also write them letters; her children, too, can write to her. When I had a surgical operation once, my son wrote me a letter saying "Mum, I love you, please get better, because I need you, and I can't live without you." His letter affected me, and I soon recovered (female nurse 6, Hospital B).

This suggestion was admired by most of the nurses in the group, including myself. The nurses agreed to apply this method to the women in the unit. At the end of the group discussion, I thanked them again for their time and effort, and talked about how I had learned from their experiences. I have led the discussion again and asked the nurses to tell me about their experiences of sharing the focus group discussion. The next section draws in some of the nurses' accounts after the focus group meeting.

8.5 Reflecting on practice: the nurses' comments after the group discussion

At the end of the group discussion, the nurses talked about how they had learned from the women's experiences, which would help them to apply some of the suggestions to their patients. In Hospital A, the time passed quickly, and the nurses were in a hurry to start their second shift duty. One nurse acknowledged the discussion, and said that she had learned a lot from the suggestions:

I feel that I learned a lot from this meeting, and this will help in my work (male nurse 2, Hospital A).

The nurses in Hospital B showed more interest in conducting further discussions in the future. Some of them felt that they had learned from the discussion:

I didn't expect that our meeting would be as exciting as that, and we'd like to thank you, because we know now, more than before, how female patients feel about the ICU nurses (female nurse 1, Hospital B).

I wish we had more meetings like this one. You know, this meeting will absolutely change a lot of my ideas about female patients, and I will deal with them more carefully (male nurse, 5 Hospital B).

Thanks for all the points you proposed for discussion, it will affect the way I care for the female patients (female nurse 4, Hospital B).

This discussion was also a learning process for me as a researcher. When transcribing and translating the discussion, I found that I directed the group, rather than sharing it with them to the degree I had intended. My leadership could have affected the group dynamic and discussion. I also recognised my limited experience as a novice researcher in conducting a focus group discussion. Although I found it difficult to develop a supportive care strategy from the two focus groups discussions, I felt satisfied with my achievement in many ways. Firstly, the nurses became aware of the women's needs in their unit, and started to think about how the women patients feel about their care. Secondly, some nurses started to think more critically about their care, and decided to apply the new suggestions to their practice. Thirdly, I learned that nurses look at women's care by way of signs and symptoms, but not as a whole woman who had physical, emotional, social, and spiritual needs.

8.6 Summary

This chapter has tried to 'give voice' to the complexity which accompanies with the delivery of care by nurses for women in the intensive care unit. I have used two focus group discussions to examine issues that could assist in developing support care strategies for the women in the ICU. Through sharing different perspectives from their own practice, the critical care nurses in the study started to think more critically about their work and how the women's stories affected their care for other women patients in their units. The nurses identified principles to support the critically ill women in the ICU, such as how to care for the patients on delirium, helping the women to cover their bodies, and maintaining contact with their children. I learned from the previous discussion two main points. First, the ICU nurses considered 'caring' as a set of tasks and procedures, and did not give much attention to the female patients as a human. The emotional, social, and spiritual needs had previously had no openly acknowledged priority in the nurses' care. Second, stories from the ICU nurses showed their willingness to develop their practice into that which might be called culturally competent care.

I accepted the nursing group discussion as a learning experience for me as a novice researcher, and have reflected on the way I will conduct further group discussions with nurses in the future. I feel satisfied to have conveyed the women's voices to the

nurses in the two focus group discussions. The following conclusion chapter will discuss the principles of developing a supportive care strategy based on the women's accounts and the nurses' focus group discussions.

Conclusion

9.1 Introduction

In this study I have sought to examine the complexities and multi-dimensional effects of critical illness on participants' experiences over time. This included time points shortly after their transfer from the ICU and within two to six months after their discharge. Additionally I have also outlined the principles of the development of supportive care strategies for the Jordanian female patients in the ICU based on their needs and the nurses' focus group discussions. This chapter reflects on the methodology and findings of my study, and highlights key findings and implications for nursing care.

The analysis of participants' accounts adds substantially to our understanding of the Muslim woman's experiences of critical illness within the eastern Jordanian culture. It also highlights the need to understand a wide range of factors that may impact on patients' experiences including their cultural and religious identity. In particular, the data suggest that meeting the needs of Muslim female patients in the ICU would be enhanced by paying attention to cultural differences among the critically ill patients, especially those who have an eastern cultural background.

This final chapter is divided into four sections. Section 1 provides a summary of all the chapters in the thesis. Section 2 outlines the unique contribution of this study, discussing the significance and limitations of the findings. It is divided into three sub-sections: listening to Jordanian women's voices, Muslim women's experience of suffering, and Muslim women's experience of their bodies. Here I drew on findings presented in chapters 5, 6 and 7, and then I highlight the limitations of the study. Section 3 highlights the implications of the findings for nursing care, with the discussion here including caring for Muslim women and alleviation of suffering. I suggest ways forward to inform the development of a supportive care strategy, based on participants' experiences and the nurses' focus group discussions. Finally, I reflect on my development of and the ways in which I will develop the research in the future.

9.1.1 Summary of Chapters

In chapter 1, I introduce the importance of carrying out this study and reflect upon my own experiences and knowledge. In chapter 2, I present a review of available literature related to patients' experiences in ICU and to the use of narrative in stories of illness. This situates the study within the context of the wider literature, and identifies gaps in the literature.

Chapter 3 describes the philosophical position that underpins this study, and the use of narrative as a methodology. The chapter is divided into three sections: Section 1 examines the application of the narrative within different schools, the rationale for choosing narrative as a methodological approach as well as the potential limitations of employing this approach. Section 2 discusses my reflections on fieldwork, focusing particularly on the process of data collection and analysis. Section 3 discusses the way in which I conducted the nurses' focus group discussions in the selected hospitals. Chapter 4 then provides a brief introduction to each respondent alongside a brief account of the context of their interview(s). In this chapter I also identify how my participants widened my understanding of patients' experiences in the ICU.

Chapter 5 explores the experience of suffering and pain as multi-dimensional, with complex and overlapping issues. Here I argue that the experience of physical pain is part of many participants' suffering, especially when the pain is severe overwhelming, and disrupts their sleep. However, for some participants I identify how pain is considered as part of their illness process that has to be endured in order to recover. All the women experienced 'nafsi' suffering and describe their emotional and social losses, especially losing connections with their family. For the majority of my participants, the presence of their family was vital for their psychological and emotional well-being, and some women considered the family as an essential element of their life. The women's narratives are also pervaded with the experience of uncertainty and fear, the latter is connected with the experience of what I call 'vicarious death' when facing extreme suffering. Participants feared that their health could deteriorate further at any time during their stay in the ICU, and some feared they might die. Some participants witnessed the death of other patients, thus vicariously experienced death leading to fears of their own death. Once transferred to

the ward, the women started to re-evaluate their life and thanked Allah for being rescued from their critical conditions. The women, who lived in limbo and ambiguity, experienced the vicarious death through ‘hathayan’. I discuss the ways in which participants make sense of their experiences, showing how this is closely connected to their Islamic beliefs and manifest in the endurance of suffering and praying to Allah. The experience of suffering not only affected the women’s perception of life and death; I also identify how this changed their experience of time. The temporal element of the women’s accounts shows that time is divided into ‘lost time’ and the ‘suffering time’. Lost time is connected to the loss of their memory, due to unconsciousness or sedation. Suffering time describes the telling of their stories, which lack a temporal sequence or chronological order. The women, when telling their stories, moved backward to their past events, and forward to their present, but did not consider the future as part of their time.

The experience of suffering is connected to the women’s experience of their bodies. In Chapter 6, an analysis of the concept of ‘body work’ is presented: the ‘dependent body’ captures the women’s experiences of changes of their physical status, from care providers into those needing care. This involved the experience of a sense of paralysis or disablement, and a complete dependence on their family or nurses. The ‘social body’ describes the women’s feelings and emotions toward their family members. The latter assisted in the care of the women’s bodies, but distress, frustration and a sense of loneliness were experienced by the women as a result of the loss of verbal communication with their family members. The ‘cultural body’ describes the effect of cultural norms and Islamic religious beliefs on the women’s interpretation of their experiences, and the interpretation of male nursing care in the ICU. The ‘mechanical body’ describes the women’s experiences of the ICU machines as extensions of their bodies, and a sense of limbo and ambiguity during the ICU stay.

Chapter 7 discusses the changes in the women’s experiences of suffering and ‘bodywork’ two to six months after being discharged from the hospital. This recovery period raises many physical, emotional, social, and spiritual issues, which in turn impact on the women’s experiences in their everyday lives. Changes in physical performance, due to the loss of muscle mass or neurological deficit, are

manifest and described by many women as feelings of tiredness and weakness and difficulties in eating. Some women changed their home environment to cope with their new conditions of illness. This reflects their feelings of fear and frustration, and some women had difficulties in sleeping when recalling the traumatic events in the ICU. Surviving critical illness provided many participants with new meanings to their lives. The majority of the women described that the illness had provided them with the opportunity to value family unity and support. For some it was a lesson to strengthen their role as mothers and others positively reevaluated their lives and their futures.

Chapter 8 moves on to reflect on some of the women's accounts from the nurses' perspectives. Three main topics were discussed with the nurses: communication between nurses and the women as patients, the women's need to cover their bodies, and the women's need to see their children. Though fully developing a supportive care strategy for these women was unfortunately not possible, these discussions enhanced the nurses' awareness of the women's needs, and helped them think about solutions that would help future female patients in their units.

9.2 The unique contribution of this study

This study provides several new dimensions to the knowledge and understanding of Muslim women's experiences in and after the ICU. This includes adopting a narrative approach to listen to the women's voices, and the impact of social and cultural factors on patients' experiences of suffering and of the 'body'. The study also identifies ways in which women's suffering may be alleviated and the importance of addressing religious and cultural preferences in the delivery of care. Finally I draw upon the participants' accounts and the focus groups with nurses to develop an outline of a supportive care strategy that would assist the future delivery of Jordanian ICU nursing care.

9.2.1 *Listening to Jordanian women's voices* (Narrative methodology)

The current findings add to a growing body of literature on the use of narrative as an approach in research. This study uses a narrative approach to access rich accounts of

critically ill Jordanian women's experiences. The aim is to place the women's stories in the centre of nursing care, and to identify principles to support and help this client group. Applying a narrative approach to this study is useful for the research area in many ways.

Firstly, the women's narratives provide rich, in-depth accounts of women who experience critical illness, through following them after they are discharged from hospital. Traditional approaches of exploring the patients' critical illness rely mainly on either quantifying the number of the patients who recall their events in the ICU, using tools such as questionnaires, Likert-scale charts or structured questions, or using phenomenological methods to describe the patients' experiences, in relation to a specific phenomenon and usually on one occasion. All of these can provide valuable knowledge of the patients' conditions, which health care personnel can use to improve the quality of their service. However, none of these methods is likely to get to the heart of the patient's story, and, in particular, how the story unfolds, shifts and changes over time. Adopting a longitudinal narrative approach enabled my participants to provide accounts of what they perceived to be important aspects of their experiences and to reflect on their experiences over time.

Secondly, the women's narratives identify the importance of their cultural and religious background, aspects which may not be uncovered by quantitative approaches. Participants identified a number of ways in which their religious and cultural identity impact on their care. This included stories related to the covering of their bodies, their perceptions of the care they received from male nurses or doctors, their perceptions of their social and family support, and their stories about their connection with Allah during the experience of extreme suffering. These provide rich accounts of how Muslim women, living within the Islamic eastern culture, make sense of their critical illness experiences.

More recently, other research has employed the use of stories as central to the patients' experiences. One example is the exploration of patients' accounts by the DIPEX project, which reflects upon the experience of critically ill patients in the UK (DIPEX, 2007). These stories have some shared elements to those in my study, connected to experiences of suffering, pain, the loss of familiar environment,

communication difficulties, and positive or negative experiences with nursing care. However, my study contributes a new dimension regarding the ways in which patients' religious and cultural background can impact on constructions of their stories. The women's needs such as covering the body, asking for help from Allah during their suffering, and the close relationships with the family are relatively unique to the women within the Jordanian culture but these experiences could also transferable to other Muslim women who live in western countries- as I will discuss below.

Thirdly, I identify how the process of translating the narrative in this study can be a useful tool for teaching and learning. Translating the stories literally from an Arabic language into English can change the cultural meaning of some words. I thus adopted the approach of translating the meaning instead of the words of the sentences in order to avoid losing such meanings from women's accounts. Using 'backward'⁷³ translation in some of the narrative accounts can additionally ensure that the stories do not lose their original meanings. For example, some Arabic words have no literal translation and could thus lose their cultural meanings if a translation is attempted. This includes words such as 'nafsi', 'haram', 'hathayan', which I have retained in their Arabic form, with a more literal translation provided in a footnote. The issues of translation raised in this study could help many international researchers who have conducted their studies in a language different from English. Some qualitative studies, reflecting on the translation issues from different languages into English, stress on the use of meaning of the words to avoid losing the meaning of the cultural context (Twinn, 1997; Esposito; 2001). These studies, however, provide limited reflections on how they address the translation issues within their findings and how they dealt with the words that could lose their cultural meanings.

9.2.2 Muslim women's experiences of suffering

Data from my study provides a significant contribution to existing understandings of Jordanian Muslim women's perspectives and experiences of suffering and pain amongst in the ICU. The experiences of suffering among the Jordanian women's in

⁷³ I consider translation a text from Arabic language in to English Language as forward translation, then translation the same English text into Arabic using different translator I called backward translation.

this study are pervaded with multidimensional factors, many of which continue to have an impact on women's life after being discharged from the ICU.

The first dimension of the women's suffering is the experience of physical pain. Although some women see physical pain as a continuum of their suffering before their admission into the ICU, the experience of pain is interlinked with the suffering of these women when the pain is severe, overwhelming, and disturbing to their sleep. The study also shows that the pain is connected to many losses and changes during the stay in the ICU, such as the loss of body control, the presence of the unfamiliar ICU environment, and the sudden onset of the critical illness, which makes it difficult for the women in the ICU to make sense of their experiences.

My data offers further support to findings from earlier studies conducted in the 1980s and early 1990s, which identify that physical pain and environmental stressors as the most challenging experiences in the ICU (Hewitt, 1970; Jones, 1979; Ballard, 1980; Heath, 1989; Bergbom-Engberg and Haljamae, 1989; Cochran and Ganong, 1989; Johnson and Sexton, 1990; Turner, 1990). For patients, being in the ICU environment is stressful and causes anxiety and fear (Clark et al, 1995; Soehren, 1995; Watts and Brooks, 1997; Chornock, 1998; Hall- Lord, 1998; Topf, 2000) A study from the last few years explores the experience of eight British patients who were on mechanical ventilation, and points out that physical pain was part of the patients' experiences in the ICU, with the pain described as severe enough to disturb the patient's sleep (Johnson, 2001). Being connected to a ventilator machine also left patients with a feeling of loss of bodily control, which had a significant effect on their psychological wellbeing. This study adds that the nurses play a primary role in decreasing the women's physical suffering. When the nurses meet the women's basic needs, the latter would describe the former as supportive, even the 'angels of mercy'. The findings in this study suggest that the physical pain cannot be assessed or clearly understood without taken into consideration the other stressors that made the patients suffer in the ICU.

My study additionally highlights the importance of help and support from the family to the critically ill women, identifying a second dimension in the experience of suffering, which is related to the separation and loss of the family's togetherness and

support. This 'nafsi' suffering is connected to the women's feelings of loneliness and social isolation, particularly from their family, the presence of whose members are described by some elderly women as helping them to regain their former life. In chapter 6, the concept 'social body' is used to explore how, in the Jordanian culture, illness is regarded as a family concern not just an individual one. Examples show how the family helps many women to meet some of their physical needs as well as to provide psychological and emotional support to them. This led to the women remembering how they felt frustrated and depressed during the time when they were unable to communicate verbally with their family members. Chapter 7 goes onto provide an insight into how the women's families provided their primary care after their discharge from the hospital and, in addition, how the social relationship with neighbours and relatives is strengthened during this time.

The findings of these chapters assist our understanding of the role of social support, mainly from the family, in helping and supporting critically ill women within the Jordanian culture. The family's help and support are paramount during the women's experiences in the ICU, as well as after their discharge. Social support includes not only helping with the physical care and emotional recovery, but also has a practical dimension such as family members taking care of the children whilst women were in the ICU. For some women, their children are an inseparable part of their life, to the point that they want to live for their children. A wide body of knowledge emphasises the importance of family help and support in decreasing the negative experiences in the ICU environment (Cutler and Garner, 1995; Kollöff et al, 1997; Bergbom and Askwall, 2000; Hupcey, 2001; McKinley and Deeny, 2002; Strahan and Brown, 2005; Samuelsson et al, 2007). These findings, however, do not provide any insight into the particular perspectives and experiences that people from non western cultures may have.

The findings of this study support those from earlier studies that emphasise the meaning of social support as experienced by the patients of different cultures (Chin, 1990; Bergbom and Askwall, 2000; Hupcey, 2000; Forsberg et al, 2000; Papathanassoglou and Patiraki, 2003; Barrio et al, 2004). In a study conducted within the American culture, Hupcey (2001) asserts that family support was the primary need of 30 ICU patients, who spent a week in the ICU and were then discharged.

Family support here is identified as providing patients with a sense of happiness and safety. Family support for some patients in the Swedish culture, as discussed by Bergbom and Askwall (2000), is connected to the presence of close family members, such as their husbands and children, who provide them with a sense of safety, love, and being alive. In the Taiwanese culture, family support is understood as regular visits to the patients and care-taking of their children at home (Chin, 1990). My study adds to the above observations that family support is a primary concern for the critically ill women in a Muslim culture. It further highlights how for women who are mothers, caring for their children is the most important part of their social life and identity, and how they feel frustrated when they cannot meet their children's needs.

The fourth dimension of suffering is related to the experience of 'vicarious death'. This occurred when patients struggled to make sense of their experiences and sudden change in health, or when they witnessed the death of other ill people around them. It is a period when women were living with uncertainty and ambiguity. This existential type of suffering is connected to the struggle between life and death, when the person reaches extreme suffering and feels that life could end at any time.

The women's narratives of suffering indicate not only that they are vulnerable, but also that they lose their integrity as 'a whole woman', as they live through their critical illness. Unlike patients who experience chronic illnesses, or have disabilities (see Kleinman, 1988, Charmaz, 1983; Seymour, 1998), the critically ill women in this study underwent a rapid and unexpected loss and change of their health condition, and some would fall into unconsciousness before their admission into the ICU. They had limited time to think about, or make sense of what has happened to their bodies during their time in the ICU. In addition, the loss of their familiar environment and of social support was sudden and unexpected. The experience of extreme suffering led some of the participants to experience unreal events, such as hallucinations or delirium (hathayan). For the women in my study, a primary meaning of these experiences was related to their asking for help and the desire to be close to the mercy and support from Allah. These Islamic religious beliefs appeared to help them to alleviate their painful experiences and get through their extreme suffering. These aspects of existential suffering, experienced when the person loses

control over life and ponders on death, have been discussed by some studies but it is an area for future investigation. A few studies connect the experience of suffering in the ICU to religious beliefs (Hawley, 1998; Douglas, 1989; Barrio et al, 2004). Barrio et al., 2004 study of the experiences of 10 ICU patients in Spain points out that some patients found the meanings of their experiences closely connected to their Christian beliefs. They discuss how patients felt in need of God's support which gave them a sense of peacefulness. Some patients mentioned that they prayed to God many times during their stay in the ICU. Other studies conducted with patients suffering from life-threatening illnesses also show that religious beliefs provide the cancer patients with a sense of hope (Hawley, 1998, Puchalski and O'Donnell, 2005, Mount et al, 2007; Rasmussen and Elverdam, 2007). None of these studies, however, describe the experiences of suffering from the Muslim women's points of view. The findings in this study contribute to this small body of work which considers religious dimensions to patients' suffering, demonstrating the influence of Islamic beliefs on enduring extreme suffering.

9.2.3 Muslim women's experiences of their body

My findings additionally enhance an understanding of how Muslim women interpret the experience of their body in Jordanian cultural context. I indicated how the bodywork has physical, social, cultural, and mechanical elements. The physical and social elements have been discussed in the previous section, and the emphasis here will be on the cultural and mechanical elements.

This study shows that cultural norms and religious beliefs shape how the Muslim women make sense of their bodies in the ICU. Covering the body is a basic need expressed by most of the women in this study. Some participants identified how they felt exposed and at risk of losing an essential aspect of their cultural heritage when they were unable to cover their bodies. Some connected wearing the ICU gown to the loss of their modesty and privacy, which are important elements of their culture. This was interpreted as a shame and 'loss of honour' for the elderly women, who are often accustomed to wearing a long dress. Furthermore, women in my study all identified a preference to receive care from a female nurse. The women use the word 'Haram' which captures the transgression involved when male nurses bath them or clean their genital area. It seems that 'bodywork', as described by Lawler (1991), is problematic

not only for the nurses, but also for some particular patients, who consider this care as an invasion of their privacy and modesty.

The experience of the body is examined in the wider literature as the 'lived body' (Madjar, 1997), or the body as a social entity (Charmaz, 1983; Frank, 1990; Lawton, 2000). Feminist studies have also discussed the experience of the female body as different from the male body (Harding, 1987, Phoenix, 1994, Maynard and Purvis, 1994; Madjar, 1997). One study conducted in Greece shows that the patients interpret their experiences with their bodies as a continuum of their old body before their admission into the ICU, after which the body took a different shape after a period of time spent in the ICU. The bodies in this study are interconnected with the patients' feelings of loneliness and strangeness, as they have limited contact with their family and friends (Papathanassoglou and Patiraki, 2003). None of the studies, however, describe how the body is experienced in different cultures, nor the effect of culture and religion on shaping the body's experiences.

The findings of my study also discuss the relationship between the body and the ICU technology from the women's perspectives. An important part of the women's experiences relates to the ways in which they interpret the presence of the ICU machines in relation to their bodies. The findings show that women's experiences of the machinery contributed to levels of stress and discomfort, but some women also acknowledged their reliance on the machines for their survival. Furthermore, some women, who described the experience of living in limbo and ambiguity, considered the ICU machines as part of their bodies. The findings in this study agree with previous studies stating that patients experience ICU machines as stressful (Cochran and Ganong, 1989; Smith, 1989; Carnevale, 1999; Cornock, 1998; Hweidi, 2007). However my findings also indicate that these experiences are more complex, demonstrating how the presence of machines can also provide a meaning of security and safety to some women, whilst giving a meaning of survival to some patients and becoming integral to the changed body for others (McKinley et al, 2002).

9.3 Limitations of the study

The findings of this study are limited, since in order to be included in the study, the women had to be well enough to be able to speak and take part in an interview. There maybe many other perspectives that I have not been able to access from those women who are unable, subsequent to critical illness, to communicate their needs or story verbally. This may include those who have already been discharged from the ICU and have permanent mechanical ventilation, those who are semiconscious, cognitively impaired or in a vegetative state.

Furthermore, the study includes only women's experiences. It must be noted that the experiences of the male Jordanian patients could be different or could share some similarities. Further studies of the male patients and the comparison between the men's and the women's accounts is recommended for future researchers.

The study explores mainly the experiences of the women within 2-6 months after their discharge, but these experiences might change over a longer period of time, after one year for example. Future research is recommended to follow up the patients for longer time.

Furthermore, all the women recruited in this study are from the one major city in Jordan, as the geographical place could have an impact on the women's experiences. Critically ill women in the rural areas, for example, may have different stories and needs.

The study finds that the family members are also affected by the patients' critical illness, but does not explore the family members' experiences. It is recommended to explore the experiences of caring for their critically ill family members. There are vast numbers of research exploring the experiences of family members in the ICU (Johnson et al, 1999; Nelson et al, 2005; Feritas et al., 2007; Maxwell, and Stuenkel, 2007); this is one of the reasons that I did not take this focus.

9.4 Implications of the study

The findings of this study have a number of important implications for future nursing practice particularly in Jordan and in places where Muslim women are cared from during critical illness. This section has three main subsections: the alleviation of the women's suffering, caring for Muslim women, and the establishment of principles for the development of supportive care strategy.

9.4.1 The alleviation of the women's suffering

The findings of this study emphasise that the women's experiences in the ICU are pervaded with physical, emotional, social, and religious elements of suffering. Participants' accounts identify stories of suffering and pain and aspects of their needs that were not always met. The women's experiences of their bodies highlight important cultural interpretations of the body experiences, as well as their perceptions of the relationship between the body and the machines. In contrast, the nurses' focus group discussions reveal that the nurses tended to be more concerned with patients' symptoms and with the practical tasks of nursing care.

It appears that the nurses adopt a medical model of care, where greater importance is focused on curing patients. This includes practical care and the monitoring of ICU machinery. In this highly technological and inhuman environment, patients' emotional needs are sometimes neglected. This model of care fails to meet the cultural needs of the women in this study as it does not address the particular needs related to Jordanian women's cultural norms and religious beliefs. The findings of this study suggest a call for the ICU nurses to find a new model of care based on meeting the women's physical, emotional, social, cultural, and religious needs.

One way of improving the care for this client group and interlinking between the nurses' view and the women's needs is through applying the concept of palliative care to the care provided in the Jordanian ICUs. The development of hospice and palliative care has influence on the care provided in the dying people in the ICU (Curtis and Rubenfeld, 2001). This influence impacts on the care within the intensive care settings in several different ways. Firstly, the WHO definition of palliative

care⁷⁴ is an approach which improves the quality of life of the patients and their families, while facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of the early identification and impeccable assessment and treatment of pain and other physical, psychosocial, and spiritual problems (WHO, 2007). The application of this definition could help to develop a nursing care that not only relieves the physical pain, but also stresses on the values of emotional, social, and spiritual dimensions of care. It could then be applied to all those facing life-limiting illness, or risking death with critical illness. Secondly, the development of hospice care has modified the attention of the intensive care practitioners from curing the patient's disease and using high technological devices into maximizing the comfort and respect for ill people at the end of their lives (Block, 2001; Curtis and Rubenfeld, 2001, Foley, 2001, Seymour, 2001; Clark, 2002). Palliative care in Jordan is a necessity not only for the dying people in ICUs, but also for the women who suffer from a critical illness; an illness which all too frequently affects their lives long after their discharge. The improvement of the Jordanian ICU nursing care should rely mainly on providing a palliative approach to care, with emphasis on meeting the physical, psychological, social, and spiritual needs of the individual woman, and treating the women with respect and dignity.

9.4.2 The caring for Muslim women

This study highlights the importance of considering the religious and cultural preferences among Muslim women in the critical care settings. Covering the body is the basic need for the Muslim women in the Jordanian ICU. In addition, seeking care from female healthcare providers is highly preferable. An essential aspect of the women's needs is to avoid the male nurses or physicians from touching their bodies or providing 'private body' care such as bathing women or helping in cleaning the genital area. These findings could be transferable to other Muslim women who are admitted into the ICU in many western countries like the UK or the USA. These findings provide a new area of care for Muslim women both in the Jordanian ICUs and the ICUs in many western countries.

⁷⁴ This definition is available [online] from <http://www.who.int/cancer/palliative/definition/en>. Retrieved on [March, 20th, 2008].

While sharing these findings with a number of ICU nurses both in Jordan and in the UK, the discussions on the need of the women's to cover their bodies in the ICU with the Jordanian nurses aroused significant empathy with these women. Some nurses in Jordan suggested providing the women with double ICU gown so they can cover their bodies. Sharing the findings with ICU nurses in the British Association of Critical Care Nursing conference (see poster presentation in Appendix E) gave rise to different perspectives. Many nurses reflected that they have limited knowledge about the experiences of Muslim women in the ICU, although there are many Muslim women admitted into their units. One nurse recalled:

I never thought about the Muslim women, I see them many times wearing a scarf and putting on a long dress but I did not fully understand this aspect of their religious needs until our discussion today (ICU nurse, 2007, personal comments).

9.5 The establishment of principles to inform the development of supportive care strategy

The study also aims to establish principles of supportive care strategy to enhance nursing care for this client group in Jordan. These strategies are based on the women's needs and the nurses' focus group discussions. Parts of these needs have already been discussed in the previous section. These principles are:

1) The findings show that the ICU environment is considered strange and unfamiliar, with many machines that frightened the women with the loss of their senses of body control. ICU nurses should have an orientation plan for the newly admitted patients and may develop arrangements for pre-ICU visits for the patients who are to undergo major surgeries (Simpson, 1991).

2) The study finds that many women have experienced long-term physical and psychological issues at home, and it points out the need for preparing the women for their transfer from the ICU to the ward or to their homes. There is a need to discuss with the women about the transfer plans and to provide information on what the women may expect to face at home. It also recommends designing a plan that follows up these women at home and provides a continual care. Follow up services especially for the ICU patient is a fundamental necessity (Hall-Smith et al, 1997; McKinney and Deeny,2002; Lof et al, 2006; Pattison et al, 2007; Storli et al, 2008).

3) The findings show the importance of good- communication between the nurses and the women. All the women in this study requested the ‘human’ element of care. Nurses should meet physical, emotional, social, end religious needs as discussed in the previous section

4) All the women emphasised the importance of family support and help during and after their time in the ICU. Nurses should be aware of such need and help from the family and its involvement in the care of the women in the ICU.

5) The women asked for attentions to their cultural and religious needs such as the covering of their bodies, and they asked to be cared by female nurses. The women’s preference should be respected when allocating the nurses to the patients in the ICU.

6) The explanation of the nursing procedures is a basic need addressed by both the nurses and the women.

7) The women bring up the need to meet with their children or to talk to them, and many female nurses who are mothers also stressed this. It would be important to allow the telephone conversations between the women and their children in the ICU, or to let the women keep the photos of their children (Clarke and Harriuson, 2001).

8) Nurses should be aware of the frustration from the women’s incapability to communicate verbally. Encouraging the women to use nonverbal communication by using charts or writing down notes may be helpful (Menzel and Milwaukee, 1998).

The findings from this study, although they cannot be generalised in any statistical sense, are transferable. The principles of the findings are summarised in the following Table (9.1).

Table 9.1 Principles to inform the development of supportive care strategy

<p>The women's needs</p>	<ol style="list-style-type: none"> 1. Orient the patients with information about the ICU, familiarise them to the surroundings, and explain why they are admitted to the ICU. 2. Help the women who are unable to communicate verbally or on ventilator to communicate nonverbally by incorporating communication aids such as charts and writing boards. 3. Help the women to feel comforted through decreasing the intensity of their pain and minimise the environmental stressors such as the noise, the light, and the nurses' conversations. 4. Encourage the women's family to get involved with the provided care, and encourage the women to communicate with the family either verbally or none verbally. 5. Help the close family members to communicate with the female patients and provide support and help. 6. Treat the women as 'human' and provide individual care for their 'nafsi' needs. 7. Maintain the privacy of the women's bodies by allowing them to wear scarf, and to cover their bodies. 8. Maintain privacy during the nursing procedures. 9. Male nurses should provide a care that is culturally acceptable, and should also respect the women's request of receiving care from female nurses concerning their bathing and the cleaning of their genital areas. 10. Maintain the women's religious needs such as reading from Holly Qur'an, praying or making wishes to Allah. 11. Provide opportunities for the women to get involved in their care planning and activities.
<p>Nurses' care from the focus group discussion</p>	<ol style="list-style-type: none"> 12. Explain to the patients about the use of the machines and monitors during their first time in the ICU. 13. Listen to the patients' requests and needs. Help the patients to express their feelings and to share their experiences. 14. Develop a trustful relationship with the patients and their family that would help in providing the care for the patients and their family. 15. Provide the women with extra gowns to cover their bodies in the ICU. The nurses suggested a long gown with long sleeves to help the women in covering their bodies. 16. Care for the patients who suffer from hallucination or delusion: <ol style="list-style-type: none"> a. Keep observing the patient. b. Explain the nursing procedures and instructions. c. Provide orientation to the ICU environment and machines. d. Explain to the family about the patient's condition and encourage the family to help in orienting the patient to their surrounding. e. Reiterate the nursing information and instructions always, and make sure that the patient understands them. 17. Encourage the family to get involved with the patient's care as it would help the family to cope with their stress. 18. Maintain effective communications through explanations on the nursing procedures and the share the women on caring for themselves. 19. Help the women to communicate with their children via telephone or provide photos of their children. 20. Keep the curtains closed to separate the patients especially during the nursing procedures to maintain privacy

9.6 Final reflections

This study explores women's experiences of critical illness in Jordanian intensive care units. The study findings revealed three main areas: the women's experiences of suffering and pain; their experience of body care; and the impact of the ICU experiences on their lives after discharge home.

Experiences of suffering were pervaded with physical, emotional, social and temporal dimensions and were interlinked for the women with pain that was often severe, overwhelming, and disturbing to their sleep. The notion of 'nafsi' suffering was employed to describe the women's emotional and social losses, such as loss of family support, which they experienced. The notion of 'vicarious death' was used to explain the mortal fear women experienced in witnessing the death of others and in coming so close to their own demise.

This study highlights the importance of considering the cultural and religious context in which Muslim women experience critical illness. The study recommendations focus on the need to base nursing care in critical care units on an understanding of the physical, emotional, social, and religious elements of suffering, by exploring the potential of a palliative care approach for nursing critically ill people. In addition, study reveals how the recovery period raised many physical, emotional, social, and religious issues for the women, which in turn impacted on their experiences of their everyday lives. Some women interpreted the meaning of the critical illness experiences as an opportunity to value family unity and neighbours' support. For other women, the illness experiences gave them lessons that strengthened their role as mothers and helped them to think positively about their future.

My future plan is to share the study findings and recommendations by publishing in peer reviewed nursing Journals. I hope also, on my return to Jordan, to be able to develop further research in this field to address the following issues:

To conduct a qualitative research study involving both male and female patients to compare and contrast their accounts of critical illness.

To conduct research with the ICU nurses to develop supportive care strategies for the

patients in the ICU; this could be through using an action research.

To conduct further qualitative research about the needs of family and relatives in the Jordanian context.

To conduct a longitudinal study which would enable me to follow women who have been critically ill for a longer period than has been possible in this study.

As a member of the faculty at the University of Jordan, I would like to develop an over all plan to study the possibilities of applying the palliative care model in the nursing care in Jordan. This plan will be discussed with the King Abdullah Research Development Canter and developed through conducting conferences at national level and including all the policy makers and higher institutes in Jordan.

Finally, it is worth to point out the leaning experiences that I have gained through three years of living in this country. I learned to listen to the voices of others, the women, the nurses, and including my own voice. I learned to reflect on my own experiences and learning. A major challenge in conducting this study has been the difficulty in writing when English is a second language for me; however, I accepted the challenge and have tried my best to reach a high standard of academic writing.

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SUPPLEMENTARY DOCUMENTS

Summary of supplementary data

Appendix A supplementary

1. Patient Invitation Card (English and Arabic).
2. Patient Information Sheet.
3. Patient Consent form.
4. Nurse Cover Letter.
5. Nurse Information Sheet.
6. Nurse consent form
7. Nurse Reply slip.
8. Ethical Approval Protocol (patients).
9. Ethical Approval Protocol (nurses).

Appendix B

1. Patient Information sheet (in Arabic)
2. Patient Consent form (in Arabic).
3. Nurse Cover Letter (in Arabic).
4. Nurse Information Sheet (in Arabic).
5. Nurse consent form (in Arabic).
6. Nurse Reply slip (in Arabic).
7. A summary of Ethical approval process and the Ethical approval documents from the University of Sheffield and both hospitals.

Appendix C

Description of the women who included and excluded in the study. Study sample and population.

Appendix D

Samples of the translation from Arabic language in to English Language, then Back translation.

All themes in the Study [preliminary analysis].

Appendix E

The Poster presented in the (22nd) British Association of Critical Care Nursing (BACCN) Conference

Appendix A

1. Patient Invitation Card (English and Arabic).
2. Patient Information Sheet.
3. Patient Consent form.
4. Nurse Cover Letter.
5. Nurse Information Sheet.
6. Nurse consent form
7. Nurse Reply slip.
8. Ethical Approval Protocol (patients).
9. Ethical Approval Protocol (nurses).

Appendix A, number 1:



THE UNIVERSITY OF SHEFFIELD :
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الباحثة: رقية الزيلائي.
كلية التمريض / الجامعة الأردنية
جامعة شيفلد / بريطانيا



R. Zeilani : (00962) 0795395018
E-mail: r_zeilani@yahoo.com

Invitation Card (patient)⁷⁵

Research Title: Experiencing Intensive Care: Women's Voices in Jordan
Researcher Name: Ruqayya Zeilani

Dear.....

I am writing to invite you to take part in a research study. My name is Ruqayya Zeilani; I am a researcher at The University of Jordan and a PhD student at The University of Sheffield (in the United Kingdom). I am conducting a study to understand more about Women's experiences in critical care units. As part of my study, I aim to interview women who have spent more than 48 hours in critical care and are then discharged to the ward. The information gained from the research will help the nurses to improve the care provided to critically ill women.

If you are happy for me (Ruqayya) to contact you to discuss the project further and give you detailed information about the study, please returned back the second copy of this card to Mr.....in your ward.

Thank you for your help and co-operation

Yours sincerely
Ruqayya Zeilani

عزيزتي المشاركة:
أنا الباحثة رقية الزيلائي , باحثة من الجامعة الأردنية. أقوم بعمل دراسة تهدف إلى معرفة الخبرات التي تكتسبها المرأة الأردنية في أثناء تواجدها في قسم العناية الحثيثة ورأيها بالعناية التمريضية المقدمة. تتضمن هذه الدراسة مقابلتك على مراحل عدة: بعد خروجك من قسم الرعاية الحثيثة, في البيت بعد خروجك من المستشفى لمرة أو عدة مرات و حسب ماتريئة مناسبة.
إن إشتراكك في هذه الدراسة سيفيد في تحسين الرعاية التمريضية المقدمة للمرضى في أقسام الرعاية الحثيثة و إظهار أهمية رأي المريضة في العناية التمريضية المقدمة
ستعامل جميع معلوماتك بسرية تامة, ولن يكون هناك اي تأثير على العناية الصحية المقدمة لك في المستقبل.
إذا رغبت في المشاركة في هذه الدراسة أرجو إخبار الممرضة/الممرض المسؤول أو الإتصال على هاتف رقم:
.....

⁷⁵ This Card Translated into Arabic Language.

Appendix A, number 2:



THE UNIVERSITY OF SHEFFIELD :

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كلية التمريض/ الجامعة الأردنية
جامعة شيفلد/ بريطانيا



R. Zeilani : (00962) 0795395018
E-mail: r_zeilani@yahoo.com

Information sheet (patient)

Study title

“Experiencing Intensive Care: Women’s Voices in Jordan”

The study

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Take time to consider whether or not you wish to take part. Please contact me to ask about anything that is not clear or if you would like more information.

Thank you for reading this information sheet.

What is the purpose of the study?

This study aims to collect information from women patients about their experiences of critical illness in the Jordanian intensive care units (ICUs). This information will be used to help the nurses to meet the needs of critically ill female patients in the ICU and improve the quality of care.

Why have I been chosen?

You are being invited to take part in this research because you have been in the intensive care unit. You are one of about 10-15 women who are being asked to share your experiences of critical illness after discharge from the ICU. I hope to learn from listening to your experiences and find

ways to encourage nurses to develop the care provided to women in the intensive care unit.

Do I have to take part?

No. It is entirely up to you whether or not to take part. If you decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part, you are still free to change your mind and withdraw at any time, without giving a reason. A decision to withdraw at any time, or decision not to take part, will not affect the standard of care you receive.

What will happen if I take part?

If you are interested in taking part in the study, I will come back to see you in the ward and ask you to take part into the study. Then I will explain the project in more detail and answer any questions you may have and we will agree on a time and a place for an interview.

With your permission, I would like to interview you after your transfer from the intensive care to the ward at a place and time convenient to you. Later on, I would like to interview you at home one month after you discharged from the ICU. We may arrange a third interview if we have further topics to discuss. The interview will take the form of a conversation and you can give as much or little information as you want. The conversation will continue approximately 1-2 hours.

Also with your permission, I would need to tape record the interview to avoid taking notes during our conversation. This record will be listened to only by me (Ruqayya Zeilani) and none of your personal details will be included. The recording will be transcribed. The tapes and the transcripts will be made anonymous and stored securely.

What are the possible disadvantages and risks of taking part?

Any disadvantage or risk related to this study is unlikely. As you have been recently discharged from the intensive care unit, it is possible that you may become upset when talking about your experiences. If this happens and you want to stop the interview at any time, you can do so.

Will my taking part in the study be kept confidential?

If you consent to take part in the study, this will be kept strictly confidential. The only person that will know who has taken part is the researcher (Ruqayya Zeilani). All of the transcripts will be returned back to you at the end of the interview process so that you can remove any information you do not like to share. Any information collected about you will have your name and address removed so that you cannot be recognised from it.

What are the possible benefits of taking part?

It is not anticipated that you will experience any direct benefit as a result of taking part in this study. However, some people find it is helpful to talk about their experiences. This helps them to feel released and make sense of their experiences.

What will happen to the results of the study?

The findings of the study will be summarized and then written up in the form of important issues. These issues will be discussed with a group of critical care nurses to develop support care strategies for women in the intensive care unit. In addition, the summary will be translated by me (Ruqayya Zeilani) and written up as part of my doctoral thesis.

What if something goes wrong?

It is extremely unlikely that anything will go wrong as a result of taking part in this study. However, if you feel unhappy about continuing the interview the researcher will stop the interview immediately. Unfortunately, there are no support mechanisms for the patients in the hospital but I will try my best to provide you with one-to-one social support. If during the course of the interview, you say anything about your health that causes concern, with your permission I will let your doctor know.

Who has reviewed the study?

The study has been reviewed by the Research Ethics Committee at The University of Sheffield in the United Kingdom, The Research Ethics Committee at The University of Jordan, and the Ethics committee in each hospital. If you have any concerns about the way the study is being conducted, you may call the contact person in the hospital as provided below:

Name of the Hospital	Contact person	Address
A Hospital		
B Hospital		

What if I have further questions?

You may contact the researcher, Ruqayya Zeilani if you have any further questions about the study. If you are interested in taking part, the researcher will contact you and discuss the project in more details.

Contact for further information.

Miss Ruqayya Zeilani, The researcher.

Tel: 06/5355000 ext.2479

Mobile: 0795395018

Email: r_zeilani@yahoo.com

Thank you for your assistance.

Yours sincerely

R.S. Zeilani

Appendix A, number 3:



THE UNIVERSITY OF SHEFFIELD :

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الباحثة: رقية الزيلاي.
كلية التمريض / الجامعة الأردنية
جامعة شيفلد / بريطانيا



R. Zeilani : (00962) 0795395018

E-mail: r_zeilani@yahoo.com

Hospital Number:

Patient Identification Number for this project:

CONSENT FORM (Patient)

Title of Project:

Name of Researcher:

Please check Initial box

1. I confirm that I have read and understand the information sheet dated ... for the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected.
3. I understand that sections of any of my research records where appropriate may be Looked at by responsible individuals from the Ethics Committee or from regulatory authorities where it is relevant to my taking part in research. I give permission for these individuals to have access to my records.
4. I agree to take part in the above study.

Name of Participant:

.....

Date:

.....

Signature:

.....

Name of person taking consent
(if different from researcher)

.....

Date:

.....

Signature:

.....

Researcher:

.....

Date:

.....

Signature:

.....

1 for participant, 1 for researcher, 1 to be kept with hospital notes

Appendix A, number 4:



THE UNIVERSITY OF SHEFFIELD :

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الباحثة: رقية الزيلاي.
كلية التمريض/ الجامعة الأردنية
جامعة شيفلد/ بريطانيا



R. Zeilani : (00962) 0795395018
E-mail: r_zeilani@yahoo.com

Cover Letter (Nurse)

Dear

I am writing to invite you to participate in a research study. The study aims to understand more about women's experiences in the critical care unit (ICU). The study consists of two parts, presentation of the research finding that related to the women's experiences in the ICU and a focus group discussion.

I would be grateful for up to two hours of your time to hear more about your experiences and thoughts that related to the care provided to women patients in the ICU. It may also be useful for you to hear about the women experiences in the ICU from their perspective. Thus, the presentation will explore women's experiences in ICU after they are discharged to the ward following critical illness.

Your thoughts and experiences will be most helpful in informing the development of supportive care strategies to this client group. The focus group discussion will include 8-12 nurses working in the ICU. The discussion will take place in the meeting room in your hospital. Drinks and sandwiches will be provided.

I would be grateful if you read the study information that I have enclosed with this letter. If you are happy for me (Ruqayya) to contact you to discuss the project further, please complete the reply slip and return in the envelope provided to the following address:

To :Miss Ruqayya Zeilani
The University of Jordan
School of Nursing and Midwifery
PO Box. 12941.
Fax: 5355000/2679.

Thank you for your help and co-operation

Yours sincerely
Ruqayya Zeilani

Appendix A, number 5:



THE UNIVERSITY OF SHEFFIELD :

SCHOOL OF NURSING AND MIDWIFERY

Bartolome House
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Tel: (0114) 2229710
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الباحثة: رقية الزيلاي.
كلية التمريض / الجامعة الأردنية
جامعة شيفلد / بريطانيا



R. Zeilani : (00962) 0795395018

E-mail: r_zeilani@yahoo.com

Information sheet (Nurse)

Study title

“Experiencing Intensive Care: Women’s Voices in Jordan”

The study

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Take time to consider whether or not you wish to take part. Please contact me to ask about anything that is not clear or if you would like more information.

Thank you for reading this information sheet.

What is the purpose of the study?

This study aims to collect information from women patients about their experiences of critical illness in Jordanian intensive care units (ICUs). This information will be used to help the nurses to meet the needs of critically ill female patients in the ICU and to improve the quality of nurses’ care

Why have I been chosen?

You are being invited to take part in this research because you are a critical care staff nurse working in the intensive care unit in The University Hospital/ Al-Basheer Hospital. All the staff nurses working in the intensive care units in your hospital are invited to join the focus group discussion. I would like to share with you and your colleagues the findings from my study of women’s experiences during their ICU stay and discuss how to develop supportive care strategies for this client group.

Do I have to take part?

No. It is entirely up to you whether or not to take part. If you decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to change your mind and withdraw at any time, without giving a reason. A

decision to withdraw at any time, or decision not to take part, will not affect your position in your department.

What will happen if I take part?

I would like to conduct a group discussion at a time when you are out of duty. The group will consist of 10-12 nurses. First I will ask you to share your views in a small group of 4-5 others. I will ask to have a copy of the summary of your discussion recorded by the group leader. Then, we will have a plenary discussion. With your permission, I will record this on a mini-disc.

If you are interested in taking part in the study, you are asked to return the reply slip to the researcher (Ruqayya Zeilani) in the envelope provided. Ruqayya will then contact you to explain the study in more detail and answer any questions you may have.

What are the possible disadvantages and risks of taking part?

Any disadvantage or risk related to taking part in this study is very unlikely.

Will my taking part in the study be kept confidential?

If you consent to take part in the study this will be kept strictly confidential. All your information will be kept confidential. Any information, which is shared, will have your name and address removed so that you cannot be recognised from it. All the information will be made anonymous and stored securely.

What are the possible benefits of taking part?

Participation in the discussion may help you to develop your knowledge about women's experiences in the intensive care unit and the patients' needs during their ICU stay. In addition, this may help to improve the quality of care you provide to your patients.

What will happen to the results of the study?

The strategies developed will be translated and written up as part of the researcher's PhD thesis. The study may be published in an international journal and will be presented at an international conference.

What if something goes wrong?

It is extremely unlikely that anything will go wrong as a result of taking part in this study. You can withdraw from the study at any time and without any question.

Who has reviewed the study?

The study has been reviewed by Research Ethics Committee at The University of Sheffield in the United Kingdom, The Research Ethics Committee at The University of Jordan, and the Ethics committee in each hospital. If you have any concerns about the way the study is being

conducted, you may call the contact person in each hospital as provided below:

Name of the Hospital	Contact person	Address
A Hospital	omitted	omitted
B Hospital	omitted	omitted

What if I have Further questions?

You may contact the researcher, Ruqayya Zeilani if you have any further questions about the study. If you are interested in taking part, please complete the reply slip and return it to Ruqayya in the envelope provided. Ruqayya will then contact you and discuss the study in more details.

Contact for further information.

Miss Ruqayya Zeilani, The Researcher.

Tel: 06/5355000 ext.2479

Mobile: 0795395018

Email: r_zeilani@yahoo.com

Thank you for your assistance.

Yours sincerely

R.S. Zeilani

Appendix A, number 6:



THE UNIVERSITY OF SHEFFIELD :

SCHOOL OF NURSING AND MIDWIFERY

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الباحثة: رقية الزيلاي.
كلية التمريض / الجامعة الأردنية
جامعة شيفلد / بريطانيا



R. Zeilani : (00962) 0795395018

E-mail: r_zeilani@yahoo.com

Hospital Number:

Patient Identification Number for this project:

CONSENT FORM (Nurse)

Title of Project:

Name of Researcher:

Please
Initial
box

1. I confirm that I have read and understand the information sheet dated for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected.

3. I understand that sections of any of my research records where appropriate may be looked at by responsible individuals from the Ethics Committee or from regulatory authorities where it is relevant to my taking part in research. I give permission for these individuals to have access to my records.

4. I agree to take part in the above study.

Name of Participant:
.....

Date:
.....

Signature:
.....

Researcher:
.....

Date:
.....

Signature:
.....

1 for participant, 1 for researcher

Appendix A, number 7:

Experiencing Intensive Care: Women's Voices in Jordan

Participant Reply Slip: Nurse

I confirm that have read the information about the above research study.

I am interested in taking part in a focus group as part of the research.

I am happy for Ruqayya Zeilani to contact me to arrange the group interview at a time and place convenient to me.

Name:

Contact Address:

.....

.....

.....

Telephone number:

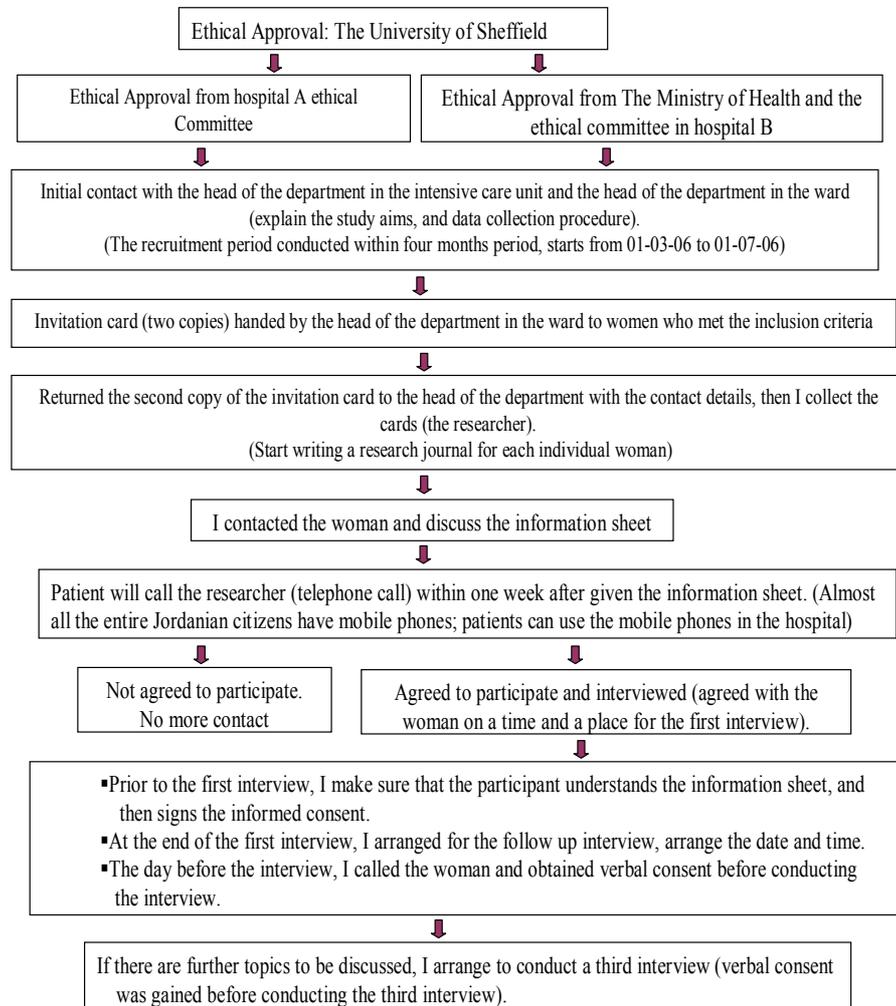
Email (If present):

Signature:

Appendix A, number 8:

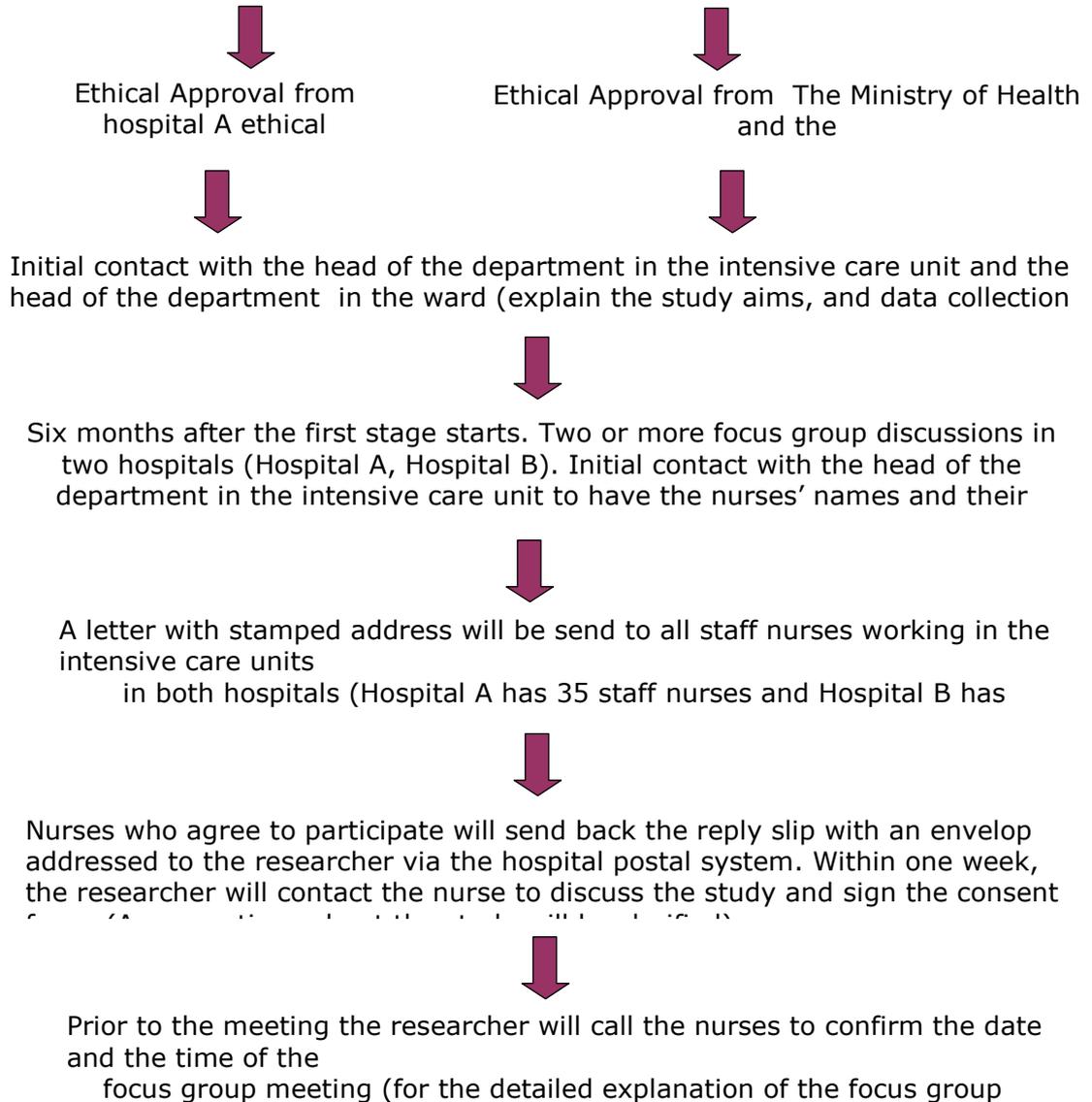
The following chart summarise the protocol that the researcher will use:

1- Patient:



2- Nurses:

Ethical Approval: The University



Appendix B

1. Patient Information sheet (in Arabic)
2. Patient Consent form (in Arabic).
3. Nurse Cover Letter (in Arabic).
4. Nurse Information Sheet (in Arabic).
5. Nurse consent form (in Arabic).
6. Nurse Reply slip (in Arabic).
7. A summary of Ethical approval process from The University Hospital.

Appendix B, number 1:



THE UNIVERSITY OF SHEFFIELD :

SCHOOL OF NURSING AND MIDWIFERY

Bartolome House

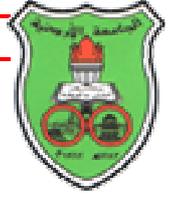
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الباحثة: رقية الزيلاي.
كلية التمريض/ الجامعة الأردنية
جامعة شيفلد/ بريطانيا

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معلومات عن الدراسة(المشاركة)

العنوان:

صوت المرأة الأردنية في أقسام العناية المركزة

الدراسة:

هذه دعوة للإشتراك في بحثٍ قيل ان تقرر الرغبة في الإشتراك (او عدم الرغبة) أرجو قراءة امعلومات المرفقة عن مشروع البحث. اذا رغبت في اية معلومات إضافية او من المعلومات التوفرة غير واضحة بالنسبة لك ارجو ان لا تتردد بالإتصال بي .

ما هو الهدف من الدراسة؟

تهدف الدراسة الى معرفة الخبرات التي تمر فيها المرأة الأردنية عند دخولها قسم الرعاية الحثيثة ورأيها بالرعاية التمريضية المقدمة. هذه المعلومات ستفيد في تحسين الرعاية التمريضية المقدمة للمريضات في اقسام الرعاية الحثيثة.

لماذا تم إختيارى فى البحث؟

تم إختيارك لأنك احدى النساء اللواتي قضين مدة في قسم الرعاية الحثيثة وتلقيت رعاية تمريضية في ذلك القسم. ارجب بالتعلم من خبراتك و اصر على تحسين الرعاية التمريضية لجميع المريضات في اقسام الرعاية الحثيثة.

هل من الضروري المشاركة فى البحث؟

لا. لك حرية الإختيار في المشاكة او عدم المشاركة في البحث . حتى لو رغبت في المشاركة وغيرت رأيك بعد فترة يمكنك الإنسحاب من الدراسة متى شئت. إن اي قرارك بالإنسحاب لن يؤثر على الرعاية التمريضية المقدمة لك في المستقبل.

ماذا سيحدث اذا وافقت بالمشاركة فى البحث؟

اذا وافقت بالإشتراك ستتظم الباحثة موعد لعقد المقابلة. بعد ذلك سيتم مقابلتك عدة مرات, الأولى بعد خروجك من قسم الرعاية الحثيثة, الثانية بعد خروجك من المستشفى بحوالي ثلاثة اسابيع. وقد يتم عقد مقابلة ثالثة اذا دعت الضرورة. ايضاً بعد اذنك سيتم تسجيل المقابلة على شريط خاص لأغراض البحث ولن يتم سماعه إلا من قبلي (رقية).

هل هناك فوائد من المشاركة فى البحث؟

ان اشترارك في البحث سيفيد مرضى اخرين سيدخلون قسم الرعاية الحثيثة.

هل هناك مساوئ من المشاركة فى البحث؟

ان اشترارك في البحث لن يكون لة اي اثر سلبي عليك, لكن اذا شعرت ان اي سؤال قد يسبب لك اي ازعاج لك الحرية في عدم الإجابة او إيقاف المقابلة. بعد إذنك اذا وجدت ان حالتك الصحية تحتاج رعاية سأقوم بإخبار طبيبك وحسب موافقتك.

مل ستعامل معلوماتى بسرية؟

جميع معلوماتك ستعامل بسرية تامة. لن يطلع اي طرف ثالث على معلوماتك, كما ان اي معلومة يتم فيها ذكر إسمك او معلومات شخصية عنك سيتم الغاءها من الترجمة.

ماذا سيحدث لنتائج البحث؟

سيتم عرض نتائج الدراسة بعدة طرق، بعض الآراء من المرضى بدون اسم سيتم مناقشتها مع الممرضين، سيتم كتابة النتائج في رسالة الدكتوراة للباحثة، سيتم نشر مقالة باللغة الإنجليزية عن خبرات الأردنيين في اقسام الرعاية الحثثة

من سيطلع على نتائج البحث:

النتائج سيتم ترجمتها باللغة الانجليزية (بدون اسماء)، ثم سيتم عرضها على مشرفي رسالة الدكتوراة.
إذا اردت مزيداً من المعلومات:

العنوان	الشخص الذي يمكنك الإتصال به	أسم الجامعة
مستشفى الجامعة الأردنية ص ب 11942	السيد حسين كتوعة	مستشفى الجامعة الأردنية
مستشفى البشير الحكومي ت 47074074	السيد محمد العائزة	مستشفى البشير الحكومي

لمزيد من المعلومات الرجاء الإتصال ب:

الباحثة رقية الزيلائي،
الجامعة الأردنية/ كلية التمريض.

ت: 0795395018

البريد الإلكتروني: r_zeilani@yahoo.com

شاكراً لكم حسن تعاونكم

الباحثة

رقية الزيلائي

Appendix B, number 2: يمكنك الإتصال على كل من



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نموذج الموافقة (المشاركة)

إسم الباحثة:

عنوان البحث:



الرجاء وضع إشارة في الدائرة :



1- أقر بأنّي قرأت المعلومات المرفقة في معلومات المشارك و فهمتها.



2- أفر بأن المشاركة في الدراسة إختيارية وأن لي الحق في الإنسحاب من الدراسة متى شئت.



3- أقر بأن معلوماتي ستعامل بسرية تامة و اسمح للباحثة بالإطلاع على معلوماتي الطبية.



4- أوافق على المشاركة في الدراسة.

إسم المشاركة: التاريخ: التوقيع:

الشخص الموقع نموذج الموافقة: التاريخ: التوقيع:

الباحثة: التاريخ: التوقيع:

نسخة المشاركة, نسخة الباحثة, نسخة المستشفى



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عزيري الممرض / الممرضة

ماذا تقول المريضة عن قسم العناية المركزة. دراسة تقوم بها الباحثة رقية الزيلاي لمعرفة رأي الممرضات في العناية التمريضية المقدمة في أقسام العناية المركزة. هل ترغب بالإطلاع على نتائج البحث

عزيري الممرض/عزيرتي الممرضة:.....

أرغب في ان اطلعك على نتائج دراستي التي تتضمن رأي الممرضات في العناية التمريضية المقدمة في أقسام العناية المركزة. وان اتعلم من خبراتك عن الرعاية المثلى للمريضات. سيتم عقد ورشة عمل في قاعة الاجتماعات في مستشفى لفتح الحوار حول اساليب دعم الممرضات في اقسام العناية الحثيثة.

اذا اردت تفاصيل الدراسة الرجاء قراءة المعلومات المرفقة. اذا رغبت في المشاركة الرجاء الاتصال بالباحثة مباشرة او الرد على العنوان التالي:

رقية الزيلاي
الجامعة الأردنية
كلية التمريض

ص. ب: 12941

فاكس: 5355000/2679

تلفون: 0795395018

شاكرا لك حسن تعاونك
الباحثة
رقية الزيلاي



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**معلومات عن الدراسة(المررض)
العنوان:**

صوت المرأة الأردنية في أقسام العناية المركزة

الدراسة:

هذه دعوة للإشتراك في بحثٍ قبل ان تقرر الرغبة في الإشتراك (او عدم الرغبة) أرجو قراءة المعلومات المرفقة عن مشروع البحث. اذا رغبت في اية معلومات إضافية, او ان المعلومات التوفرة غير واضحة بالنسبة لك ارجو ان لا تتردد بالاتصال بي .

ما هو الهدف من الدراسة؟

تهدف الدراسة الى معرفة الخبرات التي تمر فيها المرأة الأردنية عند دخولها قسم الرعاية الحثيثة ورأيها بالرعاية التمريضية المقدمة. هذه المعلومات ستفيد في تحسين الرعاية التمريضية المقدمة للمريضات في اقسام الرعاية الحثيثة.

لماذا تم إختيارى فى البحث؟

تم إختيارك لأنك من الممرضين العاملين في قسم الرعاية الحثيثة, وعندك خبرات عن المرضى في اقسام الرعاية الحثيثة. ارجب بالتعلم من خبراتك و اتمنى ان شاركك الرأي في إيجاد طرق لدعم و تحسين الرعاية التمريضية لجميع المريضات في اقسام الرعاية الحثيثة.

هل من الضروري المشاركة فى البحث؟

لا. لك حرية الإختيار في المشاكة او عدم المشاركة في البحث . حتى لو رغبت في المشاركة وغيرت رأيك بعد فترة يمكنك الإنسحاب من الدراسة متى شئت. إن اي قرارك بالإنسحاب لن يؤثر على عملك في الحقل التمريضي في المستقبل.

ماذا سيحدث اذا وافقت بالمشاركة فى البحث؟

اذا وافقت بالإشتراك ستتظم الباحثة موعد لعقد المقابلة. بعد ذلك سيتم عقد ورشة عمل في بتاريخ سيتم في الورشة مناقشة ما تم جمعة من معلومات عن المريضات ثم سيتم مناقشة طرق دعم المريضات. بعد إنذك سيتم تسجيل المناقشة لأغراض البحث.

هل هناك فوائد من المشاركة فى البحث؟

ان اشتراكك في البحث سيفيد في تطوير الرعاية التمريضية للمريضات, وقد تستفيد من خبرات الممرضين الاخرين في البحث ل مرضى اخرين سيدخلون قسم الرعاية الحثيثة.

هل هناك مساوئ من المشاركة فى البحث؟

ان اشتراكك في البحث لن يكون لة اي اثر سلبي عليك, لكن اذا شعرت ان اي سؤال قد يسبب لك اي ازعاج , لك الحرية في عدم الإجابة او عدم إكمال اللقاء.

مل ستعامل معلوماتى بسرية؟

جميع معلوماتك ستعامل بسرية تامة. ان المعلومات ستكون عامة ولن يكون هناك اي معلومات شخصية عنك. وتأكيذا على ذلك فإن اي معلومة يتم فيها ذكر إسمك او معلومات شخصية عنك سيتم الغاءها من الترجمة.

ماذا سيحدث لنتائج البحث؟

سيتم عرض نتائج الدراسة بعدة طرق, سيتم كتابة النتائج في رسالة الدكتوراة للباحثة, سيتم نشر مقالة باللغة الانجليزية عن خبرات الأردنيين في اقسام الرعاية الحثيثة. ستم عرض نتائج البحث في مؤتمر التمريض العالمي.

من سيطلع على نتائج البحث:

النتائج سيتم ترجمتها باللغة الانجليزية (بدون اسماء), ثم سيتم عرضها على مشرفي رسالة الدكتوراة.
إذا اردت مزيداً من المعلومات حول الدراسة من أسأل؟

يمكنك الإتصال على كل من:

العنوان	الشخص الذي يمكنك الإتصال به	اسم الجامعة

لمزيد من المعلومات الرجاء الإتصال ب:

الباحثة رقية الزيلائي,
الجامعة الأردنية/ كلية التمريض.

ت: 0795395018

البريد الإلكتروني: r_zeilani@yahoo.com

شاكراً لكم حسن تعاونكم
الباحثة

رقية الزيلائي



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نموذج الموافقة (الممرض)

إسم الباحثة:

عنوان البحث:



الرجاء وضع إشارة في ادايرة :



1- أقر بأني قرأت المعلومات المرفقة في معلومات المشارك و فهمتها.



2- أفر بأن المشاركة في الدراسة إختيارية وأن لي الحق في الإنسحاب من الدراسة متى شئت.



3- أقر بأن معلوماتي ستعامل بسرية تامة و اسمح للباحثة بالإطلاع على معلوماتي..



4- أوافق على المشاركة في الدراسة.

إسم المشاركة: التاريخ: التوقيع:

الباحثة: التاريخ: التوقيع:

نسخة المشارك, نسخة الباحثة

Appendix B, Number 7.

Ethical approval forms.

All letters from the ethical approval committee are in Arabic Language.

- Ethical approval- The ` University of Sheffield.
- The Ethical Committee at the University of Jordan sent a letter to the director of the proposed hospitals [hospital A and hospital B].
- The Ethical Committee and the director of each hospital sent their recommendations to the Vice-President for Academic Affairs at the university of Jordan.

Appendix C

Description of the women who included and excluded in the study. Study sample and population.

1- Descriptions of the patients who admitted to Hospital A during the period between [01/03/06- 30/06/06]:

TOTAL ADMISSION TO THE ICU	335 PATIENTS.	[112 FEMALE PATIENTS, 223 MALE PATIENTS INCLUDING PAEDIATRIC PATIENTS
Number of female patients admitted to the ICU	112	Including the paediatric patients
Number of deaths in the ICU	22	[13 female, 9 male]

Table 3:2: description of the participants included in the study, their age, medical diagnosis, days in the ICU, days in the hospital, number of follow up interviews (see section 3.8.5)

Profile for female patients who met the inclusion criteria but who were not included

NO	NAME	AGE	DIAGNOSIS	COMMENTS
1	All names are deleted for research purposes	78 years	Post CPR, Respiratory failure	patient refused consent
2		56 years	Respiratory failure	Did not send back the second copy of the invitation card
3		92 years	CVA, Post hemorrhagic shock, IHD, HTN	Patient transferred to private sector hospital.
4		82 years	CVA post cranial surgery	Refused consent.
5		63 years	Asthma, respiratory failure.	Did not send back the second copy of the invitation card.
6		33 years	RTA, Head injury	For financial reasons, patient transferred to military hospital.
7		25 years	RTA	Did not send back the second copy of the invitation card.
8		96 years	Post surgery	High ICP, patient transferred to the neuro- surgical unit.
9		53 years	Post open heart surgery	Did not send back the second copy of the invitation card.
10		37 yrs	Falling down	Sent to neuro ICU for monitoring.
11		87 years	Heart failure	Spent two days, sent to the CCU for open heart surgery.

Number of female patients who were not eligible for inclusion:

PATIENTS	NUMBER	COMMENTS
Patients who are below 18 years old	23	[13 female 20 male]. Paediatric between the age of 15 to 17 admitted to the adult ICU. Paediatrics who were very critical e.g: children who had open heart surgery.
Number of female patients who spent less that 24 hours in the ICU	46	Patients admitted to the intensive care for observation due to homodynamic instability.
Female patients who are in Coma or Brain death	6	Four in coma, one brain death, one on vegetative status.
Female patients who are unable to speak due to neurological illness,	2	Patient had RTA, affect her motor function in the brain. Patient developed CVA in the ICU and loss her ability to talk.
Female patients who had mental disorder before the hospitalization. [e.g: hallucination or delirium]	1	Patient was confused.

2- Descriptions of the patients who admitted to Hospital B during the period between [01/03/06- 30/06/06]:

TOTAL ADMISSION TO THE ICU	221 PATIENTS.	[99 FEMALE PATIENTS, 122 MALE PATIENTS INCLUDING PAEDIATRIC PATIENTS]
Number of female patients admitted to the ICU	99	Including paediatric patients.
Number of deaths in the ICU	45	[28 female, 17 male]

- Profile for female patients who met the inclusion criteria but who were not included in the study

NAMES	AGE	DIAGNOSIS	REASON FOR EXCLUSION
1	33 years	Coma, Drug overdose	Suicide attempt, family problems, patient is under the protection of the women abuse police. legal problem.
2	26 years	Falling down	Did not send back the second copy of the invitation card
3	76 years	CVA	Family transferred the patient to private sector hospital.
4	82 years	Aspiration Pneumonia	Refused consent.
5	93 years	Coma, Uncontrolled HTN.	Family problems with hospital staff transfer the patient to private sector hospital.
6	35 years	RTA, Head injury	Did not send back the second copy of the invitation card.
7	25 years	RTA, multiple trauma	Did not send back the second copy of the invitation card
8		Post CPR, Renal failure	Family problems, discharged home against medical advice.
9	36 years	Falling down, head injury	Patient is a prisoner, with two solders with her, for legal reasons unable to follow up.

Number of female patients who were not eligible for inclusion:

PATIENTS	NUMBER	COMMENTS
Patients who are below 18 years old	16	[9 female and 7 male]. Paediatric between the ages of 14 to 17 admitted to the adult ICU.
Number of female patients spent less that 24 hours in the ICU	32	Transferred to other units or to other hospitals.
Female patients who are in Coma or Brain death	3	One has Ca- brain. One confused due to head trauma [legal case]. One was in vegetative state.
Female patients who are unable to speak due to neurological illness,	4	Two had CVA and loss motor functions. One has epilepsy. One has head trauma.
Psychological problems	1	Confused, she was diagnosed with schizophrenia

The diagram of the women interviewed:

WOMEN INTERVIEWED	HOSPITAL A	HOSPITAL B
Women who admitted to the ICU	112	99
The population of women patients	42	33
Women who met the inclusion criteria	22	15
Women who consent to participate in the study	10	6
Women interviewed (1 st interview)	10	6
Women interviewed (2 nd interview)	5	6
Women interviewed (3 rd interview)	0	2
Total number of interviews in each hospital	15	14
Total number of interviews	29	

Appendix D: Samples of translation

Example1

Forward Translation:

ج: تستطيعين التخيل أن كل حياتي كنت بصحة جيدة، الشئ الوحيد الذي كنت أشكو منه هو الم في مفاصلي وبعض الضيق في صدري. ثم فجأة أجد نفسي في مكان حيث فقط الناس المرضى يوضعون فيه. هذه المرة الأولى بالنسبة لي أن أكون في غرفة العناية لمركزه، انها بيئة غريبة علي كليا، لا اعرف أي شخص هناك ولا احد من عائلتي معي ليقدم لي الدعم او ليقفل من قلتي. لقد رأيت زوجي في الخارج ولكن لم استطع ان أناديه لأنهم كانوا يضعون أنبوب في فمي، لقد كان شعور مريع، نعم. أتذكر أنني كنت أحاول للتنفس لكنني لم استطع، لقد شعرت ان الهواء يعبر إلى رئتي كل وقت لقد حاولت التنفس. لقد تمنيت لو أنني أستطيع الوصول إلى الأنبوب واسحبه من فمي ولكن كان هناك الكثير من الإبر والأسلاك في يدي وفي كل حركة افعلها اسمع الآلة تصدر صوت بجانب سريري.
ر: "اممم"، اخبريني اكثر عن شعورك حينها؟

H: [You can imagine that all my life I was in a good health, the only complains was joints pain and slight tightness in my chest. Then all of sudden I found my self in a place where only critical people are kept]-1⁷⁶.

[This is the first time for me to be in the intensive care, It is a totally strange environment to me, I do not know any body there and no one from my family with me for a support or at least to decrease my worries]-2.

[I saw my husband out side but I could not call him because they were butting a tube in my mouth, it was a horrible feeling, Yeah. I remember that I was trying to breath but I couldn't do that, I felt air blows into my lungs every time I tried to take a breath. I wished if I could reach the tube and pull it a way from my mouth but there where many lines and needles in my arms and every movement I did, I heard the machine gives alarms next to my bed]-3.

R: Could you tell me more about what happened to you during that time?-4

Back Translation:

تستطيعين التخيل أن كل حياتي كنت بصحة جيدة، الشئ الوحيد الذي كنت أشكو منه هو الم في مفاصلي وبعض الضيق في [ج: 1-
[صدري. ثم فجأة أجد نفسي في مكان حيث فقط الناس المرضى يوضعون فيه
2- هذه المرة الأولى بالنسبة لي أن أكون في غرفة العناية المركزة، إنها بيئة غريبة علي كليا، لا اعرف أي شخص هناك ولا احد من [2-
[عائلتي معي ليقدم لي الدعم أو ليقفل من قلتي
لقد رأيت زوجي في الخارج ولكن لم استطع ان أناديه لأنهم كانوا يضعون أنبوب في فمي، لقد كان شعور مريع، نعم. أتذكر أنني كنت [3-
حاول التنفس لكنني لم استطع، لقد شعرت ان الهواء يعبر إلى رئتي كل وقت لقد حاولت التنفس. لقد تمنيت لو أنني أستطيع الوصول إلى
الأنبوب واسحبه من فمي ولكن كان هناك الكثير من الإبر والأسلاك في يدي وفي كل حركة افعلها اسمع الآلة تصدر صوت بجانب
[سريري
ر: "اممم"، اخبريني اكثر عن شعورك حينها؟

⁷⁶Then translated each paragraph individually. The numbers represent the way how I divided the text into paragraphs

Continue-

شعرت كأنني إنسانه مشلولة. شعرت بالأسف على نفسي لأنه من قبل، كان الكل يعتمد علي، لقد اعتدت الاعتناء بزوجي وأبنائي. نعم. لقد كنت فعلا كالمشلولة في العناية المركزة، لقد كنت معتمدة كلياً على الآخرين، اعني الممرضات والأطباء يفعلون كل شيء لي، كل شيء، لا أستطيع التخيل كم كنت ضعيفة، لقد احتجت المساعدة في كل شيء افعله، حتى في استخدام الحمام لم أستطع التحكم. "الإجراءات" لي تبولي. لقد كنت ابلل فراشي لذا كانوا يضعون لي حفاض التبول (فوطه) ليحافظوا على جفافي وكل وقت كانت الممرضات يغيرن سرير وينظفني. لقد شعرت بالخجل والإحراج. لقد أردت فعلا انتهاء ذلك. (تصمت) ولكن لا تفهميني خطأ، كانت الممرضات با متعاونات ولطيفات، لقد حاولن جاهدا ان لا يجعلوني اشعر بأنني عبء ثقيل. لقد حاولوا حتى ان يجعلونني أساعد في تغيير فوطتي عليا بقيت سبعة عشر يوما في غرفة العناية المركزة. الممرضات فعلوا كل شيء لي وحاولوا بأفضل ما عندهم ليساعدوني على الأكل، الاستحمام والذهاب إلى الحمام

Forward translation:

H: [I felt like a paralyzed person. I felt sorry for myself because before every body depends on me, I used to take care for my husband and my kids. Yes. I was really paralyzed in the intensive care unit, I was totally dependent on others, I mean nurses and doctors do every thing for me, all the "Ejra'at". Oh, I cannot imagine how weak was I, I needed help in every thing I did, even in using the toilet I could not control my bladder]-4. [I used to wet my bed so they used incontinence nappy (pad) to keeping me dry and every time nurses wanted to change the bed and clean me. I felt so embarrassed and shay. I really wanted that to end. (Silence) But don't understand me wrongly, the nurses were very helpful and kind, they tried hard not to let me feel as a burden. They even tried to let me help in changing my nappy]-5.

[I actually stayed seventeen days in the unit. Nurses did every thing to me and they tried their best to help me with eating, bathing and toileting]-6.

Back translation:

شعرت كأنني إنسانه مشلولة. شعرت بالأسف على نفسي لأنه من قبل، كان الكل يعتمد علي، لقد اعتدت الاعتناء بزوجي [ح:4]- [أبنائي. نعم. لقد كنت فعلا كالمشلولة في العناية المركزة، لقد كنت معتمدة كلياً على الآخرين، اعني الممرضات والأطباء يفعلون كل شيء لي، كل "الإجراءات".

اه، لا أستطيع التخيل كم كنت ضعيفة، لقد احتجت المساعدة في كل شيء افعله، حتى في استخدام الحمام لم أستطع التحكم في [5]. تبولي. لقد كنت ابلل فراشي لذا كانوا يضعون لي حفاض التبول (فوطه) ليحافظوا على جفافي وكل وقت كانت الممرضات يغيرن سرير وينظفني. لقد شعرت بالخجل والإحراج. لقد أردت فعلا انتهاء ذلك. (تصمت) ولكن لا تفهميني خطأ، كانت الممرضات با متعاونات ولطيفات، لقد حاولن جاهدا ان لا يجعلوني اشعر بأنني عبء ثقيل. لقد حاولوا حتى ان يجعلونني أساعد في تغيير فوطتي

نا فعليا بقيت سبعة عشر يوما في غرفة العناية المركزة. الممرضات فعلوا كل شيء لي وحاولوا بأفضل ما عندهم ليساعدوني على [6 الأكل، الاستحمام والذهاب إلى الحمام

Example 2

Forward translation:

، لم أرى أحدا حولي. في البداية لم اعرف أين أنا، تعرفين كنت
ر: أه.. كان ذلك صعبا علي!!
بناتي يحببن ان يروني كل يوم، الممرضات سمحن لهن برويتي مره واحده، اشتقت لهن كثيرا .. سكوت .. م م !! أتذكر اني
طلبت من الطبيب ان يسمح لي بروية ابنتي الكبرى، بكت كثيرا عندما راتني ، كنت خائفة جدا من ان تتأثر من ذلك. أو ان يحصل
لها اي مكروه. كنت ارفض دائما ان ارى بناتي. أم م .. سالني زوجي عدة مرات إن كنت أريد ان أرى بناتي، ولكني رفضت..
نعم رفضت.
س: لماذا
كنت قلقه، قلقه من أن اقل المرض لهن كنت افتقدهن كثيرا، تمنيت لو أستطيع رؤيتهن!! المرض المعدي خطير، لا أريد أن اقل
لهن العدوى بمرضى، أنا أحبهن كثيرا.. أه..!! أتمنى أن تتاح لي الفرصة لأراهن، أتمنى أن أرى طفلي، أتمنى ان ارضعها،
احضنها، ولكن تعرفين؟ لن ارضعها من حليبي إلا إذا سمح لي الأطباء بذلك، فربما تصاب بالعدوى من حليبي او من الدواء الذى
أخذه. بناتي هن الآن الأهم في حياتي، يجب ان اعتنى بهن بجد ان لا اغضب منهن!!

M: [Oh!! It was difficult for me!!, I missed my daughters

My daughters like to see me every day, nurses allowed them to see me once, I missed them a lot – silence- um!]-1

[I was refusing all the time to see my daughters. Umm, my husband asked me many times if I wanted to see my daughters but I refused, yeah, I refused].-2

R: Why?]-3

[I was worried, I worried that I might transmit illness to them although I was missing them a lot and wished to see them!!, but I was worried; Infectious illness is dangerous!! I don't like them to be infected by my illness, I like them very much].-4

[Umm, the doctor and nurses told me that there is no danger of getting the illness transmitted to them, oh, I couldn't. I couldn't tolerate to see my daughters suffering. It is the mother's feeling; I had a very hard time; the time I had in the ICU. It was very difficult, full of pains. I used to look at my arms full of blue area, needles every where].-5

[Oh!! If only I had the chance to see them, I wish I could see my baby, the youngest poor baby, I wish I could feed her, hug her, uh!! I miss her too much. But you know? I won't feed her with my milk unless doctors allowed me to, perhaps she might be infected by my milk or by the medicine I take!! My daughters are now the most important in my life, I should take care of them. I shouldn't be angry with them!!].-6

Back translation:

لم أرى أحدا حولي. في البداية لم اعرف أين أنا، تعرفين ICفتحت عيناى فى مكان غريب جدا، لم اكن ابدا فى العنايه المركزه [1]
كنت [2] !!
بناتي يحببن ان يروني كل يوم، الممرضات سمحن لهن برويتي مره واحده، اشتقت لهن كثيرا سكوت [3].
[4] م م !! أتذكر اني طلبت من الطبيب ان يسمح لي بروية ابنتي الكبرى، بكت كثيرا عندما راتني ،كنت خائفة جدا من ان تتأثر من ذلك. أو ان يحصل لها اي مكروه. كنت ارفض دائما ان ارى بناتي. أم م [5]
[5] سالني زوجي عدة مرات إن كنت أريد ان أرى بناتي، ولكني رفضت.. نعم رفضت.
كنت قلقه، قلقه من أن اقل المرض لهن كنت افتقدهن كثيرا، تمنيت لو أستطيع رؤيتهن!! المرض المعدي خطير، لا أريد أن اقل لهن
العدوى بمرضى، أنا أحبهن كثيرا.. أه..!! أتمنى أن تتاح لي الفرصة لأراهن، أتمنى أن أرى طفلي، أتمنى ان ارضعها، احضنها،
ولكن تعرفين؟ لن ارضعها من حليبي إلا إذا سمح لي الأطباء بذلك، فربما تصاب بالعدوى من حليبي او من الدواء الذى أخذه. بناتي
[6] هن الآن الأهم في حياتي، يجب ان اعتنى بهن بجد ان لا اغضب منهن!!

Appendix D

All themes in the study [preliminary analysis]

- ◆ Afraid to re-visit the hospital
- ◆ Alarm [physical pain].
- ◆ Alhamdulillah [thanks Allah]
- ◆ Alhamdulillah [thanks God] I pass it [the critical time in the ICU].
- ◆ All neighbours did 'talleh'
- ◆ Allah won't let me be alone
- ◆ angels- very kind nurses
- ◆ Bad dreams at night- recall events in the ICU.
- ◆ Became self- dependent.
- ◆ becoming stronger
- ◆ Being a mother-difficult.
- ◆ being with safe hands [nurses].
- ◆ bodily changes
- ◆ Body cannot carry me any more
- ◆ Body is too weak
- ◆ cannot concentrate after illness
- ◆ Cannot describe the time.
- ◆ Cannot eat
- ◆ Cannot live without drinking coffee- change of diet regimen
- ◆ Cannot live without her children
- ◆ Cannot live without machines
- ◆ Cannot move my body
- ◆ cannot see the light [dab experiences]
- ◆ Care for children
- ◆ Care for others
- ◆ Children need a lot of care
- ◆ Children's responsibility- difficult.
- ◆ Costs of medicine, expensive.
- ◆ Dealing with symptoms
- ◆ Depend on myself
- ◆ Dependent on herself
- ◆ Dependent on nurses
- ◆ Difficult to help them- crying
- ◆ Difficulty sleeping- pain at night
- ◆ do not know future
- ◆ Do not want to remember.
- ◆ Do the Omreh as soon as possible
- ◆ Doctor shopping
- ◆ Eat less fat and fibres- change of diet
- ◆ Eat to fill my hunger
- ◆ Exposed in front of men
- ◆ Facing new challenges
- ◆ Facing things together
- ◆ Family assistance in caring Short gown
- ◆ Family cheers me up
- ◆ Fast Sudden Events.
- ◆ Fear and uncertainty
- ◆ Feel very weak, not like before (her illness).
- ◆ Feeling "Aster"
- ◆ Feeling exposed
- ◆ feeling in pain
- ◆ Feeling naked Uncovered all the time
- ◆ Feeling weakness in hands

- ◆ Felt a burden on her daughter
- ◆ Felt frustrated May be it (illness) will come again- fear
- ◆ Financial hardship
- ◆ Full of pain(s)
- ◆ full of tubes
- ◆ Full of tubes and lines
- ◆ gaining the strength
- ◆ Having the right to know
- ◆ Help the children all her life
- ◆ Horrible pain
- ◆ I am under Allah's will
- ◆ I cannot guess what will happen
- ◆ I get my life again.
- ◆ I have 'hathayan' there...
- ◆ I may pass away at any time.
- ◆ ICU full of machines
- ◆ ICU is a place of death
- ◆ Khalas- it over
- ◆ Life is blessed - with family
- ◆ Life is with family
- ◆ Live on the first floor- cannot move up stairs.
- ◆ Lived with mother-in-law for short period
- ◆ Living as different person
- ◆ living at risk
- ◆ Looking after the children in future
- ◆ looking back to illness- survive
- ◆ Looking forward to studying at university
- ◆ loss of my family
- ◆ Loss of the ability to talk
- ◆ Lost her self, no concentration.
- ◆ Machines do everything.
- ◆ machines every where
- ◆ Machines everywhere.
- ◆ making new friends
- ◆ Male cannot touch the body
- ◆ Male nurses providing care
- ◆ Men and women in the same unit
- ◆ Miss the children
- ◆ Miss the family member
- ◆ Miss the husband
- ◆ Most difficult time in life
- ◆ Moved close to family
- ◆ Moved the bed- at home
- ◆ My body hurts
- ◆ My Body Hurts.
- ◆ My body is so weak
- ◆ My life comes to me a gain [with the family]
- ◆ My life totally changed [at home]
- ◆ My pain was 'Nafsi'
- ◆ Nail digging in my leg
- ◆ Need to chat with friends
- ◆ Neighbours' shared her worries
- ◆ No appetite
- ◆ no body heard me.
- ◆ No body know what was wrong with her.
- ◆ No more fluids- fluid restrictions
- ◆ No more money.
- ◆ No privacy

- ◆ Nobody cares
- ◆ Nobody to talk with
- ◆ not know the time
- ◆ Nurses are caring
- ◆ Nurses are too busy to talk
- ◆ nurses wants reda Allah
- ◆ People there [in the ICU] are near to death.
- ◆ personal changes
- ◆ Pray to Allah – to thank him [at home]
- ◆ Praying to Allah My legs cannot carry me any more
- ◆ Preferring female nurses
- ◆ Protect my body
- ◆ Putting the clock close to bed
- ◆ Rearrange the house
- ◆ Red marks all over my body
- ◆ Relatives did 'talleh'
- ◆ Religion support
- ◆ restore family relationship
- ◆ Scared of death Allah helps the young men dying.
- ◆ scary all the time
- ◆ See children before, dying.
- ◆ Sense of release.
- ◆ Sharing feelings- with neighbours
- ◆ Sisters help all the time
- ◆ Started to pray- after illness
- ◆ suffering- no help [nurses]
- ◆ taking on a nee role
- ◆ Talked to her neighbours about her difficult time.
- ◆ Thank Allah for every thing
- ◆ Thank Allah, if I was still alive.
- ◆ Thanks Allah, that I am still alive.
- ◆ The illness is over
- ◆ Tiredness
- ◆ Trapped by physical changes
- ◆ Trying to hold the family together
- ◆ uncertainty
- ◆ Unfamiliar environment.
- ◆ Visiting Mecca Going for Mecca to do Omreh
- ◆ Wants to see her children grow up.
- ◆ Where I am loss of body control
- ◆ Woke up during the night- remember the ICU

Appendix E: Poster

Women's Experiences of Bodily Care in the Intensive Care Unit (ICU)



The University of
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Study Aim

This paper describes Jordanian Muslim women's experiences of their bodies during critical illness.



Background

- Body work involves touching, manipulating and assessing the bodies of self or others (Twigg 2006, P137).
- Nurses' care is basically concerned with body work (Lawler 1991).
- Stories are one way of accessing the lived experience and embodiment of illness (Kleinman 1988; Frank 1995).
- A small number of existing studies shed light on the importance of bodywork in patients' experiences in intensive care (Johansson and Fjellman-Wiklund 2005; Karami 1979).

Methodology and Methods

- Longitudinal narrative study.
- Ethical approval was gained from two hospitals in Jordan.
- Sixteen women agreed to participate and signed consent form.
- Two to three in-depth interviews carried out with each woman.
- Narrative analysis applied.
- Data was translated from Arabic into English, then back into Arabic.

The findings

The concept 'Bodywork' was used as a framework to explore women's experiences in the ICU. Analysis showed that 'bodywork' comprised four sub-concepts:

- **The dependent body.**
- **The social body.**
- **The mechanical body.**
- **The cultural body.**

The dependent body

- The women lost control over their bodies and felt paralysed and shocked.
- The women felt shame and stigma when nurses helped them with their basic needs.

I was really paralyzed in the intensive care unit. Oh, I cannot imagine how weak was I, I needed help in every thing, even in using the toilet. I could not control my bladder. I used to wet my bed so they used incontinence pad to keep me dry, and every time nurses wanted to change the bed and clean me. I felt so embarrassed and shy. I really wanted that to end (woman 1, first interview).

The mechanical body

- The women considered the ICU machines as vital to survive but they were also a source of stress and discomfort.
- Some women trusted the ICU machines more than their own bodies.

I was very scared; machines controlled my body, every thing was working by machines. I felt that I could not get out of these machines (Woman14, second interview).

The social body

- The women felt loneliness and strangeness in the ICU.
- Their family provided psychological and emotional support.

It is a totally strange environment. I do not know any body there, and no one from my family with me for a support or at least to decrease my worries (woman2, first interview).

The cultural body

- The women preferred to receive care from female nurses.
- Men were not allowed to touch the women's body or do bathing.
- The women felt exposed when they had to wear the ICU gown.

I was without clothes dear, I mean that thin gown was very short, and I couldn't cover my body, I felt shamed from myself because I never been in that way [with the gown] ...It is the culture my dear, we need to cover our body, I couldn't imagine that my children would look at me with that bad gown. I couldn't remove my scarf, I need to put on the blanket all the time to hide myself in front of my children and my visitors, it was difficult to be like this all the time. (woman 13, second interview).

Discussion and Conclusions

- For Jordanian women, loss of body control was linked to feelings of shame and stigma.
- Family support was crucial for critically ill women.
- Jordanian women preferred to receive care from female nurses.
- Nurses' gender should be taken into consideration when providing care for Muslim women in the ICU.
- Cultural needs are a crucial aspect to be taken into consideration when planning the care for critically ill women.

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