Exploring the experience of communication in the care of children with palliative care needs: the perspectives of nurses, family carers and physicians in Jordan

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ABSTRACT

Background: Despite having limited access to specialist palliative care, countries can successfully satisfy palliative care needs by ensuring all health professionals are properly trained and educated in their respective roles. Effective communication is a fundamental element in ensuring the quality of care provided to children with palliative care needs and has a considerable effect on the well-being of children as well as their relatives and care professionals. Nonetheless, a broad overview of the existing literature reveals that nurses often feel inadequately trained or prepared in terms of the communication skills needed to deal with the difficult situations. They often lack the confidence to communicate properly with parents or to deal with difficult questions or issues of conflict. Whilst this seems to echo studies previously conducted across a range of countries worldwide, research shows that countries with an Arab culture face slightly different issues in terms of disclosing serious prognoses to families. The current study is the first to examine communication between children, parents, and health professionals, in the care of children with non-malignant life-threatening and life-limiting illnesses in Jordan, and in particular the cultural and spiritual context that affects this communication.

Purpose: The purpose of the current study is to explore the experience of communication in the care of children with palliative care needs, from the perspective of physicians, nurses, and mothers in Jordan.

Methods: this study employed a collective qualitative case study approach. It was conducted in three paediatric units in a Jordanian hospital. Each case comprised a child aged 1-12 years, their most involved family carer (mothers), physician(s) and nurse(s). Two data collection methods were employed: participant observation and semi-structured interviews with three categories of participants: mothers, physicians, and the nurses who cared for the children that participated in this study.

Findings: the study was based on 15 cases, with a total of 197 observational hours and 60 interviews (conducted with 15 mothers, 12 physicians and 21 nurses). The findings indicate that a protective approach was taken by the study participants as they communicated together regarding their children's care. The children attempted to shelter their parents from distress by not disclosing any anxiety or fear they were experiencing and parents similarly protected their children by not providing them with the all the details of their condition. In addition, parents avoided any situations where illness might be mentioned. Professional boundaries were adhered to by nurses as they cared for children and their families to avoid becoming emotionally involved. The nurses concentrated on routine care tasks as opposed to providing emotional support to children in order to avoid the significant emotional distress associated with the inevitable passing of the child. Doctors behaved similarly and avoided discussing death or other bad news with children to protect the well-being of children and families as well their own.

Conclusion: These findings have implications. In the first instance, investigating the reasoning behind parents' decisions to talk (or not) to their children about the details of their illnesses is a substantial issue. The findings of the current study indicate that while open and honest communication between parents and children is crucial, not all mothers agree with open communication about death with their children. Therefore, any future intervention planned for them should respect their autonomy and decisions. However, the role of health professionals could be significant, especially increasing the parents' awareness of their children's protective approach and its consequences on their mental and psychological health could be one of the most important interventions to improve mutual communication between parents and children.

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CONFERENCE PRESENTATIONS FROM THIS STUDY

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LIST OF ACRONYMS

ALL	Acute lymphoblastic leukaemia
JPCI	Jordan Palliative Care Initiatives
CP	Cerebral Palsy
CBC	Children Palliative Care
EOL	End of Life
ESRD	End Stage Renal Disease
INCB	International Narcotics Control Board
ICD	Impaired Cognitive Development
ICPCN	International Children Palliative Care Network
KAUH	King Abdullah University Hospital
KHCC	King Hussien Cancer Center
MOH	Ministery of Health
NICU	Neonatal Intensive Care Unit
NLTIs	Neurodegenerative Life-Threatening Illnesses
NS	Nephrotic Syndrome
PICU	Paediatric Intensive Care Unit
PRH	Prince Rahma Hospital
RMS	Royal Medical Services
RN	Registered Nurse
SCBU	Special Care Baby Unit
TOF	Tetralogy of Fallot
WHO	World Health Organisation

CHAPTER 1: BACKGROUND

1.1. Personal reflection

It was during my work as a nurse in a paediatric unit in a Jordanian hospital and as a lecturer on a paediatric clinical course for nurses across different hospitals that I developed an interest in the subject of children’s palliative care. I gained great insights into the experiences of those living and working with these illnesses by working so closely with them.

It is unfortunately the case in Jordan that palliative care is concentrated on children with cancer, to the detriment of those with other life-threatening or life-limiting illnesses, who receive no specialised care. Thus, children with conditions such as CP, ESRD and myelomeningocele are treated in medical wards or PICU, neither of which have palliative care programs. Their placement in these wards also means that the nurses assigned to them are overworked, and prioritise biomedical tasks in line with the hospital policy which seems to encourage professionals to focus on undertaking physical tasks more than emotional ones by limiting the accountability to the documentation of completed physical tasks. Moreover, they have neither the time nor the training to provide emotional support to children with these conditions and their families, who are therefore deprived of the psychological, emotional, and even spiritual support that they so desperately need. Furthermore, there is no bereavement care available, meaning it is far less likely that parents will manage to cope after the death of their child.

Another issue worth noting is the separation that usually happens between the parents and the health professionals after the death of the child. In the absence of bereavement care, parents often feel a double loss following the death of their child; not only have they lost a child but also the close ties that inevitably developed with that child’s healthcare professionals and the treating hospital. Some parents want to have contact with the health care professionals who were responsible for their children after their death (D'Agostino et al., 2008; Meert et al., 2007)

In summary, Staff need to become aware and competent in palliative care principles and key skills, even if they are never going to be specialists. Having already noted the emphasis placed on care for cancer patients in Jordan, this study will concentrate on palliative care for children with other life-limiting conditions.

1.2. Glossary of Terms

Below is a glossary of the key terms used in this thesis, set out so as to clarify their meaning within the context of this study.

1.2.1. Palliative care

- The World Health Organization defines palliative care as:

> ‘‘an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual’’ (World Health Organization, 2002).

1.2.2. General versus specialist palliative care

A distinction must be made between general palliative care and specialist palliative care. The former is delivered by primary care professionals and specialists, like oncologists for example, who have acquired a range of basic palliative care skills and expertise for caring for patients with life-threatening or life-limiting diseases (The European Association for Palliative Care, 2009). While these people do not offer palliative care in their fields, they must still be adequately trained in this area (Council of Europe, 2003). The present study concentrates on the general palliative care approach that is required by all health care professionals who provide care for children with palliative care needs. This refers to healthcare professionals that do not work in the field of palliative care specifically but are still required to be trained and knowledgeable in this area.

Nonetheless, some patients may have life threatening conditions that necessitate the need for an advanced specialist palliative care team (Clinical Standards Board for Scotland, 2002). In such cases, the palliative care team includes those whose work focuses primarily on the delivery of palliative care (The European Association for Palliative Care, 2009; Craig et al., 2007). As such, these healthcare professionals require a more detailed level of training and knowledge to satisfy the more complex needs of patients (Council of Europe, 2003).

1.2.3. Children

One of this study's principal data sources is the observation of communications between children, their parents, and health professionals. Obviously, it is difficult to assess the nature of communication between infants and their parents. Additionally, communications between adolescents and their parents can be different from other children's age groups. On this basis, adolescent groups (12-18 years old) and infants (less than 1 year old) have been excluded from the study. Thus, as supported by Young (2013), any reference to children is limited to those between 1 and 12 years old. These can be separated into three categories: toddler (1-3 years), pre-school (3-5 years), and school-age children (6-12 years).

1.2.4. Life-limiting illness

Life- limiting illness is defined as "a condition where premature death is usual, for example, Duchenne muscular dystrophy" (Craig et al., 2007: 2).

1.2.5. Life-threatening illness

Life-threatening illness is "one where there is a high probability of premature death due to severe illness, but there is also a chance of long-term survival to adulthood. For example, children receiving cancer treatment or admitted to intensive care after an acute injury " (Craig et al., 2007: 2).

1.2.6. WHO definition of palliative care for children

- Palliative care for children is:

> "The active total care of the child's body, mind and spirit, and also involves giving support to the family. It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease" (World Health Organisation, 1998:8) .

1.2.7. Conditions eligible for paediatric palliative care

- "Category 1: Life-threatening conditions for which curative treatment may be feasible but can fail. Where access to palliative care services may be necessary when treatment fails or during an acute crisis, irrespective of the duration of that threat to life. On reaching long term remission or following successful curative treatment there is no longer a need for palliative care services. For example: cancer, irreversible organ failures of heart, liver, kidney;

- *Category 2:* Conditions where premature death is inevitable, where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities. Examples: Cystic Fibrosis, Duchenne Muscular Dystrophy;

- *Category 3:* Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years. examples: Batten disease, Mucopolysaccharidoses;

- *Category 4:* Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death. Examples: severe cerebral palsy, multiple disabilities e.g. following brain or spinal cord injury, complex health care needs, and a high risk of an unpredictable life-threatening event or episode" (ACT, 2009:8).

1.2.8. End of life

"End-of-life care may be used synonymously with palliative care or hospice care, with end of life understood as an extended period of one to two years during which the patient/family and health professionals become aware of the life-limiting nature of their illness" (The European Association for Palliative Care, 2009: 282).

1.2.9. Interpersonal communication [1]

"A cyclic, reciprocal, interactive and dynamic process with value, cultural, and cognitive variables that influence its transmission and reception" (Arnold and Boggs, 2013:13). In the current study communication includes the interaction

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[1] See Section 2.2. for further details

between the children and healthcare professionals, but also to the interaction between children and their relatives as well as the interaction between different healthcare professionals involved in the care (The European Association for Palliative Care, 2009).

1.3. Significance of the study

The promotion of the patient’s physical and psychological well-being when their condition is non-responsive to curative treatment is one of the key objectives of palliative care (Wallace, 2001). The manner in which palliative care principles and processes are combined is referred to as the palliative care approach and this includes all procedures undertaken in both specialised and non-specialised palliative care settings (The European Association for Palliative Care, 2009). Thus, knowledge of palliative care principles is a necessity for anyone operating in non-specialised palliative care units as they all play a role in the delivery of palliative care (Council of Europe, 2003).

Effective communication between care givers, patients and their families is perhaps one of the most crucial of all the practices involved the delivery of high quality palliative care (Citak et al., 2013; The European Association for Palliative Care, 2009). Patients should be invited to participate actively in the communication process as this has been shown to enhance the quality of patient care (Sowden et al., 2001; National Institute for Health and Clinical Excellence, 2004). According to Citak et al. (2013), nurses have the power to determine the emotional needs of patients and their families and can enhance their well-being by communicating openly and effectively. The attitude of health care professionals and the manner in which they interact with patients and families can be enhanced through communication training, which may also increase their confidence when delivering particularly difficult information regarding the diagnosis or prognosis of the patient (National Institute for Health and Clinical Excellence, 2004). As such, resources to improve the quality of communication are required (Council of Europe, 2003). These resources can include appropriate training programmes, allocated time for communicating with families and healthcare teams and access to the most advanced information technology systems.

Nonetheless, many nurses who work with children suffering from life-threatening conditions feel anxious when communicating with patients, parents and other health care providers. The findings of several studies revealed that the most common challenge encountered by nurses who work with children with palliative care needs was communication with children and their families (Amery et al., 2010; Chen et al., 2013; Contro et al., 2004; Lee and Dupree, 2008; Papadatou and Bellali, 2002; Papadatou et al., 2001; Yam et al., 2001; Peng et al., 2013; Tubbs-Cooley et al., 2011). The nurses reported being poorly prepared to communicate with children with palliative care needs and their families, feeling inadequately prepared to provide support to families facing loss, and lacking the confidence to deal with difficult questions and conflict. Furthermore, several studies indicate that nurses would like to receive further communication training in order to learn how to communicate with families in delicate or critical situations, such as discussing the "Do not resuscitate" status of the patient or delivering news that the patient has died (Citak et al., 2013; Papadatou and Bellali, 2002; Papadatou et al., 2001; Yam et al., 2001).

Additionally, communication is significantly affected by culture; therefore, applying children palliative care principles across the board internationally may be difficult when what is acceptable in one culture is absolutely rejected by another. For example, the Japanese, Chinese, and Greeks have been shown to adopt a more protective approach than other cultures when it comes to the discussion of serious diagnoses with their children (Kato et al., 2004; Martinson et al., 1994; Papadatou et al., 1996; Sagara and Pickett, 1998). In particular, the Chinese leave children out of decision making, and tend not to share sad or negative news with them or with others. Although Faulkner (1997) points to the plethora of studies that advise how best to disclose bad news to parents and families, additional studies should be undertaken to determine how communication preferences are affected by culture and nationality.

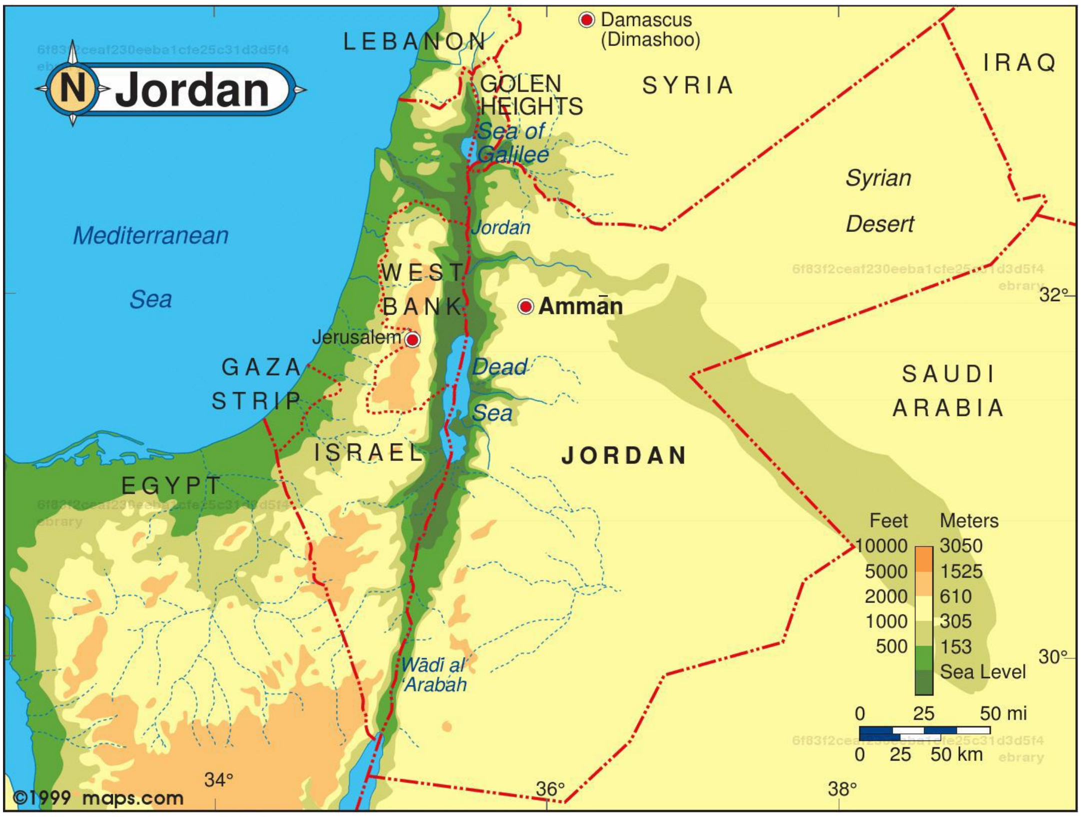
A further issue requiring attention is the awareness and understanding of death on the part of the children needing palliative care. However, it is important to be aware that not all children with palliative care needs will be dying as such. Indeed, the need for palliative exists even for those who suffer from life-threatening diseases in which the children could survive with no morbidity. The important factor is whether children and their families are forced to experience the possibility of death – that is what triggers the need for this care (Thompson, 2015). This was identified in the Delphi study conducted by the International Children's Palliative Care Network (ICPCN) in over 50 countries worldwide as being a top research priority (Downing et al., 2015). This issue recurs frequently throughout my research and was analysed closely. An awareness and appreciation of death is considered to be a milestone of successful communication with children. Indeed, communication with children has been defined and expressed in relation to this very issue, as addressed in Section 5.2.1. The importance of this is reinforced by the fact that the openness of communication between parents and children about death is often dictated by the parents' own impression of their child's level of awareness.

This study is not only significant because it is the first to investigate communication with child patients in Jordan who have non-malignant life-threatening and life-limiting illnesses, but because it will also analyse the cultural and spiritual context within which this communication occurs. It is hoped that the findings of this research will provide the empirical evidence needed to improve clinical practice, education, and further research into children palliative care. Moreover, in order to gain a holistic account of the experience of communication, I explored it from the perspective of the parents, physicians, and nurses.

1.4. The Jordanian context

Jordan is an Arab country located in the Middle East. It occupies an area of 89,000 km² (The world Factbook, 2012) with an estimated population of 7.93 million (United Nations, 2016) (Figure 1). Cancer is the second cause of death among the Jordanian population after cardiovascular diseases (Ministry of Health, 2012). Seventy percent of newly-diagnosed cases present late to the health care system, with the result that most patients die within one year of their diagnosis, thereby increasing the need for palliative care services in Jordan (Stjernsward et al., 2007; Silbermann et al., 2012).

Palliative care requirements have driven the King Hussein Cancer Centre (KHCC) to create a comprehensive palliative care programme designed for healthcare providers and patients (Shamieh and Hui, 2015). Based in Jordan, the KHCC is the biggest cancer centre in the country and provides care to at least half of all Jordanian cancer patients (Shamieh and Hui, 2015). Patients at the KHCC qualify for palliative care services if and when required and the facility now offers the most cohesive palliative care programme in the country, providing patients with the best possible care in light of their unique health status, values and treatment preferences (Silbermann et al., 2012).



Hypsometric Map Asia Jordan. Santa Barbara, US: Maps.com, 1999. ProQuest ebrary. Web. 17 November 2016.

Figure 1: Map of Jordan

Source: (Maps.com, 1999)

In 2001, the Jordan Palliative Care Initiatives (JPCI) model of palliative care for the Middle East was initiated in Jordan with the collaboration of multiple stakeholders, such as Jordan Ministry of Health (MOH), WHO Jordan, WHO Collaborating Centre for Palliative Care in Oxford, and the King Hussein Cancer Center (KHCC) (Stjernsward et al., 2007; Bingley and Clark, 2009). Since the initiation of this model, several improvements have been achieved in terms of providing high-quality palliative care (see Table 1).

One of the most important improvements to palliative care in Jordan is the gradual increase of morphine prescriptions, which significantly improve pain and symptom management (Stjernsward et al., 2007). This was achieved by overcoming barriers to opioid administration, such as fear of addiction among patients and health workers. Furthermore, medical palliative care education was developed and implemented to reduce the effect of "opioid phobia", representing a successful deployment of evidence-based practice (EBP) by Jordanian advanced nursing practitioners (Bingley and Clark, 2009; Stjernsward et al., 2007). Currently, specialist palliative care services are mainly provided by three organisations: KHCC, Al-Malath Foundation for Humanistic Care, and Al-Basheer Hospital (Silbermann et al., 2012).

Table 1: Major outcomes of JPCI on the WHO public health strategy

Adapted from (Stjernsward et al., 2007)

Category	Major intermediate and long-term outcomes
Policy	There are significant efforts to persuade policy makers to incorporate the palliative care project into the Jordan National Cancer Control Plan and other policies of MOH.
Drug availability	Before 2004, oncologists could only prescribe a three-day dose of an opioid. This has increased to ten-day prescriptions since 2004. Before 2004, the opioid importation quota was 2 kg/year. By 2004, it was increased to 7 kg/year. 10 mg intermediate-release morphine tablets are now made in Amman.
Education	Palliative care is included in the curriculum of undergraduate nursing students (Bingley and Clark, 2009) Master's degrees in palliative care are now offered by Jordan University.
Implementation	Approximately 30 patients per year received palliative care in the Al-Malath foundation in 2003. This number increased to 800 patients per year by 2006. KHCC admits 400 patients per year for palliative care, 60-80 per month, of whom 30-40 receive home care. Opioid consumption increased in KHCC from 2.5 kg in 2005 to 5 kg in 2006.

However, the government does not direct any funds or support towards palliative care and the aforementioned phenomenon of ‘opioid phobia’ continues to prevail to a certain extent amongst healthcare professionals and the public (Al Khalaileh and Al Qadire, 2012; Al Qadire and Al Khalaileh, 2014; Omran et al., 2014). As a result, politicians, professionals, and other public servants, all of whom are in a position to influence palliative care policy, lack the necessary understanding and awareness to make a positive impact (Bingley and Clark, 2009). Jordanians are thus deprived of palliative care services, as few organisations offer them, and the emphasis remains on acute, curative care. Abdel-Razeq et al. (2015) state that this has led to negative attitudes towards care for seriously-ill patients.

In Jordan, no hospitals specialise in the provision of paediatric palliative care (Al- Rimawi, 2012). However, the KHCC founded a multidisciplinary paediatric palliative care programme in 2005 (Silbermann et al., 2012). This programme is delivered by a team of specialists from different fields, including a paediatric oncology consultant, general paediatrician, a nurse coordinator, a social worker, a psychologist and a pharmacist. This team offers palliative care services round the clock to children who are admitted to hospital. However, Silbermann et al. (2012) emphasise that palliative home care service is not currently provided.

1.5. Thesis structure

This thesis consists of nine chapters. Chapter One is introductory, and gives a short summary of the research background, including a personal reflection. Current literature on communication in paediatric palliative care is examined in Chapter Two, which is divided into several parts. The first of these addresses the definition of communication within the context of nursing and palliative care by current literature on the topic. The second section discusses the study's theoretical context, and the following section introduces issues related to the discussion of death and other sensitive issues with children, together with an analysis of the exchange of information between parents and health professionals. The final part examines the challenges to effective communication identified by the study participants. On a more general level, this section allows identification of the research gaps that informed this study's objectives.

The methods and methodology of the current study are set out in Chapter Three, including an explanation of the reasoning behind the choice of methodology and a description of the study design. This chapter specifically addresses the choice of a collective qualitative case study. Details are presented concerning the research process (study setting, recruitment of participants, sampling strategy, and research methods) and the study participants themselves. The chapter also describes in detail how data were obtained, managed, and analysed, and includes a discussion of the ethical principles involved in the data collection, as well as the ways in which the rigour of the study was improved. In that respect, it was also imperative that this chapter included an acknowledgement of my own bias in terms of social background and personal assumptions made prior to embarking on the research.

Chapter Four introduces the cases presented in the study. It provides individual case profiles within their contexts, and details that will help to view each case according to its particular merits while remaining true to the case-study approach. The profiles are provided alongside a visual presentation of every case, which includes some contextual details related to the children's illnesses, such as the age of diagnosis and the type of health professionals mostly involved in their care. Each profile also outlines the family structure, depicting the composition of the families and the type of family carers. This provides further contextual information, which contributes to further understanding of each case background. It also prepares the ground for the fuller presentation of the main qualitative findings in the subsequent three chapters (Five to Seven).

Chapter Five illustrates how mutual protection dominates interactions between children, families, and health professionals. In addition, it illustrates the issues that maintain this protection, as well as its consequences for children, parents, and professionals. Several examples of real-life situations are given, which comprehensively highlight the different aspects of protection.

Chapter Six examines how a number of stances were taken by mothers according to the circumstances they had to deal with during the ordeal of their children's illness. The mothers sought to compassionately support their children, particularly when they were going through painful invasive procedures, and also for the various psychological consequences of their illnesses. The mothers also portrayed themselves as having to display additional assertiveness in the hope of helping their children to fight their illness, if they experienced tiredness and exhaustion. The capability to embody various communication roles with their children was not uniform for all of the women, however. A number of elements influenced their capability to manage their methods of communication with health practitioners and their children. The precise roles embodied by the mothers were circumstantial, subject to their perception of the appropriate role required for them to play in order to facilitate communication between themselves and the experts, or their children.

Challenges and obstacles to effective communication between mothers, children, and healthcare professionals are discussed in Chapter Seven, in terms of the participants' own perceptions of these problems. Difficulties in communicating meaningfully with hospital staff was a common problem encountered by mothers, followed by the struggle to provide the best possible care for their children under extremely stressful circumstances. The challenges faced by healthcare professionals in engaging with the parents and children are also considered in this chapter.

In Chapter Eight, the study findings are analysed in the context of the relevant literature and theories. The chapter comprises several parts, the first of which reviews the degree of protection adopted by the study participants and the means through which this level of protection is maintained. This is followed by a discussion of the preservation of hope by the mothers in the face of the continuous deterioration of their children's health. The chapter also looks at the level of parental participation in the treatment decision-making process, and finally examines what the study participants identified as the main difficulties in maintaining effective communication.

The final chapter concludes the study by summarising its principle findings as well as its contribution to the knowledge on paediatric palliative care. The first part of this chapter identifies the key contributions of the research, followed by an overview of the implications of the research findings for clinical practice, education, and future research. The final section acknowledges both the weaknesses and strengths of the research.

CHAPTER 2: LITERATURE REVIEW

2.1. Introduction

This chapter reviews the existing research into the experiences of communication among parents and health professionals in the care of children with palliative care needs. It also identifies any gaps in the literature to justify the current study. This review can be divided into several sections. The first section introduces several definitions of communication to show how it is conceptualised within the context of this study. This is followed by the theoretical context upon which this study is located and discussed. A systematic review, which appraises studies conducted in this area in order to identify any relevant gaps in the literature and so justify this research study is detailed in the following section. Several key themes emerge from the review, such as parental experiences of communication with children about illness and impending death. This theme also clarifies the effect of culture on the amount of information families prefer to share with their children about the incurable nature of their disease. The manner of exchanging information between parents and health professionals is also described and analysed in the following theme. The final theme explains the challenges to effective communication as families and professionals perceive them. The chapter concludes by uncovering the gaps in the literature from which the research aims and questions have emerged.

2.2. Conceptual issues in communication in nursing

Arnold and Boggs (2013) define interpersonal communication as "A cyclic, reciprocal, interactive and dynamic process with value, cultural, and cognitive variables that influence its transmission and reception" (p.13). The fundamental components in an act of communication are sender, recipient, message, and context. Signals are transmitted and received by people (Hollinger and Buschmann, 1993), then encoded and decoded (e.g. written and read) in order to be understood (Davies, 1994). According to the previous definition, interpersonal communication comprises of the relationship dimension, which is non-verbal communication, and the content dimension, which is made up of the verbal communication. As we know, non-verbal communication is used to clarify and amplify verbal messages.

Many researchers argue that nursing communication is not merely the transmission of information messages, but that it also includes the transmission of feelings and emotions, as well as recognition of the feelings and emotions of patients and their families (Beale et al., 2005; Levetown, 2008; Nielson, 2012). The importance of interaction and communication has been recognised since the inception of nursing science (e.g. Florence Nightingale in the nineteenth century), and it is increasingly acknowledged by nursing researchers today (Fleischer et al., 2009). Since nurses spend the most time with patients and their relatives, the duty of communicating effectively inevitably falls on their shoulders in the first instance. Palliative care for children is an emotional area, and it affects not only the patients and their families, but also the nursing staff involved.

Interaction and communication are two terms widely used synonymously in the literature without clarification or distinction of the specific differences between them (Fleischer et al., 2009). It has been stated that communication is a special subtype of interaction (Hansebo and Kihlgren, 2002), although some researchers defined interaction as observable behaviour during communication (Oliver and Redfern, 1991). Usher and Monkley (2001) describe communication as a tool which can be used in order to promote interaction. Fleischer et al. (2009) conclude in their systematic review study that the differentiation between these two concepts seems to be a theoretical issue, and they are in fact difficult to describe or define without reference to each other.

Communication is a key component in the field of palliative care. The term is often associated with specific tasks centred on the biomedical concern for the patient’s journey such as breaking bad news or obtaining informed consent, rather than an exploration of psychosocial or emotional issues (Goldman et al., 2006). However, nurses’ communication roles in palliative care extend from being supportive to physicians during certain tasks such as breaking bad news to communicating effectively and compassionately with patients and their families throughout the whole progression of the disease (Wittenberg-Lyles et al., 2013). The area of palliative care for children is emotionally distressing for patients, relatives, and health care providers. Therefore, the emphasis should be on all aspects of communication, such as the child's understanding of illness and death, the type of information given to the child about their illness or prognosis, whether they are able to express their worries and anxieties, and whether the child and family are able to communicate openly about these issues (Gaab et al., 2013a; Van Der Geest et al., 2015a).

It has been found that two communication behaviours adopted by nurses are crucial to enduring patients' needs are fully met. (Kruijver et al., 2000). These are: instrumental behaviours, which are important to inform patients about their disease and treatment, and affective behaviours, such as providing comfort and trust and showing respect for patients. Both behaviours are essential for the achievement of patient-focused communication. Affective behaviour was found to be important for both the quality of nursing care and for patient satisfaction (Attree, 2001; Bensing, 1991). The present study will focus on both communication behaviours as being integral to patient-focused communication rather than task-focused communication.

To conclude, communication in nursing is a broad concept that extends from the verbal and nonverbal transmission of messages to include a humanistic care approach. The context of children's palliative care is a health situation that requires more attention to be paid to the emotional aspects of care, anxiety relief, expression of feelings, and active listening, in addition to the type and content of the information provided about the disease and prognosis. Therefore, Arnold and Boggs (2013) definition of communication is appropriate for the objectives of the present study.

2.3. Theoretical context of the study

The purpose of this section is to explain the theoretical context upon which this study is based. There are several theories and models that explain communication, interactions, and relationships in the hospital context, such as Peplau's theory of interpersonal relations (1997), Roy's adaptation model (1970), Watson's theory of human caring (1997), and King's theory of goal attainment (1992). Although any of these theories could work as a theoretical guide for the research process, they are not optimally sensitive to the context of palliative care, which features unique, sensitive, contexts concerning highly-distressing issues associated with dying patients, especially when those patients are children. Because of this, literature relevant to theories concerning health care provision for dying people was searched, to explore insights into factors that influence communication between health care professionals and patients, taking into consideration the patients' developmental stages. Table 2 provides a brief summary of the major models, explaining the patients' responses to the act of dying for adult patients. However, the later sections discuss other complementary models which are more developmentally congruent for children.

Table 2: The major models explaining patients' responses to dying for adult patients

Theory or Model	Author	Major assumption
Five stages of grief	Kubler-Ross (1969)	Five psychological responses to death have been identified: denial, anger, bargaining, depression and acceptance.
A three-stage model for the process of dying	Buckman (1993)	Patients react to impeding death in a way that is suitable to their personalities as well as their past experience of coping with difficulties, instead of being the product of a unidirectional process of coping.
The readiness to die theory	Copp (1997), Copp (1996)	The body is perceived as a separate entity from the personal self in an attempt to explain patients' readiness to die. In addition, Copp (1996) has drawn up four categories which describe whether someone is ready to die, both emotionally and biologically. These categories are: (a) person ready, body ready; (b) person ready, body not ready; (c) person not ready, body ready; (d) person not ready, body not ready.
Awareness context theory	Glaser and Strauss (1965)	Four distinctive awareness contexts affecting the way people interact with each other within the hospital context: closed awareness, suspected awareness, mutual pretence awareness, and open awareness.

Despite almost half a century passing since its original formulation, the awareness to death theory of Glaser and Strauss (1965) remains one of the most important in the end of life context, as it is grounded in everyday realities as well as being useful in contemporary hospital settings. Awareness context theory drew attention to the importance of disclosing information to dying patients at a time when it was common for a patient to die in a closed awareness context. Although current healthcare systems prefer open context awareness in terms of disclosing information about the disease to patients, there was a significant change when this theory was first implemented, followed by extensive literature that encouraged the open awareness context (Field and Copp, 1999).

However, Glaser and Strauss's theory has been criticised for not considering some factors that could affect awareness, such as the emotional states of the patients and families when they receive information (Timmermans, 1994). Timmermans (1994) argues that emotional crises can interfere with cognitive abilities, possibly affecting awareness. Giving information to the patients does not, therefore, mean that they are fully aware that they are dying. Furthermore, an open context awareness culture might raise problems for those patients who use denial mechanisms in order to cope with their impending death (Copp, 1998).

Awareness context theory is focused on adult awareness of the dying process, and does not mention the effect of the cognitive developmental stage on awareness. This means that it is not suitable for researching how children perceive their terminal diseases, how their families and health personnel perceive that awareness, or the appropriate developmental stage at which children start to recognise that they are dying. Because these questions are not addressed by awareness context theory, other theories more compatible with the awareness context of dying children will be used to complement the Glaser and Strauss theory, particularly with regard to the effect of the cognitive developmental stage of the child on their awareness.

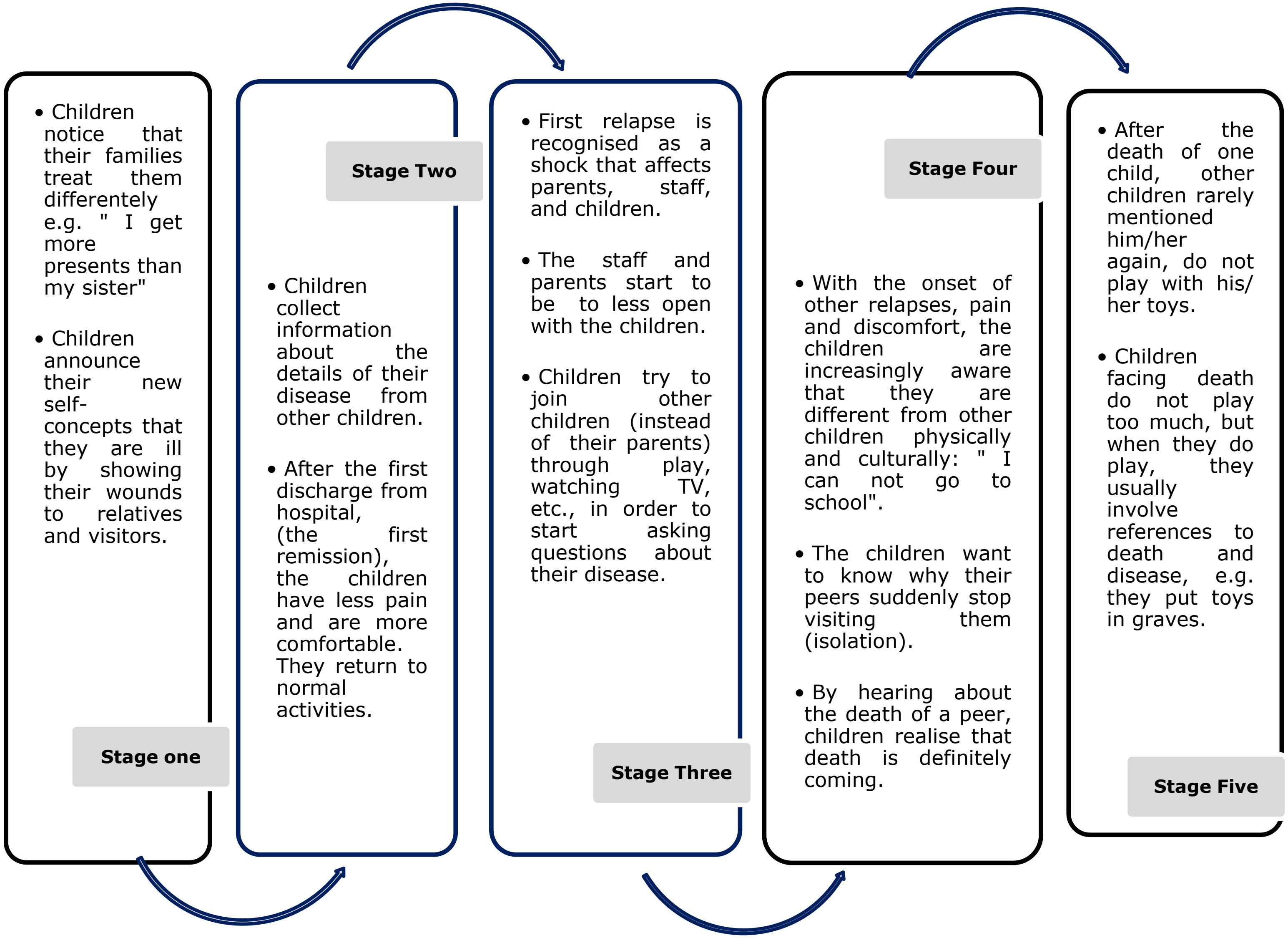
According to Piagetian developmental theory, the immediate and irreversible nature of death will not be fully understood before the age of 11-16 years of age, at which time the child's thoughts become more concrete, organised and logical (Beale et al., 2005). Younger children are unable to distinguish between their own perspectives and those of others about death, and they are generally affected by 'magical thinking' (Santrok, 2009). This could imply that all information and decisions related to their dying should be kept to parents and staff members, as children under 11-16 years old are perceived to be unable to fully understand the irreversibility of death. However, as Kubler-Ross (1969) explained, the awareness of death should be viewed as a pre-conscious awareness and not a conscious intellectual knowledge; the recognition of death is present before logical thinking develops. She argued that this preconscious awareness frequently happens with children who suffer from life-threatening conditions as a result of the additional experience they gain because of their condition.

Bluebond-Langner (1978) argues in her book *The Private Worlds of Dying Children* that children are generally fully aware of their terminal illness and treatment, even if their parents try to conceal it. Using an ethnographic approach, Bluebond-Langner (1978) describes the stages of awareness (based on awareness context theory) for leukaemic children (see

Figure **2**) having spent nine months observing children in a paediatric hospital in the USA and interviewing them, their parents, and staff. She states that children are competent social actors because of the additional experience they have from being seriously ill.

Ironically, children may actually conceal the awareness of their impending death in order to protect their parents (by maintaining the pretence that they are not terminally ill), and to meet societal expectations of dying children. The research of Bluebond-Langner (1978) was supported by several recent studies (Clarke et al., 2005; Goldman and Christie, 1993; Patenaude, 2005; Van Der Geest et al., 2015a), which assert that increasing age alone does not necessarily explain cognitive development, as there are several factors which should be taken into consideration, such as the children's individual life experiences, which affect their ability to understand.

To conclude, paediatric palliative care is complex, because children have different developmental stages and cognitive abilities to adults and other children. Bluebond-Lagner's (1978) work, which complements the awareness context theory developed by Glaser and Strauss (1965) seems to be an appropriate model for explaining the context of communication between health care professionals, children with palliative care needs, and their families. This theoretical framework can also provide appropriate clarification of the challenges that nurses may face while working with them. The insights of Bluebond-Langner (1978) and Kubler-Rose (1969) suggest open communication with children and avoidance of the closed awareness frequently adopted by many hospital staff, with the cooperation of the children's families. However, there is a debate in the literature regarding whether adopting an open awareness is the best course of action for children, as it could be argued that not all parents want their children want to know their diagnosis. Furthermore, it is not possible to make generalisable recommendations about the care of ill children and their families, since each case will be very different, and in order to be culturally sensitive, it will be the parents' wishes that take pre-eminence, especially concerning the care of small children. Indeed, one of the aims of this study is to look at cultural issues in training – open awareness may not be culturally possible in Jordan.



Stage one

- Children notice that their families treat them differentely e.g. " I get more presents than my sister"
- Children announce their new self-concepts that they are ill by showing their wounds to relatives and visitors.

Stage Two

- Children collect information about the details of their disease from other children.
- After the first discharge from hospital, (the first remission), the children have less pain and are more comfortable. They return to normal activities.

Stage Three

- First relapse is recognised as a shock that affects parents, staff, and children.
- The staff and parents start to be to less open with the children.
- Children try to join other children (instead of their parents) through play, watching TV, etc., in order to start asking questions about their disease.

Stage Four

- With the onset of other relapses, pain and discomfort, the children are increasingly aware that they are different from other children physically and culturally: " I can not go to school".
- The children want to know why their peers suddenly stop visiting them (isolation).
- By hearing about the death of a peer, children realise that death is definitely coming.

Stage Five

- After the death of one child, other children rarely mentioned him/her again, do not play with his/ her toys.
- Children facing death do not play too much, but when they do play, they usually involve references to death and disease, e.g. they put toys in graves.

Figure 2: Stages of awareness for dying children as defined by Bluebond-Lagner's (1978)

2.4. Reviewing the literature

This section reviews the international literature and explores issues related to the experiences of health care providers and parents in the care of children with palliative care needs. A mixed-method systematic review is a synthesis in which the data included is extracted from several published quantitative, qualitative, and mixed primary-level articles (Heyvaert et al., 2011). The integration of quantitative and qualitative evidence has been much used in research and practice (Heyvaert et al., 2011). This originates from the notion that combining quantitative and qualitative evidence in mixed-method synthesis will draw on the strengths of both approaches. This methodology is employed in many research domains (Pluye et al., 2009; Sandelowski et al., 2006). The purpose of this review is to appraise the research conducted in this area and identify any gaps in the literature in order to justify the study.

2.4.1. The aim of the review

The aim of this systematic review was to identify existing evidence about the experiences of communication in the care of children with palliative care needs, from the perspectives of health care providers and parents.

2.4.2. Selection Criteria

To be included in this review, studies had to contain information about communication in the care of children with palliative care needs. In order to understand communication in a comprehensive manner, a wide range of perspectives and experiences are included such as health professionals (i.e. physicians and nurses), parents, and children. It is recognised that health professionals who work in non-specialised palliative care settings could benefit from the principles and philosophy of the general palliative care approach. This review seeks all studies that investigate the phenomenon of communication in both specialised and non-specialised paediatric palliative care contexts (i.e. home, hospital, and hospice). This will assist in identifying the gaps in the literature among all of these settings, where it is important for palliative care principles to be applied. Only articles published in English were included in this study, which led to the exclusion of some articles written in other languages. However, as translation is costly, and most medical research worldwide is published in English, only articles written in English are included. Moreover, all papers should be published as full articles in a journal during or after 2000, as the essence of communication in the care of children with palliative care needs is likely to be different before this period. Only primary studies were sought including quantitative, qualitative, and mixed-methods designs (Dahan-Oliel et al., 2012; Karimi and Clark, 2016; Tsimicalis et al., 2016). Hence, abstracts and reviews, editorials, review studies, study protocols and commentaries were excluded from the review. Finally, studies that achieved higher than 25% in the mixed-method appraisal tool (MMAT) were included in the current review (Section 2.4.4). Table 3 presents the inclusion criteria.

Table 3: the inclusion criteria adopted for the current review

	Inclusion criteria
Language	• Papers published in English
Year of publication	• The search was limited to studies conducted from 2000 onwards.
The design of the studies	• Primary studies: quantitative, qualitative, mixed methods
Phenomenon	• The study should contain information related to communication in the care of children with palliative care needs.[2]
Perspective	• All perspectives: health professionals (i.e. physicians and nurses) and/or parents and/or children are included. Studies which report the perspectives of bereaved parents are also included.
Population	• Papers where the age of children is any range from birth to 18 years old.
Context	• Studies conducted in either specialised or non-specialised palliative care setting (i.e. home, hospital, hospice).
Publication status	• Published in a journal.
Quality of the studies (MMAT)	• Studies with scores > 25% (*).

2.4.3. Search strategy

The search strategy was developed with the assistant of an expert librarian. In addition to the manual search, the electronic databases of CINAHL, Cochrane, PubMed, OVID, Social Care Online, Web of Science, Scopus, and ProQuest were searched between 1st November 2014 to 12 December 2014 (Table 4).

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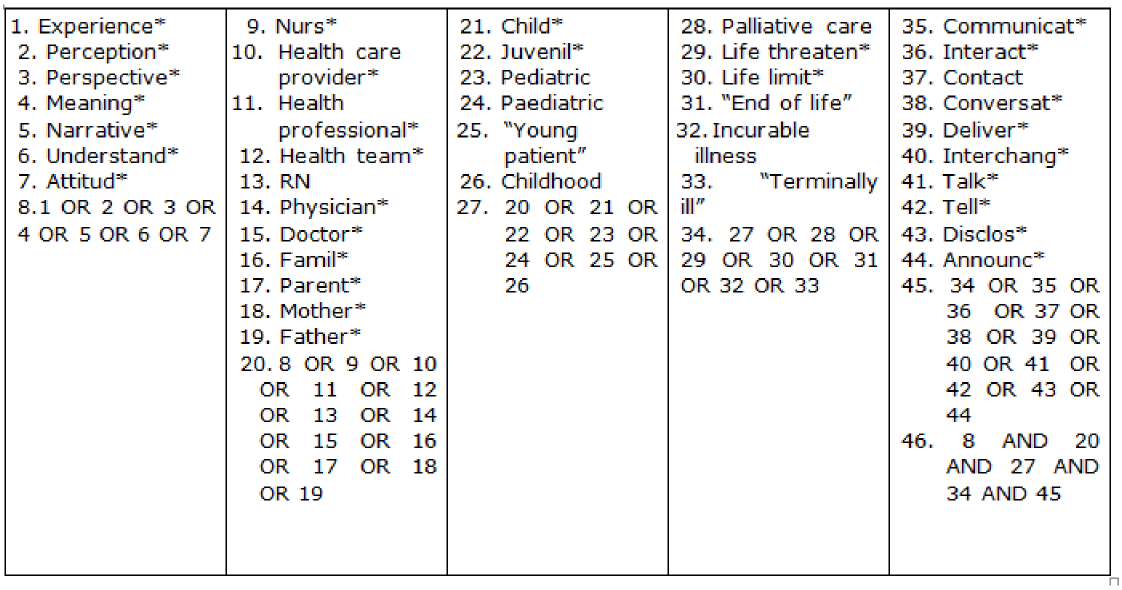
[2] See Glossary of terms to identify children’s conditions that are eligible for palliative care (Section 1.2.7).

However, the review was renewed in order to involve the most recent studies, which were added later. The search terms used MeSH-term and/or text word search or combinations. The key words relevant to the subject searched are summarised in Table 5.

Table 4: The list of databases used for this review

Name of database	**No.of hits**	**Related papers**	**Title, abstract**
CINAHL via EBSCO	290	70	Title, abstract, keywords
Cochrane	98	1	Abstract
PubMed	230	5	Title
MEDLINE (OVID) 1996 - Present	91	34	Title, abstract
Social Care Online	115	0	Title
Web of Science	89	25	Title
Scopus	371	70	Title
ProQuest	27	9	Title
Science-direct	1166	20	Title
Manual search (specialised journals, Google Scholar, ResearchGate, the reference list of potential papers)	80	35	Title, abstract.
Total	**2477**	269	

Table 5: The search terms used for the current review



1. Experience*
2. Perception*
3. Perspective*
4. Meaning*
5. Narrative*
6. Understand*
7. Attitud*
8. 1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7
9. Nurs*
10. Health care provider*
11. Health professional*
12. Health team*
13. RN
14. Physician*
15. Doctor*
16. Famil*
17. Parent*
18. Mother*
19. Father*
20. 8 OR 9 OR 10 OR 11 OR 12 OR 13 OR 14 OR 15 OR 16 OR 17 OR 18 OR 19
21. Child*
22. Juvenil*
23. Pediatric
24. Paediatric
25. "Young patient"
26. Childhood
27. 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26
28. Palliative care
29. Life threaten*
30. Life limit*
31. "End of life"
32. Incurable illness
33. "Terminally ill"
34. 27 OR 28 OR 29 OR 30 OR 31 OR 32 OR 33
35. Communicat*
36. Interact*
37. Contact
38. Conversat*
39. Deliver*
40. Interchang*
41. Talk*
42. Tell*
43. Disclos*
44. Announc*
45. 34 OR 35 OR 36 OR 37 OR 38 OR 39 OR 40 OR 41 OR 42 OR 43 OR 44
46. 8 AND 20 AND 27 AND 34 AND 45

2.4.4. Quality Assessment

The quality of the studies was assessed using the mixed-method appraisal tool (MMAT-version 2011) (Pluye, 2011; Pluye et al., 2009) (Table 6). There is no agreement on the criteria for appraising reviews that include qualitative, quantitative, and mixed-method designs (Dahan-Oliel et al., 2012). However, this tool is valid and reliable for assessing the quality of mixed-method studies (Pace et al., 2012). Therefore, it was adopted for assessing the quality of the current reviews. According to the MMAT, the checklist score varies from 0%, where none of the criteria are met, to 100% where all are met. In the current review, studies equal to or less than 25% (only one criterion met) were excluded. Only two studies which did not meet the quality appraisal criteria were excluded: Contro et al. (2004) and Costello and Trinder-Brook (2000). Both of them scored 25% and were excluded. Although Seth (2010) did not report sufficient information about the methodology used and also scored 25%, I did not exclude it from the review because of the lack of evidence regarding cultural perspectives related to communications between children with cancer and their families (see Table 7).

2.4.5. Data analysis

After getting the full text of each study, data extraction was performed, followed by the summarising of the findings of the included studies. The extracted data included: author, year, context and setting, study aim, design, sampling strategy, data collection methods, and key findings for each study. In order to ensure that all aspects of the systematic review were included, the Preferred Reporting Item for Systematic Reviews, and Meta-Analysis (PRISMA) checklist and flowchart were used (Moher et al., 2009).

In order to synthesise the quantitative and qualitative findings, an inductive thematic analysis of the findings of the studies was used (Dahan-Oliel et al., 2012; Pope et al., 2006; Tsimicalis et al., 2016). Thematic analysis is a qualitative methodology that is suitable for literature reviews as it can be used for synthesising original qualitative, quantitative, and mixed-method research designs through the extraction of themes and subthemes (Crowe and Sheppard, 2011; Fereday and Muir-Cochrane, 2006).

Table 6: MMAT mixed-methods appraisal tool

Study designs	Methodological quality criteria
Qualitative	1.1. Are the sources of qualitative data (archives. documents, informants, observations) relevant to address the research question (objective)? 1.2. Is the process for analysing qualitative data relevant to address the research question (objective)? 1.3. Is appropriate consideration given to how findings relate to the context, e.g. the setting, in which the data were collected? 1.4. Is appropriate consideration given to how findings relate to researchers' influence, e.g. through their interactions with participants?
Quantitative randomized controlled (trials)	2.1. Is there a clear description of the randomization (or an appropriate sequence generation)? 2.2. Is there a clear description of the allocation concealment (or blinding when applicable)? 2.3. Are there complete outcome data (80 % or above)? 2.4. Is there low withdrawal/dropout (below 20 %)?
Quantitative non-randomized	3.1. Are participants (organizations) recruited in a way that minimized selection bias? 3.2. Are measurements appropriate (clear origin, or validity known, or standard instrument; and absence of contamination between groups when appropriate) regarding the exposure/intervention and outcomes? 3.3. In the groups being compared (exposed vs. non-exposed; with intervention vs. without; cases vs. controls), are the participants comparable, or do researchers take into account (control for) the difference between these groups? 3.4. Are there complete outcome data (80 % or above), and, when applicable, an acceptable response rate (60 % or above), or an acceptable follow-up rate (depending on the duration of follow-up)?
Quantitative descriptive	4.1. Is the sampling strategy relevant to address the quantitative research question (quantitative aspect of the mixed-methods question)? 4.2. Is the sample representative of the population understudy? 4.3. Are measurements appropriate (clear origin, or validity known, or standard instrument)? 4.4. Is there an acceptable response rate (60 % or above)?
Mixed-methods	5.1. Is the mixed-methods research design relevant to address the qualitative and quantitative research questions (or objectives), or the qualitative and quantitative aspects of the mixed-methods question (or objective)? 5.2. Is the integration of qualitative and quantitative data (or results*) relevant to address the research question (or objective)? 5.3. Is appropriate consideration given to the limitations associated with this integration, e.g. the divergence of qualitative and quantitative data (or results*) in a triangulation design? Criteria for the qualitative component (1.1 to 1.4), and appropriate criteria for the quantitative component (2.1 to 2.4, or 3.1 to 3.4, or 4.1 to 4.4), must also be applied.

* These two items are not considered as double-barreled items since in mixed-methods research, (1) there may be research questions (quantitative research) or research objectives (qualitative research), and (2) data may be integrated, and/or qualitative findings and quantitative results can be integrated.

The synthesis is performed in an inductive manner, as themes are generated from the data according to the meanings and the richness of the data (data-driven) but not according to previously-established theories (Fereday and Muir-Cochrane, 2006). It also has the ability to capture common themes, whatever the design of the study (Dahan-Oliel et al., 2012). In the current research, this was performed by extracting the findings of all studies into one table in Microsoft Word. All findings were manually coded in order to initiate the initial categories, which were discussed with my supervisors. Then, after reading and re-reading the categories, I organised and consolidated them into meaningful condensed themes (Braun and Clarke, 2006; Dahan-Oliel et al., 2012). The final themes express the pattern of the experience of communication in the qualitative and quantitative evidence.

2.4.6. Findings

2.4.6.1. Search strategy and selection criteria

2,477 hits were returned and imported into Endnote X7 reference manager. Sixty eight duplicate articles were removed. Titles and/or abstracts were screened for relevance, and of these 569 were retained, as they were relevant to the research brief. Abstracts and full text articles of these 569 studies were reviewed and 84 were selected as they matched the inclusion criteria. The remaining 84 papers were retrieved and read in full. Finally, after applying the inclusion criteria, the total number of papers accepted for the current review was thirty eight (see Figure 3: Flow of information through the different phases of a systematic review**.**). The data for the studies was extracted and presented in Table 7.

2.4.6.2. Study characteristics and quality appraisal

Of the selected 38 studies, 28 are qualitative, seven are quantitative, and three are mixed-method. The studies were conducted in a variety of countries: Uganda, Jordan, USA, UK, Taiwan, Turkey, Ireland, Poland, Brazil, Australia, Switzerland, Sweden, Netherland, Lebanon, Spain, Greece, and China. Several methodological approaches were adopted in this review as is shown in Table 7. In the 28 qualitative papers, a qualitative approach was employed including phenomenology, grounded theory, and a general qualitative approach using a variety of data collection methods such as interviews, focus groups, and observations. The quantitative papers used were mainly a cross-sectional design, and the mixed-methods part was cross-sectional with interviews, focus groups with in-depth interviews, self-rating surveys, and a focus group.

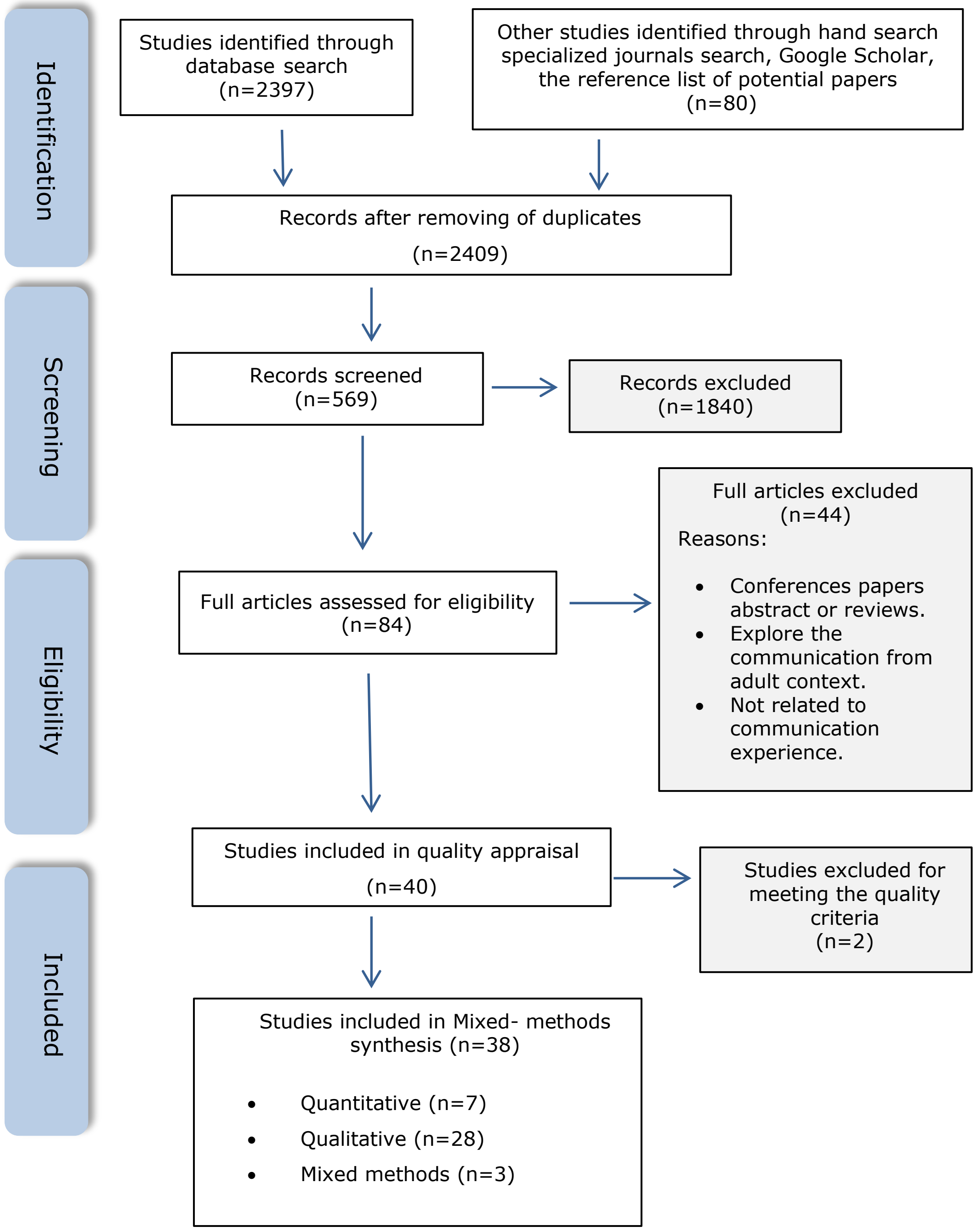


Figure 3: Flow of information through the different phases of a systematic review.

The studies were conducted in a wide range of settings, such as parents' homes, paediatric hospice programmes, cancer centres, and hospital settings (PICU, NICU, paediatric haematology and oncology units, and a child inpatient cardiology unit). There is a variety of children's life-threatening and life-limiting conditions, included in these studies; however, malignant conditions such as acute lymphoblastic leukaemia are the most frequent.

Some of the qualitative studies had certain limitations, such as unclear philosophical assumptions; not stating the inclusion criteria for sampling procedures; not reporting ethical approval procedures; unclear methods of improving rigour and trustworthiness; and lack of consideration of the investigators' awareness of their own reflexivity (and how that could affect the results). The quantitative studies also had limitations, such as small sample sizes, which were not calculated using pre-study considerations of statistical power; using convenient sampling techniques; and introducing selection bias by using online surveys, which could eliminate the response rates, and in turn threaten both the internal and external validity of the results.

2.4.7. Strength and limitations

This review has its own strengths and limitations. In order to get all of the potential research studies from the literature, a rigorous approach was applied using mixed methods of reviewing literature. It is permitted for quantitative, qualitative, and mixed-method design to be synthesised in one review. This helps to get integrated insights into the research subject. Moreover, including a wide range of study aims, methodologies, and sample characteristics enabled me to gain a comprehensive insight of the overarching themes. This improves the transferability of the findings into other similar settings. The wide contextual backgrounds upon which this review is built can also facilitate comparisons between these different contexts, including different cultural and age subgroups. However, this review also has some limitations. Including only articles published in English could exclude the findings of some articles in other languages. This could limit the transferability of the findings of this review into other non-English settings.

Table 7: Data Extraction for the studies included in the systematic review

Study, context	**Aim**	**Design, Methods**	**Settings**	**Sampling strategy**	**MMAT Score**
Amery et al. (2010) ***Uganda***	To explore the health providers' educational needs	Mixed-method: self-rating survey, log book of problem cases and focus group	Three hospice sites in Uganda	6 doctors, 41 nurses, and 3 clinical officers	**
Arabiat et al. (2011) ***Jordan***	To investigate mothers' experiences of communication with their children about cancer diagnosis	Open-ended /semi-structured interviews	pediatric oncology clinics	51 mothers of children who are diagnosed with cancer	**
Bartel et al. (2000) ***USA***	To explore the experiences of physicians when they attempt to provide optimal care for families of children who suffer from sudden, acute life-threatening conditions	Focus groups & in-depth interviews	Intensive care unit of an urban pediatric teaching hospital.	Twenty-two pediatric intensive care unit physicians,	****
Chen & Huang (2013). ***Taiwan***	To investigate the attitudes of neonatal nurses who work with dying neonates toward nursing care.	A cross-sectional design/ Survey	Four NICUs at four medical centres in Taiwan	80 neonatal nurses	***
Citak et al. (2013) ***Turkey***	To explore the communication challenges of paediatric haematology/ oncology nurses with patients and their families.	qualitative study Focus group technique (3 focus groups)	A pediatric hematology/ oncology hospital in Ankara.	21 paediatric Hematology /oncology nursing staff	***
Clarke et al. (2005) ***UK***	To explore parental perception of what to tell children about their illnesses and to instigate factors influence parental communication with their children.	A semi-structured interviews	Four major cancer centres within the UK,	55 mothers of children who are newly diagnosed with acute lymphoblastic leukaemia	**

Study, context	**Aim**	**Design, Methods**	**Settings**	**Sampling strategy**	**MMAT Score**
Contro et al. (2002) ***USA***	To investigate the experiences of deceased families and their suggestions for improving the quality of end-of-life care	Qualitative design Semi- structured interviews	One Children's Hospital	Sixty-eight family members of 44 deceased children	***
Cook et al. (2012) ***USA***	To explore behaviours and coping mechanisms used by paediatric nurses who care for dying children.	Qualitative descriptive design using focus groups	Children's academic centre specifically inpatient cardiology unit.	17 staff nurses and 5 nurse practitioners.	****
Coyne et al. (2014) ***Ireland***	To investigate the participation of children in shared decision-making (SDM) from multiple perspectives	Qualitative design Semi- structured interviews	One hematology oncology unit	Children aged 7- 16 years (n= 20). Parents (n =22). HCPs (n = 40).	***
Dangel et al. (2000) ***Poland***	To measure the quality of a paeditric hospice home care program.	Cross sectional design (Survey)	Hospice home care program	parents or primary caretakers of 87 children who had died under the hospice home care	**
Davies et al. (2003) ***UK***	To explore parents' experiences of care by pediatricians including diagnostic disclosure of a life-limiting condition in their child.	Qualitative design In-depth interviews	Parent's homes	30 families whose child was diagnosed with a life-limiting condition.	***
El Halal et al. (2013) ***Brazil***	To evaluate the quality of care offered to terminally ill children and their families in the last days of life	Semi- structured interviews	Two Brazilian Pediatric Intensive Care Units (PICUs)	Parents of a child who had died in one of the PICUs	***
Epstein (2010) ***USA***	To explore the obligations of nurses and physicians in providing end-of-life care.	A hermeneutic phenomenological approach semi-structured interview	A single newborn intensive care unit	Nineteen nurses and 11 physicians	***

Study, context	Aim	Design, Methods	Settings	Sampling strategy	MMAT Score
Gaab et al. (2013) ***Australia***	To explore the decisions of the primary caregivers toward communicating about death with children involved in pediatric palliative.	Semi- structured interviews	Participants' homes or workplaces (according to convenience)	primary caregivers with children who have life-limiting illnesses	***
Hendricks-Ferguson (2007) ***USA***	To examine parents' attitudes toward the timing and method used by health care providers to introduce EOL options for their child.	Telephone interviews	Hospice program at one hospital	28 parents, 19 mothers and nine fathers	***
Hsiao et al. (2007) ***USA***	To explore the perceptions of children with life-limiting illnesses and their parents toward the facilitative and obstructive aspects of physicians' communication.	Mixed Method Questionnaire & Semi – structured interviews	Two children's hospitals and one pediatric hospice	20 Parents and children	***
Inglin et al. (2011) ***Switzerland***	To explore the perceptions and needs of families who care for a child with a life-limiting disease	Semi- structured interviews	Four children's hospitals	Fifteen parents whose child had received palliative care or had died within the previous 2 years	***
Kastel et al. (2011) ***Sweden***	To understand parents' perceptions on information in childhood cancer care.	Qualitative design Semi- structured interviews	A pediatric oncology ward	Eight families with children diagnosed with cancer	**
Kilicarslan-Toruner and Akgun-Citak (2013) ***Turkey***	To explore the experience of decision making and information seeking behave iours of parents whose children with cancer.	Qualitative design Semi-strucuted interviews	Paediatric hematology-oncology inpatient clinic of a university hospital	15 parents of children with cancer	***

Study, context	**Aim**	**Design, Methods**	**Settings**	**Sampling strategy**	**MMAT Score**
Kreicbergs et al. (2004) ***Sweden***	To investigate whether parents of children who died because of malignant disease should talk about death with their children	Descriptive study Questionnaire	Parents' names were taken from Sweden death registry. Questionnaires were sent for parents' home	429 bereaved parents	****
Lee et al. (2008) ***USA***	To describe the experiences of paediatric intensive care unit health professionals who care for children who are dying.	Qualitative design Semi structured interviews	A large PICU	29 staff members. Participants included physicians nurses, and psychosocial support personnel	***
Mack et al. (2006) ***USA***	To examine the preferences of parents toward the prognostic information of their children with cancer	Cross sectional study Survey	Cancer institute and children's hospital	194 parents of children with cancer	***
Majdalani et al. (2014) ***Lebanon***	To understand the lived experience of Lebanese parents of children admitted to the PICU.	Phenomenology In-depth semi-structured interviews & observation field notes	PICU in a tertiary hospital.	10 parents (mother or father)	***
McGrath (2001) ***Australia***	To investigate the experience of ALL treatment from the perspectives of children, parents and well siblings.	Qualitative approach open end interviews with study participants at 3 different point of treatment trajectory	Haematology and Oncology Unit of the Royal Children's Hospital (RCH).	12 parents of children with ALL	***
Montoya-Juarez et al. (2013). ***Spain***	To explore parents' perspective on suffering	Semi-structured interviews	Two Pediatric Units at two University Hospitals	Parents of children with terminal illness (13 parents)	***
Peng & Chen (2013) ***Taiwan***	To explore the experiences of neonatal nurses in terms of caring for dying neonates and to assess their educational needs.	A cross-sectional survey	Three NICUs at three medical centres	115 nurses	***

Study, context	**Aim**	**Design, Methods**	**Settings**	**Sampling strategy**	**MMAT Score**
Papadatou & Bellali (2002) ***Greece***	To explore and compare the grief reactions and experiences of Greek nurses and physicians who provide care to dying children with cancer.	Semi-structured interviews	Major paediatric oncology units	16 paediatric oncology nurses and 14 oncologists	**
Papadatou & Martinson (2001) ***Greece and Hong Kong***	To explore the experiences of nurses who work with dying children in oncology and critical care units in Greece and Hong Kong	Semi-structured interviews	Oncology units and ICUs located in two paediatric hospitals in both Athens & Hong kong	24 Chinese nurses and 39 Greek nurses.	**
Price et al. (2013) ***UK***	To investigate health and social care professionals' perspectives on developing services for children with life limiting conditions	Focus groups using nominal group technique	Children's cancer unit and a children's hospice	35 health and social care professionals	****
Ringnér et al. (2011) ***Sweden***	To investigate the experience of parents toward seeking and using information regarding to their children cancer illness	Qualitative approach Four focus groups and 4 individual interviews	Paeditric oncology treatment center	14 parents of children with cancer participated In the focus group	***
Seth (2010) ***India***	To investigate parental perceptions to telling a child with cancer about the disease & to assess their views on participation of children in decision making for treatment	Open ended questionnaire (qualitative analysis)	One hospital	25 parents of pediatric cancer patients	*
Steele (2006) ***Canada***	To understand the experience of families with a child who has Neurodegenerative life threatening illnesses (NLTI).	Grounded Theory Observations & semi- structured interviews	Pediatric hospice care program	29 family members were interviewed 10 sick children were observed	**

Study, context	**Aim**	**Design, Methods**	**Settings**	**Sampling strategy**	**MMAT Score**
Stenmaker et al. (2010) ***Sweden***	To investigate physicians concerns and psychosocial issues related to their work with paeditric oncology.	Qualitative design Grounded Theory/ Semi- structured interviews	At a University campus	Ten physicians with more than 10 yrs. experience working with paeditric oncology	***
Tubbs-Cooley & Santucci (2011) ***USA***	To describe palliative care aims and problems as rated by paediatric nurses.	A cross-sectional survey- web-based Questionnaire	A freestanding children's hospital.	410 nurses	**
Van Der Geest et al., 2015 ***Netherland***	To understand reasons of parents decision to talk about death with their children with incurable cancer.	Qualitative design Open ended questionnaire Qualitative analysis (framework analysis)	Paediatric haematology/ oncology	86 bereaved parents of 56 children who died because of cancer	**
Wolf et al. (2000) ***USA***	To assess the understanding of parents of the prognosis of children died because of cancer.	Quantitative Cross- sectional design	Cancer institute and children's hospital	103 bereaved parents and 42 paediatric oncologists	****
Yam et al. (2001) ***China***	To investigate the experiences of Hong Kong nurses who work in neonatal unit in terms of caring for dying infants.	Semi-structured interviews	SCBU and NICU of a major teaching hospital in Hong Kong	10 RN	**
Zacler et al. (2010) ***UK***	To investigate the experiences of end of life for children with brain tumors and their families	3 semi structured focus group interviews	Children's Hospital, London Health Sciences Centre.	25 parents of 17 children who had died of brain tumors.	***

Scores vary from * (25 %)–one criterion met to **** (100 %)–all criteria met.

2.5. Identified themes

The following are the overarching themes result from the inductive analysis and synthesis of the studies included in the review (Figure 4).

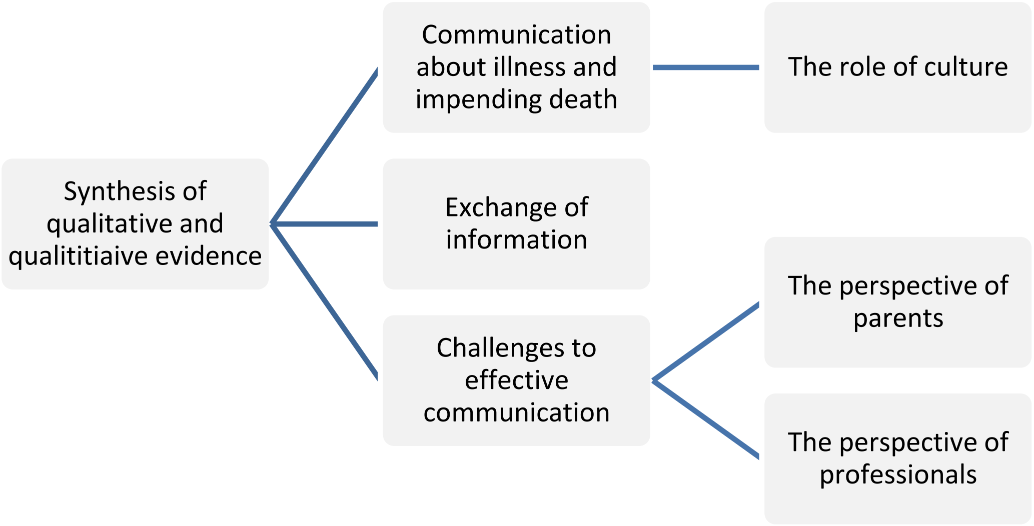


Figure 4: The themes and subthemes result after synthesis of the literature

2.5.1. Communication with children about illness and impending death

The current review shows that parents tend to protect their children when they are discussing their illnesses with them, particularly where they have a life-threatening or life-limiting condition. Parents do not often wish to discuss death with children, and find this topic difficult, painful and hard to touch upon in any detail (Van Der Geest et al., 2015a; Dangel et al., 2000). A number of studies have illustrated this protective approach (Dangel et al., 2000; Gaab et al., 2013b; Seth, 2010; Van Der Geest et al., 2015a; Zelcer et al., 2010; Kreicbergs et al., 2004). For example, a recent study of bereaved Dutch parents, investigated the reasons for their decisions to discuss death with their children who had incurable diseases (Van Der Geest et al., 2015a). The findings show that 55 of 86 parents who responded did not discuss the children's impending deaths with them, while 31 parents did. These findings (Van Der Geest et al. (2015a) concur with a study in Sweden that examined parental decisions on talking about death with their children with malignant diseases (Kreicbergs et al., 2004). Findings from the large survey show that overall 147 (34%) of the 429 parents who participated had talked with their children about death, while the majority of them (282 parents) had not.

Furthermore, Seth (2010) found that 65 per cent of families were not in favour of sharing diagnoses with children –even if they were over the age of 18. Nearly 60% (14/23) of parents in the aforementioned study, felt that children should not even be made aware of the side effects of their treatment, especially the long-term effects. In line with these findings, Dangel et al. (2000) found that 75% (60/80) of Polish parents or primary caretakers of dying children did not talk honestly with the children about death.

There has been no work in Jordan which specifically investigates discussions of death between parents and children at any stage of their illnesses. However, one Jordanian study conducted by Arabiat et al. (2011) investigates the communications of Jordanian mothers with their children regarding their cancer diagnosis. The content analysis of the semi-structured interviews revealed that 16 out of 51 mothers gave their children no information about their cancer. This figure is divided into two categories. The first indicates that the children knew nothing or had no discussion about their cancer at all (8 mothers). The second shows that the mothers gave false accounts of the diseases, for example by informing children that they had a blood virus, anaemia, or kidney stone (8 mothers).

Additionally, a few studies reported several reasons behind the parents' decisions of whether or not to talk with their children about death (Dangel et al., 2000; Gaab et al., 2013b; Van Der Geest et al., 2015a; Zelcer et al., 2010). For example, Gaab et al. (2013b) found that New Zealand primary caregivers avoided talking to their children, who were receiving palliative care, about their illness and impending death. This was to protect them from the emotional burden and loss of hope that might result from such discussions. Additionally, some caregivers hesitated to raise the topic of death as they did not want to tell their children in a bad way, or transfer bad news to them, especially when they perceived that their children already understood all of the necessary information and had no need for further discussions. This is consistent with Van Der Geest et al. (2015a), in which the parents aimed to protect their children from the pain and anguish that might have resulted from extinguishing their hope for a cure. Another parent in the same study had a sense of fear regarding the child's response, and was afraid of preventing the child from enjoying the last days of their life.

A Polish study by Dangel et al. (2000) cited several reasons why the majority of parents and primary caretakers did not discuss death with their children, who went on to die in hospice care. The perspectives were that the children were too young to understand death, that there was a lack of time, that having such discussions was difficult, fear of the children's reaction, and the refusal of the children themselves to talk about it. Another reason was cited by Zelcer et al. (2010), who studied 25 bereaved parents of 17 children who died of brain tumours in the UK. The thematic analysis of the three focus groups showed that some parents avoided discussing death with their children because they were in denial. The parents were afraid they might destroy their children's hopes of a cure, despite the children's high awareness of the advanced nature of their illness, and having the major role in guiding their parents in preparing them for death. Finally, family caregivers reported that they experienced difficulty in breaking bad news, perceiving that they lacked the skills needed to inform their children in an appropriate way, without the help of health professionals (Gaab et al., 2013b).

The previously-mentioned studies have some limitations. For example, as shown by Arabiat et al. (2011), the stages of the children's cancer were not indicated. This could be significant for understanding the changes in interaction at different stages of the cancer, and how the manner of communication the mothers adopted with their children changed over time. The previously-mentioned studies only considered the interactions to have taken place at one point in time. However, communication is a dynamic process that usually changes with time according to different environmental, social, and emotional factors. One of the current study's aims is to explore how the parents changed their interaction styles over time, and according to the different stages of the diseases.

Moreover, Gaab et al. (2013b) do not consider the effect of the child's age on the primary caregivers' decisions of whether to protect them from information concerning death. No information is given about the age of the children that participated in the study or whether this affected the caregivers' decisions to discuss death with them. In other studies, such as (Arabiat et al., 2011), where mothers of children of aged 7-16 were recruited, and (Seth, 2010), where parents of children between 10-18 years were recruited, no information is given about the parents' manner of communication with the younger children. This could make the issue more complex, as it could be affected by parental perceptions about the children's awareness of death. Parents who perceive their children to be too young for such discussions could adopt a more protective approach with their children than those who believe that their children understand death. To address this research gap, this study will explore communication with a younger age group, (1-12 years), and more weight will be given to the communication of sensitive topics with younger children.

The majority of studies were conducted on children with cancer (Arabiat et al., 2011; Kreicbergs et al., 2004; Seth, 2010; Van Der Geest et al., 2015a), and less attention was given to children with non-malignant life-threatening illnesses. The uncertainty of prognoses in non-malignant life-threatening illness (compared to cancer), could add another layer of complexity to the communication of prognostic information between parents and health professionals. The current study will investigate differences in the degree of openness (if present) between health professionals and parents of children with non-malignant life-threatening and life-limiting illnesses.

Gaab et al. (2013b) and Seth (2010) did not provide any information about parents' perceptions of their children's cognitive abilities and whether or not they were able to understand death. There is evidence that this significantly affects communications between parents and children. Kreicbergs et al. (2004) found that parents who thought that their children understood death regretted not discussing the subject with them more than those who felt that their children did not understand it. In the current study, the perception of parents toward their children's awareness to death will be investigated. This is significant for understanding whether parents who perceive their children to have a higher awareness adopt an open approach to communication with them.

Moreover, a few studies (Kreicbergs et al., 2004; Van Der Geest et al., 2015a) investigated the experience of discussing death with bereaved parents retrospectively. These studies provide information about whether parents regretted their decisions on talking to their children about death a long time after their children had died. Nevertheless, they reported contradictory findings. As we have already seen, Kreicbergs et al. (2004) reported that, out of a sample of 258 parents, the 147 who spoke about death to their child were glad to have done so, and the rest of the sample regretted not having broached the topic. In the Van Der Geest et al. (2015a) study, some parents did not feel positive about the conversations they had with their children regarding death. They experienced negative feelings because of the children's emotional reactions. One parent mentioned that it would have been better if she had prepared herself before having this kind of conversation with her son. Although Kreicbergs et al.'s (2004) findings show that none of the parents regretted discussing death with their children, which encouraged an open attitude with children about their impending death, no information was given as to whether those mothers received any training or support on how to discuss such sensitive issues. This open attitude could also be influenced by the educational level of the mothers, which is not given in this study.

The current study therefore provides extensive contextual information about the participants, including details about whether the mothers received any training or not. The aforementioned contradictory finding calls for further qualitative studies (probably of a longitudinal design) to be conducted to investigate in depth the long-term effects of parental decisions to talk or not talk with their children about death. A longitudinal study is, however, outside the remit of the current study due to time limitations. However, this could be compensated for this, by interviewing bereaved parents to investigate whether their decisions and attitudes towards their decisions have changed with time, and the reasons for any such changes.

2.5.1.1. The role of culture

The parents' cultural background affects how much information they preferred to share with their children about the incurable nature of their diseases (Papadatou and Bellali, 2002). Conservative cultures demonstrate collusion behaviours in terms of keeping patients unaware of their diagnosis, as these cultures often believe that telling the patient the truth will deprive the patient of hope, thereby adding to their distress (Seth, 2010). For example, it is common in Greek culture not to inform children about their diagnosis; rather, information about poor prognoses and the imminent death of child patients is communicated exclusively between physicians and parents, who usually attempt to adopt a protective approach with their children (Papadatou and Bellali, 2002; Papadatou et al., 2001). Greek nurses could therefore face difficulties when children who have no awareness of their diagnosis ask questions about their diseases and prognoses.

In India, Seth (2010) found that the majority of families (65%) did not want their children, who were receiving chemotherapy, to be informed about their diagnosis. In addition, the majority of them (60%) asserted that their children should not be told about the adverse effects of their treatment, especially the long-term outcomes. This is in keeping with an identified Indian cultural characteristic that parents are very unwilling to deliver bad news to their children, and attempt to delay the process as much as possible (Seth, 2010).

On the other hand, the cultural milieu of some parents encouraged them to initiate open discussions with their children concerning death. For example, as shown by Gaab et al. (2013a), a few primary caregivers were encouraged to speak with their children with the aim of preparing them for death. This was partly due to the indigenous (Maori) tradition in New Zealand whereby parents are encouraged to investigate concepts related to death with their children.

Jordan's conservative culture does not support revealing cancer diagnoses to children (Arabiat et al., 2011). However, further explanation is needed to provide deeper insights into the aspects of Jordanian culture that particularly affect communication. Jordanian culture is derived from Arab-Islamic culture. The current study will identify some Jordanian cultural beliefs, especially those that significantly affect communication, in order to explain the way this culture shapes and reflects the interactions between patients, parents, and health workers in the study setting. This particularly concerns the meaning and philosophy of disease, types of discussion among the study participants regarding end of life issues and death, as well as the issue of hope and the communication of expectations of death.

In summary, the approach of parents towards the discussion of sensitive issues concerning death with their children is significantly affected by the cultural background of the families. Conservative cultures encourage collusion behaviours which tend to keep patients (especially children) unaware of the incurable nature of the disease. Greek, Indian, and Arab cultures are examples of conservative cultures in which the families prefer not to tell children of their end of life status. Conversely, the Maori tradition in New Zealand fosters a tendency to encourage more open communication between children and their families regarding their prognosis. However, further studies are needed to look into collusion attitudes (if present) in Jordanian culture.

2.5.2. Exchange of information between health professionals and parents

Informational exchange is a critical element of communication among health professionals and parents (Hsiao et al., 2007). Receiving and obtaining adequate information is reported by families to be helpful in ameliorating the fears and uncertainties related to their children's illness (Freeman et al., 2004; Steele, 2006; Hsiao et al., 2007). Parents who are well informed about their children's illnesses feel safe and secure despite any uncertainty about the prognosis (Ringner et al., 2011). Further, providing timely accurate information about the child's condition on a regular basis is perceived to be one of the basic rights of critically-ill children (Bartel et al., 2000). Parents appreciate effective health care professionals, because they provide them with honest information (Contro et al., 2002; Inglin et al., 2011; Ringner et al., 2011).

Some studies express the importance of continuously providing parents with honest and detailed information about their children's diseases (Mack et al., 2006; Ringner et al., 2011). For instance, Mack et al. (2006) carried out a survey in the USA, and questioned 194 parents and physicians of children with cancer, to determine the parents' preferences for prognostic information about their children. The findings show that 87 per cent of those parents express the desire to receive as much information as possible. The 36 per cent of parents who found prognostic diagnosis either upsetting or very upsetting wanted to have more information about the prognosis than parents who were not emotionally upset by the prognosis. Further, Parents who perceived the information as upsetting still mentioned that knowing the prognosis was important, and helped them make decisions. However, in Mack et al. (2006), parents were only surveyed at one point in time, which limited the possibilities of investigating whether those parents later changed their perceptions of the amount of information they preferred to receive.

Despite the accumulation of evidence that supports the importance and benefits of giving parents detailed information, there is less evidence to support the notion that providing negative information about a prognosis has a harmful effect on both parents and children (Mack and Joffe, 2014). As highlighted by Stenmarker et al. (2010), physicians reported that "Being a messenger of life-threatening conditions" (p.483) is a major concern associated with informing patients/families about a recurrent disease and the transition to palliative care. Similarly, a qualitative study (nominal group technique) held in the UK also reported that health professionals who were involved with treating children with life-limiting diseases found it stressful and difficult to undertake "truth telling" (p.75). This was identified by 35 health and social professionals recruited in one children cancer unit in a children's hospice (Price et al., 2013).

However, according to some studies (Kastel et al., 2011; McGrath et al., 2007), the amount of information given to families can be different from one family to another. A longitudinal Australian qualitative study conducted by McGrath et al. (2007) investigated experiences related to the treatment of paediatric acute lymphoblastic leukaemia (ALL). Experiences of 62 families from the perspectives of parents, children, and well siblings over a five year period were sought. The findings of the open-ended interviews show that there was considerable variation in the parents' needs for information. A few participants mentioned that detailed information was of assistance to them. However, other parents in the same study demonstrated that much of the information about the child's condition could be very challenging for the parents to cope with, and could be a source of anxiety, especially with regard to the side effects of the treatment. Some parents asked for details about the condition of their children, and then regretted it later (McGrath et al., 2007). Some parents coped with the information overload by taking the information a little at a time, and leaving spaces in between to digest it (McGrath et al., 2007).

The contradictory findings between the Australian study and others such as (Mack et al., 2006), reveal the need for other studies that consider the change of parents' informational needs over time. The current study investigates the effect of time on the parents' decisions and also examines whether or not they regret their decision to know every detail about the progression of their children's illness. However, there has been no work in Jordan to specifically explore individualised parental information needs and how they change over different periods of time.

2.5.3. Challenges to effective communication

Ineffective communication could have an adverse effect on patients and health professionals alike. For patients, it could increase the level of depression, anxiety, and hopelessness that contribute to a lower quality of life (Citak et al., 2013). It could also lead to burnout and stress among paediatric nurses because of their lack of communication skills, which could lead to negative experiences for them when they interact with patients (Borhani et al., 2013; Price et al., 2013; Yam et al., 2001). The following paragraphs show the reported challenges to effective communication as seen by parents and health professionals.

2.5.3.1. The perspective of parents

Parents highlight the importance of physicians and nurses not using medical language and jargon (Kastel et al., 2011; Contro et al., 2002; El Halal et al., 2013; Davies et al., 2003), and avoiding the use of English in non-English speaking countries (e.g. Lebanon) or for minorities who are not native English speakers (Majdalani et al., 2014; Contro et al., 2002). For instance, a phenomenological study conducted by (Majdalani et al., 2014) investigated the lived experience of Lebanese parents of children admitted to PICU in a tertiary hospital. The analysis of the interviews conducted with the ten parents (fathers and mothers) found that the use of medical language by the physicians and nurses affected the relationship between the parents and the professionals. The parents reported that they did not understand the information given to them by the health professionals when they used medical jargon or English. However, the above studies did not explain the possible impact of using medical or English language in depth, how this lack of understanding negatively affected the nature of communications between the parents and health professionals, or the process of medical decision making. Further investigation of the explanations and impact of using medical jargon on parents is undertaken in the current study.

Furthermore, several studies found that parents reported receiving mixed messages about their children’s condition from different health team members, which exaggerated their distress and confusion (Contro et al., 2004; Contro et al., 2002; Kastel et al., 2011). Kastel et al (2011) conducted a qualitative study focussing on eight Swedish families, whose children had been diagnosed with cancer; to determine what the parents thought of the quality of the information they were being given. They found that the number of people who communicated with the parents impacted negatively on their experience, since they had different relationships with each of the various health professionals. This affected the quality of communications because of the diversity of viewpoints they presented. This is congruent with the findings of Contro et al. (2002), which show that some families reported receiving contradictory or conflicting recommendations about the treatment of their children. This increased their confusion and anxiety, and added an extra layer of stress to the families' burden. The families therefore asserted their need to receive information from a single, familiar, care provider.

2.5.3.2. The perspectives of health professionals

Health professionals report several challenges that affected effective communication with each other, and nurses report challenges when they communicated with the parents. For example, physicians reported difficulties in judging how much information should be given to parents (Epstein, 2010), finding it difficult to evaluate how much information each individual family needed. Nurses face several challenges communicating with patients or their families, and in many situations they found themselves being unprepared to act or behave in a proper way. The major communication challenges found in the literature are responding to difficult questions, conflicts with families and inadequate skills to support grieving families.

2.5.3.2.1. Responding to difficult questions

Nurses state that they find it difficult to answer questions about the prognosis when talking to dying children and their families. When children are not given any information about their disease, this reflects the nurses' inabilities to communicate appropriately with them (Amery et al., 2010; Papadatou and Bellali, 2002; Papadatou et al., 2001; Citak et al., 2013). Nurses report that they avoided answering questions from children and families, as they are often uninformed about the disease and its therapy. They hesitate to provide this information on the behalf of physicians, whose responsibility it is to communicate information about diagnoses and major procedures in such hospitals.

It is possible that the nurses' anxiety about discussing poor prognoses comes from the cultural background within which they are providing nursing care. Papadatou and Bellali (2002) have noted that, in Greek culture, physicians do not tell children about their diagnosis. In addition, if the prognosis is poor and death is close and likely, it is the physician who shares the news with the parents, and they normally shield their child from this knowledge (Papadatou and Bellali, 2002; Papadatou et al., 2001). Therefore, Greek nurses face difficulties when children, who have no awareness about their diagnosis, try to ask questions.

Amery et al. (2010) focussed on Uganda in their study, which looked at the need for education among the palliative care health professionals charged with looking after children in three hospices in that country. Fifty health professionals, which included a total of 41 nurses, gave their views through a focus group, log book analysis and a self-assessing survey. The general consensus was that communicating with children posed great difficulties, particularly if the staff had to explain conditions, outlooks and share bad news. The respondents felt they were not adequately trained to cope with the children's emotional states or reactions of denial. However, Amery's study did not report cultural factors in disclosing poor prognosis to children. Cultural factors can affect how much explanation is usually disclosed to children with palliative care needs. It is important to understand whether or not cultural norms of disclosing disease information to children could exaggerate the challenges faced by nurses when answering children's difficult questions which support the need for further studies.

2.5.3.2.2. Conflicts with families

Some studies examined conflict with patients' families as a communication barrier faced by nurses working with children with palliative care needs (Citak et al., 2013; Papadatou et al., 2001; Price et al., 2013). Health and social professionals described themselves as being the target of parents' stress and anger (Price et al., 2013). Price et al. (2013) mention that at least some degree of conflict was associated with a wide range of issues in child palliative care, such as talking about death with children, the location of care, addressing their siblings' needs, and withdrawal from fluid, medication, and food. In these situations, the professionals felt themselves powerless and unable to ease the fears and stress of families (and themselves). Furthermore, according to Citak et al. (2013), Turkish nurses apportion their communication difficulties to the negative responses given by some families as a result of their children’s disease, which can be expressed by blaming nurses. The nurses relate this to the exhaustion felt by the families, their inability to support their children, their attitudes to the disease, and sometimes their exposure to other parents.

Another reason for conflict reported by nurses in the previous study was the inability to maintain professional boundaries because of the long periods that patients and their families stay in hospital (Citak et al., 2013). Nurses faced challenges in maintaining professional boundaries when they tried to balance their emotional involvement with the families and their professional roles. Consequently, the relationship between nurses and patients' families, particularly the children's mothers, tended to shift in a non-professional direction.

In Citak et al. (2013), however, it seems that there is some ambiguity about whether the inability to maintain professional boundaries negatively altered communications between nurses, child patients and their families. The study did not clarify the negative consequences that could result from greater intimacy or closeness between the nurses and the families, and this is a subject that could require further investigation. Finally, dealing with demanding and manipulative parents is another communication difficulty experienced by Chinese nurses, who felt that they were unprepared to deal with such situations (Papadatou et al., 2001).

Nurses did not agree on the degree and type of involvement they needed to share with their patients. (Cook et al., 2012) found different attitudes to professional boundaries when he studied how paediatric nurses look after dying children in an acute care cardiology unit in the USA. Nurses at this children’s academic tertiary-care centre differed in their views on professional boundaries. Some individuals created their own line of involvement which they would not cross; others stated that each case was unique and their responses were determined by the relationship they had with the patients and their families (Cook et al., 2012). The current study explores in depth the pros and cons of each approach to the degree of involvement between children, families, and health professionals.

Children's suffering during terminal illness would inevitably impact on their relationships with healthcare professionals and their own families. Parents report that their children expressed anger, apathy, and sadness toward their health care providers as signs of their suffering (Montoya-Juárez et al., 2013).

2.5.3.2.3. Inadequate communication skills

Several studies address nurses' wishes to acquire additional communication skills in order to help them to deal appropriately with families, especially in critical situations, such as informing families of sudden death, the transition from curative to palliative care, and discussing Don't Resuscitate status (Kilicarslan-Toruner and Akgun-Citak, 2013; Papadatou and Bellali, 2002; Papadatou et al., 2001; Yam et al., 2001; Amery et al., 2010; Chen et al., 2013; Lee and Dupree, 2008; Tubbs-Cooley et al., 2011; Peng et al., 2013).

As we have seen earlier, Papadatou et al. (2001) established that nurses find it difficult to communicate with dying children, particularly if the latter become withdrawn and depressed, and if the nurses are asked for a prognosis by the child or the family. Citak et al. (2013) adds that this breakdown in communication affects nurses negatively, and makes them lose motivation. Yam et al. (2001) found that nurses were at a loss as to how to deal with grieving parents and did not know how to comfort them. This lack of training led nurses to feel like uncomfortable bystanders, unable to offer the support parents obviously needed at a stressful time.

2.6. Conclusion and gaps in literature

The above literature review introduces a preliminary understanding of parental and health professional's experiences regarding their experiences of communication in the care of children with palliative care needs. Several gaps were identified in the existing literature that justify the need for further research.

Although there is a growing body of knowledge about communication with children with life-limiting and life-threatening illnesses, all of these studies focus only on one aspect of communication. For example, Citak’s (2013) study explores communication challenges reported by nurses who work with leukemic children in Turkey. Relatively less attention was given to the other aspects of communication such as breaking bad news, the types of discussion between parents and children, and communications about parental involvement in the decision making process.

Furthermore, the previous studies report communication challenges within different national cultures (e.g. Greece, Netherland, New Zealand, India, Canada, Sweden, China, Taiwan, Turkey, Uganda, and the US). However, Arab culture differs significantly from these cultures in many respects, and specifically with Western culture with regard to disclosing prognosis information to children. In Jordan, a traditional Arab culture, mothers do not see any value in revealing cancer diagnosis to their children (Arabiat et al., 2011), and this could negatively affect communications between the nurses and children. No Jordanian or Arabic studies were found that explore the experiences of communication faced by nurses or other health care professionals. This study will therefore be the first to shed light on this communication experience from the perspectives of Jordanian nurses, physicians, and family carers. This justifies the present study.

In addition, it is evident that there is a requirement for a multidisciplinary approach to research, which will provide those who work with children with appropriate evidence on a daily basis (Downing et al., 2015). It is important to investigate phenomena related to communication within hospitals from multiple perspectives, due to the fact that modern care is provided by multidisciplinary teams of health care providers, and it also involves the patients and their relatives. However, there is a need for more research into how communication is viewed by nurses, physicians and family carers in the area of paediatric palliative care.

Moreover, children who were treated in non-specialised cancer hospitals could be more likely to be exposed to a protective communication style by their parents and professionals. In the current study, the children were treated in a non-specialised hospital. This means that children with life-limiting and life-threatening conditions were mixed with children with acute illnesses. Therefore, the additional awareness the children could gain by communicating with other children in the same circumstances could be less than those with malignant diseases.

In Jordan, children with malignant diseases are usually treated in specialised hospitals, and this improves their opportunity to gain higher awareness. Although some literature acknowledges moving from close awareness toward open awareness among children with malignant diseases (Clarke et al., 2005), this perspective might be less applicable to children with other conditions, because they are more likely to be affected by the protection approach their environment adopts with them. The current study will investigate this issue in greater depth.

Finally, communication is a spontaneous and continuous social interaction that needs to be observed as a process in the field rather than as isolated individual experiences. The few studies found in the literature related to this topic did not focus on observation in order to increase their rigour, or using a variety of data collection methods suitable for the research objectives and questions.

CHAPTER 3: METHODOLOGY

3.1. Introduction

This chapter describes the research strategy that was adopted to explore the experience of communication in the care of children with palliative care needs. The chapter consists of several sections: the first highlights the philosophical position that informs the research strategy and design. The second addresses the study design, familiarising the reader with some details of the qualitative case study approach. This section also outlines how the case study and the units of analysis were determined. The third section gives a brief description of the setting where the study was conducted, followed by the sampling strategy employed. The fourth section describes the process of accessing and recruiting the participants. Participants' characteristics and demographical information are also provided in this section. The research methods employed are detailed in the fifth section. The sixth section portrays the strategy of data analysis used, including how data were handled and managed, and the technique of coding, with figures illustrating the coding process. Ethical considerations are given in section seven, including the different ethical principles that guided the collection of data. The eighth section presents the strategies used to enhance the trustworthiness of the study in detail. Finally, in the last section, I introduce my reflexive account to recognise how my social background and assumptions may have affected the findings of the study.

3.2. Philosophical underpinning of the study

The study is grounded in the interpretive constructivist tradition, which focuses on multiple subjective understandings of the social world, and how meaning is created by individuals through social interaction with each other, within particular cultural and historical contexts (Creswell, 2013b). The study explores family carers', physicians', and nurses' experiences of communication at the bedside of children with palliative care needs, in a Jordanian hospital.

In a constructivist worldview there are "local and specific co-constructed realities" (Guba and Lincoln, 1989: 195) resulting from the exchange of meaning, and interaction between groups of individuals. In this study, every participant had a particular perspective on communication experiences. For example, the nurses perceived themselves as having different challenges to the physicians, because of their different work conditions, while mothers focused on their children's situations, and may not have fully recognised the work conditions and challenges the health care staff faced. Furthermore, the groups of participants shared 'local' realities with each other. For example, the nurses shared views about several things, such as the hospital and work environment, which were different to those of other groups, such as the physicians. However, all participants had some common goals (e.g. the wellbeing and care of the child).

Crotty (1998) points out that humans imbue the world in which they live with meaning, based on their own experiences and cultural milieu. With this in mind, I designed the study to enable investigation of the phenomenon of interest – in this study, communication – within a specific context. This is congruent with the qualitative case-study research approach that is usually adopted when the phenomenon of interest involves real-life interactions and behaviours, events, processes, and relationships (Creswell, 2013a; Yin, 2012; Yin, 2014).

The emphasis of the case study approach is to include "thick descriptions" that go beyond describing facts and details (the surface appearance), but also include the intellectual efforts of the researcher to represent other people's constructions of their behaviours and actions (the underlying meaning of their action) (Geertz, 1973; Creswell, 2013a). Thick description goes beyond recording what participants are doing; it presents context, details, emotions, and the type of social relationships that connect people. It inserts history into experience and then establishes the significance of the experience or events for the participants. Thick description gives the researcher the tools to gather the voices, feelings, actions and stories of the participants – as well as take a holistic approach and record group interactions (Holloway, 1997; Denzin, 2001). Thin description, on the other hand, is a superficial description that does not explore the underlying meanings of the cultural members (Holloway, 1997).

During the data collection period of my study, especially during participant observation, I sought to include adequate details about the children's lives, education, and socioeconomic status in the form of field notes. I introduced this detailed information to the reader in order to let them feel and experience how the children lived within their contexts of hospital and home. I then tried to interpret their underlying behaviours, feelings, attitudes, and communication styles based on that background information. I interpreted the participants' hidden meanings, feelings, and intentions toward their actions during my narrative analysis of each case as well as during the cross-case analysis. This was helpful to enable the reader to experience the case and make naturalistic generalisations, which contribute to the transferability of the findings to similar contexts (Stake, 1995) (Section3.11.2).

Despite the high homogeneity of the Jordanian population in terms of having shared characteristics such as language and culture, there are still differences in attitudes and beliefs, due to factors such as family context, social class, and religious affiliation. The hospital recruited for this study receives patients from various social backgrounds, and so their experiences were expected to be different. Because of this, I investigated the phenomena of interest comprehensively, as the goal of this research is to rely as much as possible on the participants' views of their situations (Creswell, 2007). The health care providers also had different points of view, which were affected by several factors, such as their experience of working in hospitals and their level of education.

In constructivism, the role of the researcher as an active participant in the construction of meaning is recognised (Crotty, 1998; Watzlawick, 1984), and this entails assuming a reflexive stance (Evan and Kahn, 2000). Because I was the main data collection instrument in the research, reflexivity required self-awareness of my presence during the research process and how this could affect my interpretation of the findings (Primeau, 2003). During data collection, I had a continuous internal dialogue with myself about 'what I know' and 'how I know it' (Hertz, 1997). Having worked in a similar setting some years previously, I recognised the importance of being reflexive and understanding how my previous background (as a nurse and lecturer) and my previous assumptions (from my experience in a similar setting) affected my interpretations of what I experienced during the field work. Furthermore, I was sensitive to important situational dynamics between me and the participants that impacted on the creation of knowledge in this study (Section 3.12.).

According to Chen et al. (2011), constructionist research varies, depending on what is being constructed, into *objective* and *interpretive* constructivism (Chen et al., 2011). In objective constructivism, the real phenomena or behaviours are constructed, while in interpretative constructivism the meaning of phenomena is usually sought. For example, in objective constructivism, the focus is on why things occur as they do, whereas interpretive constructivism focuses on why things are defined as they are. For the purposes of this study, an interpretive constructivist approach is more appropriate, because the objective of the research is to explore the experiences and perceptions of nurses, physicians, and family carers regarding communication. This implies a meaning-centred approach (my interpretation as a researcher of their interpretation of their communication experience) rather than an explanatory approach (adopting a passive role when I explain their perceptions of communication).

3.3. Study design

3.3.1. Qualitative case study approach

A qualitative research approach can be adopted when we need to understand a complex phenomenon or experience (Creswell, 2013a; Cridland et al., 2014). This understanding can be gained directly by talking with participants at their homes or places of work and allowing them to talk about their experiences, without being influenced by previous assumptions or what we read in the literature (Krogh and Lindsay, 2009; Creswell, 2013a). In addition, when involving children, a qualitative approach is considered to be more appropriate as it actively engages them in research but also investigates their rich thoughts and feelings (Dockett et al., 2009; Mishna, 2004).

According to Creswell (2013a), there are five major research approaches to be considered when planning a qualitative research study. The main difference is in what any study is trying to accomplish, or their objectives. For example, the focus of narrative research is to explore the life of an individual, and it is usually best used when it captures the detailed stories or life experiences of a single or small number of individuals (Immy and Dawn, 2009). In the phenomenological approach, the objective is to understand the common meaning of several individuals' life experiences in relation to certain concepts or phenomena (Creswell, 2013a). It involves the construction of social reality through the perspectives of those who live the situation (Stubblefiel and Murray, 2002). Thus, phenomenology is usually grounded in the belief that truth can be found in the human experience and separation between truth and human experiences is not possible (Levasseur, 2003). Ethnography is defined as the study of the social interactions of cultural groups such as societies, organisations, communities, and teams (Reeves et al., 2013). Using this approach, the researcher describes and interprets the shared culture within certain groups (Hammersley and Atkinson, 2007; Spradley, 1980). Although ethnography is mainly a research design of anthropology, it is also adopted by other different fields such as sociology, nursing, and education (De Chesnay, 2014). The aim of grounded theory is to unveil theory that is grounded in data in an inductive manner (Byrne, 2001; Lewis, 2015). Finally, the case study approach gives an in-depth description and analysis of a case or multiple cases (Stake, 1995; Yin, 2009).

The research aims and questions of the project usually decide which type of qualitative approach is the most suitable (De Chesnay, 2014). The aim of my study is to explore communication phenomena in great depth. Communication is a contemporary event that it is best investigated using observational techniques rather than focusing on investigating the past experience of individuals, as in phenomenology, or exploring the life of individuals such as those in narratives. Moreover, the aim of my study is particularly centralised on communication phenomena rather than studying the entire culture of a certain group. Thus, I excluded ethnography. Finally, as my objective is not to develop a certain theory that is grounded in the experiences of certain people, I excluded grounded theory as well. Communications are context-based phenomena that are difficult to investigate if they are isolated from their original context (Baxter and Jack, 2008). The case study approach enabled me to ensure that the phenomenon of communication was explored using a variety of lenses instead of only one. This allowed me to capture the multifaceted nature of the communications (Baxter and Jack, 2008).

According to the research questions, the most appropriate strategy to adopt in this study is the qualitative collective case study. The focus of my research is to explore how nurses, physicians, and family carers describe their experiences of effective communication, facilitators, and challenges regarding communication in the care of children with palliative care needs. Furthermore, considering the interpretive constructivism worldview, which states that there is no single truth, triangulation was applied by finding and documenting the different perspectives of participants (nurses, physicians, and family carers) (Table 8).

Table 8: Rationale of using the case study approach in the current research

Rationale of using the case study approach in this study	Application to the research study
Allows the investigator to retain the holistic and meaningful characteristics of real-life (contemporary) events, such as group interaction and behaviours.	The aim of this research is to understand the experience of communication issues as perceived by nurses, carers, and physicians who work with children with palliative care needs. Communication with a child in a hospital setting is a contemporary real-life event.
The nature of the research questions is focused on 'how and why' inquiry (Yin, 2012; Yin, 2013; Yin, 2009).	The research questions focus on how nurses, carers, physicians describe their experience of communication with children.
To understand and investigate the phenomena in depth, encompassing important contextual conditions (Lucka et al., 2006; Salminen et al., 2006). Contextual conditions should be included because they are significantly relevant to the phenomenon under study.	Communication with children could not be separated from its context, the hospital, and more specifically the medical, surgical and PICU settings where the interactions occur. It would be impossible for me as a researcher to evaluate communication with children out of context.
The boundaries between the behaviour (phenomena) and context have not been clearly mapped out.	The boundaries between communication phenomena and context are not clear.
It is difficult to manipulate the behaviours of the individual involved in the study.	Communication behaviours are real life events which are difficult to manipulate.

The case study methodology is more flexible than any other qualitative approach (Hyett et al., 2014; Meyer, 2001; Rosenberg and Yates, 2007; Houghton et al., 2015). Therefore, it can be used as an exclusive method of research or as an adjunct to larger studies (Anthony and Jack, 2009). The literature displays a wide diversity of case study designs because of the absence of specific requirements guiding case study research (Hyett et al., 2014; Meyer, 2001; Houghton et al., 2015). This might be seen to be a strength as well as a weakness of the case study design (Meyer, 2001). The strength is in terms of the researcher being able to tailor the design and data collection procedure to the research questions, and the weakness is in terms of being exposed to criticism when rationale for methodological decisions may be perceived as weak, thus affecting which might affect the methodological rigour of the study (Rosenberg and Yates, 2007). Therefore, it is very important to demonstrate rigour by providing adequate details of the study design and an appropriate rationale of key methodological decisions including the paradigm and theoretical perspectives that influenced the study design (Hyett et al., 2014; Meyer, 2001; Sandelowski, 2000).

One of the most important strengths of the case study design is its emphasis on the use of several methods of data collection, which enables the gathering of evidence from multiple sources to gain a richer picture about the research phenomena, thus improving the rigour of the findings (Pagram, 1999; Baxter and Jack, 2008). In the current study, data were gathered by using two methods: participant observation and semi-structured interviews.

The qualitative case study approach has been explored in depth by two main writers (Stake, 1995; Stake, 2006; Yin, 2012; Yin, 2014; Yin, 2009). Stake adopts a social constructivist approach, while Yin adopts a case study approach from a post-positivist point of view (Creswell, 2013b; Hyett et al., 2014). Although Yin (2009) acknowledges the use of quantitative evidence within a case study approach that strives to arrive at broad generalisations, especially within multiple case studies, he still acknowledges the value of interpretive perspective in the qualitative case study strategy (Brown, 2008). Stake (1995), however, concludes that a qualitative case study approach could be more suitable if the purpose of the research is to understand the experience and increase our knowledge of certain phenomena.

Stake (1995) asserts that the objective of a case study design is not to seek generalisation of the findings to other cases; instead, the focus is to understand these particular cases (particularisation instead of generalisation) and provide in-depth insights of the case study context. This enables transference of some of the key findings to other similar situations. Because the purpose of this study is to understand the experience of communication in greater depth, Stake's philosophy of interpretation was considered for this study, along with some aspects of Yin's methodological approach, especially regarding the research design.

3.3.2. Collective case study design

According to Stake (1995), there are three categories of case study design: intrinsic, instrumental, and collective (Stake, 1995). Intrinsic case studies focus on gaining a deep understanding of a case due to its particularity. This is guided by the researcher's interest in that case, not for learning about other cases, explaining certain problems or extending theory, but because we need to learn about that specific case. Therefore, any expectations that may arise will not have implications for other case studies.

When the objective of understanding a case is to understand certain phenomena or to provide insight into an issue, this is called an instrumental case study. This is useful for addressing research questions which need a general understanding, and we believe that we may have insight into the question by studying a particular case. Therefore, the focus is not the case itself (the case is secondary); rather the purpose of the study might be to understand certain phenomena or to answer a research question.

The third type of case study is the collective case study, in which a number of instrumental cases are examined in order to gain deep insights into a particular phenomenon. In collective case study research, each case is instrumental in getting a deep insight, but there will be an important coordination between the individual cases (Stake, 1995; Stake, 2006). In the present study, a collective design was adopted, as it speaks to the study questions, which investigate the phenomena of communication by investigating several cases rather than focusing on a case because of its particularity. This design will, therefore, help to gain an in-depth insight into the experience of communication in the care of children with palliative care needs.

3.3.3. Determining the case and units of analysis

According to Stake (1995), a suitable case for case study research should be a well-bounded, specific, complex, and functioning "thing" (e.g. a person or a programme). The case also can be some event or entity other than a single individual (Thomas, 2011; Yin, 2009). It was defined by Miles and Huberman (1994) as a "phenomenon of some sort occurring in a bounded context". The case is "in effect [the] unit of analysis" (p. 25). In order to determine my case, I asked myself what is the thing that I will analyse? Is it the child (individual) or communications (phenomena) (Baxter and Jack, 2008)? Accordingly, I defined the case in my study as 'communication-related experiences of the nurses, family carers, and physicians involved in the care of children with palliative care needs'.

In order to deeply understand the experience of communication in this context from different perspectives, there were several units of analysis for each case, including nurses, family carers, and physicians. Figure 5 illustrates the participants of each case study. The context of the cases includes the paediatric ward departments (medical, surgical, and PICU) and the hospital as a whole. The dashed lines which separate the cases from contexts indicate that the boundaries between the cases and their contexts cannot be separated. In this study, a typical case consisted of:

- The child with palliative care needs;
- One or more family carers (e.g. mother, grandmother);
- One physician;
- One or more nurses.

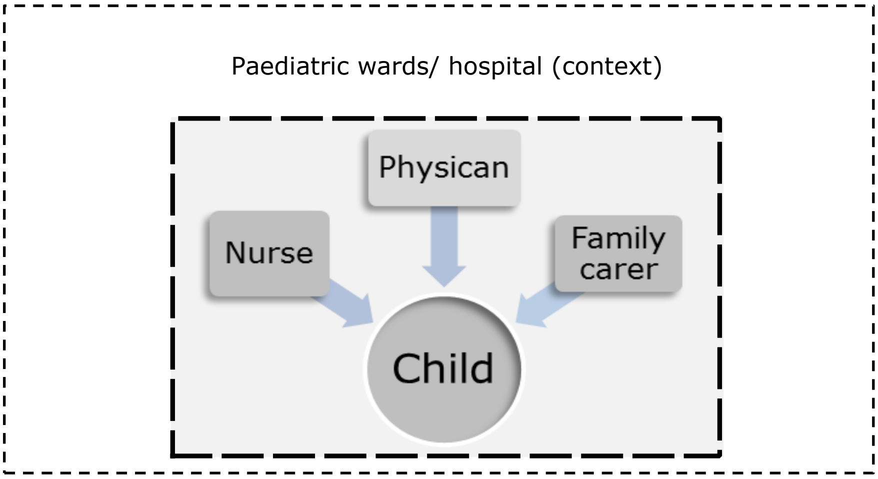


Figure 5: A typical case study

According to (Creswell, 2013b; Miles and Huberman, 1994; Stake, 1995; Thomas, 2011), it was suggested placing boundaries on a case to avoid answering questions that are very broad, and ensure that the investigation remains reasonable in scope. Creswell (2007) argues that cases should be demarcated on the basis of time and place; Stake (1995) offers another suggestion: demarcation by time and activity. Finally, Miles and Huberman (1994) suggested limiting the case by definition and context. In the current study, I bounded the collective cases I recruited by the determinants shown in Table 9.

Table 9: How I bounded case studies recruited in my study

Item	Application on my study
Time	Within 9-12 months of data collection period.
Context	Paediatric units in one Jordanian hospital.
Activity	Participant observation and interviews (individual and joint).
Definition	Communication-related experiences of the nurses, family carers, and physicians involved in the care of children with palliative care needs.

3.3.3.1. The number of cases

Regarding the number of cases that should be taken in the case study, Creswell (2013a) stated that the more cases in one study, the less depth there will be in any single case. However, Stake (2006) pointed out that the benefits of a multi-case study will be limited if there are fewer than four cases, as they will not show enough interactivity between cases with their situations. More than 15 will provide more uniqueness of interactivity than the research team and readers will be able to understand. As my objective was to gain in-depth understanding of the phenomenon of interest (communication) rather than to generalise these data, the initial plan was to recruit up to ten cases, based on the guidance of Stake (2006). However, because of the difficulty of knowing the exact time of hospitalisation for each child, I recruited several families to case studies who only stayed at hospital for one day, and this affected my ability to gain an in-depth understanding of them. I was not able to predict that some families would discharge against medical advice (such as Basil) while another child died on the second day of my recruitment (Nagam) (see

Section 3.8.). Because of this I made the pragmatic decision to continue to recruit further cases until I reached saturation of data.

3.4. The setting of the study

Jordan has a four-tier health system comprising the Ministry of Health, Jordanian Army, Ministry of Higher Education and private health sector (World Health Organisation, 2011) (Figure 6). The main difference between these sectors is the degree to which the government underwrites health insurance; the public sector is completely covered by the government, and so is essentially free for those who have a governmental health insurance. However, this sector is considered to be overburdened (Zamil et al., 2012). The private sector receives no direct government funding (although some programmes or patients receive subsidies), and provides high quality premium health services (Zamil et al., 2012). The university hospital sector is partially covered by the government, and falls somewhere between the mainstream public and private hospitals in terms of the cost of the health services it provides.

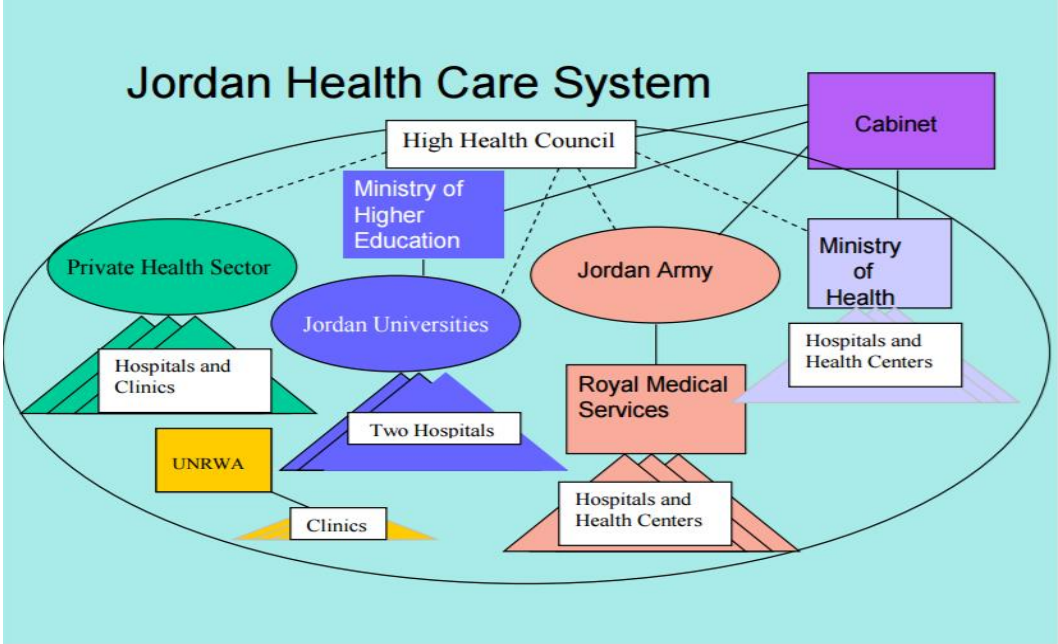


Figure 6: Jordan’s health care sub-systems. Source: (WHO, 2011:24)

The rationale behind choosing this study hospital in particular was that it is one of the major university hospitals in Jordan, which provides health services for a large and varied proportion of the population. Health services are highly concentrated in Jordan's major cities, reflecting the demographic concentration (i.e. urbanisation) of the population, which makes this hospital a major healthcare provider. Moreover, the transferability of the findings into other settings is expected to be higher in this health sector as it is accessible by almost all social classes in Jordanian society.

This study conducted on a 500- bed capacity public hospital in Amman, Jordan (Mostaqbal's Legacy, 2013). The hospital includes three paediatric departments: the medical floor, surgical floor, and paediatric intensive care unit (PICU) (see Table 10). All paediatric departments were considered in this study in order to increase the diversity of the case studies across the hospital context. This gave the study a more in-depth understanding of the phenomenon (Stake, 2006).

Table 10: Medical, surgical, and PICU departments

	Medical department	Surgical department	PICU
Examples of patients admitted to this department	Cerebral palsy, Cystic fibrosis, End stage renal disease (ESRD).	Neural tube deficit, hydrocephalous.	All patients that need intensive care.

Most cases (n=10) were recruited from the medical paediatric department, which receives a wide range of paediatric conditions. The capacity of this ward is around 40 beds. Two cases were recruited from the PICU, a small unit with a four-bed capacity located in the medical floor, which follows the medical ward administratively. One case (Baraa, case no. 15) was recruited in the medical floor at the beginning of the study; Baraa was then transferred to the PICU because of the deterioration of his condition (uncontrolled hypertension). Two cases (involving Rosol and Mousa) were recruited in the surgical floor, which is separate from the medical department (see Table 14).

3.5. Sampling

3.5.1. The decision of whether to Interview children in the study

The decision of whether or not to interview children in the current study was not straightforward. It is essential to weigh up the risks and benefits of interviewing them (Jokinen et al., 2002) to protect them from any potential harm (Kennan et al., 2012). Although currently there is no consensus on including children in research, concerning their health and wellbeing (Helseth and Slettebø, 2004; Lambert and Glacken, 2011), according to the declaration of Helsinki, research involving children should be limited, with special justification related to their health (World Medical Association, 2000).

In qualitative health studies, participants are usually asked to discuss specific topics, which rarely cause substantial physical harm. However, there is still potential for emotional and psychological risk during the research process (Helseth and Slettebø, 2004; Jokinen et al., 2002; Kankkunen et al., 2002). In the current study, interviewing children would have had the potential to cause them significant emotional harm, as the interviews might force them to recall painful memories and events, or discuss sensitive issues concerning death and end of life issues (Helseth and Slettebø, 2004; Jokinen et al., 2002; Kankkunen et al., 2002).

Moreover, Jordan has no laws to protect the rights and welfare of children, and other vulnerable groups, when it comes to participate in research (Ramahi and Silverman, 2009). I decided to avoid interviewing children in the current study in order to avoid any potential harm to them.

3.5.2. Sampling strategy

The cases were chosen by identifying children first via the clinical staff and then building up a case around them. A purposeful sampling strategy was adopted to find children in order to build up the whole case. Because of their limited number, and because they were treated in non-specialised palliative care units, as well as being admitted to hospital in different times, it was difficult to make comparisons and take samples based on certain characteristics (i.e. maximum variation sampling). Therefore, their recruitment was based on their presence in the hospital specifically when they were admitted to the previously-mentioned departments where the research was conducted, as shown in Table 11.

Table 11: Sampling strategy for the multiple case study design adopted for this study

Participants	Adopted strategy	Rationale
Children	Purposeful sampling strategy They were chosen when they were admitted to the hospital, specifically to the previously-mentioned paediatric departments.	This hospital has no specialised unit for palliative care for children; therefore, children are usually admitted to hospital at different time periods, consequently, it is difficult to make comparisons and take samples based on certain characteristics.
Health care professionals	Identified with the help of the families who agreed to participate in the study.	The familes of eligible children have more experience with the health care professionals, who are the most involved with the care of their children.

3.5.3. Inclusion Criteria

Table 12 demonstrates the inclusion criteria adopted when recruiting the study participants with the rationale:

Table 12: The inclusion criteria adopted when recruiting the study participants

Inclusion Criteria	Rationale
Children aged between 1-12 years old.	I excluded infant and adolescents age groups as their communication with their parents and health care providers is significantly different from other age groups of children. This is supported by (Young, 2013).
Admitted to the hospital's paediatric units diagnosed with a condition eligible for palliative care.	See Section 1.2.7 to identify conditions that satisfy eligibility for children's palliative care.
Agree to participate in the study and their children give assent for researcher to build up the case around them and to be observed by the researcher where applicable (school age children).	Assent refers to "acquiescence" (Royal College of Paediatric and Child Health, 2000). Children are considered able to give assent if they are over 6 years old with a health status that enables them to decide whether to participate (Cree et al., 2002; Jokinen et al., 2002; Royal College of Paediatric and Child Health, 2000).

3.6. Access and recruitment

3.6.1. Access to the prospective participants

After receiving ethical approval from the recruited hospital, I met the heads of the medical and nursing units to explain the aims and objectives of the study. I then met the head nurses of both medical and surgical paediatric floors (gatekeepers) to seek their assistance in terms of approaching the parents of the children who were eligible to participate in the study, to discuss the aims and objectives of the study. They welcomed participation in the study and demonstrated their intention to help. The cooperation of the professional gatekeepers helped me to gain the cooperation of other professionals and key people and smoothed the path of my research (Holloway and Wheeler, 2002).

To obtain and maintain access to the study participants, it was important to inform all professional gatekeepers about my research study, therefore with the cooperation of the head of medical and nursing departments of both floors, an announcement of the research was put on the bulletin board of each department, enabling the health care providers to get an idea of the research. Moreover, an internal memo was sent to both medical and nursing staff on both floors. I gave copies of an Arabic version giving a brief description of the study to the heads of both nursing departments to be disseminated among nurses assigned for admission rooms in both departments, and those gatekeepers verbally discussed the study during the normal hospital policy identification session that is usually given for all new admissions.[3]

The head nurses of the paediatric departments nominated charge nurses to assist me in approaching parents about participating in the study when they were not available themselves. This facilitated the recruitment process and reduced the 'gatekeeping effect', as the approach to the parents concerning the study was made by different health care providers, thus eliminating some possible bias (see Section 3.6.2).

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[3] The hospital policy identification session is a routine educational session given by an assigned nurse in the department to inform children and parents about the hospital policy, their rights and duties, and safety issues such as the location of emergency exits in the department etc.

To enable the head nurses to approach parents about the study, I gave them some important documents, such as an information sheet, inclusion criteria, a list of eligible cases and copies of Arabic version leaflets to be given to all newly-admitted cases. These documents helped them to identify the parents of eligible children so that they could approach them for further discussion of the study. The children's names and details were hidden from me until they agreed to be approached for informed consent to participate in the study (Stalker et al., 2004; Jokinen et al., 2002). Those who showed an interest in the study agreed to be approached for their permission to participate. They were asked to meet me so that I could provide further details, answer any questions they had, and ask their permission to develop a case study around their child. This included gaining their consent to be observed and interviewed.

Subsequent to discussing the aim and objectives of the study and asking their permission to participate, every parent received an invitation letter as well as a written information sheet and consent form (see Appendices B & E). They were encouraged to take the time needed (approximately three days) to decide whether to accept or not and to consult other people to get their opinion. However, the majority of participants gave me their decision the same day.

In addition, after getting the parents' permission to approach their children for the study, those children able to give assent [4] (Basil, Latifa, Sewar, Issa, Hala, Amjad, Firas, and Qusai) were asked for permission to build up the case study around them as well as to be observed (see Table 14). Nagam, Issa, Rashad, and Qasim were unable to give permission because their health conditions reduced their ability to do so, despite them being of appropriate age to give consent (school age). Their parents decided on their behalf.

All the parents who agreed to take part in the study signed a consent form prior to joining. Furthermore, arrangements regarding the place and time of the interviews were made. The majority of parents preferred to be interviewed at the bedside in order to keep themselves close to their children. The parents

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[4] See Section 3.10.2.1 for further details about obtaining informed assent from children.

of eligible children were asked to nominate the physicians and nurses most involved with their children's care.

I gave invitation letters, which included information sheets and consent forms, to those nurses and physicians that were eligible to participate in the study (see Appendices C, D, F, and G). I contacted the nurses and physicians who agreed to participate in order to discuss the study, sign the consent forms and determine the time and place of the interviews. The observational period was very accommodating for the majority of health care providers, and I did not face challenges when I asked them to participate.

Indeed, of those who were asked to participate, only one health care provider declined. Five parents refused to participate, all of whom were approached at the paediatric medical departments. I approached two newly-admitted mothers personally; one of them gave her consent after one day of being approached, however she changed her mind after consulting her husband and her relatives. I respected her right to withdraw from the study at any stage. The other carer I approached did not expect a prolonged study period, especially the observation phase, as she expected her child to be discharged after one or two days. The charge nurses who approached the other three carers who refused suggested what might have contributed to their refusal. One of them was a new admission to the hospital who had transferred in from another hospital. She was not oriented in the department and the nurses did not know her well. The second carer had some family visitors at the time of being approached by the nurse, which might have put her under some social pressures. The last carer preferred not to disclose her reasons for not participating in the study (see Figure 7: A summary of the recruitment process of the study)

3.6.2. The gatekeeping effect

Gatekeeping may influence research studies in several ways. For example institutional gatekeepers (e.g. an ethical committee) can limit the conditions of entry, and access to data and respondents can be restricted by professional gatekeepers (e.g. the heads of medical and nursing departments) (Broadhead and Rist, 1976).

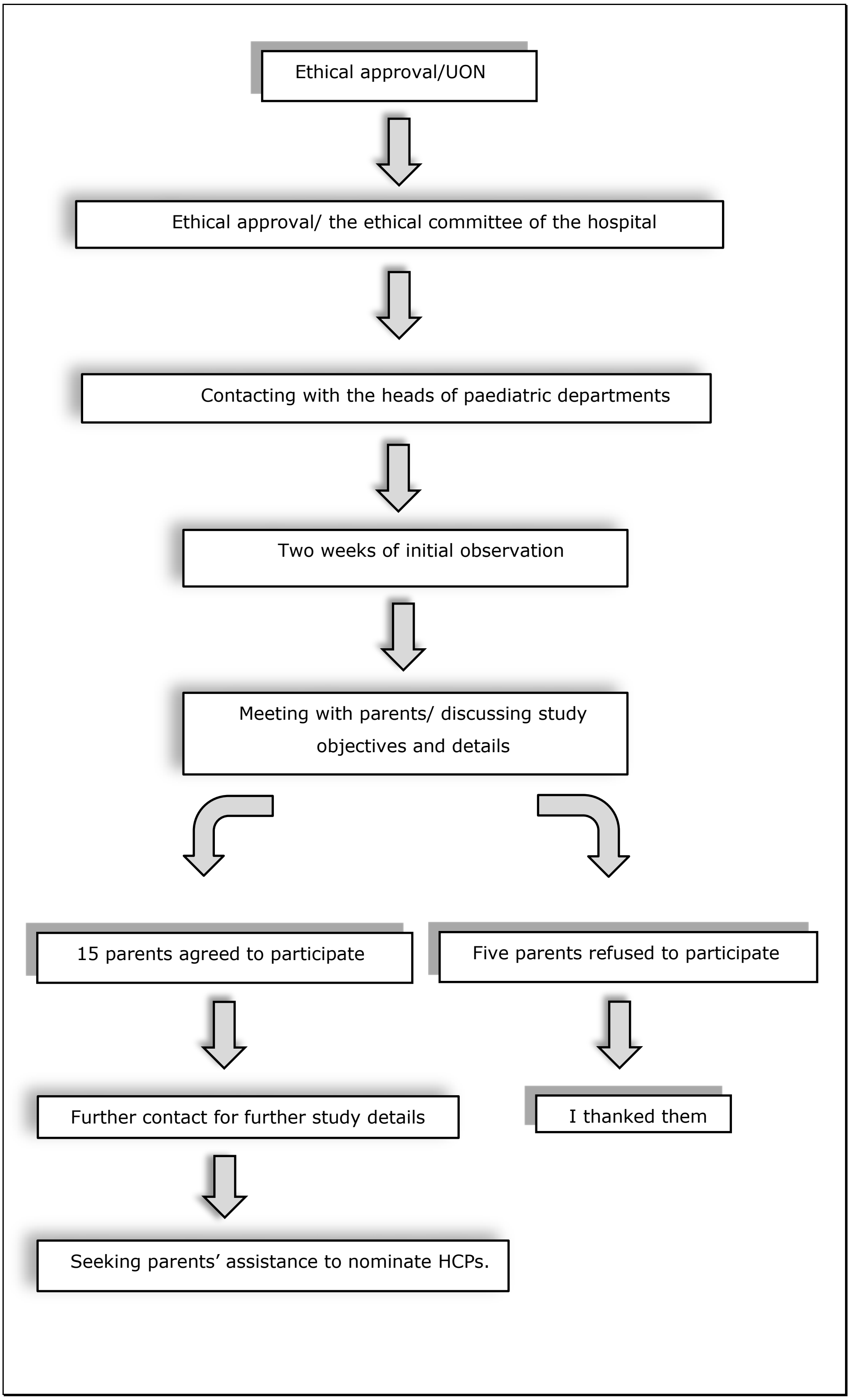

Figure 7: A summary of the recruitment process of the study

In order to overcome such gatekeeping barriers I tried to involve health care professionals in my study from the outset, including in my informal conversations with them (Hudson et al., 2005). I continuously discussed research issues and challenges, seeking their opinions to develop a sense of ownership.

Throughout these discussions, I informed them and listened to their feedback about the recruitment process. This reduced misunderstandings and misconceptions about the research. I also reminded the professional gatekeepers that they had the opportunity to withdraw from the study at any time if they felt themselves to be overwhelmed with their routine tasks (Hudson et al., 2005).

In addition, having more than one gatekeeper distributed throughout the recruitment shifts eliminated gatekeeping issues resulting from the gatekeepers' relationships with the families (see Table 13). As a researcher, I had a role to ensure that the gatekeepers were not violating ethical research principles. In spite of being sometimes unavoidable, this has negative consequences, such as the restriction of patient autonomy and negative effects on the research quality (Hudson et al., 2005).

Table 13: Factors in the gatekeeping effect

Family factors	Family-clinician contact and relationship	Clinician factors
Wellbeing and circumstances. Engagement and communication with health care professionals. Anticipation reaction to participation.	Family-clinician contact. Family-clinician relationship.	Available time. Confidence. Forgetting/ remembering to introduce study. Perceived benefits of the study to patient/ family.

3.6.3. Participants' characteristics

3.6.3.1. Children's details

The majority of children recruited in the study were school-aged.[5] Three of them were toddlers (Rosol, Mousa, and Suha) and one was a preschool child (Baraa). Nine were boys and six were girls, with varying diagnoses. Children with renal disease were the most numerous,[6] followed by those with neurological conditions (Rosol, Mousa, Issa, Rashad, Qasim and Suha). Finally, one child with congenital heart defects (Issa) participated (see Table 14 for further details).

3.6.3.2. Participants' details

The characteristics of study participants groups are presented in Table 15. A total of 15 family carers participated in the study, all of whom were mothers (n=15). Moreover, three other relatives who assisted the mother in the care of the child (father, maternal grandmother, and sister-in-law) participated in the joint interviews conducted with the mothers. In Rosol's case, there were two family carers, the mother and grandmother. The mother was the main carer; however, the grandmother came to stay to enable her daughter to take a rest at home. Other children (Nagam and Sewar) were visited by some of their relatives, such as Nagam's father and Sewar's sister in-law during the period of data collection, therefore they participated in the joint interviews held with mothers.

The majority of mothers were housewives, two of them school teachers, and one was a university student. In terms of education, the majority of the family carers finished primary or secondary school and then quit school in order to take care of their children. However, three of them were graduates and two of them had a higher diploma. There were 33 health care provider participants. Nurses were the most involved participants (n=21), followed by physicians (n=12). Among the physicians who participated in the study, there were seven

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[5] Basil, Nagam, Latifa, Sewar, Issa, Hala, Amjad, Ragad, Firas, Qusai, and Qasim.

[6] Basil, Nagam, Latifa, Sewar, Hala, Amjad, Firas, Qusai, and Baraa.

specialists and five residents. The nurses' areas of work varied significantly: there was one head nurse, two first charge nurses, seventeen registered nurses, and one practical nurse. The majority of nurses were bachelor's degree holders in nursing (n=17). Only one nurse had a high diploma (two years). Three nurses were master's degree holders.

Table 14: Children's significant details

Case no.	Pseudonym	Gender	Age	Diagnosis	Consent taken From	Setting
1.	Rosol	♀	13 Months	Meaningomyelocele hydrocephalus	Mother	Surgical floor
2.	Basil	♂	10 yrs.	Nephrotic syndrome	Mother	Medical floor
3.	Nagam	♀	7 yrs.	ESRD	Mother	PICU
4.	Latifa	♀	6 yrs.	ESRD	Mother	Medical floor
5.	Mousa	♂	2 yrs.	Hydrocephalus	Mother	Surgical floor
6.	Sewar	♀	10 yrs.	ESRD	Mother	Medical floor
7.	Issa	♂	9 yrs.	TOF ICA Seizure	Mother	Medical floor
8.	Hala	♀	12 yrs.	Nephrotic syndrome	Mother	Medical floor
9.	Amjad	♂	12 yrs.	Nephrotic syndrome	Mother	Medical floor
10.	Rashad	♂	15 months	Cerebral Palsy	Mother	Medical floor
11.	Firas	♂	10 yrs.	Nephrotic syndrome	Mother	Medical floor
12.	Qusai	♂	11 yrs.	Nephrotic syndrome	Mother	Medical floor
13.	Qasim	♂	9 yrs.	Cerebral Palsy	Mother	Medical floor
14.	Suha	♀	12 Months	Cerebral Palsy	Mother	PICU
15.	Baraa	♂	3 yrs.	ESRD	Mother	Medical floor & PICU

Table 15: Characteristics of study participants groups

Category of participants	Characteristics	Number
Family carers	Age group (years)	
	20- 30	3
	31-40	3
	More than 40	9
	Relationship to child	
	Mother	15
	Marital status	
	Married	15
	Widow	
	Divorce	
	Literacy level	
	Primary level	4
	Secondary level	5
	Diploma (2 years)	2
	University student	1
	BSc	3
	Occupation	
	Housewife	12
	Teacher	2
	Student	1
Physicians	**Speciality**	
	Specialist	7
	Resident	5
Nurses	**Level of occupation**	
	Head nurse	1
	Charge nurse	2
	Registered Nurse	17
	Practical nurse	1
	Level of education	
	MSc	2
	BSc	18
	Higher diploma	1

3.7. Research Methods

One of the major characteristics of the case study approach is the use of multiple sources of data collection, which produces data of greater reliability than would be obtained using a single source of information (Stake, 1995). Based on Lincoln and Guba (1985), using multiple data sources improves the dependability of the findings, which is one criterion of the trustworthiness of qualitative research (see Section 3.11.3).

The current research is mainly focused on participant observation and semi-structured interviews. Moreover, there were informal conversations during the observational period, which provided another source of data. Using multiple data sources provided richer and more inclusive insights into the experience of communication from the perspectives of family carers, physicians, and nurses.

This study began with a preliminary period of observation in order to build rapport with the study participants and understand the context of every case. During the observations, some informal conversations were documented as field notes. At the end of the observation period, or shortly afterwards, digital recorded interviews were arranged to undertake a more formal semi-structured interview with the adult study participants.

3.7.1. Participant observation

Participant observation is usually used to triangulate the information taken in interviews (Merriam and Tisdell, 2015). It is different from the interview, as it presents a first-hand encounter with the phenomenon. This is contrary to the interview, which gives a secondary source of understanding the phenomenon (Merriam and Tisdell, 2015). In this study, participant observation was implemented to observe the communication between family carers, nurses, and physicians with each other as well as with the children within the context of the paediatric departments of the recruited hospital.

Unstructured observation was employed as this is congruent with the interpretive constructivist approach. This acknowledges the importance of the context in which knowledge is constructed between the researcher and the 'researched' (Mulhall, 2003). In the early stages of the research, I had general ideas of what to observe (communication between the nurses, family carers, and physicians). I tried, therefore, to observe and record as many notes as I could. However, as the study progressed, the observation became more focused (Hammersley and Atkinson, 1995; Schensul and LeCompte, 2013; Spradley, 1980). The physical environment and context of the interaction was considered as well. As a researcher, I needed to clarify my role as an observer within the research field. Based on Gold (1958), researchers may be classified into four categories according to their roles of observation and to what extent the participants are informed about the observation (Table 16).

Table 16: The role of the researcher in observational studies adapted from (Gold, 1958)

Classification	The role in the field of observation	Informed consent/ deception
The complete observer.	Maintains some distance, does not interact with participants.	The role is concealed from the participants.
The complete participant.	Interacts within the social situation.	The role is concealed from the participants.
The observer as participant.	Undertakes intermittent observation alongside interviewing.	The role is known.
The participant as observer.	Undertakes prolonged observation and is involved in all activities in the organisation.	The role is known.

In this study, I adopted the role of participant as observer for ethical reasons, and I did not conceal my role as a researcher. In order to improve the outcome of my observations, my initial plan was to participate in simple nursing activities as well as accompanying the assigned nurses as they carried out their care duties. The idea of this was to help me gain insights into the interactions between nurses, children, and parents (Kawulich, 2005). However, it was difficult to keep to one role throughout the whole period of observation (Mason, 2002; Mulhall, 2003). For example, in some circumstances I needed to adopt the observer role, such as when I attended a consultation session between the family and the physicians. In other circumstances, I took on the participant role in performing certain nursing tasks, such as double checking with nurses on the calculation of medication doses. Therefore, I would locate my role within the participant-observer continuum based on the situation and my ability to perform both roles (Mason, 2002; Mulhall, 2003; Patton, 2002).

To identify my role during the research, I introduced myself as a researcher who had clinical experience in paediatric settings. Moreover, I clarified that I currently had no formal nursing role and that my main role was as a researcher. This reduced the power imbalance between me and the participants. However, it was difficult to control the way people perceived my identity in the field (Mason, 2002). This was very clear with cases 6 and 15. I had worked with Sewar and Baraa as a nurse a few years previously, and several times I felt that the family carers of the two children saw me as a nurse, or sometimes as a friend. Therefore, I continuously reminded the participants of my main role as a researcher.

Observations were undertaken during the morning or afternoon shifts.[7] The night shift was excluded from the study in order to prevent any sleeping disturbances to the patients and their families. The preliminary observation period (around two weeks) was very helpful in terms of getting myself known, building rapport, and gaining broad consent from the health care providers. Informal conversations and socialisation were helpful in this regard (Balsiger and Lambelet, 2014). In addition to the preliminary observation period, I gained permission to attend some consultations with doctors/residents as well as observing and accompanying the assigned nurses during their work with the participants.

3.7.1.1. The observational field

I kept the focus of my observation on the cases that met the study's inclusion criteria and those who agreed to participate in my study and their context. I did not observe any other interactions related to other patients who were not included as cases in my study. Obtaining informed consent from all who came to these units was not practical (Watts, 2011). However, I thought that it was important to inform all occupants on the wards about the study. Thus, I

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[7] The hospital morning shift runs from 7 a.m. to 3 p.m.; the afternoon shift runs from 2 p.m. to 11 p.m.

prepared a research leaflet that included information about the nature of the research (Watts, 2011). Nurses who were assigned to the new admissions were given copies of an Arabic version of the leaflet for distribution to all newly-admitted patients. The nurses were also asked to give a brief verbal description of the study during the hospital policy identification session. Furthermore, if these ward occupants refused to be observed by me,[8] the nurses offered them the option to opt out of the observation field (mainly the nursing station, doctor's office and participants' bedsides). I did not document any information except that related to the children for (and from) whom I obtained consent, in order to protect the confidentiality of the other children. However, I did not receive any information that any family or health care providers asked to opt out of the observational field of my study.

3.7.1.2. Observational period

In order to achieve the saturation of the data collected for each case, I budgeted for the observations to take enough time (i.e. not less than one week per case). Moreover, I planned to join the shift from its beginning, to help me to observe the interaction between nurses and other participants during the shift handover. However, I found it difficult pragmatically to observe the same case for one complete shift, for several reasons. For example, the nurse I accompanied during the participant observation was assigned to several patients that were not included in my study.[9] Therefore, she often became busy performing procedures for them, or even receiving new admissions. I found it difficult to accompany her for the whole shift, because I needed to protect the confidentiality of the other children and their families, so instead I spent this time with the family carers of the participating children. However, it was not appropriate to stay with family carers for long periods (more than three hours) as they could become busy receiving visitors, making phone calls, going to eat, and other activities. Although they did not disclose

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[8] Although I did not wish to observe children who were not participants in the study, it could happen without my intention. For example, I could see them while I worked with the assigned nurse at the nursing station; however, they were not of interest to me as they were not part of the study.

[9] In this hospital, a paediatric nurse is usually assigned to 8-20 patients; the nurse-patient ratio in paediatric ICU is up to 1:4.

this to me due to cultural sensitivities that venerate the rights of the guest (which was how they regarded me), I was aware that sometimes they wished me to leave. Therefore, I used to stay around 2-6 hours per shift, except when I worked with more than one child, when I stayed for a longer period. Further details regarding the length of participant observation for each case are shown in Table 17.

Table 17: The length of the participant observations in the study

Case no.	Pseudonym	Setting	Approximate time of P.O (hrs)
1.	Rosol	Surgical floor	25 hrs.
2.	Basil	Medical floor	3hrs.
3.	Nagam	PICU	4 hrs.
4.	Latifa	Medical floor	5 hrs.
5.	Mousa	Surgical floor	30 hrs.
6.	Sewar	Medical floor	20 hrs.
7.	Issa	Medical floor	9 hrs.
8.	Hala	Medical floor	17 hrs.
9.	Amjad	Medical floor	6 hrs.
10.	Rashad	Medical floor	9 hrs.
11.	Firas	Medical floor	9 hrs.
12.	Qusai	Medical floor	12 hrs.
13.	Qasim	Medical floor	6 hrs.
14.	Suha	PICU	20 hrs.
15.	Baraa	Medical floor & PICU	22 hrs.
	Total		197 hrs.

In order to protect the privacy and dignity of the patients and their families, no intimate care for children was observed. However, for some cases, I obtained permission to attend a private family meeting with the key informants in the family. For example, in Case 6 (Sewar), I attended a few discussions with key visitors (Sewar’s sister in law) who gave me significant information beyond those insights provided by her mother.

3.7.1.3. Field notes

Field notes are a fundamental part of observation. Taking notes is an essential part of connecting the researcher and their subjects in the writing of ethnographic reports (Wolfinger, 2002). During my fieldwork, I recorded field notes that included verbal interactions and conversations with study participants as well as non-verbal elements of the research settings. Moreover, I was concerned with developing a reflexive analysis of my role in the data collection and interpretation and considering that as a part of the data. With regard to the suitable time for taking field notes, it is better for them to be taken as soon as the observable event happens (Mulhall, 2003; Emerson et al., 2011).

Therefore, I took notes as they occurred in the field. However, sometimes during interactions with patients and health care providers, it was difficult for me to take notes at the exact time of observation, so this was postponed to the earliest time that I was able to do so. These field notes were preliminary notes that I expanded at the end of the day (Wolfinger, 2002). Analysis of the observational notes was ongoing, as this helped me to make sure that the subsequent interviews were used to best effect, as well as giving me helpful directions related to the next observations. Field note 1 gives an example of one field note written during my fieldwork.

The focus of the note is usually narrowed over time (Spradley, 1980; Hammersley and Atkinson, 1995). Emerson suggests two methods of writing ethnographic field notes: the first strategy is the salience hierarchy, in which the researcher describes the noteworthy observation, the most interesting, and the most telling. Of course, determining what makes the information salient is highly subjective and dependant on a particular context; Emerson et al. (2011), however, provide some advice on the salient, such as focusing on deviant cases. The second strategy is the comprehensive strategy, in which a comprehensive and systematic collection of certain events is undertaken within a specific time period. One advantage of this strategy is that it enables the researcher to record events in the order that they really happened, which will help to recall detailed information collected in the field. Remembering one aspect of the event usually helps to recall the entire sequence.

Field note 1: an example of a field note

Descriptive note	Analytic note
Case 5 Mousa/ 15- 25. Jan .2015/ shift A & B/ bedside	
I was sitting with Mousa's mother in the patient's room. It consists of three beds including Mousa's, and two other empty beds. The mother and I were discussing some aspects of communication within her social life. Suddenly, the door was knocked and opened and one nurse entered with two people, a man and a woman (seems to be a couple) and a little child (seems 3-4 years old). The nurse told us that this was a new admission. The mother moved quickly to the curtains of her child's bed and closed them strictly.	The child, who is a hydrocephalic patient (with 70 cm head circumference) causes surprise for some people (based on previous observation & informal conversation with his mother), therefore she might try to protect herself and her child from the social stigma he could be exposed to.
For seven shifts' observation, Mousa's mother did not contact anybody in the hospital such as family members or other family carers (except her husband and HCPs.). It was very rare for her to emerge from her room.	She might try to protect her child from the social stigma rather than avoiding infection from other patients.

In the current study, I used both strategies when I recorded field notes. I started with the comprehensive strategy as I only had a general idea about the topic that I would collect information about. I created a list of concerns as suggested by (Lofland and Lofland, 1984; Spradley, 1980) (Table 18). However, later on in the data collection process, as I became more focused on certain issues, I started to record the salient information that was of interest to my study.

3.7.2. Informal Conversations

During the observations, I had naturally occurring conversations with the family carers as well as the health care providers who took part in the study. These conversations were conducted without interview guides or scheduled time with the participants (Mason, 2002). They had the advantage of reducing the pressure on the respondents who spoke more freely and openly as a result (Mason, 2002). I used the information gained in order to get some background information about the hospital's policies as well as building rapport with the research participants and other staff. Field notes were taken directly after the conversations and were kept in diary format for each case. They were treated and analysed in the same way as the observational field notes.

Table 18: List of concerns for note-taking in observations

Author	List of concerns
Spardley, 1980:78	Space: the physical space and place; Actor: the people involved; Activity: asset of related acts people do; Object: the physical things that are present.
Lofland and Lofland, 1984:48	Who is he? What does he do? What do you think she meant by that? What are they supposed to do?

3.7.3. Semi- structured interviews

The qualitative interview is important in the gathering of information and facts (Targum, 2011). According to Merriam (1998), these interviews are the most common data collection method in case-study research because they are effective at generating in-depth understanding of social phenomena. In order to get multiple views of the phenomenon of interest, several semi-structured interviews were conducted with the nurses, mothers, and physicians, in order to explore their experiences of communication issues. Open-ended semi-structured interviews were employed because they allowed the discussion to flow and also demonstrated the complexities of the phenomena, which are unique to certain contexts or give rise to patterns across the contexts (Yin, 2013). Based on (Kvale, 1996) guidelines, the purpose of the interview should be structured and clear. In the present study, the purpose of the interviews was outlined in the information sheet given to the interviewees, and was also given verbally before the interviews commenced.

3.7.3.1. Individual interviews

The interviews were audio-recorded using digital recorder machine, which enabled me to concentrate on listening to the interviewees rather than being distracted by detailed note-taking. However, a few written field notes were taken, especially for the non-verbal communication that occurred. At the end of each interview, I gave a brief summary of what was covered with the interviewees for verification and in order to strengthen the rigour. The venues and times of the interviews were chosen by the interviewees for their convenience.

As mentioned in Section 3.6.1, all interviews were conducted in the hospital wards, the majority of them at the bedside. However, for some carers whose children were admitted to the PICU (Nagam, Suha, and Baraa), the interviews were held in an empty lecture hall. The interviewees were given sufficient time to answer the questions, with no time pressure or coercion.

3.7.3.2. Interviews with HCPs

Individualised interviews were held with a variety of health care providers (Table 19). Two paediatric nephrologists were interviewed twice as they were nominated by two families. The length of interviews varied, being shorter with HCPs who said that they were busy. However, some interviews were longer than some participants had expected before they took part. For example, one resident asked me about the expected length of the interview. I told him that it varied, but the average time with the previous participants was between 45-60 minutes. He told me that this was a long period as he was on call, and might suddenly become busy with his patients. I reassured him that he could leave the interview if he felt that he needed to, as the patients' health is always the main priority. I told him that I might prepare for another interview if he had to leave during the current interview. Surprisingly, his interview was the longest one of all the interviews with health care providers (91 minutes).

During the interviews, I used several communication techniques to gain access to participants' experiences. For example, I used silence as a technique to give them an opportunity to express their thoughts, feelings, and experiences.

Table 19: Significant details related to interviews with HCPs

Classification of HCPs.	No. of participants	No. of interviews	Length of interview
Paediatric Nephrologist	3	5	22 minutes
			18 minutes
			80 minutes
			26 minutes
			16 minutes
Neurosurgeon	1	1	20 minutes
Paediatric Neurologist	2	2	47 minutes
			15 minutes
Paediatric pulmonologist	1	1	23 minutes
Paediatric resident	4	4	44 minutes
			30 minutes
			15 minutes
			55 minutes
Neurosurgeon resident	1	1	91 minutes
Head nurse	1	1	32 minutes
Charge nurse	2	2	66 minutes
			55 minutes
Paediatric ICU nurse	2	2	43 minutes
			45 minutes
Paediatric medical nurse	12	12	57 minutes
			41 minutes
			35 minutes
			49 minutes
			48 minutes
			70 minutes
			51 minutes
			65 minutes
			47 minutes
			29 minutes
			46 minutes
			67 minutes
Paediatric surgical nurse	4	4	35 minutes
			56 minutes
			33 minutes
			45 minutes
Total	33	35	

Being an active listener helped me to decide which issues needed to be investigated further, and helped me to control the direction of the interviews. In some cases the participants deviated from the original topic, and I needed to return them to the main thread. Also the use of reflection, restating, and summarising techniques helped me to have more confidence in the exact meaning of their words. I avoided any potentially threatening questions such as '*why'* questions and I avoided being judgmental about attitudes or beliefs, even when they were different from mine (see Field note 2). Table 20 shows the total numbers of interviews per participant group.

Field note 2: An example of how I avoided judging a mother's belief even when it was different to mine

Descriptive note	Reflective note
Case 9, 10/2/2015, 5:30 pm, bedside, visit # 2, shift B	
We were sitting at bedside … Amjad's mother was talking about reasons behind leaving school … She mentioned that the most important ambition for any girl is marriage, forming a family and having children … study comes later … secondary importance … children need continuous care from their mothers staying at home with them … the most important role for any woman is to rear her children … it is not an easy task and she does not trust anybody to help her to take care of her children … at the end … your certificate may be put in the kitchen … as you will be busy with rearing your children.	I totally disagree with this idea, however I just kept silent and listened actively to her point of view and I tried to control my facial expression in order to prohibit her from being affected by my opinion by masking my latent negative feelings about her communication. I asked her to tell me more about her thoughts on this issue without giving any personal opinion. Reflexivity helped me to listen and explore others' views without previous judgment; I might learn from them as well as understand them.

Table 20: Total number of interviews per participants' groups

Group of participants	Number
Family carers (mothers)	25
Physician	14
Nurses	21
Total	60 interviews

3.7.3.3. Joint interviews

Joint interviews are little discussed in the literature (Morris, 2001). In the present study, I did not plan to conduct joint interviews with parents. However, in the clinical setting, I faced sudden unexpected events that required me to decide before consulting the literature and my supervisors in a more detailed way. For example, some family carers told me they wished to conduct the interviews in the presence of their sick children or relatives such as husbands or other sons or daughters.

For example, Nagam’s mother (Case 3) requested to be interviewed with her husband, saying that they had no secrets from each other, and Sewar’s mother asked to be interviewed in her daughter-in-law’s presence. I respected their wishes and conducted the first interview with the presence of the relatives. However, I asked for another individual interview when I felt that they still had something they were unable to say in front of their husbands and relatives. This is supported by Morris (2001), who found in her study, about the needs of people close to those with cancer from diagnosis to end of life care in the UK, that when the couples were interviewed separately they had different views to when they were interviewed together.

On the other hand, there are some advantages of using joint interviews (Seymour et al., 1995). For example, with the presence of Nagam’s father, I observed the nature of the interaction between the two couples and the power relationship between them, noticing how the parents’ communication style could reflect on their communications with their child. It was a good opportunity that was not covered by observation, as the father was rarely present. This gave me a different range of information than the individual interviews could. For some instances, I intentionally encouraged some negotiations between the parents in order to generate insights which could be missed if I interviewed them individually. Furthermore, it is a characteristic of couples that they mutually fill each other’s information gaps (Seymour et al., 1995). This was very helpful when one of them forgot certain information and the other could provide it.

The presence of children was another issue I faced during the interviews. A few interviews were conducted in the presence of the children (Latifa, Issa, Hala, Amjad, Rashad, Firas, and Qusai). With some children (Latifa, Hala, Amjad, and Rashad), despite not requiring constant health care observation, the children suddenly joined the interviews and it was not appropriate to ask them to leave. However, I excluded sensitive themes and questions from these interviews. I felt from some mothers’ non-verbal communications that they needed to speak privately about their children, so we planned other interviews at suitable times. Table 21 gives more details about the interviews conducted for the study.

Table 21: Type and number of interviews with family carers

Case no.	Pseudonym	No.of interviews	Type of interview	Setting
1.	Rosol	2	Individual (Rosol's mother)	Bedside
2.	Basil	1	Individual (Basil's mother)	Bedside
3.	Nagam	2	1_ joint (Nagam's mother and father) 1_ individual (Nagam's mother)	Empty lecture hall
4.	Latifa	2	1_ joint (Latifa's mother and Latifa) 1_individual (Latifa's mother)	Bedside
5.	Mousa	2	Individual (Mousa's mother)	Bedside
6.	Sewar	2	1_ Individual (Sewar's mother) 1_Joint (Sewar's mother and Sewar's sister-in-law)	Bedside
7.	Issa	2	1_ joint (Issa's mother and Issa) 1_individual (Issa's mother)	Bedside
8.	Hala	2	1_ joint (mother and Hala) 1_individual (mother)	Bedside
9.	Amjad	2	1_ joint (Amjad's mother and Amjad) 1_individual (Amjad's mother)	Bedside
10.	Rashad	2	1_ joint (Rashad's mother and Rashad) 1_individual (Rashad's mother)	Bedside
11.	Firas	1	1_joint (Firas's mother)	Bedside
12.	Qusai	2	1_ joint (Qusai's mother and Qusai) 1_ individual (Qusai's mother)	Bedside
13.	Qasim	1	Joint (Qasim's mother and Qasim)	Bedside
14.	Suha	1	Individual (Suha's mother)	Empty lecture hall
15.	Baraa	1	Individual (Baraa's mother)	Empty lecture hall

3.8. Study duration

The length of data collection depends on practical and theoretical concerns (Merriam and Tisdell, 2015). Ideally, the end of data collection comes at the point of information saturation, which occurs when there is no new information or insights to be gained. In the current study, the overall length of the data collection period was around nine months, including recruitment, collection, and initial analysis of the data from the three major departments (medical, surgical, and PICU). The overall study period significantly varied; for some of the cases the study finished on the same day of participation (Basil and Qasim), while in other cases the overall study period took over a month (Mousa, Hala, and Suha; see Table 22 for further details).

Table 22: The data collection period for each case

Case (Pseudonym)	Paediatric department	Date of participation	Date of completion
Case 1 (Rosol)	Surgical floor	26.12.2014	16.01.2014
Case 2 (Basil)	Medical floor	27.12.2014	27.12.2014
Case 3 (Nagam)	PICU	29.12.2014	31.12.2014
Case 4 (Latifa)	Medical floor	28.12.2014	6.01.2015
Case 5 (Mousa)	Surgical floor	12.01.2015	17.02.2015
Case 6 (Sewar)	Medical floor	16.01.2015	25.01.2015
Case 7 (Issa)	Medical floor	02.02.2015	8.02.2015
Case 8 (Hala)	Medical floor	22.01.2015	01.03.2015
Case 9 (Amjad)	Medical floor	08.02.2015	12.02.2015
Case 10 (Rashad)	Medical floor	17.02.2015	21.02.2015
Case 11 (Firas)	Medical floor	01.03.2015	04.03.2015
Case 12 (Qusai)	Medical floor	22.03.2015	25.03.2015
Case 13 (Qasim)	Medical floor	02.04.2015	03.04.2015
Case 14 (Suha)	PICU	15.05.2015	17.06.2015
Case 15 (Baraa)	Medical floor & PICU	20.07.2015	08.08.2015

My original plan was to observe each case until achieving the saturation of information for any particular case. However, I found it helpful to be more flexible about the length of the observational period as I found every case had different conditions that either enabled or inhibited my observations. For example, one child (Basil) was discharged (against medical advice) after one day of observation, while another (Nagam) died a couple of days after my observation. Therefore, it was difficult to determine the exact time of observation for every case beforehand, because of the unpredictable nature of their health conditions. This is expected in qualitative research in nursing and palliative care.

3.9. Data analysis

Data analysis is described as "making sense out of the data. And making sense out of the data involves consolidating, reducing, and interpreting what people have said and what the researcher have seen and read. It is the process of making meaning" (Merriam and Tisdell, 2015: 202) . According to Patton (2002), qualitative analysis involves transforming data into findings. Qualitative research is based on the simultaneous collection and analysis of data (Merriam and Tisdell, 2015). Therefore, I conducted the data analysis in two stages: the primary stage, representing the initial analysis, which was simultaneous with the data collection stage. The second stage was more systematic, and started after the whole data set was collected. The following paragraphs give more detailed information regarding these two stages.

3.9.1. The initial analysis

This study used constant comparison to analyse the data – a method common to qualitative research, and one which is based on an inductive, comparative approach (Charmaz, 2014). Moreover, I was comparing the data results from the interviews with the data results from observations. I was continuously comparing different methods of data collection but I also compared data results from different participants (Ayres et al., 2003). This comparison informed the next data collection, especially when certain information was missed.

In order for the data collection to be simultaneous with data analysis, every data collection session was based on the initial analysis of the data gathered from the preceding observations and interviews (Bogdan and Biklen, 2011). Initial analysis includes reading and rereading the transcripts of the data, as well as listening to some of the records when the transcripts were not ready. I wrote notes on the margin of the transcripts.

In addition, I continuously reviewed the study objectives, which helped me to avoid being overwhelmed by the huge amount of data collected. I wrote down notes and questions that I needed to ask in the next observational session. During the data collection, as recommended by Stake (2006), I applied two strategic ways to reach new meanings about cases. In a few instances, I found significant meaning from a single instance, and there was no need to seek several observations to achieve the correspondence or pattern of data (direct interpretation). However, in the majority of the cases, I was searching for pattern and consistency through the aggregation of several instances until something could be said about them as a class. The deep meanings of information usually come from the reappearance of instances or situations over and over (Stake, 2006). This improves the credibility of the data analysis and reduces the possibility of misunderstandings in certain situations. For example, when I collected certain information or interpretations from one resource, I tried to investigate the same information using several other resources to ensure the credibility of my analysis and the interpretation of the information. To enable this, I wrote notes to investigate the same issue from different resources in several observations.

In addition, I wrote memos to record my reflections and how my presence affected the finding of the study, also recording the initial themes, ideas, and hunches that emerged from the first set of data. I benefited from the recommendations of (Bogdan and Biklen, 2011) during the initial data analysis:

- Narrowing the focus of the study: although at the beginning of the study I tried to collect as much data as I could, I tried to become more focused. Instead of recording too much data on many different things, I tried to record deep information about specific issues to gain more in-depth data, giving me a deep analysis;
- Developing analytical questions: although I had general broad questions at the time I started the study, I added other specific questions later, based on the data I collected. I reformulated some questions to be more relevant to the nature of my study;
- I organised the data collection plans and sessions based on what I found in the observations. I continuously reviewed my field notes and

memos in order to plan for the next session of data collection (interviews or observation);

- I explored the literature while I was in the field, which helped me to improve my analytic skills;
- I wrote down many observer comments, as this improves deep thinking in the data. It also improves critical thinking about the set of data.

3.9.2. The process of systematic data analysis: step by step process

The data was analysed following the frameworks of data analysis proposed by Stake (2006) and Creswell (2007), as they are very similar. Case study research, according to Stake (2006), uses two types of data analysis and interpretation. Categorical aggregation is one. This tool depends on the researcher collectively analysing instances, until a general statement can be made about them as a group. In contrast, direct interpretation, the second type, does not need multiple examples or instances, but can use a single instance and draw conclusions from closely examining it. Stake (2006) recommends using both the categorical aggregation and direct interpretation methods of analysing data. Using this approach, a researcher can trace patterns and then look for the links which exist between different categories. Once the analysis is completed, the researcher develops naturalistic generalisations. This allows readers to analyse and learn from the case for themselves or to apply the findings to a group of cases.

Stake defines the quintain as an object, phenomenon, or condition to be studied: “The quintain is the arena or holding company or umbrella for the cases we will study” (Stake, 2006: p.6). In the current study, the quintain is the communication experience as a whole. Creswell (2007) added the further step of giving a detailed description of the case to Stake’s (1995) form of data analysis. Figure 8 illustrates Creswell’s (2007) framework for coding case study research. First, a contextual ‘thick’ description of every case is employed, and then within-case thematic analysis identifies individualised themes for each case. Subsequently, cross-case theme analysis is conducted to find themes that are similar and different across cases. Finally, codes for assertions and generalisations across all cases are included. Figure 9 summarises the major steps of the data analysis procedure during the study.

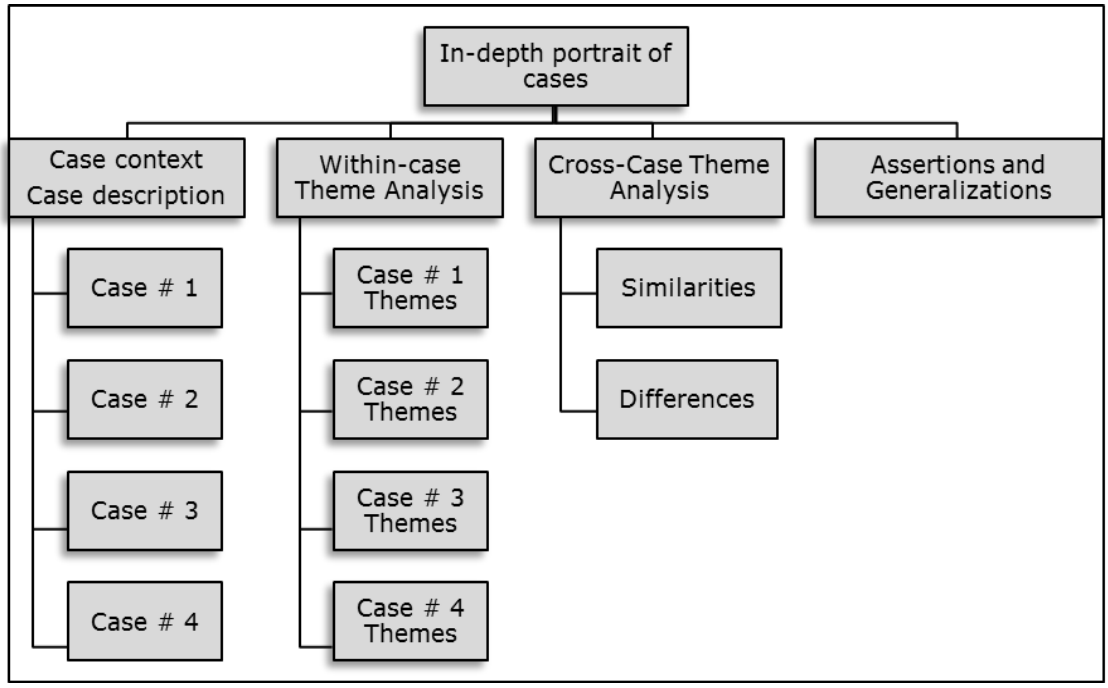


Figure 8: Template for coding a case study using the collective case approach. Source: Creswell (2013a)

3.9.2.1. Data handling and management

One of the challenges of the collective case study is data management; the researcher could hold a considerable amount more data than they are able to deal with (Merriam and Tisdell, 2015). Therefore, once I had amassed all the case data, I checked then recorded the data resources in their own folder, so it would be simple to access again at any time. This method ensured that cases were separated out and could not be confused, as well as protecting the individual contexts and stories relevant to each case from being muddled or ignored. These documents and data were saved into my computer and password protected, allowing access to me only. I also saved a separate copy on an external drive of the data set to avoid any problems such as damaged memory sticks or a computer crash.

3.9.2.2. Transcription of data

The transcription of data is considered to be an excellent way for the researcher to become familiarised with the data (Riessman, 1993). The transcription process is viewed as a key data analysis phase in interpretative qualitative research (Bird, 2005), as it helps the researcher to gain an insight about what is going on in the data (Merriam and Tisdell, 2015). However, one of its disadvantages is that it is time consuming (Lapadat and Lindsay, 1999). Since I adopted two data collection methods in this study, which resulted in the accumulation of a huge amount of information, I needed assistance to transcribe the interview data. Accordingly, I hired an assistant to transcribe the interviews, which is a common practice in qualitative research (Tilley, 2003). This enabled me to make sure that the analysis proceeded parallel to the data collection, providing me with enough time for an initial analysis of the interviews before returning to the field.

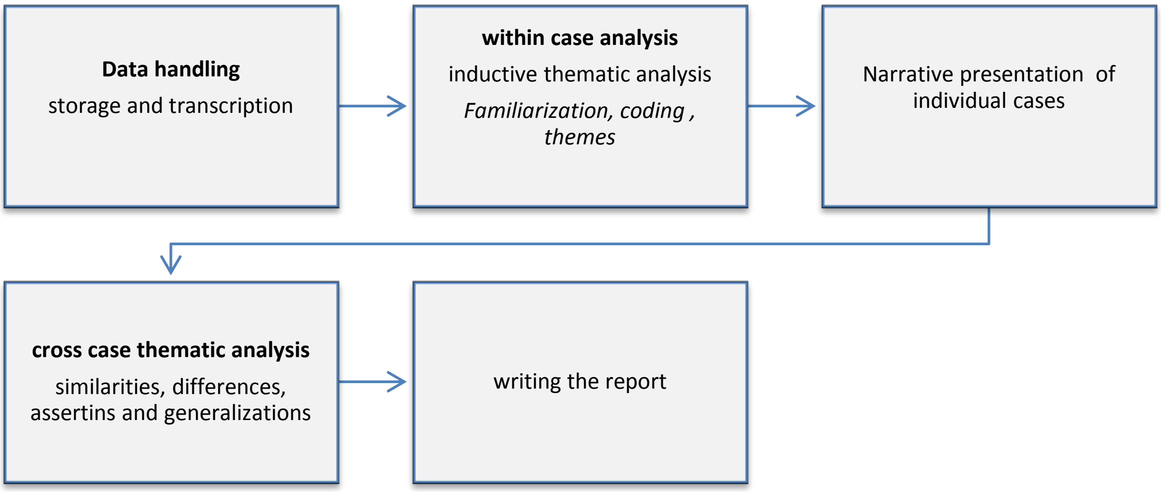


Figure 9: The overall data analysis process for the study

Braun and Clarke (2006) argue that constructivist thematic analysis does not need the same levels of detail as are required in conversation, discourse, or narrative analysis. Transcription as a part of qualitative research does not seek or claim perfection; collecting, discussing, and the processes of translation and transcription slowly precede a good enough transcript (Nikander, 2008). As thematic analysis has no single way to be conducted, there are no certain guidelines to follow when producing a transcript.

However, as recommended by (Braun and Clarke, 2006), the transcript should include a minimum requirement to produce a rigorous and thorough orthographic transcript that includes all the verbal, and sometimes non-verbal, utterances (such as coughs). I instructed the transcription assistant that it was important that the transcript contained all verbal information from the verbal account in such a way as to remain true to its original nature. In addition, I asked her to contact me if she did not understand any part of the interviews, so that we could check them together, if the voices in the recorder were not clear (this was very rare). Moreover, I listened to all of the interviews directly after data collection to make the initial analysis for some of them directly from the audio recorder. This remained the initial analysis to be performed directly after the collection of information, which reduced any incongruence between what was written in the transcript and what was recorded in the machine.

Finally, I made comparisons with some samples of the interviews in order to compare the quality of the written material with the verbal conversations. I was aware of the need to maintain the confidentiality of information when transferring data from my computer using a flash memory. I deleted all data after transferring it, and I ensured that the transcriber deleted the data after giving me her written work by flash memory as well. I sent samples of field notes, informal conversations, and formal interview transcriptions to my supervisors so that they could give me advice to improve the quality of my data collection.

3.9.2.3. Data translation

In order to avoid any limitation of the analysis that might result from analysing data from a language different to my own (Arabic), I analysed the data in the same language it was given in (Van Nes et al., 2010). Therefore, there were no differences in data gathering and transcription, or during the initial analysis – especially as the initial analysis was performed close to the data collection (Van Nes et al., 2010). This was also important as it helped me to understand the meaning of some expressions or proverbs, which was very helpful, especially during the stage of data interpretation and analysis. However, I still faced challenges when I translated some of the participants' quotations, as it is difficult to translate concepts or expressions that are culturally bounded. This could be problematic as qualitative research gives considerable importance to the participants' voices (Denzin and Lincoln, 2000). To address this issue, I hired a professional translator to support the translation process. In addition, I clarified the analysis process step by step including how the translation was undertaken. This will provide the reader with an insight into how any potential losses of meaning have been avoided by the researcher (Squires, 2009).

3.9.2.4. Within-case thematic analysis

From his perspective, Stake (2006) asserts that if the researcher considers that the situationality of individual cases is less important than understanding the whole quintain, then the multi-case design might be the wrong choice. This approach pays significant attention to the importance of protecting the contextual details of each case in order to protect the case study design. Therefore, in this stage of the research, each case was analysed as a comprehensive case. I gathered all sources of data for every case together to protect the contextual details of every case, in order to remain within the collective case study approach (Creswell, 2003). The transcriptions, memos, and field notes collected for every case were analysed using inductive thematic analysis, as detailed below.

3.9.2.5. Inductive thematic analysis

Patterns within data can be identified by two main thematic analysis approaches: inductive thematic analysis or deductive thematic analysis (Braun and Clarke, 2006). The inductive approach indicates that the themes are derived from the data itself (Patton, 1990). With inductive analysis, data is not derived from the researcher's previous theoretical assumptions. Therefore, this process codes the data individually, and does not try to make it fit any previous code frame. In this respect, inductive, thematic analysis can therefore be described as a process which is shaped by its data. However, deductive, thematic analysis is also shaped by the researcher's interests and theoretical background, so as a result it is often called theoretically-driven.

In the current study, an inductive approach was used, which is congruent with the underpinning philosophy of the study. In addition, I made another decision about the level of depth to which the themes were conceptualised, according to the work of Boyatzis (1998) who identified the level of thematic analysis as semantic or latent. The semantic level of themes looks for their superficial level without looking beyond what participants said, or the written materials. However, thematic analysis on the latent level examines the underlying ideas or assumptions of the data, including interpretation as well as description. In the current study, the latent level of data analysis, which is congruent with the constructivism paradigm, was used. The data was analysed using inductive thematic analysis with a latent level of data analysis. The following is a description of the step-by-step inductive thematic analysis utilized in this study:

- *Familiarisation with the data*

As the data collection ran in parallel with the data analysis during the process of analysis, I familiarised myself with the data by reading and rereading them during the data collection phase (Braun and Clarke, 2006). During this stage, I started to take notes and mark ideas for initial coding and also for the next data collection activity (observation, interviews, and informal conversation).

- *Generating initial codes*

Codes refer to ‘a word or short phrase that symbolically assigns a summative, salient, essence-capturing, and/or evocative attribute for a portion of language-based or visual data’ (Saldana, 2013: 3). In the beginning of my analysis, I was open to any segment of data that might be useful; this form of coding is often called ‘open coding’ (Merriam and Tisdell, 2015). I sometimes used the exact words or phrases mentioned by participants (Nvivo codes). See Appendix I which shows an example of the coding of data from one interview. Analytic coding was used in this study. Analytic coding is not merely descriptive, but includes an element of explanation and careful consideration of meaning (Richard, 2015).

- *Searching for themes*

After the process of coding was finished, I sorted the different codes into potential themes or categories. Categories are ‘conceptual elements that cover or span many individual examples (or bits or units of the data [...] previously identified) of the category’ (Merriam and Tisdell, 2015: 206). The process of combining the codes from open coding into fewer more comprehensive categories is called ‘axial coding’ (Charmaz, 2014; Corbin and Strauss, 2015).

I used a visual representation to help me sort the different codes into themes (Figure 10). These thematic maps helped me to start to think about the relationship between codes and themes within different levels:

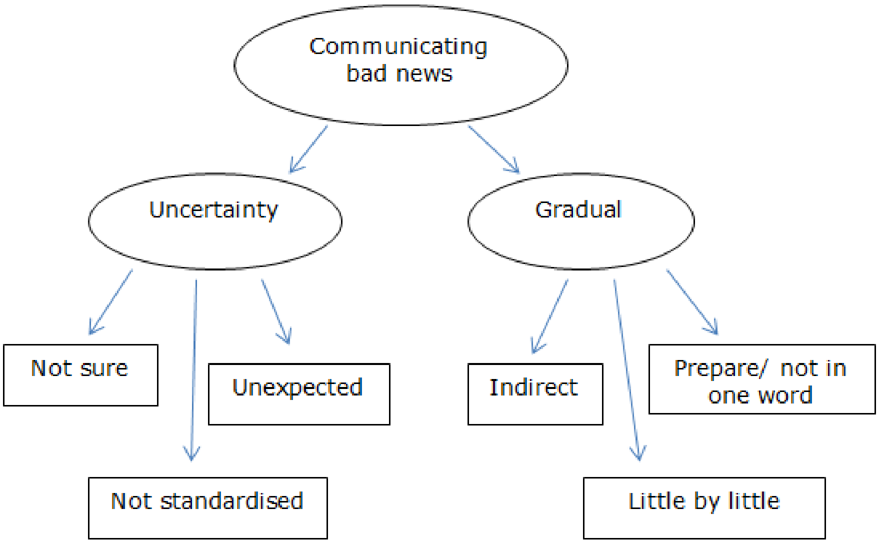


Figure 10: Visual representation of a coding map used in the study

- Reviewing themes

After reviewing the initial themes, there were some themes which were not complete. This was because there was not enough data to support them or because they were too diverse. However, there were themes that could be collapsed into each other, and other themes needed to be broken up. Patton (1990) addresses criteria for evaluating themes. The two criteria adopted here are internal homogeneity and external heterogeneity. According to these criteria, I ensured that data within themes are coherent, while data between themes should be identifiable and distinguished.

- Defining and naming themes

According to Merriam and Tisdell (2015), my themes are named according to three resources: myself, the participants' exact words, and the literature. I tried to make the themes concise and punchy, providing the reader with a sense of what the data is about (Braun and Clarke, 2006).

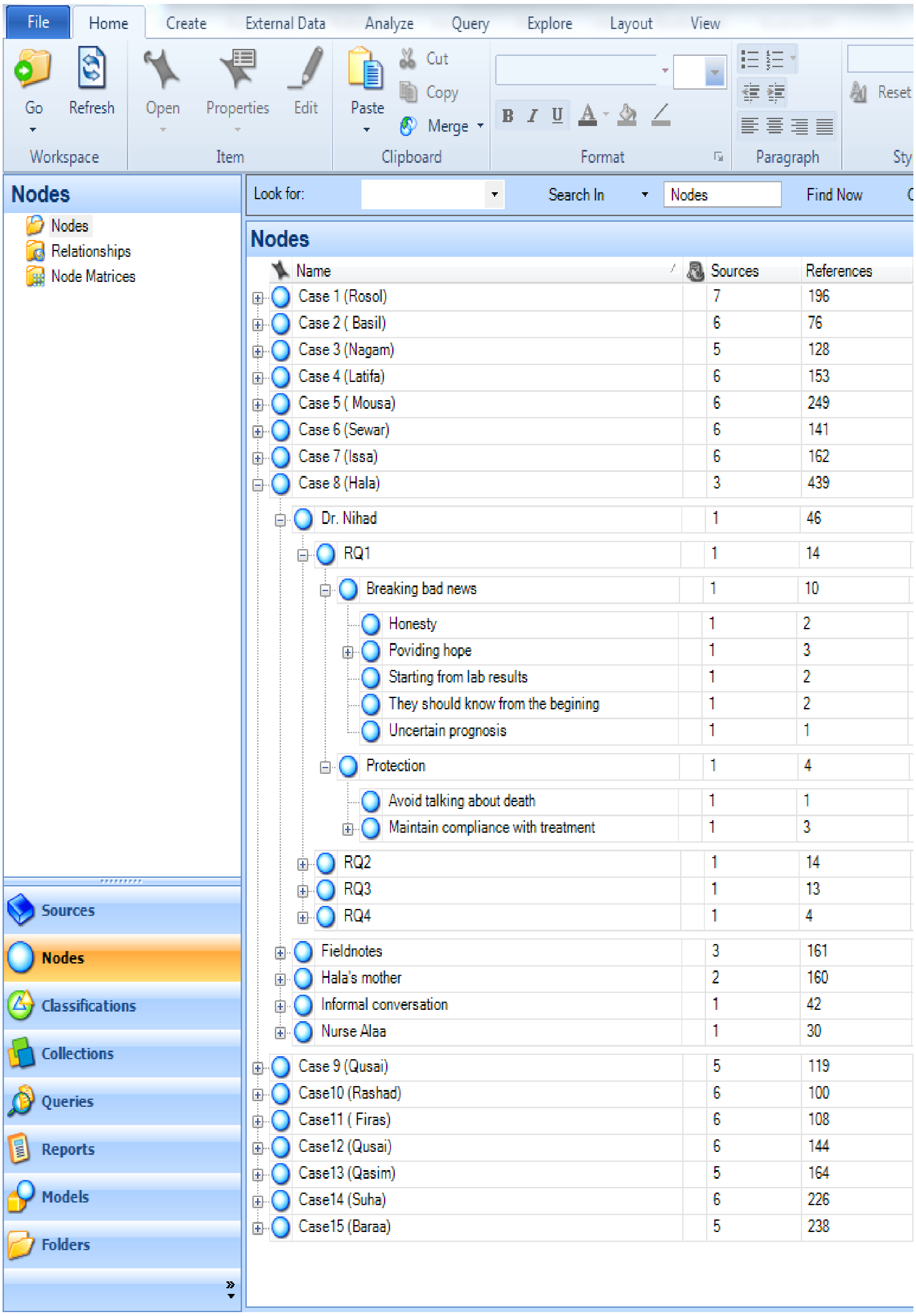
3.9.2.6. Narrative analysis of individualised cases

In addition to the thematic analysis of every case, I presented every case individually, using the narrative approach (thick description) in order to give a sense of the detail and context of each. I sent a few examples of case narratives for my supervisors for feedback, which in turn helped me to develop subsequent case narratives. As detailed in Appendix H, Hala's case analysis was presented in the form of a story, illustrating the multiple dimensions affecting her communications with her parents and the health professionals.

3.9.2.7. Cross-case theme analysis

Cross-case analysis includes collecting and analysing data from the within-case analysis. Assertions in cross-case analysis were defined by Stake (2006) as "findings about the quintain" (P.42). Cross-case analysis seeks to build assertions across all cases (Merriam and Tisdell, 2015). The objective of knowing the differences and similarities between cases is to understand the quintain well. Hence, the role of the researcher at this stage is to build general explanations that fit all cases, even if particular details for each case might vary (Yin, 2014). Subsequently, themes and subthemes created from the within-case analysis inform the themes and subthemes identified in the cross-case analysis.

Stake (2006) used worksheets to facilitate and organise the process of analysis. However, because of the huge amount of data I collected from the field, I initiated the cross-case analysis once I had gained separate findings in all fifteen cases. Instead of using this worksheet, because of the large data set I had collected, I needed software to protect these documents and also help me to reduce the size of the data. The technique of cross-case analysis using the QSR NVivo 10 software is shown below (see Figure 11, which is directly extracted from QSR NVivo 10):



Name	Sources	References
Case 1 (Rosol)	7	196
Case 2 (Basil)	6	76
Case 3 (Nagam)	5	128
Case 4 (Latifa)	6	153
Case 5 (Mousa)	6	249
Case 6 (Sewar)	6	141
Case 7 (Issa)	6	162
Case 8 (Hala)	3	439
Dr. Nihad	1	46
RQ1	1	14
Breaking bad news	1	10
Honesty	1	2
Poviding hope	1	3
Starting from lab results	1	2
They should know from the begining	1	2
Uncertain prognosis	1	1
Protection	1	4
Avoid talking about death	1	1
Maintain compliance with treatment	1	3
RQ2	1	14
RQ3	1	13
RQ4	1	4
Fieldnotes	3	161
Hala's mother	2	160
Informal conversation	1	42
Nurse Alaa	1	30
Case 9 (Qusai)	5	119
Case10 (Rashad)	6	100
Case11 (Firas)	6	108
Case12 (Qusai)	6	144
Case13 (Qasim)	5	164
Case14 (Suha)	6	226
Case15 (Baraa)	5	238

Figure 11: Nvivo extract showing the cross-case analysis

- I made case nodes for each case study as the main nodes (Case 1, Case 2, Case 3, etc.).
- I made ‘child’ nodes for each participant that included all of the interviews and informal conversations made with him or her (e.g. Dr. Nihad, Hala’s mother, Nurse Alaa).
- I made another ‘child’ node for my field notes for certain cases.
- I set the research questions (RQ1, RQ2, and RQ3) as child nodes for each participant, with field notes to answer them and give the response of each participant for all research questions. This helped me to make constant comparisons between participants within each case and between different cases (within-case and cross-case thematic analysis).

3.9.2.8. Writing the report

I presented the data in a way that shows the reader the validity of my analysis. This was done by providing sufficient evidence of the themes from the data. The information was presented so that rather than merely describing the data, it was instead presented analytically, producing arguments that related to the research questions (Braun and Clarke, 2006).

3.10. Ethical Considerations

This section addresses the ethical issues considered in the current study including the process of ethical approval gained from the recruited hospital. It also highlights the ethical principles I followed during the study period, which mitigated the risk of potential harm. These include: confidentiality, anonymity, and informed consent. In addition, this section addresses the ethical issues that emerged during the process of data collection (participant observation and interviews). Since this study recruited children, who are a vulnerable group, for observation, extra attention was paid to them to mitigate the risk of potential harm.

3.10.1. The process of ethical approval

After I gained a positive review from the ethical committee of the University of Nottingham, I applied to the hospital in which I had originally planned to conduct the study. However, because of a long delay prior to the next ethical committee meeting (more than three months) and a lack of information regarding the exact time of their next meeting, despite continuous follow-ups, I applied to a different hospital, which was the one I finally used. They gave me a positive ethical review within a few weeks of my application. Both hospitals are major university hospitals in Jordan, so the main characteristics of the planned hospital were unchanged by the switch.

I encountered several ethical issues during data collection. The major procedures that I adopted to ensure achievement of the previous principles are set out below.

3.10.2. Informed consent

Informed consent is obtained when participants give their consent in a voluntary, intelligent, clear, and manifest way (Orb et al., 2001). It is one of the means by which the right of participants' autonomy is protected (Zawistowski and Frader, 2003). The concept of informed consent extends beyond simply acquiring permission to undertake a specific procedure as it represents the exchange of information between the researcher and the potential research participants (Silverman et al., 2005 ; Nijhawan et al., 2013). In such an exchange, the participants should be able to make an informed decision without being subject to duress by being given enough information about the topic at hand. I verbally discussed the risks and benefits of the research with all participants (see Table 23), I fulfilled my responsibility as a researcher to inform participants of their rights, particularly their right to withdraw from the study without notice or justification (Corbin and Morse, 2003).

3.10.2.1. Obtaining informed assent

Informed consent to participate in research should be given only by morally-autonomous and legally-competent decision makers (Kanthimathinathan and Scholefield, 2014). Assent is an ethical term that is usually used when obtaining consent from children (Huang et al., 2016). It is defined as:

> *"An interactive process between a child and researcher involving disclosure, discussion, and a limited understanding of a proposed research activity, wherein the child freely expresses a preference for participation but has insufficient maturity to make a fully*

> *informed and autonomous decision" (Broome and Stieglitz, 1992: 149).*

Particularly when it comes to non-therapeutic qualitative research, there is some degree of controversy about when a child can give their assent (Lambert and Glacken, 2011; Huang et al., 2016), but many studies follow common practice that any child aged over 6-7 should be asked for their consent when taking part in research (Cree et al., 2002; Jokinen et al., 2002).

Table 23: Freely given and informed consents

Adapted from the Royal College of Paediatric and Child Health (2000).

Freely given	**Informed**
• No financial inducment was given for families to participate; • No pressure was exerted on families to participate; • A period of 3 days to decide whether to participate or not was given; • I encouraged the families to talk to their relatives and health professionals about the research; • I let them know that, although they may have signed a consent form, they were free to pull out of the study at any point. • I told them that they did not have to provide a reason for withdrawing from the study, but pointed out that knowing why they made this decision could be helpful both to me and the children. • I reassured them that their decision to leave the study would not have any effect on the treatment their children were receiving.	• The purpose of the study; • What the impact of the research study may have on the care of their child; • The meaning of different research terms; • The place, time, and length of the interviews; • Potential benefits and drawbacks –both short and long term. • The name of the researcher and who to contact with any queries. • The process to follow to withdraw a child from the research. • For more details see Appendix B.

In addition, the parental agreement that should accompany the child assent is essential when the child is younger than 15-16 years old (Coyne, 1998; Kankkunen et al., 2002; Kennan et al., 2012; Lambert and Glacken, 2011; Stalker et al., 2004). Children over 16 years old do not need their parents' permission, and receive the information sheet and consent form directly (Stalker et al., 2004). Consequently, I obtained assent or agreement from the children who were older than six years old who had the cognitive ability to understand the research (Royal College of Paediatric and Child Health, 2000).

In the present study, parental consent was sought first, in order to build up the case around their child and to engage in observation. Afterwards, the parents were asked to approach their children to obtain permission for me to discuss the research with them. I discussed the study with the children using understandable language in order to ensure their understanding and acceptance of the study activities (Lambert and Glacken, 2011) (Field note 3).

Field note 3: An example of how to obtain children's assent to build up the case around them and observe them during the study period

Descriptive note	Reflective note
20.03.2015, B-shift, Qusai's bedside	
I'm in Qusai's room in order to discuss with him the research aims and objectives in order to obtain his consent. His mother told me that she approached him before my coming and he was willing to know about the study, however one nurse came to the room to take his blood pressure and she took him to the procedure room to take a more accurate reading. I prepared some educational tools for Qusai (11 years old) to discuss the research with him. I created a game that included a die with six faces, and I prepared coloured cards, each of which had a question related to what I discussed in the study (for example the objective of the study). I told Qusai that after discussing the research with him we would play a game of dice whereby every number was connected to one card. If he could answer the question written in that card, he would get one point; better performance was indicated by higher scores.	I knew from the mother that Qusai does not like school, therefore I thought in a different way of education to be used with him to avoid him refusing the study because of negative associations of conventional learning methods (I did not want him to see me as a teacher thus I thought of more friendly ways of giving the information for him). I felt that this motivated Qusai to be more receptive to the study. He answered almost all questions and then I asked him to take time to think about the study and to tell me later about his decision.

Finally, the children's assent was sought to ensure their acceptance to build up the case around them and to be observed by me. However, some children were critically ill (e.g. Nagam, Rashad, and Qasim), and their health did not enable them to give assent, as they did not have the capability to understand the research terms (Baines, 2008). Several studies suggest that the focus should be on other ethical principles such as justice, beneficence, and non-maleficence, whilst safeguarding the child's future autonomy (Miller et al., 2011; Baines, 2008).

3.10.3. Confidentiality and anonymity

In the present study, a potential risk of revealing personal or sensitive information was expected. One such risk was breaking confidentiality, especially when reporting findings using verbatim accounts narrated by participants both in formal interviews and informal conversations during observation, which may have legal, social, political or financial repercussions (Corbin and Morse, 2003; Kaiser, 2009). Thus, to mitigate these effects, the participants must consent for their exact words to be used. They must also be assured that their confidentiality is guaranteed and that no information that may reveal their identity will be published. For instance, pseudonyms should be used instead of real names. In addition, great attention was paid to record handling and concealing identifiable information.

3.10.4. Ethical issues regarding participant observation

As a researcher who conducted the study in my own culture, the way in which I perceive and present results is clearly subject to the influence of my being very familiar with the setting, as I had worked in a similar setting before. In her work as an ethnographer in intensive care, Seymour (2007) noted that she made some aspects of the setting visible while others were invisible because her familiarity made her blind to some aspects of it. This reminds us of the importance of being reflexive when conducting observational research within one's own culture and professional field.

Furthermore, I realised that there was a possibility of building a close relationship with the participants as a result of the long period of observing some of them (especially children), which could contribute to a feeling of loss when the study finished and I withdrew (Murphy and Dingwall, 2001). I decided to keep my distance and try to limit any social relationships with participants, especially the children. For example, one day Hala (Case 8) asked me to play the *Happy Farm* game with her, a game where people invite their friends using their Facebook accounts. I declined, apologising for not knowing the rules, but in reality I was avoiding building a deep social relationship with her that could harm our feelings at the time of separation.

A similar situation arose when Mousa's mother asked to add me on Facebook. I refused, as it would be inappropriate for the research to turn the relationship in a more social direction. She understood that, and that it would not affect her participation in the study. However, I did not eliminate the relationship with her immediately after concluding the data collection (I observed this child for more than one month and I finished the data collection with him while he was still in the hospital). Instead, I visited Mousa several times in the hospital in order to enquire about his health condition, as I had a moral responsibility to maintain contact and avoid terminating the relationship abruptly, especially for the families.

3.10.5. Ethical issues regarding the interviews

It was difficult to inform the participants what to expect before the current study commenced. One-off consent is not suitable for this type of research (McDonnell et al., 2000). I decided to tackle this issue by ensuring that I regularly asked physicians, nurses and family carers if they were happy to continue being interviewed. This was, I believe, an important process, especially when they were faced with delicate and difficult situations which could well have sparked emotionally distressing memories or emotions (Houghton et al., 2010). I also outlined the topic area and a few questions in the information sheet to give the participants the opportunity to decide whether or not they preferred to skip some of them before the interviews started.

In spite of their popularity in qualitative research, interviews can give rise to ethical issues, such as power imbalances and the stirring up of painful emotions. The issue of power dynamics in the interview situation is one ethical concern that tends to be under-represented in literature (Kvale, 2006). The researcher has the power to initiate interviews, generate questions, as well as having a potential monopoly on interpretation (Kvale, 2006). According to Webb (1992), the relationship between a researcher and his participants should be dynamic and two-way as information is exchanged between both parties and a dialogue ensues. This is congruent with the interpretive constructivist approach that puts language at the heart of the construction process. Having worked as a nurse in the same setting a few years ago reduced the power imbalance between me as a researcher and the nurses and physicians, forming a collegial relationship rather than an unequal power relationship. Moroever, prior to the interview, I established trust with the nurses and cultivate strong listening and non-verbal communication skills in order to make them feel at ease (Tillmann-Healy, 2003).

The second ethical challenge I faced during interviews is the dilemma that resulted when interviews brought up painful memories for participants (Orb et al., 2001). This happened when the mothers of Rosol, Nagam, Mousa, Sewar, Hala, Suha, and Baraa narrated their experiences about their children who were sick or had died, which stimulated deep sadness and painful feelings.[10] In this case, despite the fact that I had expectations about the possible negative effects when discussing these emotionally-demanding topics with family carers – especially mothers – I found it difficult to decide whether to continue the interview to gain more in-depth insight or stop the interview to relieve the participants' suffering. To address this, I remained quiet when necessary to give them time to regain their composure and then asked them whether they wanted to continue the interview or to stop. None of the participants asked to stop or even postpone the interview. Furthermore, there were no extreme cases that needed referral to counselling services, as the literature advises (Orb et al., 2001).

3.10.6. Ethical issues regarding the observation of children

During the observations and family carers' interviews, the children's health status was observed. No sudden deterioration of their health happened. However, I was prepared to terminate or postpone the interviews if I experienced any emergency situations, as the children's health was an overriding priority (see Field note 4). Furthermore, all informal conversations

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[10] In the cases of Nagam, Qasim, and Baraa the parents had previous experience of the death of another child from the same disease.

with children were conducted in the presence of their families[11]. I informed the families that their children would not be given any health-related information without their permission (Crawford et al., 2013). Table 24 summarises how I applied the major ethical principles to the study.

Field note 4: Some examples showing how the children's health was an overriding priority

Descriptive notes	Analytic notes
26.12.2014, shift A, 2:15 pm, doctors' office	
Now I'm in the doctor's office in order to take Dr Raed's opinion related to recruiting one child for my research or not. Fifteen minutes ago the charge nurse told me that this child had met the inclusion criteria; however, he is in protective isolation after exposing to kidney transplantation a few months ago. He told me he thinks that this patient had low immunity, and he preferred to decrease the number of contact people or even visitors in order not to catch any infection. However, he gave me the name of another patient (Latifa) as he recently admitted her and she is on a course of antibiotics. Therefore, he advised me to recruit Latifa instead of the low-immunity child.	I followed Dr Raed's opinion as the patient's health is the highest priority during my study.

3.11. Improving the trustworthiness of the study

The literature presents a debate concerning whether or not is it appropriate to use criteria to evaluate qualitative research. For example, according to the difference in philosophical assumptions between qualitative and quantitative research, the positivistic criteria for assessing the quality of qualitative

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[11] Although the focus of this study was not to interview children, I expected them to contact me or ask questions, and it was necessary to be prepared to communicate with them.

research are rejected by Smith (1984) who suggests that qualitative research is inherently idealist[12] and anti-foundational[13] .

Table 24: The ethical principles adopted for the study

Ethical Principles	How to address ethical principles in proposed study
Informed consent	I translated consent forms from English to Arabic so that the participants could understand. I also discussed the purpose of the study and its possible implications, both positive and negative, for the participants. Furthermore, written information sheets were provided for all participants. I informed the participants that the benefits of the research would be long-term, through improving health practices, which would provide benefits for other patients and health providers.
Beneficence	I informed the participants that the benefits of the research would be long-term, through improving health practices, which would provide benefits for other patients and health providers.
Confidentiality	In both data collection methods (observation and interviews), participants were assigned pseudonyms in order to be anonymous. Scrupulous attention was paid to record-handling and concealing identifiable information. Data were saved in the personal computer of the researcher and password-protected to prevent the data from being exchanged.
Justice	Equal opportunity was given to all participants who satisfied the inclusion criteria. Moreover, participants were provided with information about the study fairly.
Non-maleficence	Information pertaining to the nature of the study was provided to minimise the anxiety or stress of the participants. In order to reduce the emotional distress of the interviewee as result of revealing sensitive information, I used a silence technique in order to give them proper time to regain their composure and then asked them whether they wanted to continue the interview or not, giving them the chance to cancel or postpone the interview.
Self-determination	Participants had the right to participate voluntarily in the study, with no coercion, and to withdraw from the study at any time without justification.

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[12] Idealist: social reality does not exist independently from the construction of the individual (Smith, 1984).

[13] Anti-foundational: because there are many constructions of reality, there can be no correct or perfect understanding (Smith, 1984).

That being said, Lincoln and Guba (1985) somewhat endorse the criteria but concur with Smith (1984) who implies that qualitative research is built upon philosophical assumptions that are quite different to those of quantitative research, meaning it must be evaluated independently. The authors proposed a new set of criteria for evaluating the trustworthiness or rigour of a qualitative research endeavour (Lincoln and Guba, 1985) (Table 25).

Table 25: Applying trustworthiness criteria for the current study adapted from (Lincoln and Guba, 1985)

Trusworthiness criteria	Application on the current study
Credibility Confidence or truth in the findings.	Prolonged engagement and persistent observation; Triangulation; Peer debriefing; Member checking; Negative case analysis.
Confirmability The findings are determined by the participants and not by the interests or motivations of the researcher.	Reflexivity; Triangulation; Audit trail.
Dependability The process of research is logical, traceable, and can be repeated.	Audit trail; External audit.
Transferability Research findings are transferable to other specific settings.	Thick description.

3.11.1. Credibility

I tried to improve the credibility of my findings through prolonged engagement with the paediatric department of the hospital and my persistent observations of each case (Lincoln and Guba, 1985; Houghton et al., 2013). The observation period for each case was different because of the different amount of time each child stayed at the hospital. However, I spent around nine months (approximately 197 hours) observing to gain a full understanding of the phenomenon of communication in a paediatric setting. I stopped collecting data when I felt the point of saturation had been reached; that is when no new data or concepts emerged.

In qualitative research, the researcher is the instrument of data analysis and interpretation. Putting in mind my philosophical orientation in this study, I recognise the presence of multiple realities, from which I may conclude that what is being seen by one person as real might be different from what has been seen by others. However, I tried to limit any misunderstandings by adopting the process of repeating the data analysis and making a critical review of what was being said (Stake, 2006). Moreover, I improved the credibility of my findings by employing a triangulation strategy (Merriam and Tisdell, 2015; Patton, 2015; Shenton, 2004). Merriam (2009), defines triangulation as ‘comparing and cross checking data collection’ (p.216). Patton (2002), asserts that triangulation strengthens the study by combining methods of data sourcing in order to have a comprehensive understanding of phenomena. Additionally, Stake (2006) argues that each research finding must be substantiated by three or more confirmations to prevent key meanings going unnoticed. The author also claims that different interpretations must be supported by the collected data and presented in a way that prevents misinterpretation by the reader.

According to (Denzin, 1978; Carter et al., 2014; Patton, 2002), the use of multiple researchers, multiple methods, multiple data sources and multiple theories to confirm emerging findings are the four types of triangulation. I improved the credibility of the findings of the current study through triangulation of data collection methods, namely interview data and participant observation. Triangulation has two main purposes: to confirm the data and to ensure that they are complete (Casey and Murphy, 2009). I confirmed the data through continuously examining and comparing the observation data with the interview data (Merriam and Tisdell, 2015). Because the analysis of my findings was undertaken in parallel with the data collection, it was easier to compare the two sources of data with each other in order to confirm each other. I also attempted to achieve completeness of data by gathering data from both resources in order to have a comprehensive picture about the phenomena (Shih, 1998). For example, in my study, the observations completed the interviews by adding some contextual details about the children under observation that were not specifically covered in the interviews (e.g. the children’s surrounding environment in the hospital, their friends, and the nature of their interactions with the health care providers). Each of the two data collection methods had particular functions, which when combined together maximized the depth of insight and the completeness of the cases and their contexts (Houghton et al., 2013). Furthermore, I enhanced the credibility of the findings using a peer debriefing technique (Lincoln and Guba, 1985). I sent examples of the interview transcripts and field notes to my supervisors for further check-up. Moreover, I sent a coded interview to my supervisors in order to assess their opinion on my coding process and decisions. I also sent samples of the Nvivo reports in order for them to see how I build the categories and themes from codes. Finally, I sent a few examples of case narratives as examples of within-case analysis to them for further checking.

Member checking can be achieved by asking participants to read the transcripts of their interviews etc., to confirm whether the words reflect what they actually intended to say (Shenton, 2004). Another way I tried to achieve credibility was by summarising the major points discussed during interviews with the participants directly after the meeting. Another strategy used for member checking was the verification of the investigator’s emerging inferences as they formed during the interviews (Miles et al., 2014).

3.11.2. Transferability

I provided thick descriptions of the research context, with detailed descriptions for readers (Stake, 1995; Lincoln and Guba, 1985; Koch, 1994) to enable them to decide whether the findings are transferable to their specific context (Graneheim and Lundman, 2004). Furthermore, the finding chapters include some examples of the raw data such as direct quotes from the participants in order for alternative interpretations to be considered (Dawson, 2009; Stake, 1995).

3.11.3. Dependability

I checked the process of the data analysis with my supervisors by sending them samples of data analysis reports (extracted from Nvivo), as well as some case narratives for evaluating the process and the quality of analysis. Furthermore, I maintained an audit trail by keeping comprehensive notes that included detailed contextual background for all data as well as a rationale for all decisions taken during the study. However, it was difficult to find an external auditor to track the research and examine both the process and product of it (Lincoln and Guba, 1985), as it is an individualised PhD study rather than the work of a research team.

3.11.4. Confirmability

Confirmability ensures that the findings of the study are shaped by the participants of the research and not my own bias, motivation, and interests (Houghton et al., 2013; Lincoln and Guba, 1985). I tried to ensure confirmability in several ways, such as using triangulation, maintaining an audit trail and promoting reflexivity throughout the research process (see 3.12.).

3.12. Reflexivity

The aim behind using reflexivity is that researchers continuously apply self-critique and self-appraisal to explain if, and how, their own experiences, values and preconceptions affected the research process (Koch and Harrington, 1998; Hesse- Biber and Leavy, 2005). Reflexivity improves the quality of qualitative research by enhancing the reader's understanding of how the researcher's position affected all stages of the research process. Using reflexivity might be a strategy employed in order to consider the researcher's subjectivity, which signposts what is happening throughout the research process to the reader. This can affect their interpretation when they read the research report (Jootum, 2009; Primeau, 2003; Jasper, 2005). Reed and Procter (1995) identify three positions that the researcher occupies: hybrid, outsider, and insider.

The outsider researcher is a researcher who has no prior experience in the field of the study; the hybrid researcher is one who undertakes research in the same research area but with other practitioners; and the insider researcher is one who conducts a research study with their own colleagues within their area of practice.

In the current study, I considered myself to be a hybrid researcher as I worked in a similar study setting (a Jordanian hospital) in a medical paediatric department for a few years. Moreover, I had another role during my clinical work, teaching third-year nursing students in the same clinical area. I found several familiarities between the previous setting in which I worked and practised with my students, and the research setting. For example, I met several health care providers with whom I had already worked (nurses, doctors, and nursing students). I also found colleagues I had worked with before among the clinical instructors. Finally, I found several children and family carers (mothers) who I had worked with before (e.g. the mothers of Sewar, Baraa, and Qasim).

The diseases managed in this hospital were very familiar to me, as I had worked with similar cases when I was employed as a RN and as a lecturer, for example, renal failure patients who needed peritoneal dialysis. I had also worked with cerebral palsy and nephrotic syndrome patients before. Therefore, at the beginning of my study, I felt that I had a mix between my previous roles as a nurse and lecturer and my current role as a researcher, as shown in Field note 5.

During data collection, I continuously asked myself about the reasons why the parents agreed to participate in my study, allowing a stranger (albeit a researcher) to observe their interactions within the hospital as well as asking questions about their private lives and their past experiences. What motivated them to participate in my research? I think there were several factors involved in this; Suha’s mother told me that she agreed to talk to me as she felt that she needed someone to hear her. She generally stays in the hospital for hours and hours in boredom, observing the readings of the monitor to which her daughter is attached or preparing some milk for her to be administered by a feeding tube. She felt lonely because it was difficult to find someone to understand her feelings about her daughter’s disease. She told me that she was able to talk to me more freely than with her relatives, as she does not trust all of them. There is no social worker service in this hospital, which increases the needs of some carers to express their feelings.

Other carers wanted to get information from me about other children who had similar diseases. For example, Suha’s mother asked me if I had recruited other children with the same condition as her daughter. Similarly, Rosol’s mother asked me about Mousa’s condition (the same disease as her daughter) and how his progression was. I told them that all information I got from the research was confidential, but I could give them the results of my study as soon as it was finished.

In order to promote reflexivity, I used several techniques during my work as a participant observer, for example to reduce the threat that the participants might feel toward my presence.

Field note 5: The mix between my previous roles as a nurse and lecturer and my current role as a researcher

Descriptive notes	Reflexive notes
03.01.2015, nursing station, A-shift	
I'm standing in the nursing station waiting for the assigned nurse to come as she will start preparation for medication. I want to attend her medication preparation for Rosol. There are nursing students standing at the nursing station. I know two of them, they were my students in the previous university in which I worked. They came to greet me and asked me to discuss with them how to write a comprehensive care plan for paediatric case study (one of their course requirements for paediatric care). I started discussing with them how to write it. They had a form of nursing care plan and they came around to me at the nursing station. During my discussion I remembered that this was not my role here (to be a clinical instructor); instead, I should adopt the role of researcher. I completed my discussion as I had already started, then I clarified to them the change of role that happened with me and I asked them to understand that now I'm a researcher, not a lecturer, and if they needed any help they should ask their instructor or ask me outside the hospital by sending an email.	I totally forgot my initial role as a researcher for a while. This might be because I recently started my data collection and I had an intrinsic desire to help my former students. I felt helpless when I apologized to them for not being able to help during the time of data collection. I realized that I needed to work on myself to minimize the effect of my presence and allow events that I was observing to happen without my interference.

First, I introduced myself in a friendly manner. I tried to react to their feelings in a pleasant and sensitive manner, showing interest in their concerns about their children's diseases. I used the same technique with health care providers, demonstrating my interest in their issues. During the initial visits, I felt that some of them were uncomfortable about my presence, especially those nurses whom I accompanied during their work with the participating children. I used the technique of self-disclosure to reduce this discomfort. For example, I spent time with them when they were not busy to talk about the study and answer their questions about it and my role in it.

I tried to make them feel that they were the experts and that I needed their experience and help, focusing on the concept that there is no right and wrong, and that all of their experiences are important. For example, one practical nurse (PN) was hesitant about participating in the study as she thought I might ask her difficult questions, because she had a lower educational level than her colleagues. I told her that every experience is unique and there is no judgment about her opinion, after which she was encouraged and agreed to participate. I also used this strategy with the mothers, by informing them that I do not have children, and therefore do not know the nature of their experience of communicating with their children. This gave them a feeling of trust in their abilities to share their important experiences.

However, despite being well known by almost all of the employees in these departments, I found that some people remained worried about my presence, especially a few specialists and one head nurse. Some of them behaved in a way that made me understand that they were anxious in my presence, for example, using justifications or rationalisations about some issues related to the nature of their work. This made it clear to me that they feared I might report malpractice in the research, or inform the administration about them. I think that this might have been related to the observational nature of my research. This had a negative effect for me as I felt that I had been given an authority that was not my own.

Based on (Seymour, 2007), preliminary informal meetings with the relevant staff (gatekeepers) were helpful to inform them about the objectives of the study. This was a practical solution to overcome the problem of mistrust. I understood their fear, and this negatively affected me as I felt that my presence could increase their anxiety, especially as they were working in a highly stressful environment. Aside from ethical concerns, this had the potential to undermine the authenticity of my observations. Therefore, as I gradually built good relations with those whom I recruited to participate in my study, I reassured them that I had no authority to tell participants any medical information, especially about their progression, cure and medication. I stressed that this was not my focus, and reminded them again that pseudonyms would be used in reporting data instead of real names. To some extent, I felt that this relieved their anxiety. For those whom I did not recruit, I asked the head of medical/nursing departments to remind them (e.g. by circulating memos) about the strict ethical principles that guided this research, and which protected them.

After several visits I felt that the uncomfortable feelings that I initially encountered among some participants started to diminish. They welcomed me every time I went and shared their new concerns and thoughts. A few of them (specialists and nurses) helped me to recruit some cases. For example, when I met them in the hospital, they directly told me about the admissions of some children that could be of interest, such as renal failure and cystic fibrosis. This was very motivating to me as it indicated my success in building trusting relationships with them, in addition to their cooperative attitude and initiative as health professionals. Moreover, I became more able to control myself and restrict my activities to the researcher role as the data collection period went on.

The level of engagement with children was another issue for me during the observation phase of my study. I felt that it was abnormal not to respond to some children, such as Baraa, when they asked me to participate in some of their activities such as drawing. Lawlor and Mattingly (2001) pointed out that failure to engage with some children’s activities during observation might be an undesirable consequence of the researcher’s attempt to be unobtrusive, as it might lead to profound disengagement among child subjects. When Baraa asked me to colour his paintings, for example, I agreed to, as I thought that he might see it as extremely unnatural for me to refuse to play with him.

I also faced the issue of taking notes in front of participants, some of whom clearly felt threatened by this (see Field note 6). Because of this, I decided to postpone writing notes until leaving the department for a break or even when I was outside the department. I also decided to take audio notes instead of written ones, as the latter are more time consuming, and they disrupt the participants' natural loquaciousness due to the perception that they are being interrogated.

Field note 6: The issue of taking notes in front of participants and how I behaved to minimise the negative effect experienced by the study participants

Descriptive notes	Reflexive notes
30.12.2014, A-shift, 10:00 am, nursing station	
I was standing at the nursing station waiting for Latifa's mother to return to her room. I had my notepad, reviewing some notes that I took yesterday about some details about Latifa. One nurse came and asked me "what are you writing? Do you write about us?" I answered her that this is the nature of my research; I usually take some field notes as another source of information. I told her that I can show her some notes related to my observation with her. She agreed with that and I showed her one note from a couple of days ago.	I felt restless when this nurse told me that she was not comfortable seeing me writing notes. Therefore, I decided to postpone writing notes until leaving the department for a break. Furthermore, I decided to depend more on the voice notes instead of written notes, as the latter are time consuming and distracting (i.e. threatening) for some participants.

To conclude, the main objective of reflexivity is to express the transparency of the decisions taken during the research process (Houghton et al., 2013). I kept a reflective diary in which I clarified how my history, background, personal interests, and the theoretical perspectives that I brought to the research field affected my decisions throughout the research process, as well as my interpretations of the research findings (Jootum, 2009; Koch, 1994).

3.13. Conclusion

This chapter has shown how the research strategy and design was developed and justified. The philosophical foundations of the study have justified the research approach, design, and data collection methods employed in the current study and guided the whole research process. Within-case analysis and cross-case analysis were adopted, paying attention to both the individualised cases and the collective case studies. Several ethical principles were followed during the study period, mitigating the risk of potential harm to participants. Several strategies and approaches were employed to improve the rigour of the study, in particular, credibility, dependability, transferability, and conformability. The final section demonstrates how I acknowledged and recognised the effects of my social background and my previous assumptions on the research process and the findings of the study.

The following chapter is concerned with the case profiles, and provides details about the individual cases within their particular context. This chapter offers further understanding of each case background, and prepares for the fuller presentation of the qualitative findings that follows.

CHAPTER 4: CASE PROFILES

4.1. Introduction

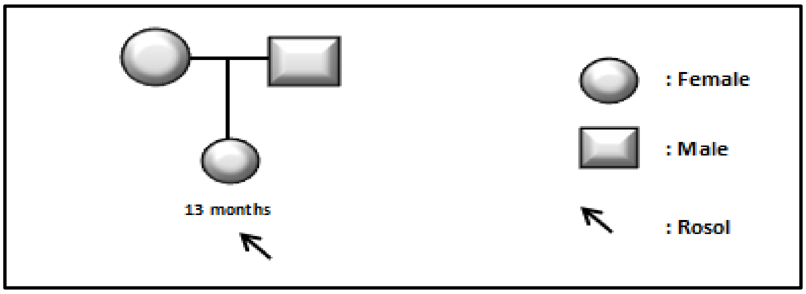
This chapter briefly presents some background details concerning the individual cases. Following the recommendation of Stake (1995) who stressed the importance of including contextual details of the cases presented in the collective case-study research, this chapter provides a contextual background for the following findings (5, 6, and 7) that result from the cross-case analysis of the data. Each case starts with a presentation of the family structure, which is followed by other essential information such as family history, socioeconomic status, and family dynamics. This is followed by a visual presentation that provides some details related to the child's health condition(s) and the family carers and health professionals who are most involved in their care. Finally, some details are given about how consent was obtained from the parents and children, which provides some insight into the process of recruiting the study participants. In line with (Bryman, 2008; Kaiser, 2009; Orb et al., 2001), children and participants are given pseudonyms to protect their anonymity.

4.2. Brief Case presentation

4.2.1. Rosol

- *Family structure*

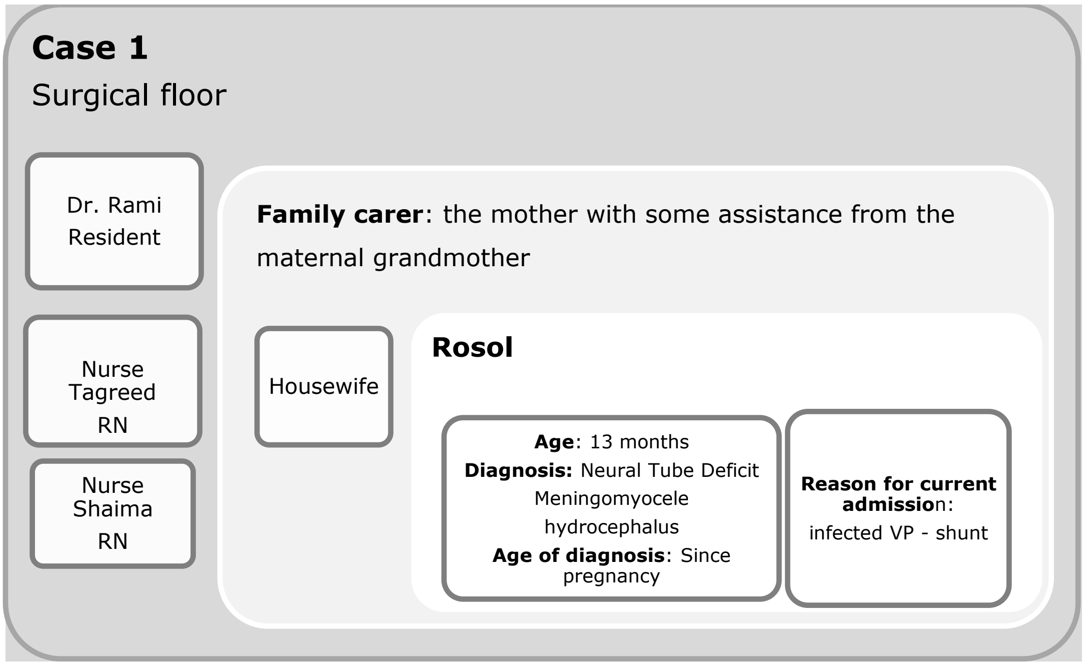
Rosol was the first child in her family. Her parents got married one year prior to her birth (see below).



- *Family history*

Rosol’s father and mother are cousins. There is a family history of hypertension (Rosol’s maternal grandmother) and diabetes (paternal grandfather and maternal grandfather), and no other known diseases.[14]

- *Case presentation*



- *Socioeconomic status*

Rosol’s mother was a university student, but she quit because of her daughter’s disease, which required her to adopt the primary caregiving role. Rosol’s father is a BSc degree holder, and works in the textiles trade. The mother described their economic status as very good. The family owns their home, which is located far from the hospital.

- *Family dynamic*

There appeared to be a good relationship between the couple. The mother described her husband as a supportive person. He supported her throughout all

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[14] The mother is the primary source of information.

phases of their child’s disease, and came every day to visit Rosol, despite them living far away from the hospital. She mentioned that he respected her opinion regarding decisions related to Rosol’s health. The grandmother mentioned that Rosol had good attachment to her parents, and described her as an interactive child who could distinguish the voices of her mother and father. She knew when someone called their names, which aroused her attention and prompted her to look for the voices.

- *Significant information*

The husband and grandmother hid Rosol’s condition from her mother at the time of birth in order to protect her from shock. However, Rosol’s mother suspected that her daughter was not well as the neonate was not given to her to breastfeed as is customary. Instead Rosol was sent to NICU. Rosol’s mother hesitated to see her daughter after finding out about her condition, however after receiving support from her husband and family, she saw her and they became more attached.

The mother suffered social stigmatisation about her daughter’s disease. The grandmother explained that some relatives described Rosol as having retardation/anomaly, and expressed sentiments to the effect that it would be better for her to die. This was very painful for the mother, who was fragile at the beginning. However, she said that she became stronger and responded to these reactions by insisting on taking even more care of her daughter than before.

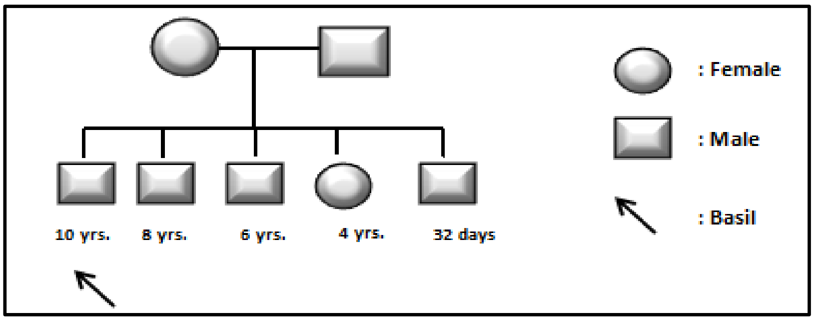
- *Obtaining consent*

Consent was given two days after discussing the study with the mother, who wanted to ask her husband; he encouraged her to participate in the study. The mother had a good level of understanding about the research as she had already taken a course related to research in the university. She had a positive attitude regarding the importance of research to improve health practice, but she felt that she needed to consult her husband first so that they could read the information sheet together before responding.

4.2.2. Basil

- *Family structure*

Basil’s family consisted of his parents, one sister and three brothers. Basil was the oldest child (see below).



- *Family history*

The mother did not know of any kidney conditions in the family. However, this family had a few diseases such as hypertension (paternal grandfather, maternal grandmother), diabetes mellitus (Basil’s two uncles) and breast cancer (maternal grandmother).

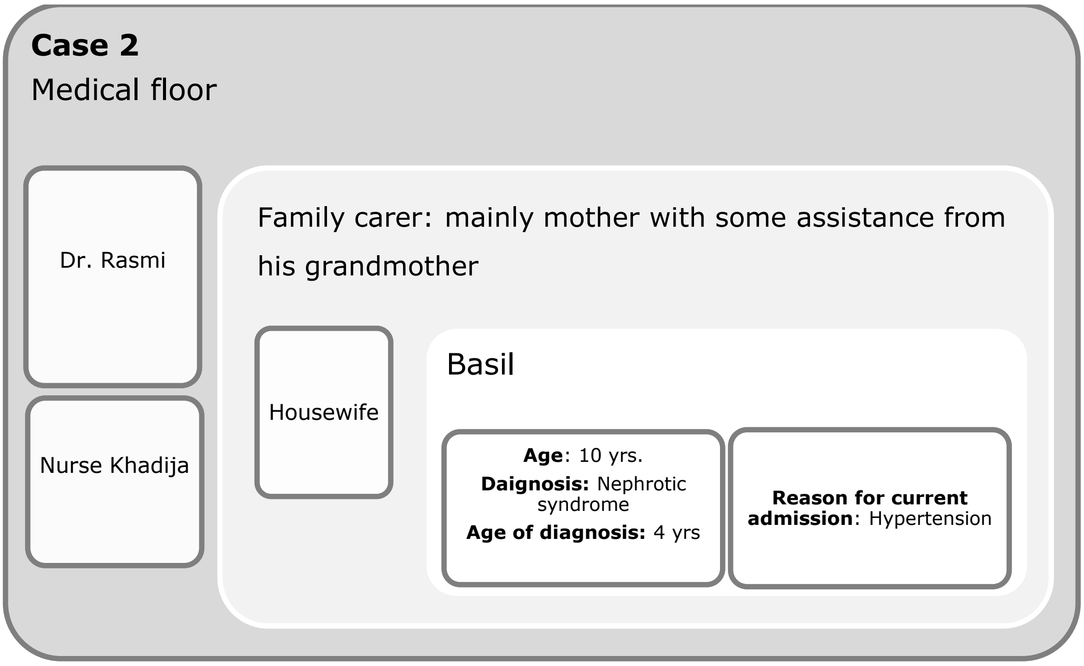
- *Socioeconomic status*

Basil’s mother has a higher-level diploma. After marriage she stayed at home to take care of her children. Basil’s father is a secondary school teacher who works close to where they live. The mother described their financial status as poor, because they have five children who need many things. They live in a small rented apartment (two rooms plus kitchen and bathroom). The father’s teaching salary is the family’s only financial resource.

- *Significant information*

The mother told me how much Basil was aware of his condition. For example, he knew about the strict diet that he should follow and he was committed to it; when his grandmother gave him a falafel sandwich he refused to eat it, telling her that it was harmful for his health as it was rich in protein. However, the mother rarely discussed Basil’s illness with him, especially any painful information, in order to protect him from suffering.

- *Case presentation*



Case 2
Medical floor

Dr. Rasmi

Nurse Khadija

Family carer: mainly mother with some assistance from his grandmother

Housewife

Basil

Age: 10 yrs.
Daignosis: Nephrotic syndrome
Age of diagnosis: 4 yrs

Reason for current admission: Hypertension

The mother told me that Basil’s academic achievement was good despite his disease; however he was concerned about social exclusion from not being able to participate with his friends in school sports. He liked sport very much and wanted to be like his friends. The mother tried to support him by continuously discussing the importance of patience with him and also tried to discourage him from comparing his situation with his friends in terms of food and exercise.

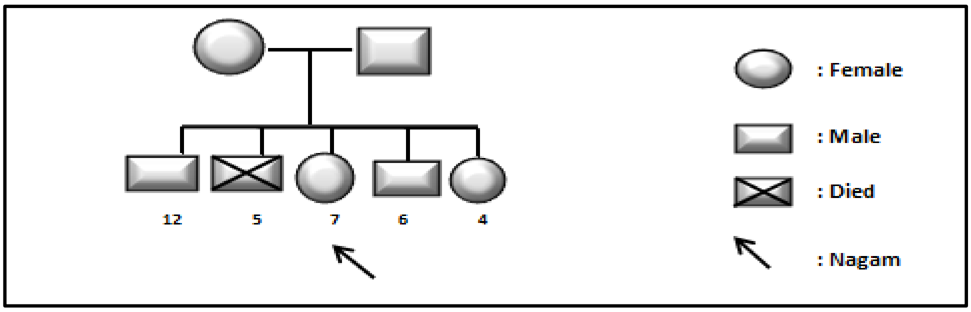
- *Family dynamics*

The mother felt that Basil had a good relationship with his brothers and sister; however, sometimes he fought with his brothers who felt jealous due to the special parental care Basil received.

4.2.3. Nagam

- *Family structure*

Nagam’s family consisted of her parents, one sister and two brothers. Nagam was the third child in her family (see below).



- *Family history*

The mother and father are cousins. There is a paternal history of thalassemia disease. Nagam’s cousins have thalassemia major, and receive regular blood transfusions. When the parents got married, there was no pre-marital screening program for beta-thalassemia. A mandatory pre-marital screening program for beta-thalassemia carriers commenced in Jordan in June 2004 (Hamamy et al., 2007). The parents were therefore not aware that their child was a thalassemia carrier. This family has a history of diabetes mellitus (maternal grandfather) and genetic kidney disease (see below). There are no other known diseases.[15]

- *The history of kidney disease in the family*

This family had a genetic kidney disease that affected two children in the family. The first child (12 years old) was delivered with no health problems, while the second child suffered from severe vomiting and diarrhoea alongside intense crying as a neonate. Within a few days of delivery his parents took him to the doctor, who diagnosed dysuria (failing to take a urine sample for investigation). The doctor transferred him to the nearest hospital where it was shown that he had irreversible deterioration of renal function, which gradually progressed to end-stage renal disease (ESRD). He was admitted to the operation room in order to insert a catheter for peritoneal dialysis, and was on peritoneal dialysis for four years. However, he had several complications (such as recurrent catheter infection, convulsions, and significantly increased blood pressure). He was undergoing preparation for haemodialysis therapy, but died before the arteriovenous fistula surgery was performed.

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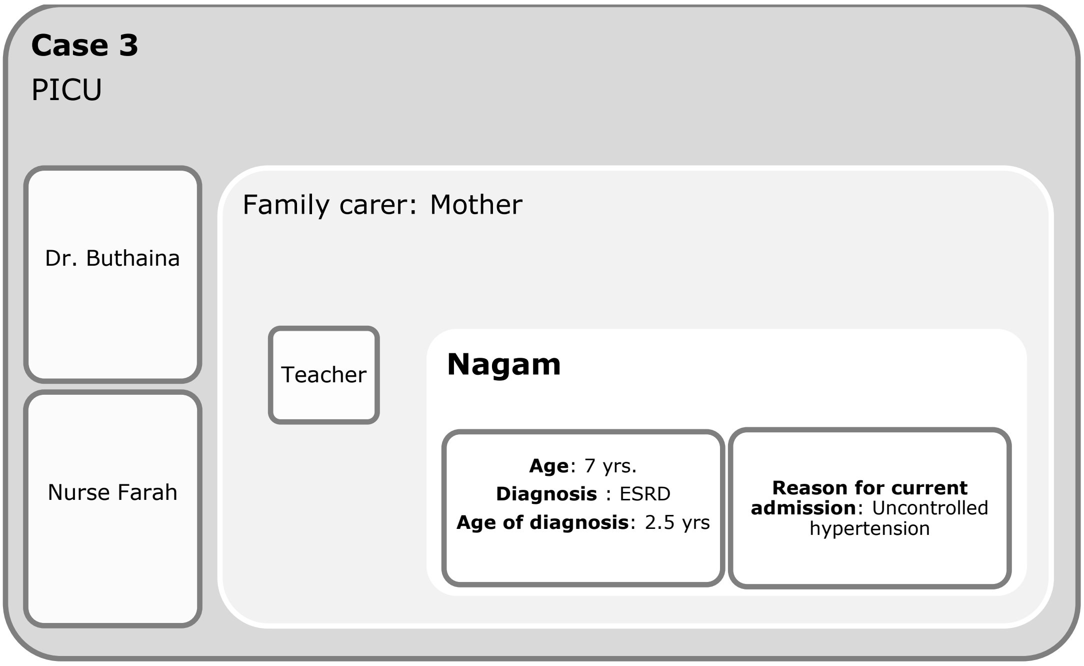
[15] Both parents were the primary source of information.

- *Case presentation*



Case 3
PICU

Dr. Buthaina

Nurse Farah

Family carer: Mother

Teacher

Nagam

Age: 7 yrs.
Diagnosis : ESRD
Age of diagnosis: 2.5 yrs

Reason for current admission: Uncontrolled hypertension

- *Socioeconomic status*

Nagam's mother is a BSc. degree holder who works as teacher in the city where the family lives. Nagam's father finished secondary school and is a self-employed; the instability of his employment increases the financial burden on the family. It is essential for the mother to work as the family does not have any other means of financial support during the periods that her husband has no work. They live in a rented apartment.

- *Significant information*

After the death of their first child, the mother did not breastfeed her children because of psychological distress. She intentionally tried to avoid making the motherhood attachment with them, so as to reduce her anticipated suffering, since she expected them to die.

The parents received very bad news about Nagam's health condition when the doctor announced her intention to stop the mechanical ventilator a few hours prior to the interview. I faced an ethical dilemma about whether to complete the interview with this couple or not. Feelings of intense guilt arose when I began to conduct the interview, and I asked them to permit me to leave and even to cancel the interview for their own sakes, but they strongly refused and insisted on being interviewed. What encouraged me to complete the interview with them was the strength of the mother during this difficult situation. Furthermore, I felt later, after the interview, that they might have needed to talk to someone at this time to share their suffering.

I felt surprised by the strength of the mother in her stoic acceptance of the death of her daughter, as well as her attempts to support her husband who was crying over the death of his daughter. It is very unusual in Jordanian culture for men to cry in public, whereas visible manifestations of grief would be expected from the mother, especially as this was her second experience of a child of hers dying from the same disease.

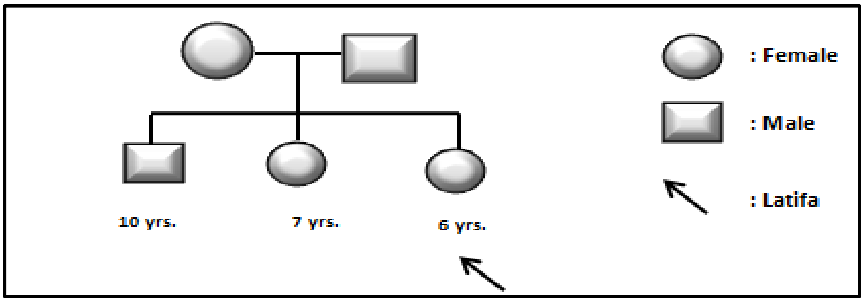
- *Family dynamics*

The mother described her relationship with her husband to be good, and this was supported by my observation and interview, as they appeared to be a very cooperative couple. The father took care of their other children while the mother was in the hospital with Nagam, and he helped her coordinate between work, home, and hospital. For example, the mother usually went to school in the morning, the father stayed with Nagam until she came to the hospital, and then the husband went home to take care of their other children. The mother mentioned that his work was significantly affected by Nagam's disease.

4.2.4. Latifa

- *Family structure*

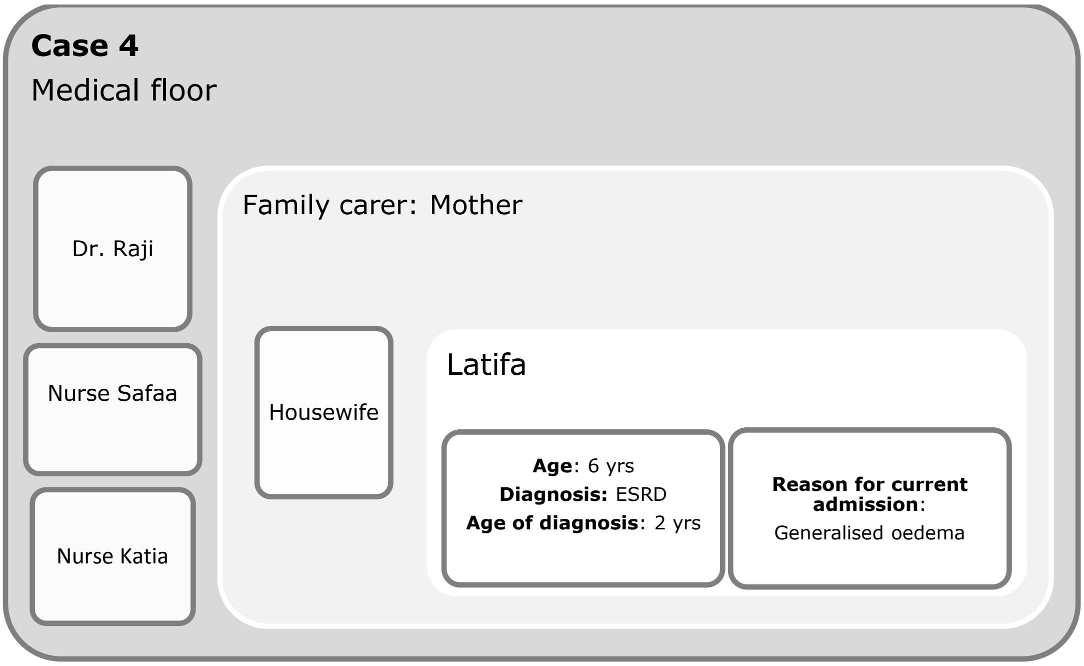
Latifa's family consisted of her parents, one sister and one brother. Latifa was the youngest child in her family (see below).



- *Family history*

The parents are cousins. The mother does not know of any renal condition in the family, but there is a history of hypertension (paternal grandmother); rheumatoid arthritis (Latifa's aunt) and heart disease (maternal grandfather); there is no other known history of disease.[16]

- *Case presentation*



- *Socioeconomic status*

Latifa's mother is a housewife. She finished primary school and got married at the age of 20. Latifa's father works as a greengrocer. He studied up to secondary school. They live with the father's parents (extended family) in a village far away from the hospital. The mother described their financial level as good, as her children go to public schools (almost free).

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[16] The mother is the primary source of information.

- *Obtaining consent*

The mother was approached by a charge nurse, who told me that the mother was a cooperative and welcoming woman. After discussing the objectives of the study with her using clear terms, she told me that she would agree to participate, even without reading the information sheet. Naturally, I refused this, and discussed with her the importance of knowing what the study entailed. I told her that she could confer with her husband, doctor, and friends, and gave her my contact phone number.

- *Family dynamics*

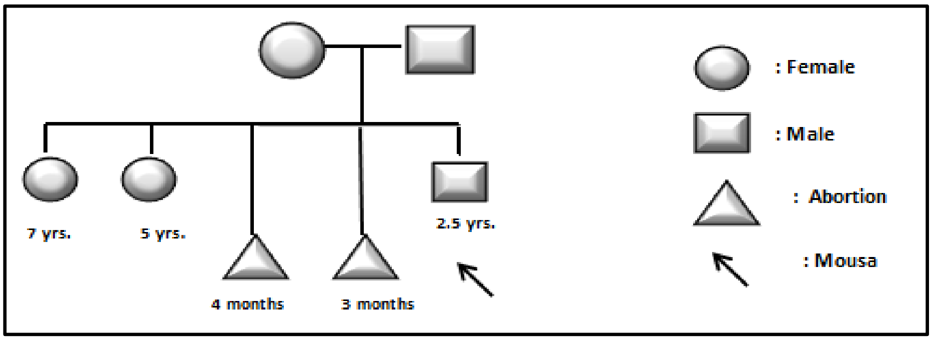
The mother said that Latifa's father treated her differently to the other children. He gave her special attention and he said that she was the best child among all of his children. Her uncles and aunties celebrated whenever she was discharged from the hospital. The mother mentioned that she also gave her special care (possibly more than her siblings) because of her health condition.

The mother described that her husband supported her during the course of their daughter's disease. She mentioned that their relationship became better as they both underwent suffering together.

4.2.5. Mousa

- *Family structure*

Mousa's family consisted of his parents and two sisters. Mousa was the youngest child.



- *Family history*

The parents are related. The mother did not know of any similar health condition in her or her husband's family.

- *Socioeconomic status*

Mousa's parents both completed their Tawjihi level,[17] and then left the education system. The mother is a housewife and the father has a small clothing shop. They live in an apartment in a city far from the hospital. The mother described their economic status as good, especially as they still had three children. However, she thought that in the future they will need to improve their financial status as she anticipated greater requirements as their children get older.

- *Significant information*

This mother suffered from social stigmatisation because of her child's big head, which encouraged her to seek solitude and isolation within the hospital. She told me that she liked to close the curtains around herself and her child. She felt bored by spending long periods in the hospital, and told me that staying there was the worst experience she had during the course of Mousa's disease.

The mother was concerned about the family dispersion that resulted from her long stay in hospital. She was worried about her two daughters, who usually stayed with the mother's family (sometimes they were split between the mother's family and the father's family). She cried when she remembered them weeping because of her situation. Moreover, the mother had concerns about the progression of Mousa's disease and was afraid of any future pregnancy that might result in the same painful experience.

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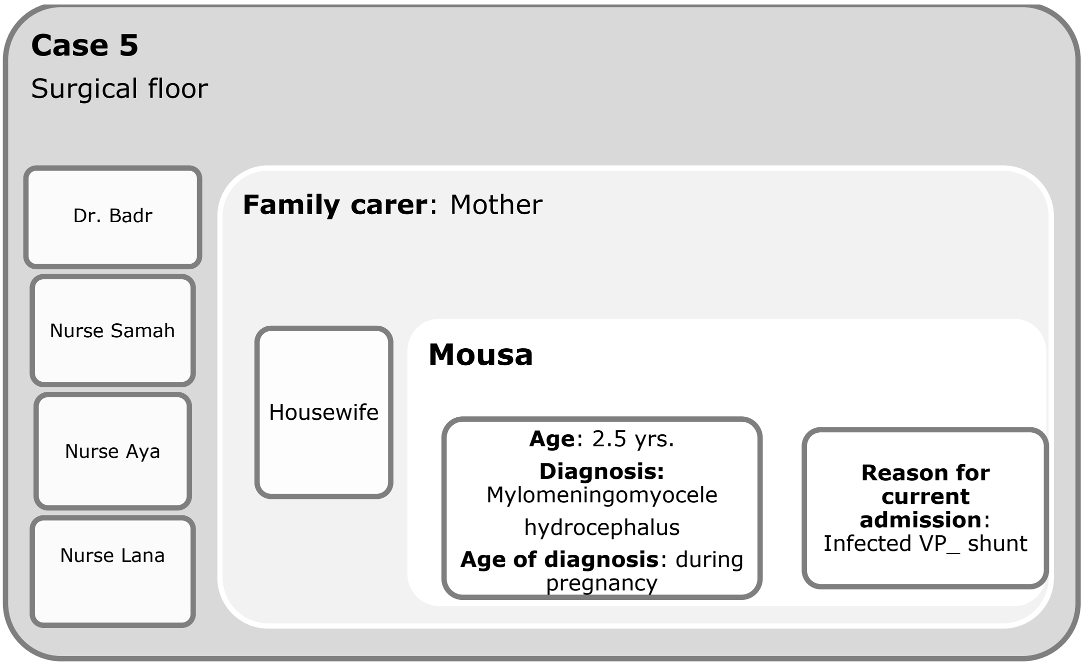
[17] The Tawjihi level in Jordan is the 12th school grade; it is the last school grade year before admission to university.

- *Case presentation*



Case 5
Surgical floor

Dr. Badr
Nurse Samah
Nurse Aya
Nurse Lana

Family carer: Mother

Housewife

Mousa

Age: 2.5 yrs.
Diagnosis: Mylomeningomyocele hydrocephalus
Age of diagnosis: during pregnancy

Reason for current admission: Infected VP_ shunt

- *Family dynamics*

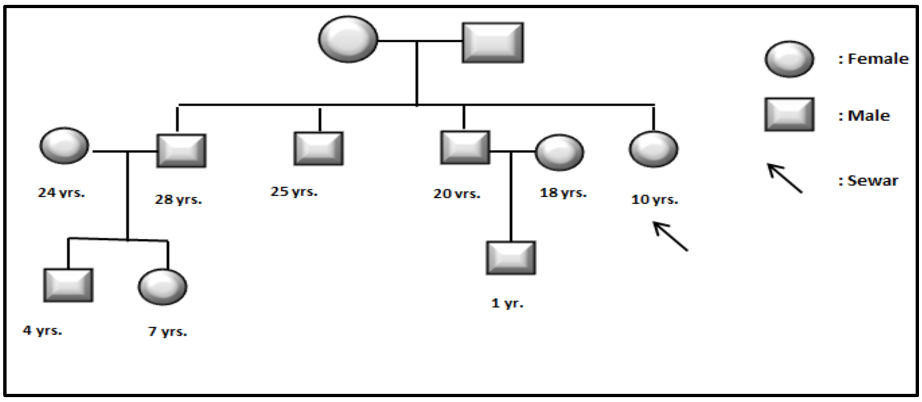
The mother described her relationship with her husband as having become stronger because of their son’s disease. She described him as the most supportive person to her, although her family was another source of support. They live quite close to the hospital, which helped her to get some rest, as her sister was able to stay with Mousa.

The mother said that her youngest daughter felt jealous of her brother, due to the perception that Mousa received more care and attention. This prompted her to knowingly misbehave. Other behaviours included being overly affectionate toward her brother, trying to show her care for him and wanting to carry him and hug and kiss him. This is a coping mechanism some children use when they are jealous.

4.2.6. Sewar

- *Family structure*

Sewar's family consisted of her parents and three brothers. She had two married brothers with children, so Sewar was the aunt of three children (see below).



- *Family history*

Sewar's uncle had renal disease and died several years ago. No other known conditions of renal disease existed in the family; however Sewar's grandmother had hypertension and coronary heart disease before death.

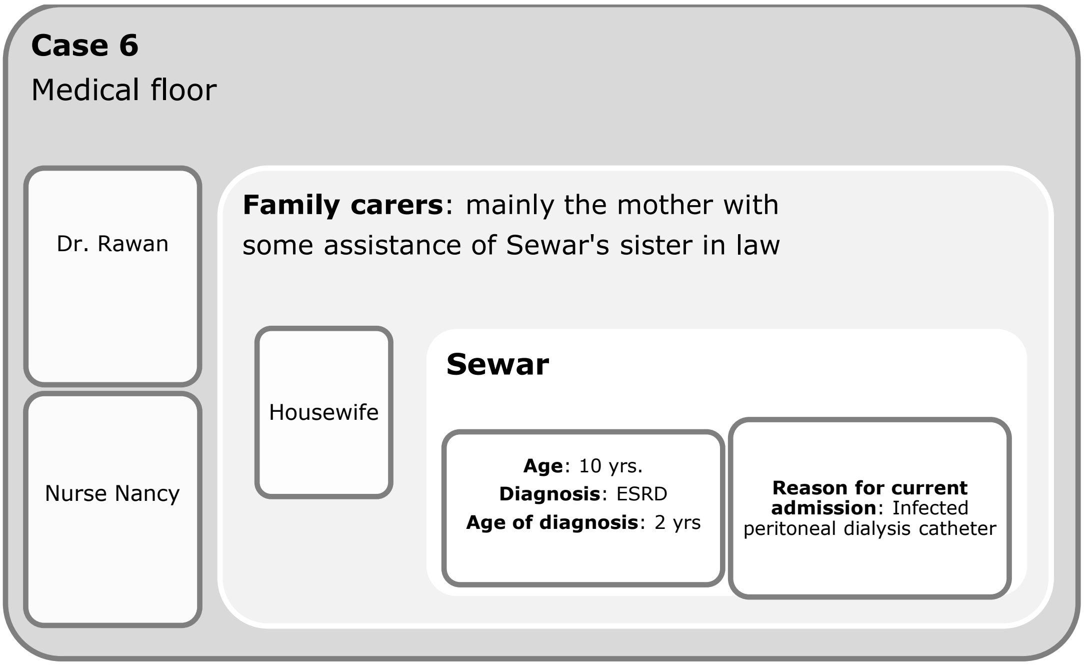
- *Socioeconomic status*

Sewar's mother left school after finishing her primary education to get married. Sewar's father is a teacher in a primary school. They live in a basement and her brothers live on the upper floors. The mother described their economic status as being very good. Her sons helped to support her with further requirements, especially those related to Sewar's needs.

- *Family dynamics*

Sewar was the youngest child in her family, and the only girl; she has two married brothers. The mother described how her daughter was given very special treatment in her family. Her father liked her very much, and never refused her requests. Moreover, Sewar had a good relationship with her brothers and their sons. Sometimes she bought food that she was prohibited from eating because of her condition (e.g. chips) for them from her pocket money.

- *Case presentation*



- *Significant information*

As with any child in Jordan, Sewar went to school at the age of six, but she left during the fourth grade because of her frequent admissions to hospital for dialysis. Sewar liked her school, and insisted that she wanted to return, but according to the regulations, she was prohibited from being registered to complete the year as she had missed too many lessons to catch up, therefore she needed to wait for the next academic year to repeat the same grade. Sewar was not happy with this, as she wanted to get out of the house and attend school like her peers.

Sewar underperformed at school because she was absent a lot. Her mother told me that some teachers did not understand this and were not sensitive to her condition, which eventually caused her to leave school completely. However, Sewar did not give up her dream of education, and took her books with her to hospital, where some nurses helped her to read and write. Nurse Faten told me that she helped Sewar to improve her reading and writing abilities when she had time, because she understood how much Sewar liked education.

Sewar was one of the most attractive and active patients in the hospital, and was a very intelligent and social child. She had a lot of friends in the hospital. Moreover, she was very aware of her condition. One time I saw nursing instructors ask her to show nursing students how peritoneal dialysis works. She was also very friendly with all of the kidney disease patients in the Paediatric Department, who are admitted to a specialised renal room with six beds.

The mother described Sewar’s high cognitive ability, especially how she noticed non-verbal communications between her doctor and her mother. She said that when the doctor gave her some information about Sewar’s condition, he usually called the mother outside the room to do so. Sewar understood this and asked the mother to tell her what the doctor had said. Sewar thought that the doctor wanted to make a psychological consultation for her, and asked her mother after he left what he wanted to hide from her. She mentioned that it was ok for her to see a psychiatrist.

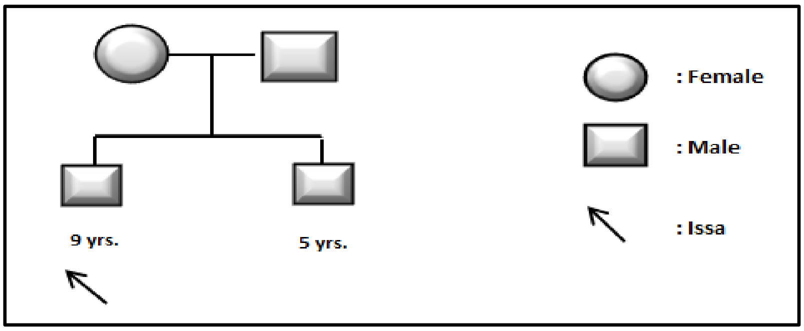
Sewar’s mother mentioned that in the beginning the doctors talked in English in order to hide some information from her. However, during their discussion about reinserting the peritoneal dialysis catheter, Sewar started crying in front of them, saying she did not want to undergo an operation. They were amazed that she had understood them, ascertaining that she had acquired some knowledge of English, and they changed their communication style afterwards, calling the mother outside the room to tell her any significant information. However, Sewar understood this as well, and her mother told me that she did not hide anything from her.

When Sewar asked, her mother told her the facts, perceiving this to be preferable to help her cope with the condition and avoid shock. The mother mentioned that Sewar insisted on knowing about her condition and cried until her mother informed her in full. The mother said that when Sewar was fully informed, she accepted the condition and everything became easier.

4.2.7. Issa

- *Family structure*

Issa's family consisted of his parents and one brother. Issa was the oldest child in his family.



- *Family history*

This family has a history of hypertension (maternal grandmother) and diabetes (paternal grandfather and maternal grandmother). The mother mentioned that she does not know of any other conditions in the family.

- *Socioeconomic status*

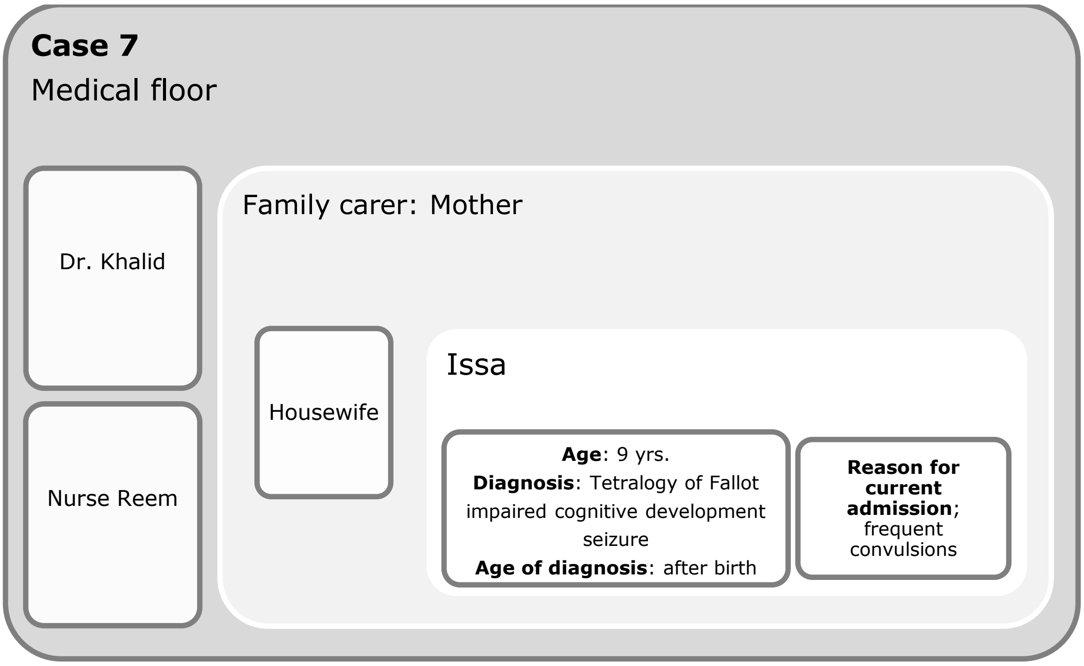
The mother studied until Tawjihi level, and then left after becoming pregnant with Issa. She is a housewife and was the primary carer for Issa. The husband has a financial diploma and works in a bank. The family lives in an apartment that was purchased in instalments through the bank.

- *Family dynamics*

The mother described her relation with her husband as being good, and their son's sickness improved their relationship, as she felt that he empathised with her suffering more than before.

The mother noticed that Issa's brother felt jealous of the attention the parents gave to Issa. Sometimes he hit his brother, while other times he sought more attention from his mother, especially when she had stayed at the hospital for a long time. She mentioned that the last time she had stayed with Issa for more than one month he had refused to talk to her on the telephone, and said to his father that he did not like his mother because she did not like him. The mother told me that she started to give more attention to her other son. Both parents tried to make him feel more responsible and to increase his awareness of his brother's illness. They gradually discussed Issa's condition with him and taught him to take care of his brother. She mentioned that he tried to be cooperative most of the time, although he could still become jealous if he thought that the parents' attention was more focused on Issa.

- *Case presentation*



Case 7
Medical floor

Dr. Khalid

Nurse Reem

Family carer: Mother

Housewife

Issa

Age: 9 yrs.
Diagnosis: Tetralogy of Fallot
impaired cognitive development
seizure
Age of diagnosis: after birth

Reason for current admission; frequent convulsions

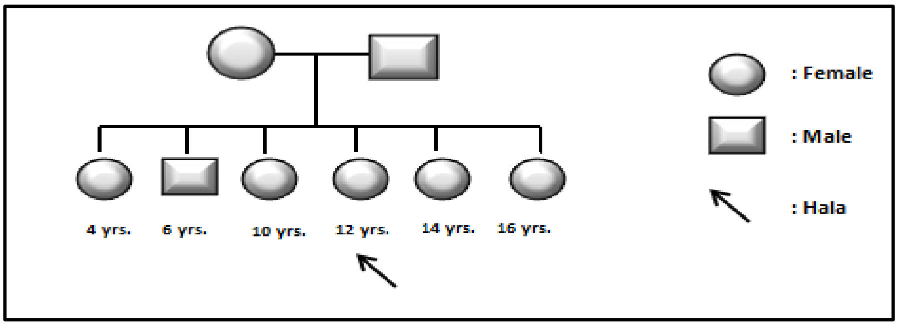
- *Significant information*

The mother was not informed about the severity of her son's condition. The doctors expected Issa to die during infancy; they informed the father of this but hid it from the mother, who only found out several years later. From her perspective, no human can decide about another's death, and the estimations about Issa were not guaranteed.

4.2.8. Hala

- *Family structure*

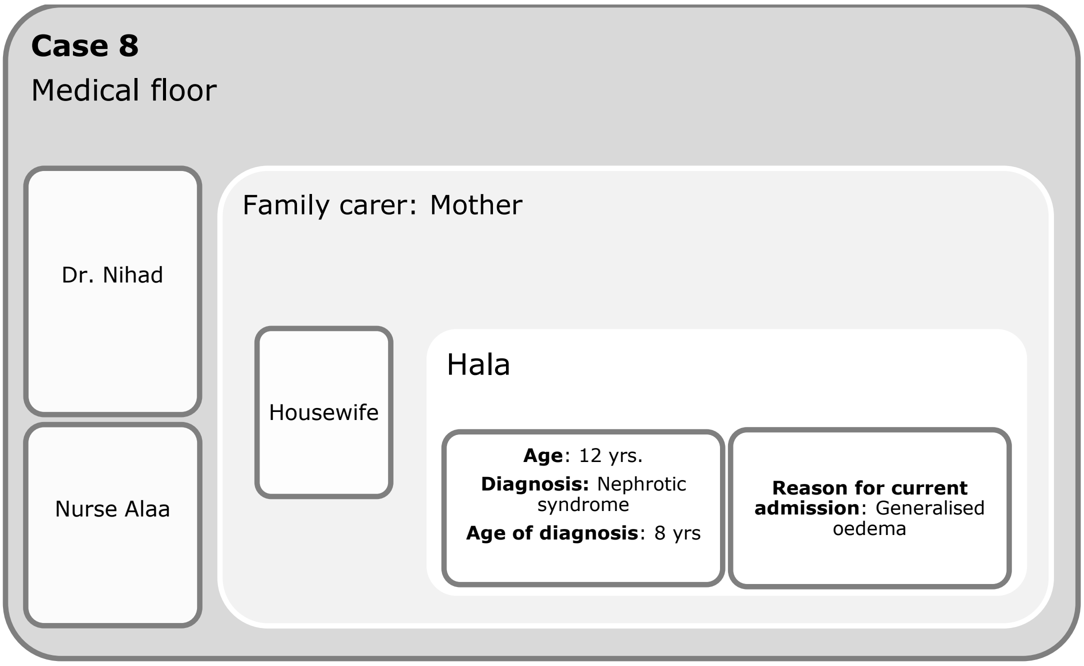
Hala’s family consisted of her parents, five sisters, and one brother. Hala was the third child.



- *Family history*

There is no family history of renal disease; however her father has a life-limiting illness that restricts his ability to work. Hala’s grandmother had hypertension before her death. There are no other known diseases in the family.

- *Case presentation*


Case 8
Medical floor

Dr. Nihad

Nurse Alaa

Family carer: Mother

Housewife

Hala

Age: 12 yrs.
Diagnosis: Nephrotic syndrome
Age of diagnosis: 8 yrs

Reason for current admission: Generalised oedema

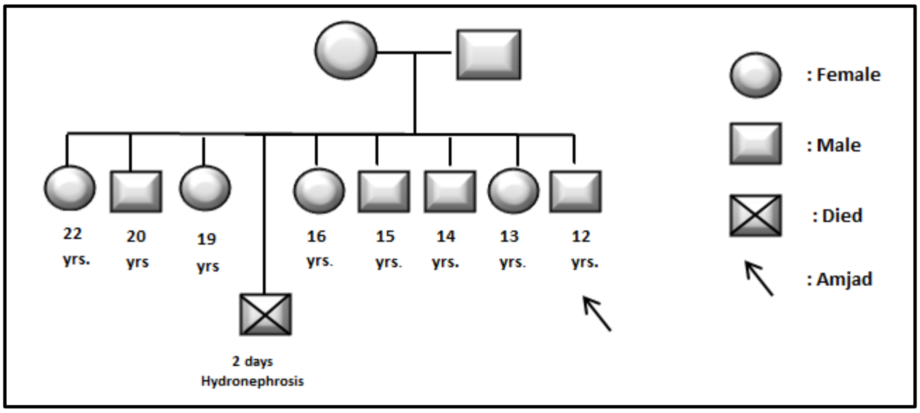
- *Socioeconomic status*

Hala’s mother finished her primary education and then left school to get married. Hala’s father did not receive any formal education but had vocational training as a car mechanic before having the life-limiting illness, which prevented him from working (see Appendix H for further details about Hala)

4.2.9. Amjad

- *Family structure*

Amjad’s family consisted of his parents, four sisters and three brothers. Amjad was the youngest child in the family (see below).



- *Family history*

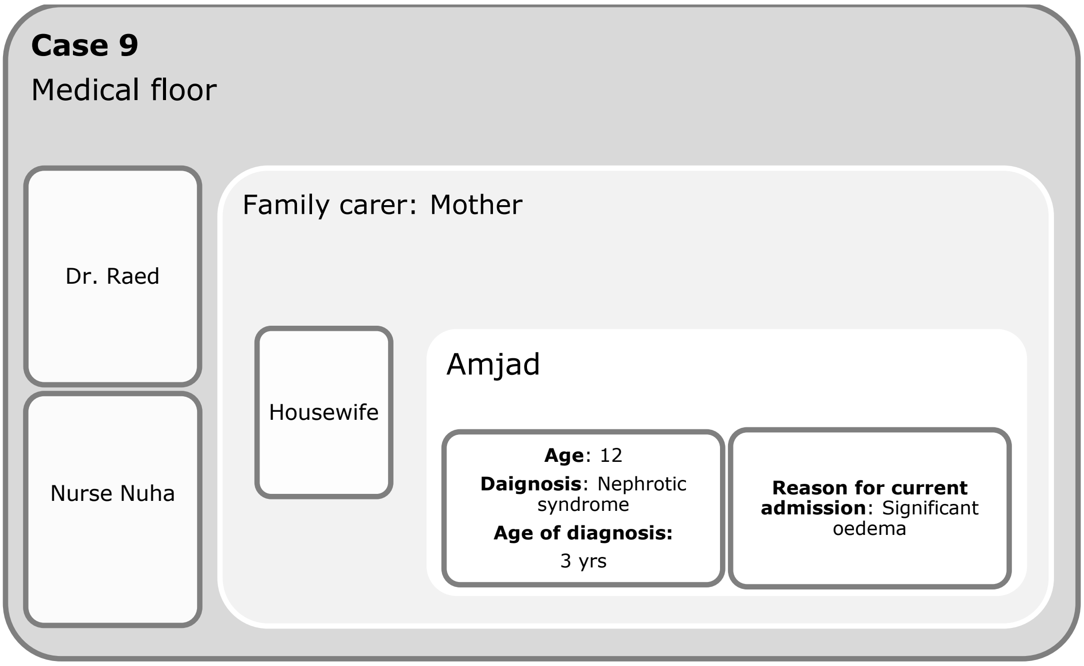
The mother mentioned that the family had a history of chronic diseases such as hypertension (her mother-in-law) and diabetes mellitus (maternal grandmother). However she had no information regarding any kidney disease within her family or her husband.

- *Socioeconomic status*

Amjad’s mother finished her primary education and then left school to get married. Amjad’s father completed his secondary school education, and then left school to work in different jobs. He was working outside the country for a few years. Currently, he works as a taxi driver. This family has poor economic status. The mother said that the father is the only one who works in the home.

However, sometimes the oldest son helps his father with some financial responsibilities.

- *Case presentation*



Case 9
Medical floor

Dr. Raed

Nurse Nuha

Family carer: Mother

Housewife

Amjad

Age: 12
Daignosis: Nephrotic syndrome
Age of diagnosis: 3 yrs

Reason for current admission: Significant oedema

- *Family dynamics*

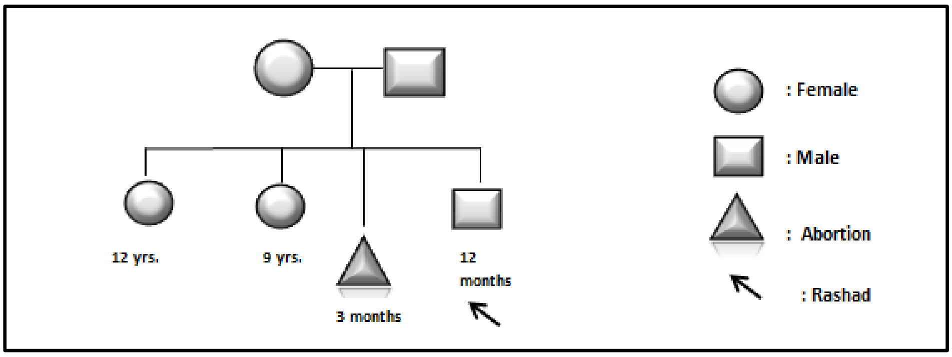
Amjad's mother and sisters described him as nervous and sensitive, and having a tendency to stay alone. This was very clear during my observations of him, where he talked to them with a sharp tone of voice. During the joint interview I did with his mother in his presence he displayed a negative attitude toward the hospital and school. He had a tendency to keep quiet; even when his mother asked him questions, he had difficulty in responding. He did not have friends in the department, which might have contributed to his frequent complaints and requests to his mother to discharge him from hospital.

When I gave him information related to the research, he showed a good level of understanding, although he was very shy toward me. He asked me to ask his mother to see if she agreed to participate in the study or not. I informed him that his independent acceptance was important, and nothing would be done without his acceptance. He finally accepted.

4.2.10. Rashad

- *Family structure*

Rashad's family consisted of his parents and two sisters. Rashad was the youngest child.



- *Family history*

According to the mother, Rashad's maternal grandmother had three children with cerebral palsy. They died two to three years after birth. Moreover, Rashad's father is a close relative of Rashad mother (cousins), which increases the chance of confluence of pathological genes. This family also has a history of diabetes (the mother's uncle and maternal grandmother).

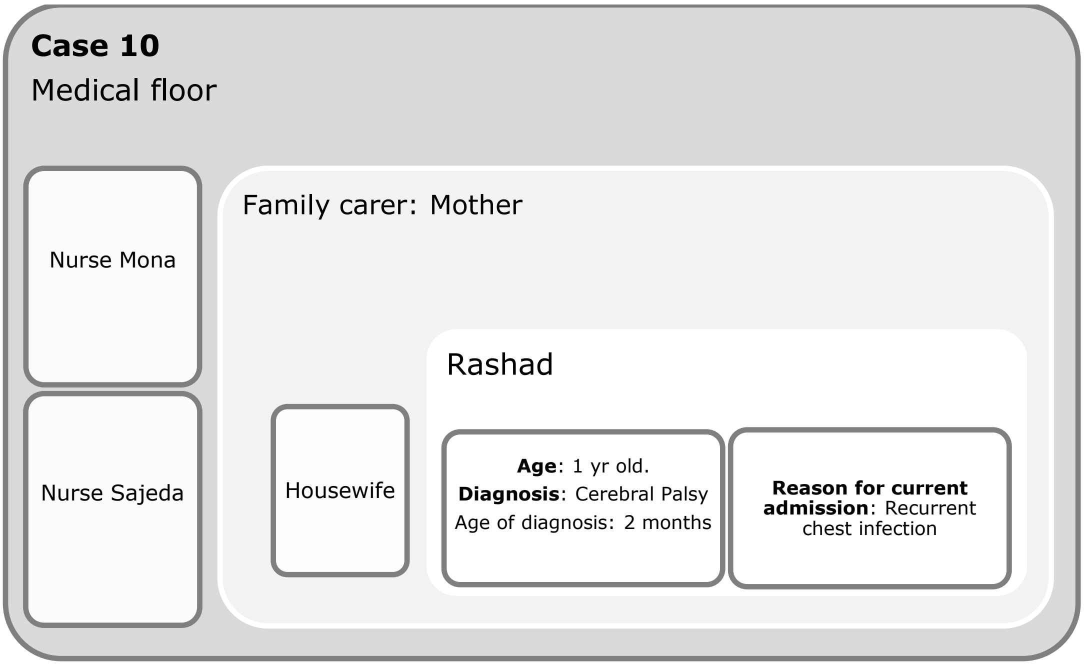
- *Socioeconomic status*

The mother is a housewife, who studied up to the 10th grade of secondary school, then left to get married at the age of 16. The father works in a restaurant as head waiter. The family lives in an independent apartment in a building that is owned by the husband's family. They live in a popular area not far from the hospital.

- *Significant information*

I very surprised by the proactive, rational approach of the mother. She was one of the few mothers who talked about the condition of her child in a non-empathic manner. She did not cry or show any signs of suffering while she was telling me about her son's illness. She was one of the carers that made me realise the huge variability of expressing feelings carers might have. She wanted a pragmatic solution to her child's problem and honest information about the disease's future progression. In spite of being recently informed about the critical nature of her child's disease, she was comfortable knowing this, instead of being lost or having false hope and then ending up disappointed. She had significant concerns about her stay in hospital, and when she might be able to go home. She mentioned that she felt tired from staying at the bedside observing the oxygen saturation of her child, and was thinking about her family, daughters, and husband. She mentioned that she did not want to spend her life in hospitals.

- *Case presentation*



- *Family dynamics*

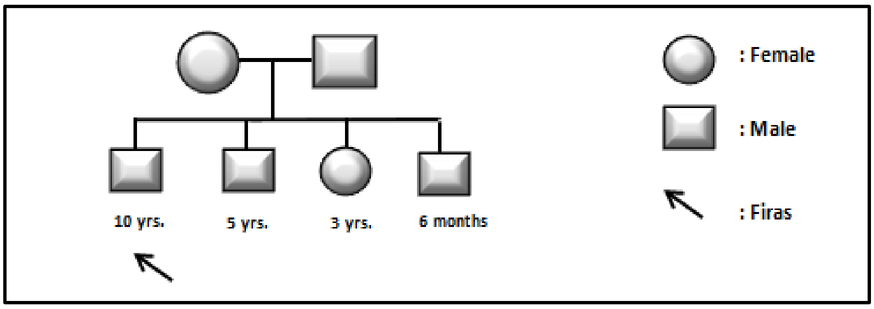
The mother said that her family status was unstable because of her long stay at the hospital. In spite of her family supporting her by taking care of her daughters, she still felt uncomfortable about their progress at school. She mentioned that she is the only one who takes care of her child. Her husband is not supportive; when he holds Rashad for five minutes, he returns him to her as he cannot bear to see him in this condition.

In spite of her acceptance of her child's condition, she experiences guilt as she feels that she is the source of the pathological genes. She told me that she usually supports her husband and asks him to be patient, as this is God's will, and they should accept it; it is not their fault.

4.2.11. Firas

- *Family structure*

The family consisted of the parents, one sister and two brothers. Firas was the oldest child.



- *Family history*

Firas's mother and father are cousins. The mother reported that she does not know any renal condition in her or her husband's families. She said that she had asked her grandmother about whether there was anyone in the family who had renal disease and that she did not know of any such conditions.

- *Socioeconomic status*

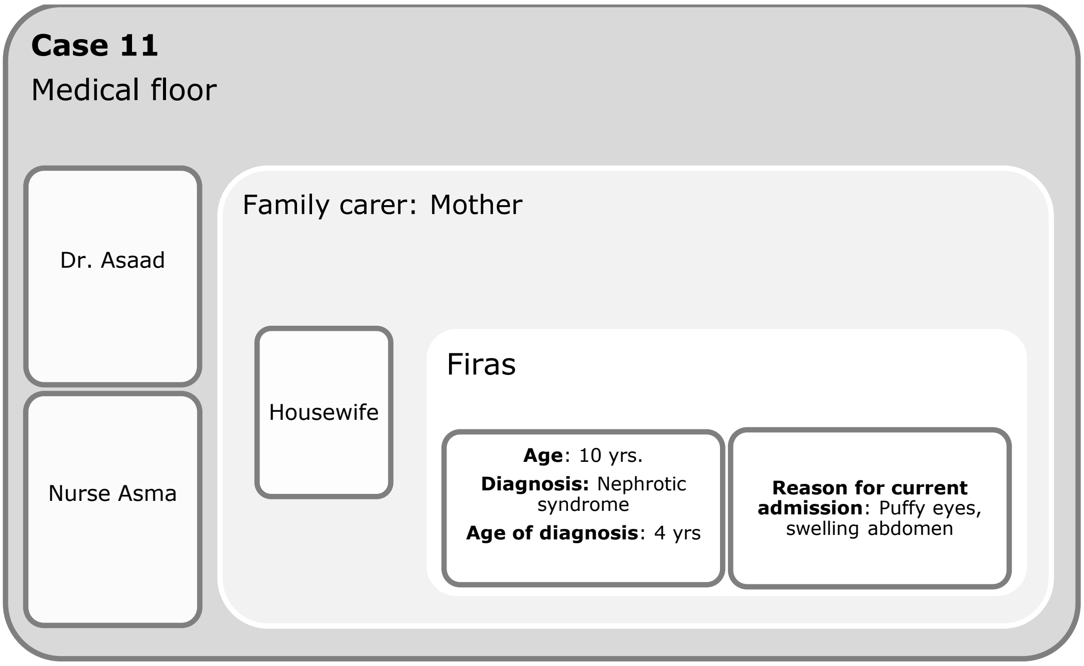
Firas's mother finished her primary education and then left school to get married. Firas's father did not receive any formal education as he worked as a greengrocer with his father from his youth and subsequently adopted this as a career. The mother described their economic status as very good, and that the father as a responsible husband who does not leave them in want of anything.

- *Significant information*

The mother reported that Firas was very connected to her and refused to have anybody else stay with him at the hospital. One time when his aunt stayed with him he started crying and asking for his mother, and refused treatment until his mother came. The mother said that this affected her other children.

She has a six-month-old infant who also needs devoted care; however, she weaned him from breastfeeding in order to stay with Firas in the hospital.

- *Case presentation*



- *Family dynamics*

The mother described her husband as cooperative and supportive. He came frequently to visit them in hospital and provide them with necessary things such as food and money. She said that in spite of his long work hours (more than 10 hours per day), he took care of his other children while she was with Firas in the hospital. Sometimes when he noticed that she was tired at home he made food and cleaned the home.

The mother said that Firas had a good relationship with his siblings; he was very connected to his sister, and usually left some sweets for her. However, he had frequent fights with his five year-old brother, who was jealous of the parental attention Firas received. These small fights were usually easily resolved as the brother liked Firas and felt compassion for him because of his disease. He told his mother that he asked God to cure Firas.

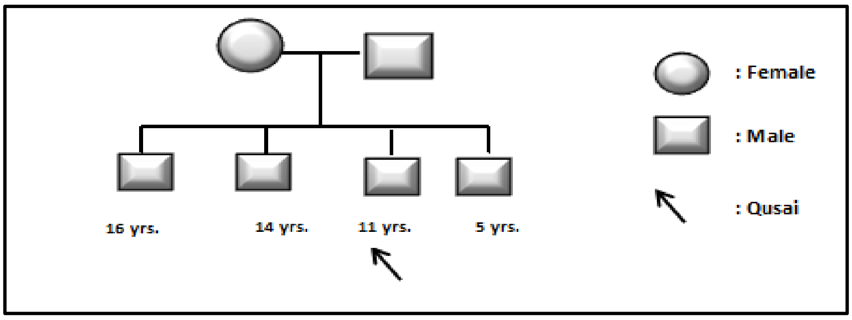
- *Obtaining Consent*

When I approached Firas's mother about the study, she said that she wanted to participate in it, but was concerned about the recording device. I understood her concerns and told her that I would write notes instead of recording during the interview. After having several conversations with her and building a trusting relationship she changed her mind (with no compulsion or coercion) and told me that I could record the interview.

4.2.12. Qusai

- *Family structure*

Qusai's family consisted of his parents and three brothers. He was the third child.



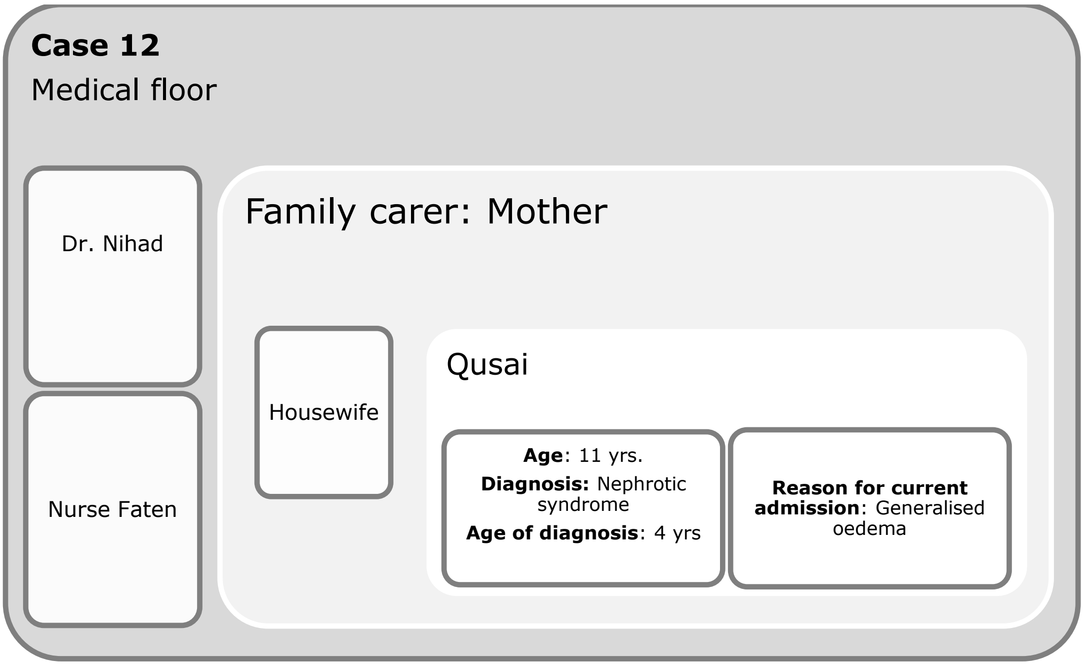
- *Family history*

The mother said that she did not know of any family history of renal disease. However, this family has a few diseases, such as hypertension (the mother), diabetes (paternal grandfather) and spinal herniated disc (maternal grandmother).

- *Socioeconomic status*

Qusai's mother finished primary education and then left school to get married. After Qusai's father left secondary school, he worked in casual jobs for several years. Currently, he works in a bakery. The mother said that they live in poverty, as her husband's salary is insufficient to cover all of their financial needs. Both parents are smokers, which exposes Qusai to being a passive smoker, and exacerbates the financial burden on the family. They rent a small basement flat.

- *Case presentation*



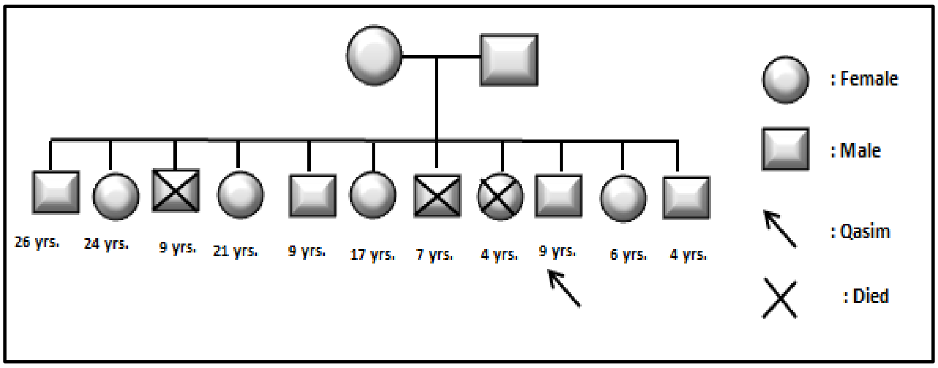
- *Family dynamics*

This family suffered from extreme family problems. The mother said that there were frequent arguments between her and her husband, which affected their sons. She described her husband as a very moody and nervous person, whose disposition affected the whole family. Domestic problems might have contributed to Qusai's absences from school and lack of compliance with his diet regimen.

4.2.13. Qasim

- *Family structure*

Qasim's family consisted of his parents, five sisters and five brothers. Qasim was the ninth child in his family (see below).

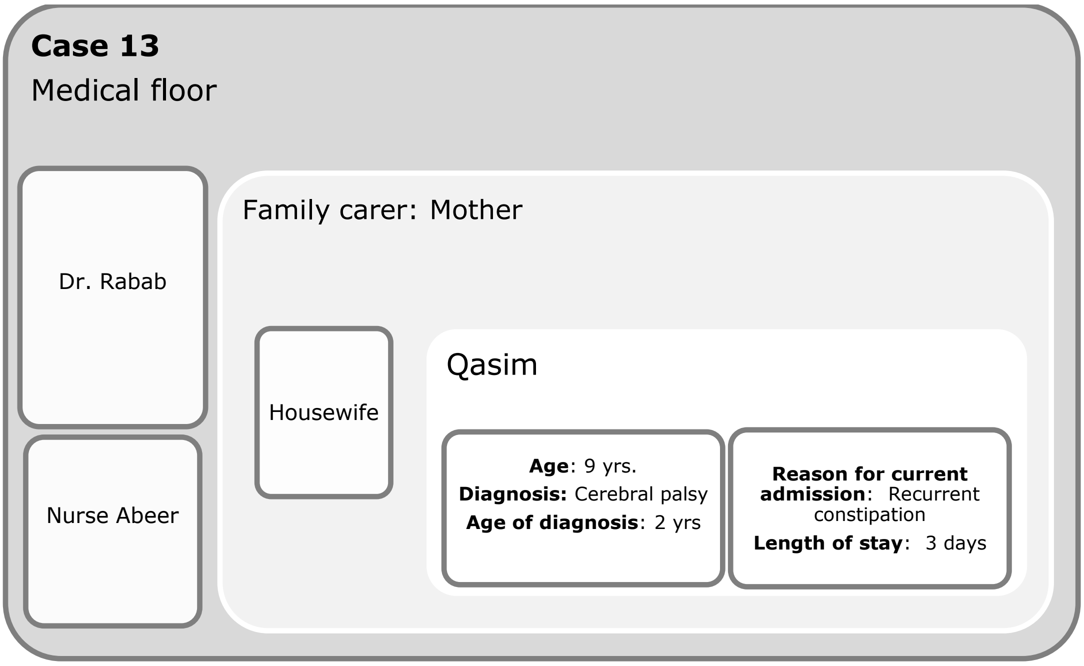


- *Family history*

The parents are cousins. The mother mentioned that they went for genetic screening but nothing was discovered. She was informed that the disease might be passed on from ancestral generations and thus may evade genetic tests.

The mother said that she had four children with cerebral palsy; three of them had died and the fourth one was Qasim, who participated in my study.

- *Case presentation*



Case 13
Medical floor

Dr. Rabab

Nurse Abeer

Family carer: Mother

Housewife

Qasim

Age: 9 yrs.
Diagnosis: Cerebral palsy
Age of diagnosis: 2 yrs

Reason for current admission: Recurrent constipation
Length of stay: 3 days

- *Socioeconomic status*

The mother did not go to school. The husband worked abroad for a few years before returning to Jordan where he owned a big electronics shop. The family described their financial level as very good. They live in an independent home located close to the hospital.

- *Significant information*

The mother suffered from social stigmatisation because of her children's sickness. She mentioned that some of her relatives were supportive while others were not, and gave examples of how she was greatly annoyed by some of her relatives' behaviours. For example, one of them came to visit with her child, who is the same age as Qasim, and she started to play and chat with him, clearly enjoying herself, in front of Qasim's mother. This was very painful for the mother who could not do the same thing with her sick child. She described this mother as being insensitive to her suffering. Moreover, she felt that some relatives were gossiping about the condition of her child when she was not there, as they abruptly stopped talking when she joined them. Sometimes she learned from their children that they were talking about Qasim. She tried to ignore these behaviours in spite of the painful feeling she had after hearing them.

The mother described how the parents were emotionally affected by their children's diseases, especially the first one, as it was the first and most difficult experience. She said that they received the first child's diagnosis as if he had just died, and this became even more difficult, as she then felt that he was dying every day in front of her eyes.

The mother told me about her suffering after the death of her children. She said that after each death, she felt lonely and that the home was empty. She used to perform daily tasks for her sick children, so it was difficult for her to adjust to them not being present. For example, a couple of days after the death of one of her children she got up and went to his room in order to feed him, only then remembering that he had died. She was in tears as she described how painful this experience was. I cried with her as I was emotionally affected by her story, and it was very difficult to maintain professional boundaries at this sensitive moment. To be honest, I was not able to act as a researcher for a short while. I felt that the mother was affected by this, and feeling more comfortable she became more open with me. I think she appreciated my feeling toward her suffering.

The mother showed me photos of some of her deceased children before and after the impact of the disease. The mother still keeps these pictures, although her sons urged her to get rid of them in order to remove anything that sparked difficult memories. She told me that she did not forget them, and she always thinks about them.

- *Family dynamics*

The mother said that her husband was supportive, and she described her other sons and daughters as being very supportive. One of her daughters (17 years old) takes care of Qasim to help her mother. She put her bed beside his in order to be close to him. Qasim knew his mother as well as his sister. The mother said that when she communicated to him, for example coming suddenly to the room to talk to him, he started crying, which made her feel that he knew she was there and wanted her to stay with him longer.

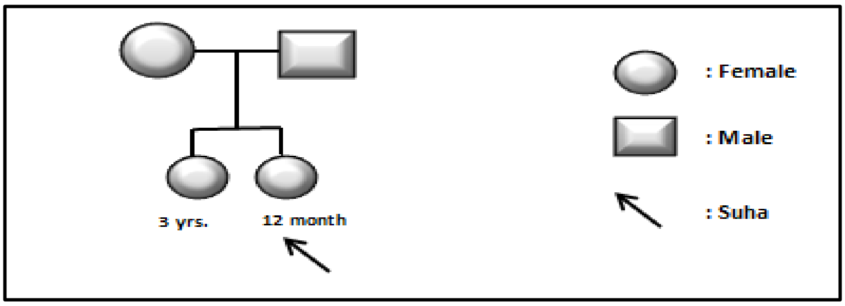
- *Obtaining Consent*

I knew this mother from before as I had worked with one of her other children in another hospital. This affected the relationship between us and facilitated her agreement to participate in the study. We encountered blurred distinctions between my legacy role as a registered nurse and my current role as a nursing researcher; sometimes I felt that she dealt with me as a nurse, and other times I felt as if we were friends. However, throughout our contact I tried to project the image of me as a researcher in terms of shaping my relationship with her by using techniques such as avoiding talking about myself and my private issues too much, and changing the subject when I felt that the conversation went in a more social direction. I also gave her more information about my research between meetings in order to remind her of my new role.

4.2.14. Suha

- *Family structure*

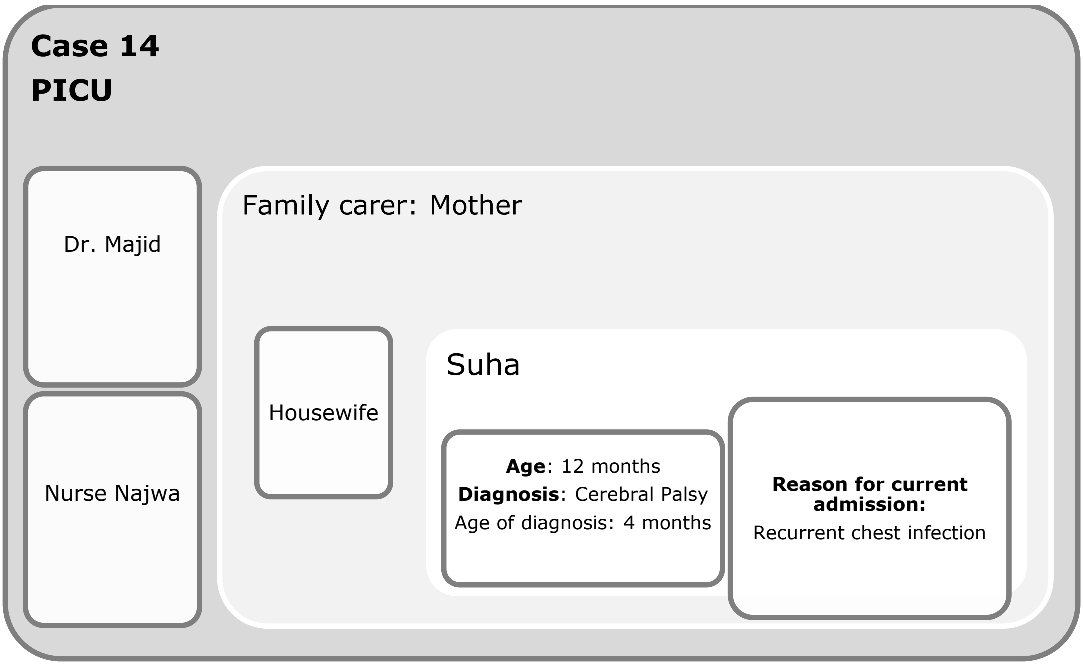
Suha’s family consisted of her parents and one sister. Suha was the youngest child.



- *Family history*

According to the mother, there is no family history of cerebral palsy in the family. The parents are not related in any way. The mother does not know of any other conditions in her or her husband’s family.

- *Case presentation*



Case 14
PICU

Dr. Majid

Nurse Najwa

Family carer: Mother

Housewife

Suha

Age: 12 months
Diagnosis: Cerebral Palsy
Age of diagnosis: 4 months

Reason for current admission:
Recurrent chest infection

- *Socioeconomic status*

Suha’s mother finished her higher diploma, and became a housewife after graduation. Suha’s father finished the 10th grade of school and then moved to vocational training for two years. He is now working as a motor vehicle technician. The mother described the financial status of the family as very good. She mentioned that they live near to the hospital in a private flat.

- *Family dynamics*

The mother described her husband as cooperative, although he was not very sensitive to the condition of his daughter. She mentioned that she was very concerned about Suha's health status whereas he was very cold and relaxed. However, he helped to perform some tasks at home and take care of their other daughters, which allowed her to take care of Suha.

- *Significant information*

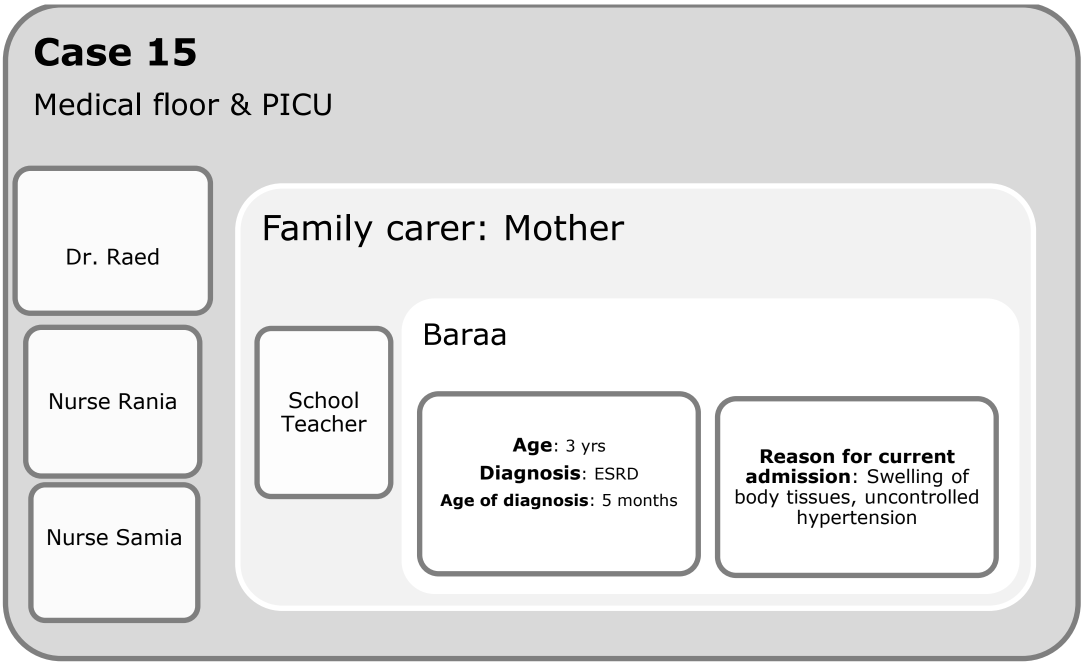
The mother was concerned about the social impact of her daughter's disease. She mentioned several times that the disease is called 'brain paralysis', and that the current name 'cerebral palsy' was only a euphemism to soften the reality. She was also concerned about the social stigmatisation her other daughters would face because of their sister's disease. She was very sensitive and afraid of being treated with pity. She felt guilty that she might be the person who transmitted the disease genes to her daughter. She felt that people might blame her or might say that she was responsible for transmitting abnormal genes. She clarified that her husband's brothers do not have any congenital diseases, although their wives are also their cousins. This is opposite to her, although her husband is not one of her relatives. This made her think about the social blame that she might get. The mother felt committed to her daughter and was concerned about any unintentional neglect that might have happened. She did not want to feel guilty in the future, particularly if her daughter died.

- *Obtaining Consent*

The mother showed her pleasure in my interviewing her, and focused on the need of the carer to talk to someone else about their suffering. She mentioned that she had freedom to talk to me, which she lacked with her relatives. She asked me to become her friend on Facebook, however I explained to her the difficulty of accepting her request, and discussed the importance of protecting the boundaries of proper research conduct. This was difficult for me because in this, and similar cases, I found it problematic to balance my personal feelings, the instinctive nursing role of compassion, and my professional position as a researcher. I concealed this dilemma from the woman, but I really felt compassion for her, and that we might have been friends in a different situation.

4.2.15. Baraa

- *Case presentation*



Case 15

Medical floor & PICU

Dr. Raed

Nurse Rania

Nurse Samia

Family carer: Mother

School Teacher

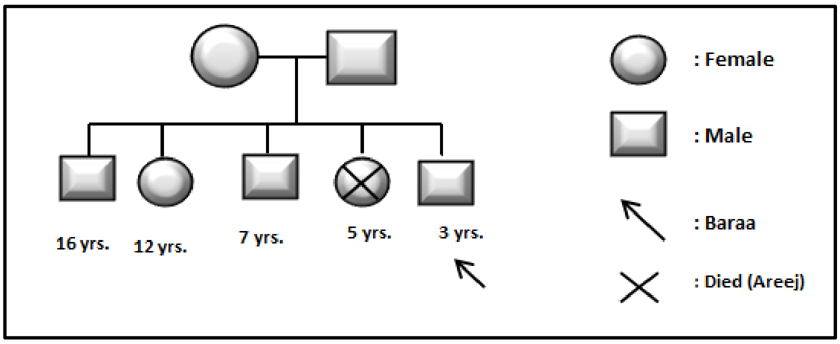
Baraa

Age: 3 yrs
Diagnosis: ESRD
Age of diagnosis: 5 months

Reason for current admission: Swelling of body tissues, uncontrolled hypertension

- *Family structure*

Baraa's family consisted of his parents, one sister and two brothers. Baraa was the youngest child in his family.



- *Family history*

Baraa is the second renal failure child in his family. His sister Areej, who suffered from ESRD, died four years previously due to illness complications, when she was five years old. Baraa’s parents had a positive congenital test result revealing that this disease is inherited in their family. However, the mother did not know of any other similar kidney condition within her own or her husband’s family.

- *Socioeconomic status*

Baraa’s mother, a bachelor’s degree holder, is a primary school teacher. Baraa’s father is a physician in a health care centre in the city where they live. They own a detached home in a city far away from the hospital. The mother described their economic status as very good, and they did not face any financial challenges, especially as the cost of children’s treatment is almost free in governmental hospitals.

- *Family dynamics*

The mother was reticent, and seemed to prefer solitude in a private room with her child. Baraa’s father came every day to see his son. Baraa was very connected to his father. During my presence, he asked his mother several times about when his father would arrive. The mother told me that her husband and family were very supportive and helped her during the long course of her children’s diseases.

- *Significant information*

This family lives in a city that is very far from the hospital. This was a significant concern for the mother. She felt lonely being so far away from her children for more than 40 days, staying in three hospitals. She said that when her child was admitted to a closer hospital a month previously she had felt that she had the support of her sisters, brothers, and other relatives through their frequent visits and their willingness to help. In the study hospital, visits from relatives were very rare (except her husband). She thought that this affected her child, who cried frequently over missing his home and friends; this was in addition to his fear of painful hospital procedures, such as the taking of blood samples.

Baraa's mother also felt worried about her other children, whose academic achievements had dropped significantly. She attributed this to her absences when accompanying Baraa during his hospital admissions. Although she was supported by her family, especially her sisters, who took care of the other children and offered to stay with Baraa in hospital instead of her, she insisted on accompanying Baraa during all of his hospital admissions. She prioritised Baraa because of his illness, perceiving his siblings as healthy children who were more able to tolerate her absence.

- *Obtaining Consent*

I had worked as a RN with Baraa's sister a few years previously when she was admitted with her mother. This had a significant impact in facilitating her participation in my study. After being approached by a senior nurse, I met both parents and had a discussion with them. I think that knowing them previously was the key factor in encouraging them to consent to participate in the study. I did not need to spend much time building a trusting relationship with the mother, as this had already been achieved. However, I felt it necessary to clarify the differences between my previous role as a nurse and my current role as a researcher.

4.3. Conclusion

This chapter provides individual case profiles in their contexts and also gives some details, which help to view each case according to its particular context and to remain true to the case study approach. These details are also significant for understanding the similarities and differences between the individual cases, and how these differences could contribute to the findings of the current study, which are presented in the following chapters (5, 6, and 7).

The next chapter presents the first part of the findings. It addresses the phenomenon of mutual protection, which dominated the communication styles of the study participants. Several aspects of protection are shown in different communication contexts, such as discussing sensitive issues concerning end of life and death, disclosing the initial diagnosis, and breaking bad news.

CHAPTER 5: QUALITATIVE FINDINGS

MUTUAL PROTECTION

5.1. Introduction

This chapter presents the experience of communications amongst the study participants in relation to the care of children. It illustrates how mutual protection dominates the nature of interactions between children, families, and health professionals. In addition, it illustrates the issues that maintain this protection, as well as its consequences for children, parents, and professionals. Several examples of real life situations are given, which comprehensively highlight the different aspects of protection. This chapter comprises three sections.

The first section outlines the protective approach adopted by the study participants towards each other, and also examines some of the issues that help to encourage and sustain this protection. The parents' perceptions of their children's awareness of their illnesses are a significant factor in interactions between the parents and their children. This section also shows how parents and professionals agreed about only disclosing partial information to the children, especially when discussing prognostic information. Other aspects of protection are also presented. Some children avoided open discussion with their families. A few mothers reported that they were not given significant information by their husbands and health professionals, who were trying to protect their feelings. The way that some staff maintained professional boundaries with families to protect themselves from the emotional distress caused by the expected loss of children is also highlighted.

The second section describes in detail the techniques adopted by health professionals to communicate unfavourable news to children and parents. Several techniques are examined, such as: honesty, gradual versus direct provision of news, depersonalisation and maintaining hope. The perception of participants regarding the best ways to give and receive bad news is also considered in this section.

The last section investigates the role of Jordanian culture in forming and affecting the participants' beliefs, which significantly shaped the manner of interaction.

5.2. Mutual protection (mothers and children)

The study participants adopted a protective approach when they communicated with each other about their children's care. The children protected their parents from sadness by not discussing their anxieties, and likewise, the parents sought to protect their children by only disclosing partial information to them. Furthermore, they sometimes tried to isolate their children from any environment where sensitive illness-related topics might be discussed. The nurses tried to keep within professional boundaries when they nursed children and parents in order to protect themselves from emotionally demanding situations. They focused on their routine tasks to try and avoid any emotional attachment that might lead to severe emotional distress if or when the expected death happened. The doctors tried to distance themselves from discussing bad news or end of life issues with the children in order to avoid harming the parents, children, and themselves.

Several factors contributed to and encouraged the protective approach that the study participants adopted towards each other. First, the unexpected nature of the children's disease; the doctors were uncertain about the future progression of some conditions (e.g. ESRD, cerebral palsy, nephrotic syndrome, meningomylocele and teratology of Fallot), and this made them very cautious about confirming future expectations. As a result, they avoided stating their expectations about disease progression. Furthermore, both the health care providers and the parents tended to make assumptions about the children's cognitive abilities when they communicated with them. Some of them treated the children as having limited cognitive abilities, especially regarding their understanding of end of life issues and death.

Moreover, some of the health care providers took this protective culture into their consideration when they communicated with the children and parents, bearing in mind the need to get the permission of parents before communicating any such information to the children. To some extent, this protective culture might be congruent with the tendency of some doctors to distance themselves from discussing sensitive issues. Finally, the stage of the disease was a significant factor affecting both the health care providers' and the parents' communication styles. For example, the doctors avoided giving detailed information about the severity of the illness with the parents in the initial stages of their children's diseases. However, discussions veered in a more serious direction when the children approached the end of life stage.

Before going into further detail about how mutual protection dominated communication between study participants, it is important to discuss the participants' perceptions about the children's awareness of their diseases, as it was the underlying factor that shaped their communication styles.

5.2.1. The children's awareness of illness: the perceptions of parents and health care providers

The perceptions of parents and health care providers toward the children's awareness of their disease (and by extension, end of life issues and death) significantly shaped the interactions between them. They also affected the extent to which they might be open when treating the children, not only in hospital, but also in the home and school. In spite of being unable to interview the children, which was not one of the objectives of this study, I tried to probe this issue with those participants in a close relationship with them, such as their carers (mothers) and the health care providers most involved with their care.

It was important to differentiate between awareness about disease and treatment, such as diet regimen and medication, and the awareness connected with issues such as the approach to the end of life, and death. Dr. Raji thought that Latifa understood some information, especially some instructions related to her disease, such as the importance of dialysis for her and the diet she should be on. He was not sure, however, whether she had the cognitive ability to understand or think about the concept of death:

> *Dr. Raji: I do not think that children of 6 or 7 years old … like Latifa … can understand that they are going to die, I do not think they understand death … I do not think that their cognitive abilities enable them to understand death. (Dr. Raji, Case 4).*

Dr. Rawan asserted that Sewar (10 years old) knew about her disease and condition very well because of the long time she had been in the hospital. She also had a smart phone connected to the internet and was therefore able to read about her disease. Furthermore, the doctor felt that Sewar, being a very clever child, knew about death anyway. Dr. Nihad asserted that Hala's high awareness of death might be associated with her having experienced the death of her friends in the department (Section 5.2.2). Nurse Sajeda believed that children younger than a certain age (e.g. ten years) might not realise that death occurs; instead, they might believe that they were coming to hospital for medication or nebulizer treatment, but they might not understand the deeper issues behind these treatments. Dr. Raed mentioned that he tried to involve Baraa (3 years old) in discussions with his parents about the instructions related to his disease. In spite of his feeling that Baraa did not understand the accurate meaning and explanation of his disease, he felt that he should be involved, as this might encourage compliance with his treatment. He did not receive any questions from Baraa to indicate awareness of death, however, and he believes that the issue of death might be difficult to discuss in Jordanian society:

> *I: Did you receive any difficult questions [18] from Baraa around some sensitive issues like any future expectations for his condition or maybe death?*
>
> *Dr. Raed: No … I did not receive this from Baraa or any young children like him … um … maybe the older children, but as you say … death [discussing death issues] … the nature of our religion … nobody talks about death for several reasons (Dr. Raed, Case 15).*

The opinions of the health care providers about the children's awareness of disease and death were not enough to reach a final conclusion, for many reasons. First, the majority of health care providers tried to distance themselves from the children during their work. Almost all interactions were

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[18] In this study, the phrase 'difficult question' refers to questions related to sensitive issues concerning end of life and death.

with their parents, not directly with them. During my observations, I did not find that children were involved in their own care, or were even heard by the majority of health care providers. Therefore, there was no open discussion between staff members and children except concerning routine daily tasks (e.g. no interactions to assess their cognitive abilities regarding their conditions). However, rather than complex psychological issues to do with the avoidance of harm, workload was the main cause of the lack of such interactions. Furthermore, staff members felt that their roles were limited to functional, biomedical tasks. Dr. Majid stated that he did not consider such issues to be part of a physician's role, and that there should be a social worker to handle this:

> *To be honest, I did not focus on these issues before … for me … my patients, I did not assess their awareness before … when they come to the clinic, I talk to them [in general], I joke with them … I think that these issues need a social worker to assess that. (Dr. Majid, case 14).*

Second, children with these types of diseases were treated in general paediatric wards and ICUs, which are not specialised for palliative care, so there was no focus on psychological issues and no effective social worker available to talk with them on a regular basis. The nurses told me that there was a social worker who came for certain cases relating to socioeconomic problems (i.e. not related to end of life), but I did not meet her during my observational period. I understood that the social worker attends intermittently for particular patients. Therefore, I needed to investigate this issue with the children's family carers who were in continuous contact with their children, to gain further knowledge and experience about this issue. Table 26 shows how the mothers perceived their children's awareness and concerns about their disease. It should be noted that I excluded children under three years old (Rosol and Mousa) and children with cerebral palsy (Suha, Qasim, and Rashad) as they had impaired cognitive abilities, as does Issa.

Table 26 indicates that the majority of children knew some basic information about their disease, which they might have learned during their frequent admissions to hospital. The children heard about their diseases from their doctors as well as from their mothers, especially when they had frequent meetings with medical and nursing students. The frequent repetition of their condition in front of others, such as their mothers' friends, other carers, or sometimes students, helped them to find out about their conditions, such as the location of their disease.

Table 26: Mothers' perceptions of their children's awareness about their disease

Child (age)	Mothers' perception of child's awareness of disease and death	Questions/ concerns
Basil (10)	*He is aware about his disease … he knows that he has kidney disease, the suitable food and what is good and what is bad for him*	*He had concerns about being unable to play with his friends. No open discussion happens between him and his parents about his disease, to protect him from pain and anxiety.*
Nagam (7)	*When I asked her [Nagam] why we are here, she told me because of kidney … She knew that her kidney is sick, she had renal failure, and she did not have the ability to urinate … she had hope of transplantation … she asked God to be cured of her disease*	*The mother told me that she did not have awareness about end of life or death. She did not ask questions, she preferred to keep silent. But she did not like hospitals.*
Latifa (6)	*She knows that she is sick*	*She asks why she had abdominal distension. No further discussions.*
Sewar (10)	*She is very very clever … having more awareness than her siblings … you saw how medical students prefer to talk to her … you saw nurses' teachers and how they … how a teacher came with her students to Sewar in order for her to discuss about her condition for them and she showed how the dialysis was done … how it enters [the dialysis solution to the peritoneal cavity] … and how it gets out … Sewar was discussing everything with them, she was very clever … may God bless her.*	*Sewar attended the death of her friends in the dialysis room (see the next section), however she avoided any discussion about this issue with her mother.*

Child (age)	Mothers' perception of child's awareness of disease and death	Questions/ concerns
Hala (12)	*I'm sure a million percent that she knows everything about her disease … but she does not like to show it … imagine … one day she brings the science book as she has a science exam, she discussed with her father her exact problem … she told him that this is the kidney and this is the grains that I have fibre in … she wanted to discuss her condition with her father because he is not educated.*	*In spite of her attempts to hide her awareness from her parents, especially her mother, she sometimes failed to conceal it. She makes comparisons with her younger sister (Lubna) and asks her mother some questions such as why she is not as tall as her sister and why she has yellow skin colour while her sisters have white skin.* *She knew about the death of her friend Sami.*
Amjad (12)	*He knows that his kidneys … for example, when he has an excess protein … or when there is an abnormality in the kidney function it becomes oedematous.*	*He asked his doctor whether he will be cured from his disease and she did not answer him, remaining silent. He does not like to discuss any issue about his disease with his mother; he becomes angry if she is exposed to such discussions. He is not a social child, he does not have friends in the department.*
Qusai (11)	*He knows that he has albumin on his kidneys … and knows that his disease is increasing, increasing … he knows everything about his condition.*	*He asked his mother "why me? Why am I a patient but others are not?" Especially when he had abdominal pain, he kept asking "my God, why me? Mum, why me?" He knew about the death of his friend (Murad).*
Firas (10)	*He knows that he has a kidney disease.*	*He said that he does not want his family to change his kidney for him. No further discussions.*
Baraa (3.5)	*He started his haemodialysis one month ago … no, no, he does not understand the nature of his disease*	*He asked his mother why he was admitted to another hospital [previously treated for haemodialysis in different hospital]. His only concern was to go home.*

Although there was a great variability in the children's awareness about their disease, which was affected by several factors such as their age, intelligence, environment, and level of socialisation, all of them gained an additional level of awareness due to having had several admissions to hospital.

Hala and Sewar may have been the most aware children among those who participated in my study, due to several issues, such as their age (12 and 10, respectively), long experience of hospital (3 and 7 years), being very sociable girls, and having several experiences of friends' deaths. On the other hand, Baraa (3.5 years old) is probably the least aware child; in addition to his young age, he moved to haemodialysis one month before the study and then moved to peritoneal dialysis for a temporary period. His condition was newly-diagnosed as ESRD. Moreover, he did not have friends in the hospital as he was protected from building relationships with other children in the hospital by his mother. It was therefore expected that his awareness would be limited.

The perceptions of mothers of their children's awareness about end of life and death issues varied significantly between the study participants. Only Hala and Sewar's mothers were sure that their children thought about such things. The mothers of Nagam, Latifa, and Baraa felt that their children were unable to understand death or end of life issues. The other carers (mothers) were not sure whether their children thought about these issues, as they avoided open discussions with them. However, in some situations the avoidance of discussing fears and anxieties came from the children as well as the mothers (Section 5.2.3).

For example, Basil, Sewar, Hala, Amjad, Qusai, and Firas refused to share their anxieties and fears about their diseases with their parents. Some mothers said that the children became very angry, and resisted any conversations with them about their illness. This might be an indication of their fears and anxieties about their future, and they may have also connected their disease with very painful feelings or experiences that they wished to escape from, in addition to trying to protect their parents. It seems that the approach the children used to protect their parents, and perhaps themselves, reveals their feelings of insecurity about their future. Generally, when one person protects another, this indicates a feeling of insecurity about expected harm, and the children likewise tried to protect their parents from danger they foresaw. If they were unaware of this danger, they would not go to such lengths to protect their parents from it; rather they might be more open with them, naïvely asking them about these issues because they wanted to know more about them.

To conclude, this discussion about children's awareness of disease and end of life issues provides background information that may explain the ways parents and health care providers communicate with children. However, this knowledge was gained from secondary sources (mothers and HCPs). Interviewing the children themselves was beyond the scope of this study, and this might be considered a limitation to the findings that needs further in-depth exploration.

5.2.2. The experience of other children's deaths

The mothers of Hala, Qusai, and Sewar shared with me their experiences of their children observing the death of other children/friends who had the same diseases. Hala's mother described the reaction of her daughter towards the death of her best friend Sami, whom she had come to know in the hospital. He was ten years old, the same age as her, and he had ESRD. His health condition had deteriorated very fast and he entered the PICU several times. After he entered the PICU he did not accept anyone feeding him except Hala; this was supported by Nurse Rania, who was the nurse assigned to Sami. When milk was given to him, he refused to drink it with the help of his mother or Nurse Rania. Hala was concerned about his health. One day Sami's mother said that Hala had asked her "Am I going to be like him?" After Sami's death, his mother rang Hala's mother. The phone was answered by Hala, and Sami's mother told her about Sami's death. Hala's mother told me that Hala gave the phone to her mother, went quickly to the bathroom and closed the door:

> *When she gave the phone to me, she entered the bathroom quickly and kept crying … her father asked her to come out, but she did not respond, she kept crying … honestly, this is the first time I saw her suffer, suffer, suffer like this … really … as a result of her suffering, I admitted her to the hospital immediately (Hala's mother, Case 8).*

Similarly, Qusai cried a lot when he found out about the death of his friend Murad, a child with kidney disease who died when he was 2.5 years old:

> *Qusai's mother: I was sitting here, then I heard a voice outside the room, I went to see what happened, I saw a woman [another carer in the department], she told me that Murad had died … I asked her not to mention that in front of Qusai … then there was another mother in the ward who came to us and said "are you sitting here, you did not know what happened?" We said "what happened?" I hoped she would not say what happened, but she said "Murad died"… in front of Qusai … when she did that I looked for Qusai …*
>
> *I: How old was Murad?*
>
> *Qusai's mother: He was a child, around 2.5 years … Qusai liked him very much … he always told me "mum take me to Murad to play with him, take me to play with him"… then I shouted at her [the mother who let Qusai knew that Murad died] … Qusai started crying, crying, telling me "mum, Murad died mum … why did he die? How did he die?"… I told him "all of us will die, it is not about a disease … suddenly someone while walking he might suddenly die"… he asked, "will he go to paradise … will he know his mother and father later?" [in the Afterlife] (Qusai's mother, Case 12).*

Sewar insisted on staying at the dialysis room [19] in order to attend the death of other children, but she concealed her suffering and avoided sharing her thoughts with others, including her mother. The mother described that when one child was dying, Sewar insisted on staying in the room of the deceased that day and stopping her other activities. The mother said that Sewar was afraid when the deaths happened; she usually closed her eyes and covered her head with a blanket, without saying a word. The mother said that she had a fever (around 40°C) after observing the death of her friends, which went on for three to four days. When I asked the mother if any conversations happened at those times, she said that Sewar did not talk in these cases, and

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[19] The dialysis room is a specialised unit on the paediatric floor that children who need peritoneal dialysis enter frequently. It is the room that Sewar usually came into when she needed peritoneal dialysis.

she became angry if her mother tried to engage her in conversation, telling her to go home.

To conclude, the experience of the death of other children with a similar condition might increase the awareness of children about their own impending death. The frequent hospitalisation of children with these types of diseases increased their awareness, especially when they were sociable and able to initiate friendships with children who had the same disease. Unlike Baraa, Hala and Sewar had more opportunities to contact other children with the same diseases, because their parents did not isolate them from other children. Baraa was stringently protected by his parents and was not encouraged to leave his bed area and initiate friendships.

5.2.3. Protection by children

The majority of children tried to protect their parents from emotional suffering due to their disease. They used several techniques to do this. For example, Baraa's mother told me that he tried to protect her from being sad, especially when she talked negatively about the progression of his condition to her relatives and friends. She said that he became sad and cried when he saw her crying and screaming when she initially found out about his diagnosis. Likewise, Qusai's mother mentioned that in spite of being a very nervous child, Qusai was demonstrably affectionate towards his mother. She mentioned that one time when she was crying after being informed about the possibility of him needing dialysis, he sat in a corner and started crying as he always did when he felt that she was suffering because of him. Hala, Sewar, and Amjad protected their parents, especially their mothers, by avoiding discussions about their conditions and diseases. Hala's mother described how her daughter tried to protect her from knowing her suffering. During my presence in the hospital Hala attended one interview with her mother. During our discussion about her disease, her mother asked her several questions about her friends with the same disease. Hala refused to answer her mother, pretending that she did not know:

> *I was sitting with Hala's mother talking about Hala's condition, suddenly Hala came to her bed and stayed there and put on her headphones that were connected to her smartphone. The mother*

> *and I realised that we needed to remove any sensitive information from our discussion. During the interview, Hala's mother referred to Hala to ask her about the progression of her friends with the same condition [Hala was the expert who knew almost all conditions in the department, especially those with the same illness as her]. Hala refused to answer her mother and pretended that she did not know [I knew that from her mother, who told me that Hala did not like to show her awareness as she described her as a secretive person]. I realised that she was trying to protect her mother and to decrease her suffering by avoiding discussing these issues with her (Case 8, Fieldnote 16).*

Sewar's mother told me that Sewar did not want to discuss her concerns with her mother and spent a lot of time with her friends, especially those with similar conditions, in the renal room, Her mother said that Sewar was not open with her over her concerns about the disease, and she did not know whether she shared anything with her friends:

> *I: Did you have any discussions with Sewar regarding her concerns about her health condition … did she complain about anything to you?*
>
> *Sewar's mother: no, no, she did not talk to me.*
>
> *I: did you initiate any discussions with her?*
>
> *Sewar's mother: she became very angry, when she gets annoyed with me or with any human … even sometimes you feel … she suddenly became angry, when she became angry it was very difficult to quieten her down … when I asked her what her problem was, she told me "nothing" and she asked me to go home.*
>
> *I: do you expect that she might complain to someone else … her friends and relatives …?*
>
> *Sewar's mother: I do not know if she complains to her friends. She had a friend called Samar, with her sisters … they were good friends*

> *for her … I do not know if she complained with them, or told them … I do not know. (Sewar's mother, Case 6)*

Some children tried to protect their parents by being more open with other relatives, and closed with their parents. For example, Sewar was more open with her sister-in-law, telling her some of her concerns regarding her feeling of stigmatisation at school, especially when her mother and sister-in-law went to change her diaper in front of the other girls. Hala was more open with her father, who had a life-limiting illness, than with her mother. Hala's mother told me that Hala tried to discuss her concerns with her father, but at the same time she tried to reassure him that even if she died, she would be happy with that, as she thought that she would be a 'bird in paradise' (a cultural expression):

> *Hala told her father that she had a lot of friends who died because of kidney disease and she is not better than them … one time I heard her … I was in kitchen, she did not notice that I was there … she told him that she is going to die … and [crying] … and … when she felt that his voice changed, she tried to reassure him by telling him not to be worry … if she died, it is ok … she will be a bird who lives in paradise … and she told him about her hopes for her sisters … she told him if she died, she wants her sisters to become doctors like Dr.Nihad … you know this was her ambition, to become a doctor (Hala's mother, Case 8).*

To sum up, the majority of children in my study tried to protect their parents using different techniques. Some of them avoided sensitive discussions around their concerns and anxieties, while others appeared to feel guilty, which was revealed by their crying when they felt that they were responsible for their parents' suffering. Some children were more open with some of their relatives and more protective with others. The next section examines how parents and health care providers played mutual roles in protecting the children.

5.2.4. Disclosing partial information to children

The families played a significant role in terms of controlling how much the children knew about their conditions. The health care providers took the families' wishes into consideration when they initiated discussions with the children about their diseases. During my study, almost all of the participants agreed that their children only needed to know partial information that was appropriate to their age and their cognitive ability. Furthermore the information provided was only to be sufficient to ensure their cooperation with treatment, such as medication compliance and undergoing investigations, as well as ensuring good adaptation to symptoms in terms of life and school. Almost all participants refused to give the children any information that would give them pain about their disease:

> *You know Qasim has cerebral palsy … but if the child is at an age and a health status that enables him to understand, we might inform him with as much information as he needs to reduce pain or complications … Because we need sometimes patient's cooperation … whether in terms of medication administration, lab investigation, or the adaptation of the symptoms in life or school … however, we never give him any painful or hope-less information (Dr. Rabab, Case 13).*

As reported by both mothers and staff, there were several reasons behind their avoidance of deep discussions with the children. The first reason was to protect them from the expected emotional suffering that might result from them being informed in comprehensive detail about their conditions. Nurse Katia, for example, did not discuss Latifa's future expectations in order to protect her from suffering:

> *I: did you have discussions with Latifa about her disease? How much should she know about her disease?*
>
> *Nurse Katia: No, no, I do not have … in my opinion she should not know a lot of details about her condition … she does not have the ability to tolerate this … half of the cure is psychological status … and if you told her that her disease is critical, then she will put in her mind that she is a sick human, she is an abnormal human.*
>
> *I: do you think that she could get this information from other resources?*

> *Nurse Katia: yes, she might know from other resources such as friends … TV … the internet … but she is still not sure that this will happen to her specifically … it is not like when you told her honestly and ensure and support her fears … if you support her fears, she will have a great fear and she will lose trust in herself … by doing this, you've killed her slowly … it is something like putting poison for her in order to die slowly (Nurse Katia, Case 4).*

Likewise, Dr. Rawan did not involve Sewar in discussions of sensitive information with her parents. She accepted the need for family approval to involve children in these kinds of conversations. She mentioned that she preferred not to inform children or even teenagers about end of life issues unless they asked about it themselves. From her experience, no child had ever asked for that before, and she thought that this might be related to the protective culture:

> *Now … how much children should know about their condition … it depends on the child himself … now some clever children know and you know that they know … Sewar is a good example; however, I do not make any type of confrontation to go to tell her or to talk with him about death (Dr. Rawan, Case 6).*

Moreover, Dr. Marwan (Sewar's doctor in a previous hospital) asked Sewar's mother to meet him alone outside Sewar's room in order to give her bad news, in order to protect Sewar from hearing it. Likewise, Drs. Raed, Rabab, Majid, and Raji did not include the children in conversations where they communicated bad news to their parents:

> *I usually drift way from saying the reality in front of the child … So I do not tell him that he needs an artificial heart which is not available here [in Jordan]… I do not tell the child about that … I do not tell him … it is difficult to tell him … even [if] he understands … no I do not say (Dr. Majid, Case 14).*

Baraa's mother tried to protect her child from the stigma of disease. She was afraid that he might be treated as a sick child, which might harm his psyche:

> *I: so … do you give him any instructions related to the types of play he needs to stick with, what types of games he can play and what types he cannot? … As you know … as a renal failure child … and how do you describe his response?*
>
> *Baraa's mother: um … from the beginning, because of his disease … you feel that his movement is not like any other children, this means you notice that he has a problem … so when his peers run, he is the first one who becomes tired … therefore, I do not feel secure regarding his health like his peers … so to get out to play outside home, my eyes are always behind him. I do not feel secure … I'm afraid that something could be uncontrollable … I know that this is the nature of their disease … Areej [Baraa's sister who died a few years ago with the same condition, ESRD] was the same.*
>
> *I: so … does he realise this … does he know that?*
>
> *Baraa's mother: no … he does not know that this is because of his disease … but he usually says "mum, I feel tired" and I tell him "come here to relax". I do not like to tell him "come, you became tired because you are sick"… no … I do not like it.*
>
> *I: you do not like to let him feel that?*
>
> *Baraa's mother: no, no … I do not like … I'm afraid of people around him continuously saying "he is sick, he is sick". He will avoid playing … this could affect his psyche … I tell him "that is enough … come and sit down"… and sometimes I ask the other children to come to watch TV as well … "let's go inside to watch TV"… I do not want to let him feel that he is different (Baraa's mother, Case 15).*

Baraa, Hala, and Sewar's mothers tried to protect their children from knowing about the death of other children with the same disease. Baraa's parents asked the hospital staff if they could stay in a separate room so they could isolate themselves from people with the same disease and avoid any contact that might draw Baraa's attention. Sewar's mother said that when one child was dying, she tried to hide this from her daughter, and asked other carers and health care providers to also hide it from her. The mother told me that she tried to distract her attention several times without success:

> *I: so could you describe for me what Sewar did when one of her friends died?*
>
> *Sewar's mother: when one of her friends was dying, I asked the doctors and students to hide this from her … however she knew, she knew by herself … she was coming and sitting down in the room … I was telling her "Sewar, go out the room go out the room" … never … she refused, I tried to prohibit her from observing this … but she was sitting on the bed … after the dying child was transferred, by around two hours, her temperature rose to 40°C … her blood pressure was elevated as well (Sewar's mother, Case 6).*

Nurse Khadija limited her discussions with Basil to giving him instructions about suitable diet and medication. She avoided conversations related to the disease itself or any future expectations. She did not go into depth when discussing his condition, hoping to help him to live like other children:

> *My relationship with Basil might be limited to focusing on performing certain procedures … I did not discuss the disease itself with him, especially when I had negative expectations about his condition … if it was a curable condition, I would tell him that you will be cured … but I expect that it is not curable … so I would not go in deep … I keep myself on the surface level … I focused only on the procedures related to the current admission in order to enable him to live normal life like any child (Nurse Khadija, Case 2).*

To conclude, in paediatric departments children have wide range of unpredictable diseases that might last for long periods, even years. During this time, parents and health care providers might avoid disclosing any negative or painful information to children in order to protect them and maintain their quality of life, especially if they are in the initial stages of their diseases and still have good physical health. The children played the same role, protecting their parents by avoiding discussions of their fears or anxieties. However, things do not always go as expected or planned, and some children might have had more awareness than others in understanding end of life issues, including death. There were several factors that affected their awareness: their age and cognitive level, the environment in which they lived, and their level of intelligence.

Moreover, the experiences some children had during their several admissions to hospital might be another factor that affected their awareness. The level of socialisation is another element; for example having several friends who died might have exaggerated their fears and anxieties over their uncertain future (e.g. Hala, Sewar, and Qusai). Although it is impossible to know what death meant to these children, their awareness of it may have been heightened in several ways. I therefore recommend that further studies explore this issue from the children's perspective, taking them as the primary source of information to explore their awareness in more depth, in environmental and cultural contexts.

5.2.5. Non-disclosure to mothers

Baraa, Rashad, Suha, and Issa's mothers mentioned that they were not given all of the details of their child's illnesses, especially bad news. Instead, the doctors informed their husbands and/or one of their relatives. This was in order to protect them from shock and suffering after hearing the information:

> *Issa's mother: we were admitted to hospital when Issa was 14 days old, the doctor informed my mother and husband about his condition … they expected him to die after a few months.*
>
> *I: Were you informed about that?*
>
> *Issa's mother: no … the doctor advised them not to inform me … just to tell me to accept his condition and live with it (Issa's mother, Case 7).*

Baraa's mother was exposed to multiple sources of protection as well. She was only given partial information about her first child (Areej) who had suffered from ESRD. The majority of the people who surrounded her, including her husband, relatives, friends, and the health care providers who treated her children, hid painful information from her. For example, the doctors used a different language in front of her in order to hide unfavorable information from her, as well as talking to her husband when he was alone. Baraa's father tried to give her some of the bad news using a gradual approach or told her indirectly, in order to protect her from experiencing shock and suffering because of the deterioration of her children's conditions.

> *Baraa's mother: When they diagnosed Areej … and you know … my husband is a doctor … he started looking for any source of information … any leaflet we found, we both read it, we searched the internet about the disease … we were looking for any case, because the disease was not familiar to me, it was new … it was the first time I heard about it … so we started to look for [information about the disease] … and sometimes I needed to translate … despite being an English teacher … [I tried to] find some articles with their translations … in order to understand … because sometimes we have a lot of things, a lot of words in English … they have other meanings in medicine … but as a person who studied English … sometimes I understand that her condition is worsening … and sometimes they tried to tell my husband something in English, and they do not know that I understood … they tried not to let me understand … but sometimes I understood that there was something dangerous.*
>
> *I: So … you meant that they tried to hide some critical information from you?*
>
> *Baraa's mother: yes … sometimes.*
>
> *I: I see …*
>
> *Baraa's mother: For example, when they saw us together they did not talk … but when my husband left the room, I noticed that they talked together … when Areej arrived at the end stages … for example when it was difficult to keep her on peritoneal dialysis … they told us … I mean they told my husband … as it was difficult [for me to cope with this] … in spite of my acceptance of her condition and her disease … they said that we want to turn her to haemo [hemodialysis] … because … that's it … we [her daughter's treatment] arrived to a stage which is hopeless with peritoneal …*

> *yes, that is one thing that my husband tried to hide it from me (Baraa's mother, Case 15).*

Relatives and friends also adopted protective approaches with Baraa's mother by giving her false reassurances.

> *Baraa's mother: In the end … when Areej became tired and she no longer benefited from treatment … he told us honestly … that she arrived to … to … as you say … the end stage … because medication was no longer of benefit to her, there was no other option except dialysis to save her life … when they started with me, they told me that the abdomen wall is like another kidney that is presented from God … and this could be a temporary stage … kidneys could return to their work again.*
>
> *I: Who told you this?*
>
> *Baraa's mother: I felt that people around me tried to simplify it [her daughter's condition] for me … or it could be right … then I realised that it was a treatment stage prior to the haemodialysis (Baraa's mother, Case 15).*

Dr. Rawan disagreed with the idea of hiding information from the mother. She mentioned that she believed that it is the right of both parents to know as much detail as they wanted about the progress of their child's disease. She insisted on the importance of both parents attending progress information sessions, especially where bad news was given. When Sewar's mother attended alone – which was the normal scenario – Dr. Rawan asked for the father to attend as she wanted to ensure that both were fully informed and understood the progress of their child's condition. She thought that by doing this she would discourage the mother from prolonged denial. Since Sewar's condition was unpredictable, and she might have had some unexpected complications, Dr. Rawan preferred to involve both parents, to avoid any blame if either of them did not know about Sewar's deteriorating condition. By doing this, she thought that she had prepared both parents for any unexpected outcomes that might happen.

Despite the attempts of some health care providers and relatives to hide information from the mothers, some of them understood hints from non-verbal communication. This had very serious consequences for the mothers when they realised that information was intentionally being hidden from them. This strategy was not appropriate, since the mothers often thought that their children's condition was more serious than it actually was, because they were aware of the deceptions. For some mothers, the fear of the unknown in such situations could be worse than knowing the reality itself. Another notable issue was the impromptu strategy of talking in different languages to try and hide information from the mothers, which could make them feel that they were being treated in a disrespectful way.

5.2.6. Maintaining professional boundaries

One of the most important techniques the health care providers used to protect themselves from suffering was the creation of emotional boundaries. Nurses tried to keep themselves from building close relationships with those children they felt had a high probability of dying, in order to minimise the grief and suffering that would result from their deaths.

According to some nurses, the majority of them decided to avoid friendly relationships with children after having painful experiences. Nurses Alaa, Mona, and Asma went through several stages until they became able to prevent themselves from building strong relationships with the children:

> *Nurse Mona: I had one experience where I liked one patient … I liked her too much and she connected to me emotionally … day by day I saw her wilt in front of my eyes … my psyche was extremely tired from that day … I prohibited myself from emotionally connecting with any patient … she came to me at the counter and said "good morning, how are you?"… One time she wrote me memorable words on a piece of paper … and she asked me to share gifts for memory … I protected her memorable words after her death for several years … her name was Samah.*
>
> *I: how old was she?*

> *Nurse Mona: she was 12 years old … she imposed herself on me … and at that time I had no experience … I was a new nurse at that time … she liked me and connected with me emotionally … and I liked her and she emotionally affected me, different from any other children … every day she came to ask other nurses about me … in the beginning her condition was stable … however, she had leukaemia … may God bless her soul … she started to have relapses gradually … She went pale and had changing colour … she started to have chemotherapy … like the leaves when they go yellow and fall down gradually, leaf by leaf … her hair was falling down … she needed emotional support … we [nurses] went to provide emotional support for her … we had a lot of pain for her condition … we did not like to show that to her … she stayed a lot of time taking chemotherapy … she was destroyed by chemotherapy … she became very tired by it … like slow poisoning … it repairs things but destroyed a lot of things … she asked for me even if I had vacation … I became very tired because of her … my psyche was significantly affected by her death … one day I was on holiday and when I returned to work … they [nurses] told me that she died [with tears] … when I was seeing her bed I remembered her … when I read her memorable words … I had extreme pain … I had extreme emotional suffering … I spent several years after her death in order to forget her … now I find myself far away from any patient who I know is going to die … I cannot tolerate this suffering … there may be some people stronger than me … but I cannot tolerate … I try to keep myself far away from these issues (Nurse Mona, Case 10).*

The majority of nurses tried to avoid emotional suffering from working with children for a long period and developing strong attachments with them. I noticed that junior nurses were more prone to building deeper relationships with children. However, after having some painful experiences, the majority of them learned to refrain from building strong relationships with those children they expected to die, in order to protect their emotional wellbeing as well as their social lives.

5.3. Communicating bad news

Communicating bad news might be considered the most significant type of interaction that happens in hospital settings. During my study, I tried to identify how the participants defined bad news, and when they considered news to be bad. However, I found that the concept of ‘bad news’ was broad, with several meanings. For example, for some participants the initial diagnosis of a serious illness was considered bad news, but for others the development of an advanced disease (i.e. subsequent to initial diagnosis) was more serious. Some carers found that the sudden death of a close relative was bad news for them, but the birth of child with congenital anomalies was also considered to be extremely bad information. For some, being admitted to hospital for relatively simple and minor procedures was considered bad news. Fundamentally, the negativity derived from news is subjective for, and unique to, each patient. This makes it more challenging for the health care providers who are responsible for giving news to calibrate their approach to the disease (biomedical) and patient (psychosocial) contexts.

The way doctors give bad news to families has an enormous effect on their acceptance of that news. In my study, the doctors used several techniques to deliver bad news to parents. Because of word limits, I had to focus on a few techniques that I found to be significant but also essential. In the following sections, I discuss honesty, direct versus gradual, depersonalisation, maintaining hope, and the role of culture.

5.3.1. Honesty

Almost all participants preferred to receive or provide bad news in an honest manner. The mothers of Nagam, Sewar, Basil, Latifa, Qasim, and Hala mentioned that they received honest information about their children’s conditions from their doctors. Baraa, Rosol, Issa, and Rashad’s mothers were disappointed, as they knew that their doctors had hidden some significant information from them. Rashad’s mother mentioned that she felt disappointed because her child’s neurological consultant did not inform her that her child’s condition (cerebral palsy) had no curative treatment. She experienced extreme shock when she learned of this from another doctor (a paediatric consultant), who told her that treatment was limited to reducing the complications of the disease:

> *Now, I will go home … if the child [Rashad] lives or dies, this is something controlled by God … when the doctor [the neurological consultant] comes, I will rebuke him: "you told me that the cure of your child needs time, and the photo [the MRI] is free … why did you not tell me from the beginning that my child will not see? … he will not be able to speak? … he will not be able to walk? … he will not understand [disturbed cognitive ability]? … you did not tell me …" I spent one year and three months coming and going back [several follow-up sessions at the hospital] (Rashad's mother, Case 10).*

Likewise, Baraa's mother preferred to be involved in everything to do with her children's conditions. She mentioned that she was given false hope about the condition of her deceased daughter (Areej), and was deflated after learning the truth:

> *Honesty is better … in order not for someone to build up hopes on things … this means [based on] the situation around him … [hopes] will not be achieved (Baraa's mother, Case 15).*

Suha's mother told me that she felt annoyed by Dr. Majid, as he gave her false reassurance about the condition of her daughter, and said that she might be improved after having physiotherapy. When a neurological consultation was asked for Suha she asked Dr. Awni, the consultant, to be honest with her as much as possible, so that she would not be surprised if something unexpected happened:

> *From the beginning I told him 'whatever my daughter has … I want you to be honest in order to … in the future whatever happened, we can behave, and anything happens to her, we will not be surprised'… I told him this in order to not be surprised (Suha's mother, Case 14).*

When she asked him, Dr. Awni was very honest and clear with her:

> *I understand it alone … he [Dr. Awni] told me "I do not want to let you live on a hope that your child will walk"… thanks God … he told me "the last thing you think about it is that your child will walk"…*

> *he told me “she will have hearing [problems] the vision … the cognitive system … all of it [multi system problem]”… he told me “the condition of your child is difficult … the thing that she has is difficult”… he told me a lot of things that my daughter at any moment may … [implicitly referring to potentiality of death] (Suha’s mother, Case 14).*

Suha’s mother insisted on the importance of receiving honest information from her doctor, and this information gave her the strength to cope with her suffering and prepare her for any bad news. However, in spite of this she did not accept negative information about her child in actuality, especially when it was given to her in a direct manner. She was unable to control her emotions. This was very clear during my observation of some consultations with her daughter’s doctor and also in some conversations she had with nurses. For example, she was unable to hide her reaction after a consultation with Dr. Majid in which she received bad news about her daughter’s condition:

> *During my way to the ICU department at Suha’s bedside I saw Dr. Majid with another resident come out from the ICU department after finishing the round with Suha. When I went to Suha’s bed, I saw Suha’s mother. After greeting her, I asked her whether anything new had happened with Suha. She mentioned me that she knew that Suha’s blood haemoglobin was 5 and she needed a blood transfusion, and her health condition was worsening. I noticed how much she was suffering; she was not able to conceal her pain. Her eyes were red, and she was unusually distracted. I noticed that she was not focused with me; therefore I apologised and explained that I did not want to disturb her. She denied her suffering, asking me to stay with her, and then I felt that she wanted someone to support her in this difficult situation, therefore I sat down to listen more to her concerns, but avoided rushing my questions, as I expected that her cognitive ability was diminished after receiving painful information about her daughter’s health (Fieldnote 4, Case 14).*

Moreover, Suha's mother became extremely annoyed by one nurse (who is a relative) when she told her that her child was "gasping", which implies nearness to death in Arabic:

> *Suha's mother: you know that nurse who accompanied you with her, Asma … two hours ago… she stayed for a period with me … she saw my daughter she told me "honestly when I saw your child last time, your daughter was gasping"… she told me like this! "Gasping", imagine! ... She should not do it like this.*
>
> *I: So how did you feel at that moment?*
>
> *Suha's mother: Since the morning I was optimistic … from the morning I was optimistic … I was looking for this [the monitor connected with Suha that showed an average HR (120-130 bpm) and acceptable O2 saturation (93%)] … thank God, thank God I'm happy … she should not do this … the manner should not be like this … even if my daughter is really like this [gasping] … you should say kind words … do not say "gasping"… there are a lot of people who are gasping and God gives them a new age … so she should be tactful (Suha's mother, Case 14).*

It seems that both the mother and the nurse looked at Suha's condition from different perspectives. The mother told me that she was informed one day previously that her child had some improvements in terms of decreased chest infection (as indicated by decreased WBC) and she had good improvement in her breathing patterns. The mother was looking for any success or improvement, even if it was short term, in her daughter's condition. Thus, the mother considered that the nurse destroyed her enthusiastic feelings toward this small improvement in her daughter's health. At that moment, Suha's mother thought that this nurse received new negative information from doctors, therefore she had significant fears.

However, the nurse (who is relatively junior) denied receiving any recent information about Suha, and viewed the issue from a different perspective. She thought that as a cerebral palsy patient who had systematic health problems and was on a mechanical ventilator being treated in the PICU department, Suha was in a very difficult situation. This conclusion might be expected by the majority of health care providers who treated Suha, including Dr. Majid; however, they did not share the information in this way with Suha's mother, in order to protect her feelings.

The attitude of Suha's mother toward the nurse who gave her negative information made me ask myself about the reason behind Suha's mother's contrasting acceptance of Dr. Awni's message. This might have been for many reasons. First, Suha's mother requested Dr. Awni to be honest with her from the beginning, so she had prepared herself to hear bad news, especially as she told me that she had already read about her daughter's disease before talking to the doctor. Second, she asked Dr. Awni about her daughter's condition for the purpose of seeking information, and probably looking for some hope about Suha's future. She might, therefore, have accepted this painful information from the main health team professional responsible for her daughter, while she did not accord this right to the nurse [20] or to anybody else not directly involved in the care of her child. These other health care professionals talking negatively about the condition of her daughter exacerbated her suffering and inspired her negative feelings about her daughter's condition. The difference in Suha's mother's responses to the two painful messages she received might have been because of the differences in the contextual framework. Accepting the first message from the doctor for certain purposes does not mean that she could accept receiving this extremely painful information from anyone else:

> *My child was admitted to the hospital this time for a chest infection, not because she is a cerebral palsy patient. I do not want anybody to remind me every time that my child is gasping that she is a CP patient. This time she was admitted because she has a chest infection, she is not going to die now. This nurse is not sensitive (Suha's mother, Case 14).*

Finally, the use of direct, blunt, terms was not accepted by all participants in my study, whatever the stage of the disease (see Section 5.3.4 for further details). Most doctors insisted on the importance of honesty when giving families bad news. Dr. Buthaina told me that she tried to give Nagam's parents

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[20] Nurse Asma was not assigned to Suha's care at the time of data collection.

honest information at the time of initial diagnosis. From her perspective, she found that this was important for building trust, as she expected them to go to other doctors to consult them. Other doctors (Asaad, Khalid, and Badr) stated that they cautioned other doctors about the importance of giving honest information to parents and avoiding false reassurance, as they might go to other doctors and discover the reality from them, which would undermine the trust relationship.

Dr. Nihad tried to inform the family about each step she took with Hala’s treatment. She found this important, as she felt that they had the right to know all of the information about the condition of their child. She also wanted to avoid the blame that might happen if the parents received false hope, and then suddenly heard painful news, such as Hala’s need for dialysis. Dr. Nihad mentioned that the shock would be significant if they discovered this information suddenly, while it might be less severe if they were prepared for it by receiving preliminary related information. Dr. Rawan advised doctors to inform parents about all expectations of their children’s health status, because there might be sudden deteriorations in some conditions that could catch the parents unawares. This would make it difficult for them to accept the condition due to a lack of preparation, and could cause parents to experience pathological grief for a long period. She also mentioned that some parents shared their bad experiences with other families, which gave a bad reputation to the institution and undermined rapport with service users.

To conclude, all of the family carers in my study wanted to receive honest and accurate information from their health care providers, but the manner in which this information was delivered had an enormous effect on their acceptance of the messages. Delivering honest information to parents entailed the adoption of a sensitive manner of communication. It seems that parents might accept bad news from a cognitive perspective; however, their emotions may still reject extremely painful information about their children’s health. Initially, some parents might not realise this conflict between cognition and emotion inside themselves. Therefore, although they might ask for complete and honest information from their child’s doctors, insensitive delivery of the information could result in intense suffering. Some doctors had learnt from experience not to be too blunt, especially when communicating the initial diagnosis, and taking the emotional reaction of the parents into consideration.

They gave honest information using a less direct or a gradual approach, especially with the mothers, in order to protect them from suffering. The following section provides detailed information about the gradual approach to conveying bad news to parents.

5.3.2. Direct versus gradual

Most participants asserted the importance of adopting a gradual approach when communicating bad news to parents, especially when they disclosed the initial diagnosis, in order to mitigate any denial or anger reactions that might ensue.

All of the health care professionals recommended preparing parents before giving them bad news. Dr. Rami stated that families do not accept the direct way of communication, and might become aggressive with the doctor who is proviings the information. Based on experience, Dr. Rami preferred a gradual approach to avoid any unfavourable reactions from parents. Moreover, Dr. Raed found that parents accepted a gradual approach over a direct approach, as he found that some of them might initially deny the reality of the disease:

> *For example, Asaad … I know that within a few years, he could have chronic kidney disease, or end stage kidney disease, he could need dialysis … to be honest, I usually tell them [his parents] gradually … because honestly they should know what will happen, of course, as I expect … but not in one word … "Your child will need dialysis" … as at that moment, they could not accept it. Some parents do not accept the disease itself … so you need to tell them little by little, not in one strike, "Asaad will be on dialysis" (Dr. Raed, Case 9).*

The carers supported the doctors' opinions in terms of their preference for receiving bad news gradually. For example, Rosol's mother mentioned that she always preferred doctors to give her bad news about her child's condition this way:

> *[I prefer to receive bad news] little by little. Usually doctors [here] say it directly … you know how … this means that most doctors give the information to your face … for me, the doctors who I deal with,*

> *I prefer them to reassure me … even if my child had a problem … to tell me in a smooth way, even if it makes me afraid … at the same time, I like them to give me hope, even if it is one percent (Rosol's mother, Case 1).*

At the beginning of my conversation with Suha's mother, she insisted on the importance of receiving honest information from her child's doctors (Section 5.3.1). Subsequently however, while conducting the formal interview (after we had built a trust relationship), she regretted her initial opinion, telling me that although she initially accepted direct honest information from her child's doctor, she had several relapses later:

> *I: So did you mean that as you received a full clear idea from Dr. Awni in the beginning, you were more able later to accept further information … as if you took a big dose so you were not affected by lesser ones?*
>
> *Suha's mother: no … when you take the big dose, you might return, after a period, to have a relapse.*
>
> *I: could you clarify that for me please?*
>
> *Suha's mother: when they give you [bad news] … gradually, little by little … your acceptance will be better than when they give it to you suddenly … yes, you initially accepted, then you break down then you accepted then you break down, do you understand? (Suha's mother, Case 14).*

The emotional status of parents directly after receiving bad news was perceived to temporarily limit their understanding of complex information about their children's conditions. Some doctors gave parents limited information in the first session of bad news and postponed more detailed information for other sessions, as they realised the limited abilities of parents to receive such information at critical junctures in the illness journey. For example, Dr. Buthaina informed Nagam's parents about the diagnosis of their child using a gradual approach, taking the parents' emotional reaction into consideration. She expected their cognitive abilities to diminish temporarily, having been affected by the shock of the news. She avoided giving them comprehensive details about their children's disease in the first session of breaking bad news.

Some health care providers took the stage of disease into account as part of their gradual, step-by-step approach. For example, Dr. Nihad mainly focused on informing Hala's parents about short-term outcomes, and avoided anticipating events in advance, especially when the disease was still in the early stages:

> *This means that I do not discuss with them [Hala's parents] about these issues [long-term expectations] because she [Hala] is still a long way from dialysis … so if I want to tell them something, I tell them about the transplant [kidney transplant] (Dr. Nihad, Case 8).*

Using a gradual approach encompasses several techniques, such as starting with lab tests when the doctors initiate a session of bad news with parents, especially when they are communicating the initial diagnosis of their children. For example, when Doctor Raji informed Latifa's parents about her initial diagnosis, he began by mentioning the results of her lab investigations (such as kidney function test):

> *You know we do not give … we do not give [bad news] directly … little by little … step by step … you know the denial stage and these things for families … but we usually try to be very honest … but in the same time we do not strike it suddenly, we do not strike it directly … especially with renal failure … we said for Latifa's parents … there was a decrease in the kidney function, maybe because of the neurologic bladder or the reflux [vesicoureteral reflux [21]] … gradual, this means … but we give the reality … we do not exaggerate or increase the values of things … but in a gradual way (Dr. Raji, Case 4).*

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[21] VUR is defined as the nonphysiologic retrograde flow of urine from the bladder up the uretha into the kidney and is the result of an insufficient vesicoureteral junction (Bogaert and Slabbaert, 2012: 19).

Likewise, Dr. Nihad informed Hala's parents about her diagnosis by starting with the results of her kidney biopsy:

> *I told them [Hala's parents] for example … "the result of the biopsy is like this" … this result of biopsy [means that she] will have renal fibrosis, for example Hala's condition is nephrosis in the kidney … this nephrosis will increase with time, not decrease … do you know how? (Dr. Nihad, Case 8).*

Similarly, Dr. Khalid told Issa's parents that he suspected that the boy might have a problem with his heart, and asked to perform an echogram to detect it. Finally, he gave them his diagnosis (tetralogy of Fallot). By doing this, Dr. Khalid prepared the parents by providing them with introductory information that included his suspicions of a heart problem, and then a description of the steps and investigations performed by the medical team before arriving at the conclusion. Dr. Khalid found that this preparatory introduction had a significant effect upon the parents' acceptance of the diagnosis.

The doctors used a gradual approach when they talked to parents about the expectation of their children's diseases, especially when these diseases had an unpredictable nature. Dr. Nihad, for example, adopted a hesitant approach when she disclosed the expectations of Hala's disease progression. This could be related to the unpredictable nature of Hala's disease (nephrotic disease) and the different responses of patients. However, Hala's mother felt confused by the loss of certainty after hearing Dr. Nihad's expectations about Hala's condition:

> *She [Dr. Nihad] told me that it could be difficult to anticipate what could happen, she [Hala] could improve, but also, keep in mind that she could be moved to dialysis … I feel confused (Hala's mother, Case 8).*

Dr. Raed also believed nephrotic syndrome to be unpredictable, and was therefore uncertain about the future expectations of the disease. He adopted a hesitant approach, so as to avoid arming the parents with false expectations, which might affect his trust relationship with them later on.

> *I believe that the nephrotic disease is an unpredictable disease, which means that nobody knows exactly what will happen with Asaad (Dr. Raed, Case 9).*

However, Asaad's mother felt afraid and insecure about her son's future as she did not have a full picture of the development of his health condition:

> *We have fear in the future … I hope I know in the future for the next days what will happen with him … I do not have any idea (Asaad's mother, Case 9).*

To sum up, the participants mentioned several reasons behind adopting a gradual approach to transferring bad news to parents. First, to mitigate the parents' reactions after hearing unexpected bad news, especially when an extreme denial reaction was likely. Second, to consider the parents' ability to understand further details after hearing bad news. This was achieved by disclosing the major news but leaving minor details for other sessions. The health care providers adopted several gradual approach techniques when they gave parents bad news. These included starting with lab investigations, allowing factual information to reduce the emotional burden on the doctor and the parents, and using a hesitancy approach, especially when disclosing future expectations. A step-by-step approach was also employed, focusing on short-term outcomes but avoiding anticipating events in advance, especially when the disease was still in the early stages, with unclear prospects.

5.3.3. Depersonalisation

Some of the health care providers [22] used a depersonalisation technique when they answered parents' questions about their children's progress, the expectations of a cure, or sometimes life expectancy. For instance, when he broke bad news to Baraa's parents, Dr. Raed did not mention Baraa specifically. Instead, he referred to similar cases that he had treated before, thereby relieving the pain that the parents might experience if he had specifically mentioned Baraa. He told me that this depersonalisation might

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[22] E.g. Drs. Khalid and Raed, and Nurses Najwa, Samah, and Mona.

decrease the sensitivity of parents and reduce the effects of conveying negative information to them:

> *I told Baraa's family that some conditions take a long time … and some conditions might have improvement, or they [the children] might take a long time until they reach adulthood (Dr. Raed, Case 15).*

Similarly, Dr. Khalid used this technique when he answered some parents' questions about the life expectancy of their children, who were approaching the advanced stages of their disease:

> *I never say that this specific child will die after one month … I say that patients who arrive at this specific stage, the majority of them, around ninety percent of them, death usually happens within two weeks, and this is in the majority of times (Dr. Khalid, Case 7).*

However, despite the view that it is appropriate to answer questions related to the future expectations of children's conditions in this way, it might also have a negative effect if it is used to inform parents about a significant deterioration in their child's condition. For example, Dr. Rawan thinks that it is crucial to be honest when informing parents about any deterioration in their children's health. This is to prevent them entering the denial stage by encouraging them to think that the bad news might not be specific to their children:

> *No, no, no, no, no … you need to be strict and clear in such situations … because families, when you said like this … they will say that there may be other conditions, but not my child … no, he is your child who has this story … this should not happen … I'm letting him in this condition to be admitted to the denial stage or … no, it is your son who has this … this means that your child is the tired person … this means the situation is bad … if he asks if you have a previous condition, which is similar to this before … "do you have experience of someone who came back from this stage"… we say "no … nobody came back from those we experienced who arrived to this stage, nobody returned back"… so you need to be honest with them, because this is a very sensitive issue, this means it will be something unethical to give them illusions or to give them*

> *inaccurate information … for me, I prefer them to be sad and cry, and have a shock, it is better than spending the whole of their lives being sad and shocked and saying that the doctor was lying to us the whole time … or he was not honest, or the doctor did not tell us … (Dr. Rawan, Case 6).*

To conclude, a depersonalisation technique was used to protect the parents' feelings when future expectations about the health progression of their child were communicated to them. However, it was seen by a few physicians to have negative consequences if used when providing parents with the current situation or deterioration of their child. These physicians wanted to discourage any misunderstandings and avoid supporting the denial reaction some families might have after information was imparted in this way.

5.3.4. Maintaining hope

Most parents wanted their doctors to provide them with hopeful information about the future progression of their children's illness. Despite their insistence on receiving honest information, they considered hope to be an essential part of life, and they found it very difficult to handle suffering without any glimmer of of it. Their ways of expressing this wish might have been different, but all of them tended to search for any source of hope that might reassure them about their children's health. Most parents explicitly mentioned a wish to receive hopeful information, and also displayed communication behaviours that indicated a continuous search for hope and reassurance.

For example, most parents asked multiple questions about their children's disease, especially after being provided with the initial diagnosis. Some health care providers felt annoyed by this behaviour, thereby revealing their misunderstanding of the reasons behind the parents repeatedly asking the same questions. For example, Dr. Nihad mentioned that she received a lot of questions from Hala's family after giving them Hala's initial diagnosis:

> *The most frequent thing, they deny … they told me "we do not know what this [the illness] means"… even if anyone asked them, they said "we do not know what our daughter has"… they said "is it both kidneys?" [that have the disease], or they ask questions such as "can we get a transplant for her? When will we be able to*

> *transplant? How we can help her? Are there any other places we can go in order to help her? (Dr. Nihad, Case 8).*

Likewise, Dr. Asaad did not understand the reason why Firas's parents asked the same questions, despite having been informed about the condition of their child:

> *There are a lot of families who entered the first day … for example Firas's mother, we already discussed with her about the condition [of Firas] … I do not know … I do not know … does she believe or does she not believe [the diagnosis]? Denial stage? You find her the second day asking me a second time … and the third day they ask the resident, although she knows what will happen … I do not know [whether] she understood the information from the first day … and did not accept the information from the first day … she was not persuaded by the information (Dr. Asaad, Case 11).*

Some parents sought knowledge from different sources to their primary doctors (see Section 7.2.3 for further details). For example, a few parents (e.g. those of Amjad, Baraa, Hala, Rashad, and Suha) researched other information sources directly after the initial diagnosis was confirmed by their primary physicians:

> *We took his file [hospital file] and went to a consultant doctor in [X hospital]; we told him "could you please discuss this for us?" (Amjad's mother, Case 9).*

It seems that not all questions the parents asked meant that they were purely looking for information about their children's disease; rather they were looking for hope or reassurance about their child's health. The majority of them used different resources to look up knowledge about the disease, such as the internet and books, as well as their primary doctors and second opinions from other doctors (Section 6.5.). All of them found out about the nature of their child's disease from such resources, yet they had a tendency to repeatedly seek reassurance or hope by frequently questioning health care providers, seeking more positive information than that which had been conveyed to them by their primary physicians. This was most frequent directly after receiving the initial diagnosis of their child’s disease, and may indicate that the parents were trying to disprove that diagnosis.

The level of hope carers had was related to the improvement of their children, which changed with time. High expectations of a total cure were gradually lowered, passing through several stages. For example, Baraa’s mother mentioned that at the beginning of her daughter Areej’s disease, she had great hopes for a total cure. She did not expect her daughter to arrive at the stage of renal failure or be moved to dialysis. This was motivated by the protection approach she was exposed to (Section 5.2.5). Areej’s parents hoped for kidney transplantation for her, but the doctors were waiting for her to gain more weight in order to be able to perform the operation. When she died, she was below the preferable weight at that time (10 kg), which discouraged them from going through the transplantation process:

> *No, not total cure … [my previous hope for Areej was] to have more period of her age … to have longer life, this means to be improved to the degree she can enter school only, something like this … no … complete cure, I was not expecting it (Baraa’s mother, Case 15).*

The majority of participants agreed on the importance of providing hope even if it added little improvement to their children’s health progress All carers needed a certain level of hope in order to be able to cope with their children’s suffering, to help them to have as normal a life as possible, and to encourage their committment to the treatment. For example, Hala’s mother looked for any improvement in Hala’s condition, even if this success was small, or a short-term hope:

> *I say thank God … the doctor told me that the kidney functions for Hala are good … what reassured me is when I asked her [doctor] how the renal functions were, [she answered] “they were good … as soon as the renal functions are good Hala is good … do not fear, reassure her”… I usually reassure her, I usually tell her you are better than others [children with the same disease], look at this [child] … she was like you [same diagnosis] but she started dialysis before you, because you take your medication regularly and you eat a suitable diet (Hala’s mother, Case 8).*

Likewise, Nagam’s mother was given hope by Dr. Buthaina about a kidney transplantation for her daughter. Nagam, in turn, also had hope regarding the transplantation. The mother mentioned that the doctors were planning to perform the required tests and examinations as a preparatory procedure preceding transplantation. However, Nagam died before these investigations were undertaken. Dr. Raed gave Baraa’s parents realistic hope by telling them that even after dialysis the option of kidney transplantation still remained. He also offered them hope from the possibility of scientific advances:

> *But always we provide them with hope … here we have the hope issue … because science is in a continuous advance … we tell them that even if the two kidneys failed completely, there are ways of dialysis even if we do not want dialysis, or the dialysis is not good, we have the option of kidney transplant … at that time they say even if we arrive there, there will be some solutions (Dr. Raed, Case 15).*

Similarly, most doctors (e.g. Drs. Asaad, Badr, Majid, Raji, and Rabab) believed that it was important to provide parents with certain amounts of hope congruent with the stage and severity of the disease. However, it is important to balance the importance of communicating honest information to parents and giving them realistic hope, especially when the condition is at an advanced stage. Some health care providers reported that they faced challenges trying to achieve this balance.

Dr. Khalid felt that hope should be always maintained, whatever the severity or the stage of the disease. He asserted that the stage of the disease might affect the way in which bad news was disclosed to the parents. For example, if the disease was still in the primary stages, he reassured parents by telling them that their child might be one of those who survived after the expected proportion of cure. Issa’s disease was not curable, so Dr. Kahlid told the parents that Issa would be kept on oral medication (e.g. Clonazepam) to control his convulsions, and would receive continuous physiotherapy and occupational therapy sessions to maintain and restore his physical functions. This meant that he could live with the disease; the news was given a positive twist, maintaining the parents’ hope and avoiding hopelessness. Finally, if the condition was in a very advanced stage and the patient might die within a very short period, then he told them that he was not talking about a cure now, but that instead, there was a lot that could be done to improve quality of life, and control pain and other symptoms.

Dr. Nihad gave hope to Hala's parents by asserting the importance of maintaining kidney function levels for as long as possible. After providing honest information regarding the very low possibility of a complete cure, she moved the focus of hope from cure to staving off dialysis as long as possible:

> *If I want to tell them something, I will tell them about kidney transplantation, because I always give them hope because she might have renal failure, but we try to keep it far away if we can, if we can protect our pressure [BP], if we take our medication, if we decrease protein in urine, if she is committed to eat less salt; if we stay like this we will be far from this dialysis … so I always give her hope, always she might have someone who might donate her a kidney and live a normal life, so the hope should not be lost, the hope should be high, we cannot lose hope (Dr. Nihad, Case 8).*

Nonetheless, there was a significant difference between honesty, which includes providing honest information for parents and patients, and providing them with negative messages, which had an extreme effect on the parents' emotions. All participants were unhappy about the concept of using hope-less or painful terms with parents and children, whatever the patient's condition:

> *The words "your condition is a hopeless case and you will die" … it is not acceptable to say it in this way to parents. If Issa's parents know that he has incurable or chronic disease, and if they ask whether it is a hopeless case, I say "there is nothing called a hopeless case … we previously were talking about the cure of the disease … now you need to live with disease" … (Dr. Khalid, Case 7).*

Rosol's mother mentioned her suffering after receiving a very negative message about her daughter's condition:

> *I cannot forget that Doctor Samer, when he came to do … [a certain procedure] for Rosol and when I asked him about her*

> *condition, he told me "you know your child is a hopeless case" … he does not know what happened to me … I stayed the whole night crying (Rosol's mother, Case 1).*

Finally, Dr. Rawan never mentioned death or hope-less terms with patients:

> *Never, never … I do not use this word [death] at all, because it has enormous effects on parents … however, we use words by which we try to send the same meaning … this means [for example] "the situation is very difficult", for example … "we try to relieve his pain … you need to ask God for him"… for example we say … with the presence of mother and father … we say "we are talking about one week, days"… when I tell them these words, it means that I'm telling them about death but without mentioning death, as I feel it is very traumatising … very traumatising, this means it is not acceptable and traumatising, this means they will not forget it … this means when they remember tomorrow [later] they will say "this doctor who said death, and hurt us", so this is hurting, the word by itself is hurting, but when we told them about hours … we are talking about anything less than one week, the situation is very difficult … so they understand … when I told them "if anyone from his relative's grandfathers want to come to see him"… I think these words are very clear … we are talking about death without the story of death … so it is the same, but you protect their feelings (Dr. Rawan, Case 6).*

To conclude, all participants agreed with informing and being informed with realistic hope for several reasons, such as promoting compliance with treatment and protecting parents' feelings. Parents tend to search for any hope, especially during the denial stage, after hearing the initial diagnosis of their children. The carers who participated in my study asserted that they were given a certain level of hope depending on their children's disease stage and severity. Finally, all health care providers were against using any painful or hope-less information with parents, as it had enormous effects on their feelings and well-being.

5.4. The role of culture

Jordanian culture is a variant of Arab-Islamic culture, which comprises two intertwined strands: the interpretation of Islamic religion, and the vernacular Arab culture. Communication is significantly affected by culture, so it was important in this study to identify some Jordanian cultural beliefs, especially those that significantly affected communication. This was undertaken in order to explain the way culture shapes and reflects interactions between patients, parents, and health workers in the study setting, particularly concerning the meaning and philosophy of disease, the types of discussion among study participants regarding end of life issues and death, the issue of hope, and communicating death expectations.

The meaning of disease for the study participants affected the way they interacted with each other. This was especially so in sensitive situations such as their reactions to initial diagnoses, giving and receiving bad news, and their reactions to the deaths of their children. Most participants had their own beliefs regarding the meaning of their children's disease, which were influenced by Islamic culture. For example, most carers (e.g. the parents of Baraa, Issa, Nagam, Rashad, and Suha) viewed the disease as a test by God to measure or evaluate their patience and acceptance of the problem, and that it was expiation for sins (as expressed by Baraa's mother). Similarly, Rashad's mother believed that her son's disease was a test to evaluate her patience, or a punishment for her sins. Suha's mother believed that everything that happened to her daughter was according to destiny and the will of God. She had a strong belief that God could revive and cure her daughter, but also that even if she died or underwent a long period of suffering, God would compensate her patience in different ways:

> *I have certainty of God … that God will compensate me, if it not by my health, He will bless my husband and daughter [her other daughter] or maybe [by providing me with] psychological peace … no matter about money or something like this, psychological happiness, blessing my daughter … this is better for me than having ten children (Suha's mother, Case 14).*

The beliefs of carers had implications for their feelings about their children's diseases. All of them demonstrated their acceptance of the disease to me. During my observation, I did not find a single carer who complained or even expressed any negative attitude toward the disease of her child, even those who had more than one ill child (i.e. the mothers of Qasim, Baraa, and Nagam). Instead, most of them (e.g. the mothers of Baraa, Rashad, Suha, and Nagam) thanked God several times in front of me to show their appreciation, not only in happy situations but also during extremely sad situations. They tried to be as patient as they could, believing that one of the meanings behind the disease of their children was to measure their patience (according to Islamic belief). For example, Nagam's mother praised God several times when Dr. Buthaina informed her that Nagam had died, and she planned to disconnect her from the mechanical ventilator the next day.

The beliefs of the majority of carers who participated in this study positively affected their communication with the health care providers. For example, Nagam's mother felt that the doctors could not cure her daughter; they could only treat her. This meant that all medical procedures were merely treatments, and that the cure itself was decided by God, the only one who could cure her daughter. This does not imply that the role of medical science was seen to be passive; she insisted on the need to undertake all trials and procedures that could increase the possibility of a cure.

Contrary to the findings of some recent studies (Alzubaidi et al., 2015; Padela et al., 2015) that view oriental fatalism as a barrier to health-seeking behaviours, this concept has in fact been dealt with extensively by Islamic scholars and disseminated among the general public. Islamic doctrine affirms that cure and illness (along with life, death, and provision) are determined by Providence, but also that this is generally exercised via the mechanisms of the physical universe in which humans live. Thus, we are expected to make conventional efforts as part of our responsibility as active creatures within the framework of divine preordainment, conscious of the fact that mechanistic actions in the universe (e.g. healthy behaviours) are merely token efforts whose fulfilment depends on destiny. On a more informal level, it is a confirmed *sunnah* (prophetic tradition) to seek medical treatment. However, the misunderstanding of some Muslims of the deep meaning of oriental fatalism could diminish their attempts to seek health services, as was found in the aforementioned studies. Doctors do whatever they can, but they trust and accept whatever the result is, as this is in the hands of God. Nagam's mother did not blame Dr. Buthaina for the death of her daughter; rather she defended the doctor against her husband's blame for the deterioration and death of Nagam, as recorded in the following field note:

> *I was talking with Nagam's mother at bedside. She was informed about the death of her daughter three hours ago [brain death]. Fifteen minutes later, Nagam's father entered the room. It seems that he was informed about the death of his daughter recently. When he entered the room, he was crying and suddenly he started to blame the doctor, saying she is responsible for the deterioration of Nagam and made her arrive at this condition. The mother started to support him, by telling him "you should be patient; you are a believer [in God]". Then she defended Dr. Buthaina, saying "she is not responsible [for Nagam's death] … she did her job … she gave medication … God cures, she did not cause the disease of our daughter" (Fieldnote 3, Case 3).*

However, because of the limited time of observation available for some participants in my research, I was not able to see the duration and applicability of this satisfaction and acceptance. During my discussions with some parents, I noticed that they did not maintain this acceptance the whole time. It was a dynamic status that changed from time to time. In certain situations, the parents complained that doctors were the cause of deteriorations in their children's health. However, this might again be because of the incongruity between beliefs and emotions that can happen in such difficult situations.

In addition to families and carers adopting this culture of acceptance, the majority of health care providers themselves shared similar beliefs about life and death. The health care providers took the prevailing culture into consideration when they communicated bad news in order to support parents and carers. During my study, the doctors took the beliefs of the parents (and probably of themselves) into account when breaking bad news:

> *So this does not mean that if they have renal failure their life went … and death is coming … so always, always their [the parents of nephrotic syndrome patients] goal from the first day, is "doctor, shall he have dialysis?"… Because they do not want dialysis … so we tell them that God determines this issue … but science says this (Dr. Raed, Case 9).*

> *Everyone … God gives everyone certain tests … disease is one example … now our role [as doctors] is to treat, not to cure … the right thing is that nobody can cure except God, but we treat them [do whatever we can] … the doctor does not cure (Dr. Badr, Case 5).*

Furthermore, the prevailing culture affected the types of discussion that happened between children and their parents regarding death. Drs. Raed and Rawan mentioned that Jordanian culture does not accept talking about death with children or even involving them in such discussions. Dr. Rawan mentioned that she was brought up to avoid such open discussions between parents and children, and she did not have any experience of children talking about or asking to discuss death or end of life issues:

> *I had one experience, one child who was ten years and a half … you looked in his eyes and you knew that he knew that he was dying, however, in the majority of situations children protect their families, they do not say in front of them that they know they are going to die, or they know that their condition is bad and the family does not want to talk … therefore, to be honest I try to be very natural … to be honest this story [issue] is very, very emotional and dramatic, so sometimes you leave things as they are, much better than you intervene in the issues of what is life and death … so this imaginary protection that they do, it is really protecting the child and family's emotions, and I do not think our culture in the Middle East is such that we can sit with a child and talk about life and death … this means about the story of life and death specifically; we were reared or as parents we know that death is right for all of us and we will die, but for me or other physicians to come and tell the guy "you have only one week [to live]", no, no (Dr. Rawan, Case 6).*

One of the most critical issues affected by culture is the issue of hope. In Islamic culture, hope is very important as it pertains to submission to God and acknowledgement of His divine power to determine and alter circumstances. In the situation of illness, Islamic belief affirms the ability of God to cure all illness or to determine death, and people can be active in this supernatural process by supplicating: "Call upon me; I will respond to you" (The Holy Quran, 40:60).

In Islamic culture, God asks people to avoid hopelessness about any difficult issue, as He has the power to change this easily if they ask him: "And whosoever fears Allah … He will make a way for him to get out [from every difficulty]. And He will provide him from [sources] he never could imagine" (The Holy Quran, 65:2-3).

These universal Islamic beliefs explain how some study participants behaved and interacted with each other regarding disease. For example, all study participants asserted the importance of providing parents with hope, reminding them of God as a source of hope. Therefore, the families did not accept doctors giving them hope-less information, as they did not consider this issue to be under the doctor's authority:

> *To talk about death as doctors never [happens] … not even one percent, it could not happen … now we as a culture, even you imagine one doctor saying about your child in your face that your child has no hope and his death is very close … the family themselves do not appreciate the doctor … the family might say they do not want him [the doctor] (Nurse Alaa, Case 8).*

Furthermore, one of the most sensitive issues around communicating bad news might be determining the specific time of death, which is taboo in Islamic religion as God exclusively determines fate:

> *Verily, Allah! With Him [Alone] is the knowledge of the Hour [judgment day], He sends down the rain, and knows that which is in the wombs. No person knows what he will earn tomorrow, and no person knows in what land he will die. Verily, Allah is All-Knower, All-Aware [of things] (The Holy Quran, 31:34).*

Therefore, the majority of participants in my study found it unacceptable to predict a time of death:

> *It is not acceptable to talk about death … or even planning for death … death and life are things controlled by God … and this idea is not acceptable in our culture … if the doctor told me this, I do not accept hearing about the upcoming death of my child … but I might accept it in another way (Nurse Khadija, Case 2).*
>
> *The nature of our religion, nobody knows the time of death (Dr, Raed, Case 15).*
>
> *Of course if God does not let humans know when they are going to die … if God hides it, why would we decide it? (Nurse Tagreed, Case 1).*

Similarly, Dr. Rami mentioned that parents do not accept being informed that their children will die within a certain period:

> *If you told parents that their child will die soon, they might have a reaction. So we tell them that they might become better, this is something controlled by God … but almost certainly his condition might be worse … he might be like this … the most important thing is not to tell him … you know here, specifically [in this culture], they hate to hear that he [the child] is going to die within a certain period (Dr. Rami, Case 1).*

However, a few doctors argued that it was beneficial to some parents to give them hints about the expected period of death using certain culturally-sensitive techniques, especially when they were requested to impart such information. Dr. Khalid mentioned that parents appreciated this as it fed their desire to have the information while also taking care of their feelings. They were glad of this and thanked him a lot when he informed them about this sensitive issue.

> *In terms of families, it depends on the manner … I did not have any problem [when informing about the expected death] the whole of my life. I practiced the subject thousands of times, but it needs*

> *technique … the technique that we say to the family, if they ask me "how long do you expect our child will live?" I used a special way for this; first, I tell him that "whatever I say, I'm a human, I do not know the unseen, I'm telling you what I expect because the majority of people in this stage experience this … this does not mean that my talk is one hundred percent accurate … sometimes it happens we expected patients to live one month and they live ten years … it happens it happens but we tell you [parents] the thing that usually happens with them [children approaching death] the majority of times but not in all times"… I never say that this specific child will die after one month … but I say that patients who arrived to this specific stage, for the majority of them, around ninety percent of them, death usually happens within two weeks, this is in the majority of times, and usually we do not give a fixed number like two weeks or one month, we say it ranges between two weeks to three months … less than three months less than six months … we give a range rather than a fixed number (Dr. Khalid, Case 7).*

Likewise, Dr. Rawan felt that it was beneficial for some families to know the expected time of death if they want to know, as they might need to make some preparations:

> *There are a lot of people who want to know the expectation of death, because they want to prepare the home, they want to call families, relatives, as they might be in another city, for example their grandfathers, uncles, I do not know who … they want to bring them … sometimes it is a type of preparation, such as the father might be in another country, she [the mother] asks me "shall I ask him to come?"… I told her "yes, ask him"… so you need to think of several issues, for example there was a patient who had a brother who wanted to travel to Egypt to study medicine … so the family told me "he wants to travel these two days, shall he travel?"… I told her I prefer not in these two days, because if you tell her "let him travel" and the child died the next day … she will not forgive me and they will blame me … that guy who travelled will feel guilty the whole of his life as he did not see his brother (Dr. Rawan, Case 6).*

Dr. Khalid and Dr. Rawan demonstrated two ways of how they create a balance between respecting Islamic religious beliefs in terms of not confirming the time of death, while pragmatically facilitating parents' life circumstances by helping them expect death within a certain time frame, under the umbrella of possibility and probability. However, it seems that the stage of the disease significantly affected this issue. Dr. Khalid and Dr. Rawan informed the parents about the expected time of death when their children were approaching death, or they were in the end of life stage, based on the families' requests. The parents accepted this issue by being prepared for it, having learned about the condition of their children gradually. They were happy with it as it facilitated their preparations for end of life and funerary arrangements. Moreover, it could be difficult, if not impossible, to discuss this issue with newly diagnosed-children (e.g. with nephrotic syndrome), who might live several years with this unpredictable progressive condition. I think that the two situations are significantly different, and this might affect the doctors' decisions about this issue.

5.5. Conclusion

This chapter illustrates how mutual protection dominated communications between the children, parents, and health care providers who participated in the study. Parents protected their children by only disclosing partial information about their disease, and avoiding mention of any negative or painful information. Similarly, children played the same role with their parents by avoiding expression of their anxieties or fears. Nurses tried to maintain professional boundaries with the children to avoid grief when death occurred. Doctors avoided involving children in any exchanges where negative information was given, not only to protect the children and their parents, but also to shield themselves from such emotionally exhausting situations.

The majority of mothers wanted their doctors to provide them with hopeful information about the future progression of their children's illness. Although some mothers asked their doctors to provide them with honest information regarding the health condition of their children, they considered hope to be essential for them to cope with caring for their children. Health professionals agreed with mothers on the importance of hope, which was congruent with the stage and severity of those patients' diseases. However, a few health care providers reported that they faced challenges when they tried to balance giving honest information to parents and providing them with hope.

The next chapter of the findings pays particular attention to how the extreme suffering the mothers faced as a result of their children’s illnesses caused their behaviour to stray beyond the boundaries of their traditional roles as mothers, providing compassion and care for their children. They adopted stances that varied along with the different care situations of their children’s disease journeys. This chapter also shows how mothers tried to calibrate their manner of interaction with their children and healthcare professionals not only according to specific care situations, but also to the different stages of their children’s diseases.

CHAPTER 6: QUALITATIVE FINDINGS

ADOPTING DIFFERENT STANCES: MOTHERS' COMMUNICATION EXPERIENCES

6.1. Introduction

This chapter describes how mothers interacted with their children and the health professionals involved in their children's care by adopting different stances according to the care situations their children faced. In some situations, the mothers described themselves as needing to be more compassionate and supportive towards their children, especially, for example, when they were exposed to painful invasive procedures, but also for different psychological reasons throughout the entire course of the disease. In other situations, the mothers described themselves as being more assertive, with the aim of helping their children to fight the disease when they felt exhausted and pessimistic. Some mothers described a need to advocate for their children's right to receive the best care possible, especially when their views conflicted with those of the healthcare professionals. Other mothers described how they learned to display as much strength as they could in front of their children in order to deal with emotionally challenging situations, and to try to encourage their children to summon up their own strength. The mothers tried to calibrate their manner of interaction with their children and the healthcare professionals according to specific care situations over the different stages of the disease. The mothers' abilities to play these different roles with their children and the health professionals were not the same across the board. The exact role the mothers adopted was situational, based on their sense of the most suitable approach for a given context.

This chapter builds on the following elements manifested from the mothers' narrations of their communication experiences with their children and the health professionals, particularly their adoption of different stances according to the situations they faced during the care of their children. The first section describes how mothers attempted to comfort their children as a way of compensating for their suffering, especially when their children were exposed to painful or irritating procedures. This section also highlights how mothers changed their priorities throughout the different stages of the diseases by giving more attention to comforting their children and making their lives as enjoyable as they could. The second section addresses how parents behaved when they needed to make significant decisions concerning their children's health. It also illustrates some of the factors that affected the degree of parental involvement in decision-making processes. The third section shows how mothers advocated for their children's rights to receive the best care, considering themselves to be the main person responsible for advocating for their children. The fourth section explores how mothers sought out different resources of information related to their children's diseases. This did not stop at a certain stage, but continued throughout the whole period of the illness. The fifth section highlights how mothers adopted a powerful role by pretending to be strong in front of their children, thereby avoiding any negative effects the children might experience by observing their parents' suffering and grieving. This section also expresses the experiences of some mothers who had a second child with the same disease. The final section addresses how the mothers insisted on accompanying their children throughout their stressful situations and procedures. It also demonstrates how they argued with the health care professionals who didn't want them to be present, due to concerns about their ability to cope with these emotionally-demanding procedures.

6.2. We aimed to comfort our children

The mothers of some children [23] attempted to comfort their child as much as possible, feeling the need to compensate them for the suffering that accompanied their disease. In the short term, the mothers tried to provide different forms of comfort, especially when their children were exposed to painful or irritating procedures. While they wanted to facilitate these procedures on medical grounds, they also wanted to support their children by attempting to relieve their pain. Over the long term, the mothers provided their children with comfort during their trials by giving them anything they wanted, realising that their lives might be dramatically cut short.

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[23] Rosol, Nagam, Latifa, Mousa, Sewar, Hala, Amjad, Qusai, Qasim, Suha, and Baraa.

6.2.1. Try to relieve their suffering

The level of comfort the mothers tried to provide for their children depended on their physical and cognitive capacities. For example, in the cases of Basil, Sewar, Hala, Amjad, Firas, Qusai, and Baraa, who did not suffer from any physical or cognitive disability, their parents comforted them by trying to normalise their lives to similar conditions as their siblings. This involved such activities as ensuring they pursued their educational ambitions, or giving them everyday home tasks to do. For example, Issa's mother learned from her son's doctor the importance of not giving Issa special treatment, so she treated him like his siblings:

> *I understood from her [the doctor who was assigned for Issa at that time] that he was tired and he needed treatment … he needed care … one of the most important things is not to provide him with special treatment … normal … to make him live as a normal person (Issa's mother, Case 7).*

This was significant in helping the children feel that they were not different or less able than their siblings, and played a role in reducing the gap between them and the other children. However, some parents tried to make their children's lives more interesting by offering them all the means of enjoyment and happiness they could. These children were treated in a special way by their parents in comparison to their brothers and sisters:

> *Her father always saying that this girl is the best among the family … when I go home … they [the family] celebrate her … they all like her … they feel glad when she returns … she is the most important child for him [the father] (Latifa's mother, Case 4).*

Another example of this approach is Mousa's mother who treated her son in a special manner, making one of his sisters jealous as a result:

> *I asked her how she describes the relationship between her child and his two sisters. She replied "it is good relationship … but my young daughter feels jealousy from the special care Mousa receives from us … she tries to behave younger than her age in order to seek my attention to her (informal conversation, Case 5).*

The mothers of Nagam, Latifa, Sewar, Issa, Hala, Amjad, Qusai, and Baraa comforted their children by giving them anything they wanted. When they realised that their children's diseases were incurable, they started to give them special treatment them to maximise their happiness in anticipation of their children's negative feelings about their prognoses:

> *I give him whatever he wants … I swear to God that sometimes I did not have money … I borrow for him to give him … for example he wants a certain shirt … he wants anything else … this means something like this (Qusai's mother, Case 12).*

6.2.2. Changing priorities

The mothers of Hala, Issa, Nagam, Sewar, Qusai, and Latifa changed the focus of their children's comfort during the progression of the disease. At some points during their illnesses, they felt that the focus on the comfort of their children should become more centred on relieving any physical or psychological discomfort rather than normalising their lives, especially in situations where these two objectives clashed (Figure 12).

In the beginning of the children's diseases the parents tried to reduce the gap between them and their siblings by making their lives as normal as possible. However, they later changed their approach to support physical and psychological comfort over other activities that might exhaust them, even if those activities helped to make their lives closer to those of their siblings. For example, Hala and Sewar had been included in the delegation of home tasks by their mothers, such as cleaning:

> *In the past, Hala used to help her sisters in cleaning … cleaning at home … but when her chest started to become tired … you know the cleaning substances affected her chest … she started to become tired … her father asked her to stop cleaning … and she stopped (Hala's mother, Case 8).*

Hala's mother supported her daughter's wish to leave school. She stated that Hala did not like school for two reasons. First, she felt tired because the school was very far from her home (half an hour's walk) and she got tired easily due to her illness, as well as feeling sweaty, and suffering from frequent tremors when she wrote using a pencil. Second, because of several absences from school, Hala had some difficulties from missing lessons, which in addition to affecting her academic understanding caused negative attitudes among her teachers that further undermined her achievement. Hala's mother weighed up the advantages and disadvantages of Hala's attending school, and felt that the disadvantages weighed heavier in the balance, as Hala would be subjected to unacceptable pressure by the physical and psychological burden of attending school.

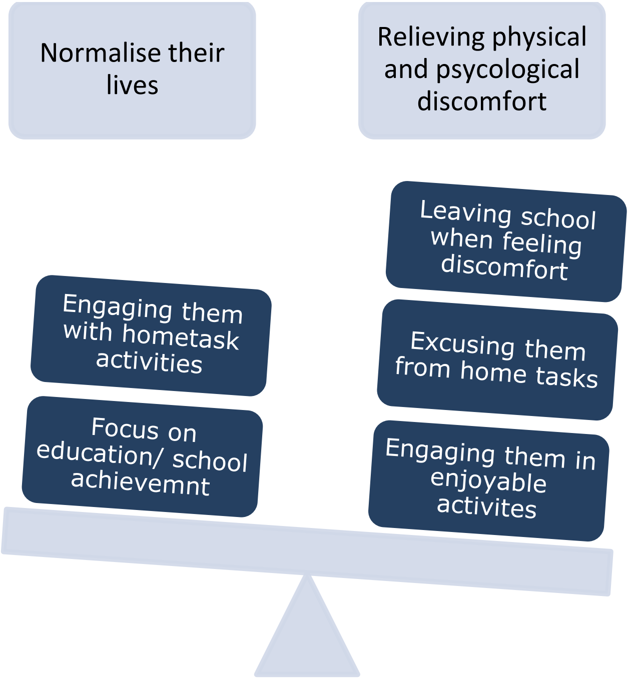


Figure 12: Changing the focus of comforting children from normalising their lives to relieving any physical or psychological discomfort over the course of their disease progression

Similarly, Latifa's parents did not register her at school. Her mother administered a peritoneal dialysis for her every six hours at home, and she felt that the school would increase her physical and mental suffering and discomfort. The nearest school is an hour's drive from their home, so Latifa's mother preferred not to expose her to any further burdens on top of her suffering from the dialysis procedures. When Latifa expressed her desire to go school like her siblings, her mother informed her that she was still too young:

> *When she asks me about school, I usually tell her that she is still too young to go … you know the school is very far from home … do you understand? (Latifa's mother, Case 4).*

Conversely, Qusai's mother supported him when he insisted on not going to school anymore. He quit school one month before conducting the participant interview with his mother. She explained that the school was located in an elevated area, and getting there every day made Qusai tired. His mother also said that the teachers complained because he did not enter the classroom; she had found him several times loitering in the corridors outside.

> *The problem is when he goes … the road is very elevated … it is like a hill … as I told you … very long way and he becomes tired … I do not know what to do … teachers are complaining about him very much … he does not attend classes … to be honest he does not attend classes … he stays at [silence] … I go by chance [to Qusai's school] … I found my son in the corridors between classes (Qusai's mother, Case 12).*

Some mothers changed their priorities, becoming less strict with their children when they wanted to eat prohibited food. As they prioritised the comfort of their children, especially in the critical stages of their diseases, they did not want to deprive them of what they wanted, even if this accelerated their deterioration. Qusai's mother was less assertive with Qusai regarding his diet, as she was concerned about depriving him of what he liked to eat. She admitted that she was afraid that he might die and that she would subsequently feel guilty for depriving him of his favourite food. Therefore, when he was eating normal food, and ignoring his low-protein diet regimen, she did not put up a strong resistance to it, although she did not encourage him in it either:

> *I'm afraid … may God not let this happen [Qusai's death] … something happens to him [i.e. death] and he asked for a certain thing to eat, therefore, I do not like to prohibit him (Qusai's mother, Case 12).*

The stage of the child's disease could have an influence on the parents when they were setting their priorities. For example, although Sewar's mother was strict with Sewar to ensure that she was following the medical regimen, such as receiving her medication, she became less assertive when Sewar's condition deteriorated to a critical stage. When Sewar was admitted to the ICU for the last time because of a significant deterioration of her health, her mother decided to give priority to her daughter's comfort, realising that her lifespan would be relatively short; therefore, she did not prevent her from eating what she wanted:

> *In the end, she became very irritable … because she became very tired while she was on oxygen … then I decided not to deprive her of anything … (Sewar's mother, Case 6).*

However, the impact of life expectancy could have a significant effect on the mothers' assessments of their priorities concerning what was best for their children. For instance, the mothers of Baraa and Qasim were very strict about adherence to the treatment regimen throughout their children's illness. Their children died suddenly at home, without any forewarning, which meant that their mothers were unprepared for their death, or to say goodbye. The uncertainty of some children's disease trajectories could have a significant effect on their parent's capacity to achieve a balance between the priorities of securing their children's commitment to their medical regimen, and comforting them.

To conclude, the parents changed their focus during the care of their children from an initial emphasis on normalising their children's lives, to relieving their physical and psychological discomfort. This change of focus accompanied changes in the parents' understanding of their children's disease over time. They became more realistic regarding the future of their children, and therefore attempted to make their lives as enjoyable and comfortable as possible. Moreover, they evaluated any activity their children performed according to how much it affected their levels of comfort. When these activities resulted in further physical or psychological effort, the mothers prioritised the comfort of their children over the benefits of the activities. They personalised their care according to perceived benefits within their expected lifespan and capabilities. Some of them agreed with their children's wishes to stop attending school, deciding that education was less important than comfort, when the school contributed more tiredness and suffering.

6.2.3. Facing the dilemma of the mothers' wishes for their children to live longer and reducing their suffering in the last stages of the disease.

The majority of mothers wished for their children to live longer. However, their ambitions for the lengthening of their children's lives were tempered by the realisation of their daily suffering, especially when the children were exposed to painful invasive treatments. When they were informed about the non-curative nature of their children's disease, some mothers felt that it was inappropriate for them to wish for their children to live longer while experiencing such great adversity. The mothers of Suha and Rashad experienced challenges when they tried to balance their maternal instincts of wishing for their children to live longer, and their compassion for their suffering child. Rashad's mother wanted her son to be comforted about his suffering:

> *This means what to do … shall I die … this means who will rear my daughters [if I die] … they have schools … they need care from their mother… now I'm thinking of my daughters [giving more priority to my daughters] … when I see my son in this situation … I cry a lot … but I try to help my husband to be patient as well … and also my family and the family of my husband … may God compensate me with another one [child] … if he dies at this age better than to suffer in this way … with needles and oxygen … I suffered too much … even his father, when he holds him for five minutes, he tells me 'take him' … he does not tolerate him because he is always tired (Rashad's mother, Case 10).*

Suha's mother asked God to choose the best way to comfort her daughter, even if this meant her demise. She separated out her own welfare as a mother and the welfare of her daughter:

> *For me as a mother says may God choose the best for her … it is right that I'm dying one thousand deaths [when she wishes that for Suha] but … I'm saying "may God comfort her, may God have mercy on her"… this means "God choose the best and the better for her" (Suha's mother, Case 14).*

> *In my heart I'm saying I wish she stays like this … I'm saying I hope God keeps her like this … just if she can eat … to be able to smell her and things like this … at the same time I'm saying no … what is this selfishness I have? ... she is suffering … she is sleeping … when I see her sleeping, I'm saying it is not fair … I should not wish this for her [to live in this manner] …what is this selfishness I have … shall I leave her sleeping like this? ... her breath comes up and down without any feeling of life while sleeping … so she does not gain benefits … I do not gain benefits too … I'm burning I'm burning for her while she is not feeling the life that she lives … what is this selfishness I have … may God choose the best for her … and the better for her … and then God will compensate her (Suha's mother, Case 14).*

However, Suha's mother's feelings about this issue were not stable or coherent; rather she expressed contradictory feelings and instincts. She wanted her daughter to be relieved of her suffering, which she implicitly knew was by death, while also wishing to postpone and avoid thinking about death. She did this by creating a synthetic world that she lived in with her daughter, avoiding the distractions of the real world. This was clear when she clarified the difference between her perspective towards the admission of her daughter to the ICU unit, and the perception of her relatives and husband. Although Suha's mother was informed by Dr. Majid about the extreme deterioration of Suha's health, she perceived that her daughter was admitted to the ICU unit for routine observation, avoiding admitting to herself that her daughter was in a life-threatening situation. She blamed her relatives and husband for believing that Suha was going to die soon:

> *They think that ICU this means that it is an intensive thing or this means she is going to die soon … but for me it is merely for observing her condition (Suha's mother, Case 14).*

However, not all mothers had the same perspective as the mothers of Suha and Rashad regarding wishing for 'the best' for their children, even if this amounted to their death. The mothers of some children (e.g. Mousa, Firas, Qusai, and Baraa) had more of a tendency to ignore the future development of their children's diseases entirely, and to stay for as long as possible with them without confronting the painful reality of impending death. Despite their inability to prevent the deteriorating health of their children in reality, they tried to postpone this process in their imaginary world. In this synthetic world, some mothers seemed to live an idealised life with their children no matter what the stage of their disease was. Even if this was only in their imagination, they decided to live this ideal life with their children for as long as possible, indefinitely ignoring or postponing any painful feelings. They even tried to prohibit other people from interacting with the world they had created for their children, as can be seen in the cases of Firas and Mousa. Mousa's mother forbade her relatives from discussing any negative information about her child's future, and tried to remain isolated from any source of open communication regarding her son's illness:

> *The mother of Mousa told me that she does not like it when people told her (may God choose the best for him) … as she feels that they mean that they wish him to die. She said it is not their business … he is my son and I feel comfortable to help him. I do not want him to die (Mousa's mother, informal conversation, case 5).*

> *No no we had a complete information about her condition [Areej] … he [Areej's doctor] honestly told us … he was telling us every step … but as a mother I was giving myself hope … this means I was placing a probability that maybe her kidneys might return to working again … something like this … her father realised that in the beginning … but lately he honestly told me they it is difficult for them to return to working again (Baraa's mother, Case 15).*

However, not every mother exhibited a single stable approach or certain degree of protection; rather, this was a dynamic issue that changed with the different stages of the diseases. It was also affected by several issues, as shown in Figure 13; for example uncertainties related to the progress of the disease. Because of the great disparity in children's life-threatening and life-limiting diseases, it is unreasonable to expect unified perceptions about how they progress, especially when considering the individual responses of different children. This could lead to further dispersion, not only for parents but also for physicians. Moreover, the protective approach might be encouraged by the communication style of the health professionals, which was generally guarded and protective with mothers.

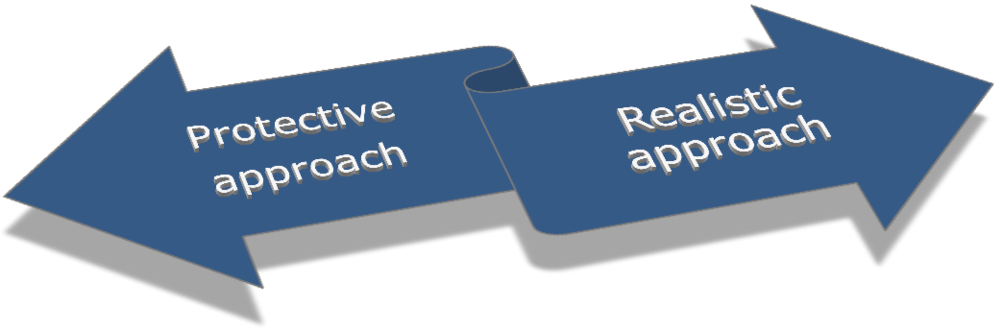


Figure 13: The continuum of protective-realistic approach

Therefore, those mothers employing a high degree of protection usually preferred to be provided with hopeful information about the disease of their children, and also showed higher sensitivity from external people or professionals who could realistically provide the current status of their children's illness. They tended to isolate themselves from the external world, as it stimulated open communication regarding the diseases of their children. In addition, they might focus more on their strong attachment to their children more than comforting them. They wanted to live with their children in a normal way – normal in the sense of life before a prognosis of the disease being terminal – for as long as they could, without disturbing them with painful thoughts related to their impending death. They were very cautious, not disclosing any negative information to their children or opening discussions related to death.

Other mothers (e.g. Sewar, Nagam, Rashad and Suha's mothers) were realistic about the extreme suffering of their children most of the time, and tended to focus more on comforting them rather than promoting their maternal attachment. They tended to initiate open discussions with their children (e.g. Sewar and Hala); even if the children themselves reacted with their own protection strategy. Moreover, they tended to be less sensitive when confronted with a painful reality in interactions with relatives or professionals. As a result, they tended to be less isolated from the outside environment, and they preferred to be given honest information rather than hopeful information. Several factors contributed to this attitude, including the time issue, which was very important when there was a rapid deterioration in the child's condition. Parents whose children had been ill for a long period and with manifest physical deterioration could be more realistic than those with children who had no physical or mental incapacity resulting from their diseases. The clear deterioration process could promote certainty and reduce distractions from contradictory information:

> *For me, between me and myself … [I know that] she will die one day … this is what I put at the head of the list … but I do not want her to die … she is my daughter … but if you tell me that she will survive … no this is not right … the kidney patient is not going to survive (Sewar's mother, Case 6).*
>
> *I always say "may God choose the best for him"… he really suffered too much … look at his neck, his body … no vein was safe from being ruptured … he is so tired (Rashad's mother, Case 10).*
>
> *Nagam's mother: When my daughter slept, I know that she … um … died … of course we feel … we are human beings … when someone sleeps for 8 days what does that mean?*
>
> *I: I see … that is probably why you were very angry the first time I met you.*
>
> *Nagam's mother: no … no … I expected that … as she [the doctor], did not move … I wanted her to move forward … she said that she consulted other doctors and they said that she clinically died, so I told her this means move on … the issue was that she was not moving onward … I want her to move onward (Nagam's mother, case 4).*
>
> *That is it … the girl is dead … she just lives on a breath machine … she [the doctor] told me that it is possible to remove it today or tomorrow … within 24 hours … I told her please do not take a long time … remove it quickly as the girl is suffering … she is suffering (Nagam's mother, Case 4).*

If we plot these different degrees of protection on the continuum shown in Figure 13, every mother changed her place on this continuum because of the previously-mentioned factors – and probably other factors not captured in this study. For example, when the mothers' protective approach was supported by other health professionals or relatives, they tended to base themselves more on the left side of the continuum. This could place an obstacle in the way of their natural advancement towards the realistic approach, because of the deterioration process of the disease. They could become more sensitive to negative information from other people, but also they could prefer to be isolated with their children, creating an idealistic bubble. However, when an open awareness was encouraged by health professionals and relatives, they were motivated to progress toward the right side of the continuum. Other factors could be examined in the same manner. As much as mothers could move from the protective approach toward the realistic approach, they were expected to effectively adapt to the expected loss of their children in the future.

6.3. The experience of decision making

Decision making includes all treatment options provided to parents in order for them to decide whether to accept or refuse different treatments for their children. In the current settings, procedures are classified as major (e.g. the vp-shunt operation for children with hydrocephalus conditions) and minor (e.g. inserting venous access, which is usually performed for the majority of children admitted to hospital).

Although in Jordan parents usually give general authorisation to the hospital to perform the necessary and recommended procedures for their children at the time of admission, they still have the right to refuse any procedure during hospitalisation. Moreover, the parents need to confirm their acceptance of any major procedure before it is performed, by signing an informed consent form suitable for that operation.

On a pragmatic level, decisions are usually taken by both parents, with input (or interference) from the extended family (which plays a larger role in collectivist societies such as Jordan). However, it is usually the father that signs the forms for major procedures. Although from a legal perspective these decisions are the responsibility of father, they showed significant variability in terms of how much they were actively involved in making the majority of health decisions for their children (Figure 14). Study findings demonstrated several factors influencing the level of the parents' involvement in decision making related to their children's illnesses, as explained below.

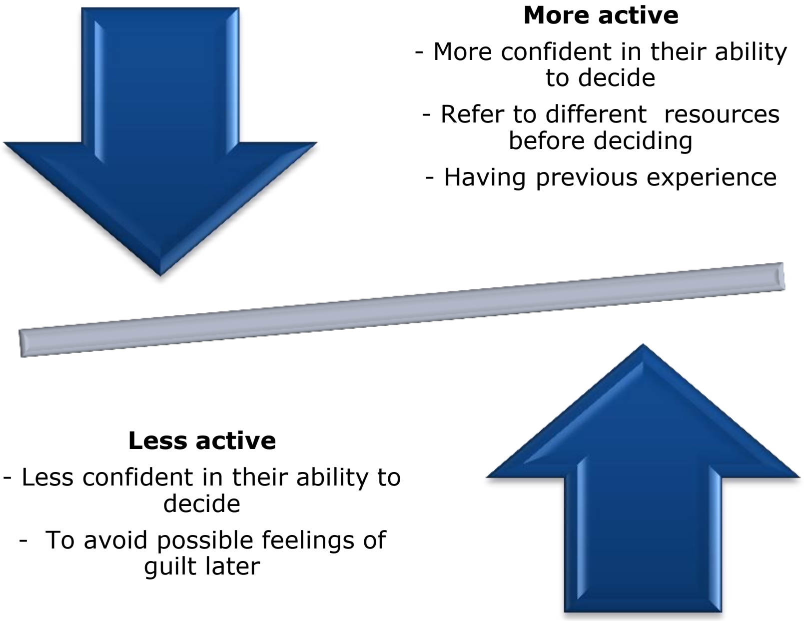


Figure 14: Mothers' different styles of decision making

6.3.1. Make it the responsibility of the doctor

The mothers of Basil, Latifa, Sewar, Issa, Hala, Suha, and Amjad preferred to give the doctor a free hand in determining the major treatment options for their children. Although the decision technically laid with the parents, as evidenced by the hospital policy of informed consent for all major procedures undertaken for children, in effect these mothers rubber-stamped the treatment options that were effectively determined by the physicians:

> *We do not like to take decisions … from the beginning we know that his treatment is difficult … we gave him [Dr. Raed] trust … whatever he does with our child, we are satisfied (Firas's mother, Case 11)*

> *To be honest, the decision is the right of the family … but we inform them about the need for performing certain treatment … for*

> *example, the shunt operation for Mousa, we told his parents all information related to this operation … but the ball is in the court of the family … nobody ever refused … to undergo to a shunt operation or something like that (Dr. Badr, Case 5).*

The mothers of Qusai, Firas, Qasim, Asaad, Suha, and Issa had little confidence in their own ability to decide the best course for their children without the doctor's help. They perceived themselves to be lay people with insufficient medical knowledge, and they were extremely fearful of making decisions that might be less effective than the course recommended by the doctor. There is an underlying culture of trusting physicians in Jordan. On the whole, Qusai's mother trusted Dr. Nihad to decide the best for her son, which did not contradict her thirst to know all of the details about her child's condition and progression. She followed Dr. Nihad's advice for the majority of treatment options related to her son, as she perceived that the doctor knew the best course of action. Similarly, Suha's mother mistrusted her ability to independently decide the best treatment options for her daughter, as she perceived the physicians to be more knowledgeable than her:

> *These are medical issues … this means I cannot choose, but the doctor, as he sees my daughter's condition … if he says a certain thing for her, shall I come and tell him "no, no"? … No, it is difficult … as based on how I evaluate something, I do not know that much about it (Suha's mother, Case 14).*

The doctors mentioned that they tried to allow for some degree of parental autonomy in choosing treatment options by providing as much information as they could about the next plan for their disease, and advising their opinion about the best decision, especially when their opinion was directly solicited:

> *We usually tell them that your child has this diagnosis … he needs an operation as soon as possible … the proportion of its success is this and that … we advise you to do it as fast as possible to preserve the child's life (Dr. Raji, Case 4).*

Firas's mother mentioned that she trusted Dr. Asaad in the treatment of her child. She perceived that the treatment of her child was difficult, and agreed with Dr. Asaad's opinions related to the majority of decisions regarding her son's illness. However, her trust seemed to be conditional to the response of her child to the treatment regimen:

> *If my child did not show any response for medication, I would say "stop the treatment, I want to discharge him and send him to another hospital" (Firas's mother, Case 11).*

On the other hand, the mothers of Baraa and Qusai did not accept the doctors' opinions absolutely; rather, they sought other resources to gain more information about some major decisions to decide the best course of action for their children. Qusai's mother sought the opinions of some friends and relatives about whether or not to go for kidney transplantation for her child in the future. Similarly, Baraa's parents asked Dr. Raed to give them all of the details about Baraa's disease. Although most times they agreed with the specialist's opinion, they usually investigated the issue using different resources that they thought would help them to decide. Most times their disagreement with Dr. Raed's opinion was fuelled by second opinions, such as other doctors, or trusted resources such as the parents of children with the same disease who had tried the same treatment. They refused several procedures when they were informed that they could be highly risky for Baraa's health:

> *For example, with Baraa, there were some conditions we intervened in based on some consultations … so there were some procedures we refused … so based on some people, they told us this procedure might be dangerous for him or something like that … even when the doctor himself encouraged us to do it … we refused (Baraa's mother, Case 15).*

In addition to trusting the doctors, it seems that feelings of guilt the mothers might get as a result of taking certain decisions related to their children's illness made the decision process more complicated. To some extent, the parents preferred to agree with the doctors' opinions in order to avoid an additional burden if the decisions had negative outcomes. For example, Suha's mother wanted to do the best for her daughter before her death. Although she was not expecting a complete cure, she intended to do anything she could that might protect her from any expected self-blame. Therefore, she wanted to transfer the responsibility for the decision from herself to the physician.

Some physicians understood the desire of parents for their assistance in some decisions. They accepted this responsibility so as to help families to avoid the guilty feelings they might have in the future:

> *I usually talk to them [Amjad's parents] … I tell them "do not be scared, I'm with you, but I could do this or that … What is your opinion?" … I usually ask them "please ask, if you do not know you can ask" … they ask me "what is your opinion?" … I tell them "I think this and that … what is your opinion?" (Dr. Raed, Case 9).*

In summary, it was clear that when the mothers had more information about the different disease options related to their children's illnesses, they had more capability and confidence to decide, but also to disagree with the doctors' opinions when they felt they needed to. This was clear with the mothers of Baraa and Qusai. Having collected as much information as possible about the different treatment options available for their children's conditions they were more proactive in deciding what they perceived to be best for their children's health.

Moreover, previous experience could make another contribution to the mothers' beliefs in their abilities to independently decide about the treatment of their children. Baraa's mother had previous experience, as this was the second child of hers with the same illness. This could add another dimension to her confidence in her ability to independently decide whatever she thought suitable for her child. However, having more information about the treatment options for their children was not necessarily enough to guarantee the mothers' trust in themselves to make decisions for their children. Although Suha's mother was perhaps the most active in terms of collecting detailed information about her daughter's disease (Section 6.5.), she did not have faith in her ability to decide the best for her daughter.

6.3.2. We do not have other options

The mothers of Nagam, Mousa, Sewar, Qasim, Suha, and Baraa were compelled to choose some treatment options for their children simply because there were no alternatives. For example, Baraa’s mother’s deceased daughter (Areej) had needed haemodialysis because of ineffective peritoneal dialysis; the health professionals informed her and her husband of the need to perform vascular access for Areej as a preparatory procedure before starting the haemodialysis. Given the risk of the operation to Areej’s life because of the analgesia required, Areej’s mother stated that this decision was very difficult for her and Areej’s father. However, Areej’s parents had no other options at that time, because the peritoneal dialysis was no longer beneficial. They felt that if she did not undergo the operation, Areej would be unable to have dialysis, and would die:

> *Yes, we signed [for vascular access operation for Areej] because if we left her, it would be the same as setting a time for [i.e. causing] the end of her life … this means at the same time, that was like there was no way … this means the peritoneal had no benefits … we did not have any options except haemo [haemodialysis], so it was like we were compelled to do it, and that was what happened in reality (Baraa’s mother, Case 15).*

Baraa’s mother felt that trying whatever treatment was available for her daughter was better than nothing. Similarly, the mothers of Mousa, Qasim, and Suha were always concerned about future guilt when trying to make decisions about any potential treatment or life-prolonging procedures that might help their child. They felt as if they would be responsible for their children’s deaths if they did not decide on the one option available.

To conclude, most of the mothers who participated in the current study preferred to transfer the role of decision making to physicians, and they perceived themselves to be less able to make independent decisions about critical issues related to the treatment of their children. There was a widespread apprehension of future guilt, which affected their ability to disagree with physicians’ opinions, especially when their own opinion might have a negative impact on their children. On the other hand, some mothers showed a proactive approach when involved with decisions about their children. They received very detailed information from primary physicians and sought out different sources of knowledge such as second opinions, reading online resources, or talking to other parents who had a child with similar circumstances. It seems that parents who were able to amass information from different sources were more confident to independently decide on critical matters related to their children’s care. Finally, those who had previous experience, such as having another child with the same condition, had a clearer decision pathway.

6.4. Being the main advocate for our children

The parents described themselves as having the responsibility to protect their children from any physical or psychological harm they faced because of their illness. They sometimes felt that they needed to intervene and advocate for their children’s right to receive the best health care available.

6.4.1. Advocate for receiving best medical care

To be able to protect their children from any expected harm, the mothers felt that they needed to observe their children and understand every procedure done for them. The mothers were not passive receivers of the treatment given to their children; instead, they were active stakeholders who tried to understand every medical or nursing procedure, and they were curious about any modifications or changes undertaken in their children’s treatment plans. The role of the mothers was not only in observing and understanding every procedure or medication given to their children; they also intervened by advocating for their children’s comfort when they felt they needed to.

6.4.2. They could make mistakes

Having lengthy experience of accompanying their children on their illness journey, many mothers’ perceptions of the inviolability of the health professionals changed over time. Although they expressed strong beliefs that the health professionals had tried their best to do their job, they came to realise that there is always the potential for mistakes and errors in health care contexts, which could potentially affect their children’s health. Some of them described health professionals as human beings who are naturally able to make mistakes, especially due to their immense workload and the pressure under which they work. These mothers did not give total responsibility for their child’s care to the nurses and doctors with blind trust; rather, they maintained some responsibility by checking and observing whatever was possible of the procedures or interventions performed on their children.

For example, Firas's mother checked the names of all medications given to him, to ensure that he was given the right medication. She asked Nurse Asma about the name of every medication given for Firas, and paid attention when he was prescribed a new medication or treatment. Rosol's mother was likewise very keen to check the medication. In addition to checking the name of the treatment prescribed for her daughter by asking the nurse, she usually noted the characteristics and colours of the medication before it was administered:

> *I know the medication from its colour … yes, I ask them what this medication is, but also when she gives [medication with] a different colour, I usually ask her to make sure (Rosol's mother, Case 1).*

Mousa's mother also took on the responsibility of double-checking the medication given for her child, even if she did not receive this information from the nurse responsible for her child:

> *She [Mousa's mother] mentions that some nurses do not provide her with information about the medication usually given for her son alone unless she asks them. For example, one time (at 12 MD the day before) the mother asked the nurse who came to put medication in the micro dropper. The mother asked "Is there any other medication after this?" She replied, "today at five o'clock". The mother said, "but I know that there are two medications that are usually given at this time, one follows another. She replied, "no, the other one will be at 5 pm" (Mousa's mother, informal conversation 13, case 5).*

6.4.3. Different focus

In some situations, during their interactions, the mothers felt that the health professionals might not prioritise their children in different situations. Instead, the nurses could give their attention to other children who had more need of their care. Furthermore, the nurses, who were busy most of the time, might have had a list of tasks they needed to finish within a certain time. Although the mothers understood that the nurses had many different tasks and patients to focus on, their own priorities were not the same as those of the nurses, since they naturally had absolute concern for their own children (Figure 15). This could be the main point of dispute contributing to conflicts between families and health professionals, as some nurses explained.

For example, Nurse Rania mentioned that she was overburdened to such a degree that she was not able to take a short break:

> *I work, work, work, sometimes I forget to drink a cup of water … I should finish my work … Suha's veins are very thin, I tried to insert cannula for her but I failed … I need to seek another nurse's help … you know her, Nurse Nancy, but she is very busy as well … this takes time (Nurse Rania, case 14).*

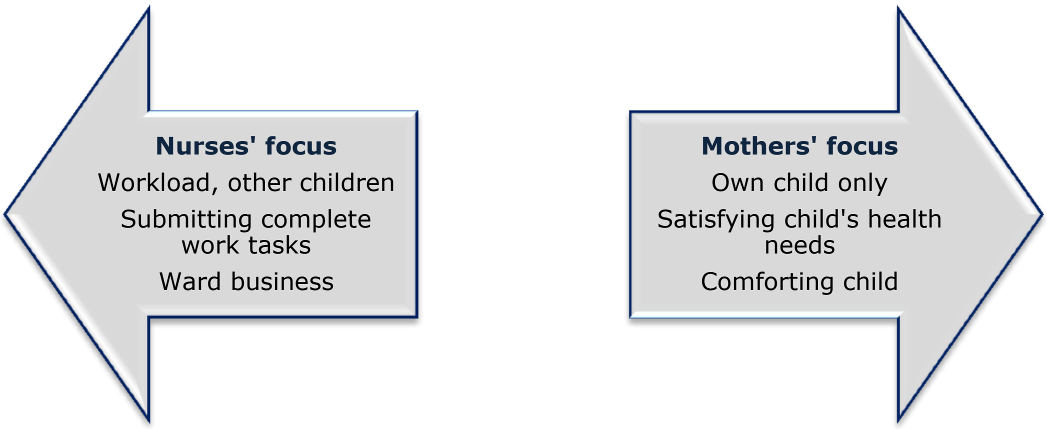


Figure 15: The difference of perceived foci of mothers and nurses during hospitalisation

Suha's mother criticised the need for some nurses to complete those work tasks for which they would be held accountable, while ignoring their children's significant needs:

> *She told me "I need to finish my work, I need to insert data on computer to finish my work that will be observed … so I don't get blamed"… but this affected me, she was too late for my daughter [inserting cannula] and I kept silent … Yes, I know that the cannula of my daughter is very difficult and it takes a long time to be inserted … if it is very difficult to insert, ask the anaesthesia [specialists], ask them to insert the cannula for her … as I heard that it stays for two months (Suha's mother, case 14).*

In addition, Nurse Asma felt disturbed by the frequent pressure exerted upon her by Firas's mother, who asked many times about the reason behind the late albumin dose for her son, as noted in the following fieldnote:

> *It is 1:30 p.m. now. I was sitting with Firas's mother and she told me that her son did not receive his medication [human albumin] until now, when it should have been started at 12:00. She was very angry about that and she left the room several times to remind Nurse Asma about it. Fifteen minutes later, I went to Nurse Asma to ask her about Firas's medication. She told me that the medication order had not arrived yet. She mentioned that Firas's mother asked her several times about albumin but she had other patients in addition to Firas, and by doing this [the mother coming several times to her to ask about the child's medication] she lost her focus on other patients. Nurse Asma told me that she felt distracted because of that. I returned to Firas's room, where the mother became very angry, telling me that this medication should be finished by 3:00 p.m., therefore it was about 2 hours late [it was 2:00 p.m. at that time]. Fifteen minutes later, Nurse Asma came to Firas's room carrying the medication and installed it; however, the medication was not running well inside Firas's intravenous line catheter [the drip was not running well, which might indicate that the intravenous catheter was out of Firas cephalic vein]. Nurse Asma tried to investigate the problem silently, then she left the room giving saline syringe in order to push the solution into Firas's hand; Firas shouted because of pain [this is another indicator that the intravenous catheter could be out of his vein]. The mother told Nurse Asma that she expected that the cannula was out of Firas's hand; however, Nurse Asma denied this and insisted that this medication should be given slowly, and that it was running at the accepted speed [sometimes when the intravenous catheter is out of the patient's vein, the medication might run slowly, being collected in the subcutaneous tissue instead of running intravenously]. The mother kept silent and Nurse Asma went out. One hour later, the medication was not running well, which was clear from the level of medication in the microdropper. Firas's mother came to the nursing station and informed Nurse Sohad [the B-shift nurse assigned for*

> *Firas after Nurse Asma] that the medication was not running for her son. Nurse Sohad found that the intravenous cannula was out and the medication was not given for Firas, and she asked him to go to the procedure room in order to insert new intravenous cannula for him (Case 11, Fieldnote 8).*

In summary, some conflicts could arise between the interests and priorities of mothers and nurses. Mothers generally prioritised their own children and their need for comfort, while nurses sought to give the best quality biomedical care, professionally, to all children in the ward.

6.5. Information-gathering experience

After being informed about their children's diagnoses, the parents of Rosol, Basil, Nagam, Latifa, Mousa, Baraa, and Suha started searching for all of the available information related to the disease. For some of the parents, such as Suha, Nagam, and Mousa’s, the responsibility for information gathering fell on the mothers more than the fathers. For Baraa, Rosol, and Basil, the responsibility was shared by both parents.

Suha’s mother perceived herself to be the principal investigator of all information related to Suha’s illness. As soon as she knew that her daughter’s disease was relatively rare, she tried to gain as much information as she could about it. She explained that the health professionals did not give her new information about the nature of her daughter’s illness because she had already collected very detailed information. She sought to determine the specific category of Suha’s disease, for example by re-reading books that she had studied when she was at the faculty a few years before. She was very curious about the degree of muscular dystrophy her daughter had. Because she had studied learning disabilities, she saw herself as having some knowledge about the disabilities her daughter might face. On the other hand, Suha’s father had less of a role in terms of gathering information about his daughter’s disease. He had a more practical role, being responsible for the financial burden that Suha’s disease had brought about. Similarly, Baraa’s parents sought out different sources of information about the illness of their children. In addition to reading books, using the internet, and seeking second opinions from doctors and people who had children with the same disease, Baraa’s parents repeated some investigations to confirm some findings or, more accurately, to try to disprove their children's diagnosis.

Despite having detailed knowledge about the diseases, the mothers of Suha, Basil, Baraa, and Mousa insisted on knowing details about every daily routine procedure or action performed for their children. They did not wait for the doctors to supply them with information about the disease's progression; instead, they took the initiation to ask doctors about every procedure:

> *I know that my daughter has [cerebral] palsy … I know that she has … but still, I want information … it still did not satisfy my needs, my eagerness … they did not saturate it … I want to know the routine procedures [done for her daughter] … even yesterday, I remember I was asking her [Nurse Rania], "Are there any blood investigations for my daughter … does she have photos [investigations] … does she have these issues?"… She told me yes … I like to reassure my daughter about what she has today (Suha's mother, Case 14).*

Not only did the mothers collect information regarding their children's diseases, but they also learned some advanced skills so that they could provide home care for them. For example, Mousa's mother learned how to perform a ventriculoperitoneal shunt tap for her son. She lived a long way from the hospital, so she learned from a doctor how to perform the procedure.

All mothers who participated in the study were informed about the non-curative nature of their children's diseases. However, they had an endless commitment to knowing all the details about the conditions and to learning new skills that supported their children's health. By investigating the issues behind the strong commitment that the mothers had toward their children's support, I identified the fear of future guilt as an issue. The parents insisted on doing whatever was possible to help their children, even when they knew that it would not lead to a cure.

6.5.1. To be free of future feelings of guilt

One of the most important motivations for the mothers' proactive gathering of information about their children's disease was their desire to be free of feelings of guilt in the future. Despite the uncertainty about the exact time of death, the mothers knew that the diseases were incurable. They realised that death was coming, even if they did not like to share that thought with other people. Therefore, they tried to escape the possibility of the future feeling of “we could have done something, but we did not”.

> *This means I try to do everything and try to know if I did something incomplete or [there was] something that could be done and I did not do it (Rosol’s mother, Case 1).*

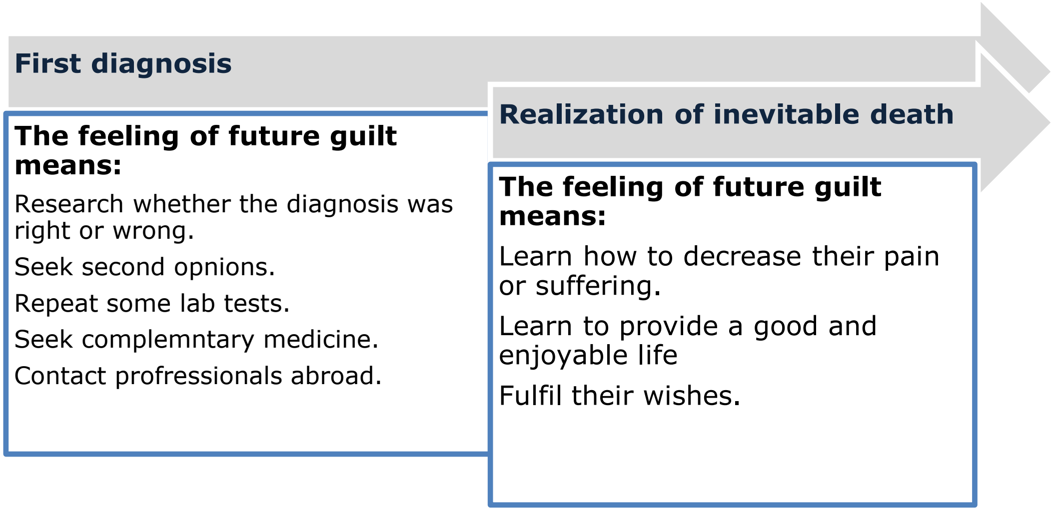
However, the stage of their children's disease might affect the type of information the mothers gathered. For example, after diagnosis, parents collected information about different treatment options that might cure their child:

> *When I came [to this hospital] the second time, he was one year old, and now he is one and three months. I said that I do not want to take him to this hospital … I took him to a private doctor, and he told me that he wanted reports [his health records] (Rashad’s mother, case 10).*

The notion of being ‘free of future guilt’ concerns the parents avoiding blaming themselves for not investigating curative solutions or alternatives, such as “we could research whether the diagnosis was right or wrong”, “we could seek second opinions” or “we could look at complementary medicine” (Figure 16).

However, when the disease is more advanced, and the parents have accepted the inevitable death of their children, the ‘free of guilt’ feeling focuses more on “we can provide them with a good and enjoyable life” or “we can fulfil their wishes” or “we can reduce their pain or suffering”. When Qasim’s mother found out about the inevitable death of his brother a few years previously, she had sought information from her relatives and neighbours. She called her neighbour who had a child with a similar condition to find out how she fed her son to keep him from vomiting. Because she did not have much experience looking after her child, who had cerebral palsy, she was more active in seeking out any measures she could use for his comfort. She mentioned how cautious she was while feeding him. Her ‘fear of future guilt’ motivated her to provide comfort rather than search for a cure:

> *This means that the most important thing is that when I will meet him in front of my God is to be free from mistake [in case she do what she should do as a mother] … therefore, now I'm saying it is impossible to leave him (Qasim's mother, Case 13).*



First diagnosis

The feeling of future guilt means:

Research whether the diagnosis was right or wrong.

Seek second opnions.

Repeat some lab tests.

Seek complemntary medicine.

Contact profressionals abroad.

Realization of inevitable death

The feeling of future guilt means:

Learn how to decrease their pain or suffering.

Learn to provide a good and enjoyable life

Fulfil their wishes.

Figure 16: Parents' 'feelings of future guilt' according to the stage of their children's disease

Sewar's mother focused on comforting her daughter and enhancing her life, as she knew the expected trajectory of her disease. She adapted herself, in anticipation of the upcoming loss of Sewar, and tried to focus on learning how to improve the life of her daughter rather than holding onto the unrealistic hope of a cure:

> *Sewar's mother: I know that renal patients usually do not improve; they go from worse to worse.*
>
> *I: how do you know that?*
>
> *Sewar's mother: renal patients have a known future … I know from experience … from people … it is impossible for a renal patient to recover … from day to day he [renal patient] will have [more] complications.*
>
> *I: How has this belief affected your interaction with Sewar?*

> *Sewar’s mother: I knew this fact from the beginning … since a long period, but … this means I tried to relieve her suffering … to help her have a good life (Sewar’s mother, Case 6).*

To conclude, the types of information parents searched for about their children's disease might indicate how much they had achieved in terms of their self-control and adaptation to the condition of their children. In other words, the type of information that the parents tended to look for could be an indicator of their success in achieving a certain level of adaptation to their impending loss. Those parents who focused on searching for cures even when they had long known about the non-curative nature of the disease might be less able to adapt to the forthcoming loss of their children than those who focused on how to live with the disease and provide a better quality of life for their children. The latter seemed to be more able to adapt themselves to the expectation of their children's loss.

6.6. We needed to show strength

A few mothers stated that they pretended to be strong in front of their children to prevent the children from feeling distressed by witnessing their suffering and grieving. The experience that the mothers gained as a result of caring for their children over a prolonged period gave them additional strength to face many challenges, which also affected their communication styles with health professionals and other people.

6.6.1. Pretending to be strong

The mothers of Basil, Nagam, Sewar, Hala, Qusai, and Baraa pretended to be strong in front of their children to help them face their suffering. At the beginning of Baraa’s illness, his mother described herself as fragile and sensitive. She was quick to cry and prone to shouting when she thought about the illness in his life. However, when she realised how Baraa was negatively affected by her sadness, she decided to hide her grief and appear strong in front of him. By doing this, she intended to transmit power to him.

> *Same time with Baraa … same … they inserted the cannula in the same area … when they inserted it into his head … it hurt me … it hurt me to the degree that I lost my control … I left him and*

> *starting crying in spite of my avoidance of crying in front of him … because he understands … for example … when my friends were talking to me at the beginning of his disease … I was crying … I was very sensitive … I was quickly affected … in spite of being happy before the call and playing with him … when he was seeing me … my facial expression significantly changed … my tears became apparent … shouting or crying … I felt that he became very sad … he knows that I'm talking about him … and I'm sad … therefore … I usually try to hide it from him … I try to be strong in front of him … (Baraa's mother, Case 15).*

Similarly, Qusai's mother described him as a warm-hearted and very sensitive child who was negatively affected when he felt that she suffered because of him. He did not like to see her crying or tired on his account; when this happened; he sat in one corner of the house and cried a lot. Because of this, she started to hide her pain from him to ease the feeling that he was making her suffer.

Other mothers pretended to be strong in front of other children, such as their children's siblings, when they asked them sensitive questions about the illnesses. Mousa's mother explained that she needed to appear strong in front of her daughters when they asked her why Mousa was unable to walk like his siblings. She described how this question brought up sadness and painful feelings about her son's illness, but she felt that she needed to simplify Mousa's illness when she described the situation to them. This was to fit in with their levels of understanding and to reduce any feelings of sadness they might have. Similarly, Suha's mother answered her niece's sensitive questions about Suha's disease when they compared her with their sister. She described how difficult she found it to discuss the illness of her daughter with a four-year-old child. However, she tried to show her strength and control over the situation when discussing her daughter's disease with others.

> *It is difficult to make little children [understand the condition of my daughter] … for example, the daughter of my brother in law who I told you about her … she asked me … she told me for example why Suha is not able to smile like Lana [her sister] … 'why doesn't your daughter walk auntie? … she is a child … it is difficult to make her*

> *understand at this age … I feel annoyed … as they are young how you can transfer this idea for them in this age? … I tell them … Suha is sick … her disease is not like Lana … she will not be able to understand in the future … she will not be able to do this and that … it is like this … now I face the difficulty that I'm discussing the status of my daughter with a little child, you know how? (Suha's mother, Case 14)*

6.6.2. The experience of having a second child with the same disease

Some mothers gained additional strength because of their long experience with their children's diseases. Those mothers who had more than one child with the same disease (e.g. those of Qasim, Baraa, and Nagam) said that the additional understanding they gained through caring for other children in the past affected their current experience in two contradictory ways (Figure 17). On one hand they described themselves as becoming stronger than before, and being better-equipped to face difficult situations, especially those related to caring for the current child. On the other hand, the grief from remembering similar experiences with their deceased children eroded their strength to endure the suffering of the current children fighting the disease. Nurse Abeer noted how Qasim's mother changed her communication style to be more flexible when she interacted with staff, especially regarding some procedures:

> *For them, they have previous experience … when there is more than one child in the family having the same condition … especially those who had two patients or more in the home, like Qasim's family … they know their child's … Qasim's condition, and understand it well … when we treat them [their children] they have more of a tendency to accept the treatment, they do not come to say "why do you do this?"… they already know … however, sometimes they become nervous with us (Nurse Abeer, Case 13).*

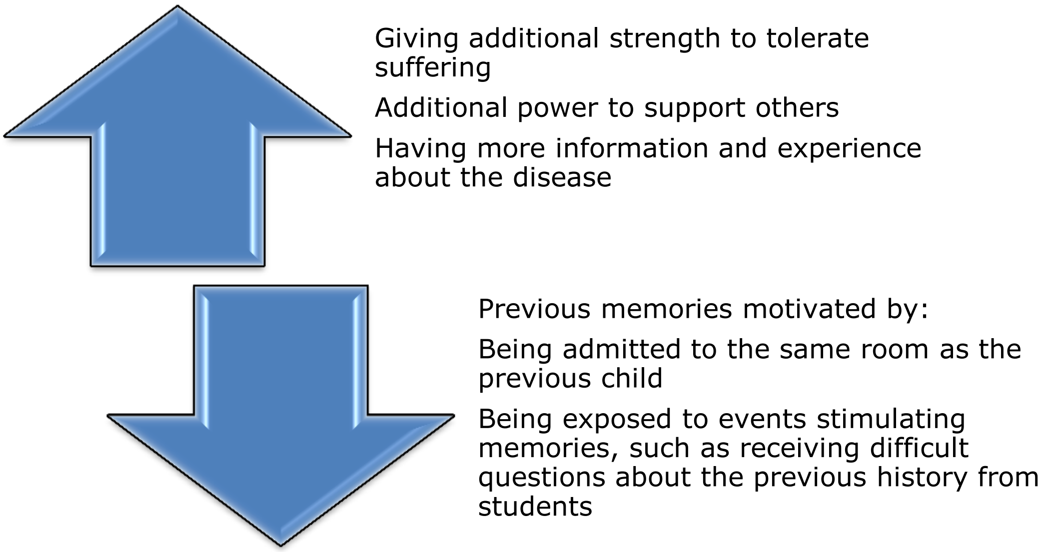


Figure 17: The effect of the previous experience of having a child with the same disease on the mother's ability to have the strength to care for the second child

The experience these mothers had because of having more than one child with the same condition gave them skills that enabled them to help in some difficult situations. Baraa's mother described how she became more confident, which helped her to assist in some emergency situations at work. For example, she helped students in her school when they had accidents or became ill:

> *Yes … I changed significantly … several things … I became stronger … even in school [she is a teacher] … if one girl has epistaxis … I can act … in the past I was afraid … for example … I do not know how to behave … now I stay with her as much as possible … you know children's school … one time an accident happened … one boy fell down from the top of the fence … he split his head open … easily … I carried him and lent him a helping hand … the old fear that I had before disappeared … after having several experiences … these things became a routine" (Baraa's mother, Case 15).*

In addition to gaining new skills, mothers with more experience could support others in extremely difficult situations. Nagam's mother supported the girl's father during the period of their daughter's death. When he cried after being informed about the death, Nagam's mother tried to be as strong as she could, and transmit this to her husband:

> *Please be quiet, be quiet, do not cry … where is your belief? … Oh Sami … instead you want to support me … now when you go home, get the Quran and read it (Nagam's mother, Case 3).*

However, previous memories of their deceased children were destructive for some mothers in different situations. They tried to downplay the effect of the negative memories on their lives in so that they could take care of the children who were in need of their care. However, there were several triggers that stimulated them to remember painful memories of their decreased children.

In spite of being described as very cooperative and showing very effective communication styles with health care professionals and friends, the mothers of Baraa and Qasim found it difficult to talk about their painful memories, for example when they were talking to medical and nursing students who wanted to study their children's cases. Rather than talk about their deceased children, they apologised and excused themselves, in an attempt to protect themselves from their painful memories. They expected the students' questions to probe the family history of disease, which would require them to remember their history.

For instance, Baraa's mother was afraid of attracting her son's attention if she discussed her family history with the students. In this way, she tried to protect Baraa from knowing any upsetting information, and keep up the appearance of being a strong mother in front of him. She found it easier to apologise to the students to avoid drawing Baraa's attention to the issue:

> *Baraa's mother: That is why … when medical and pharmacy students come to take Baraa as a case in order to discuss about him … I apologised.*
>
> *I: You apologized? …*
>
> *Baraa's mother: Because they will repeat the history completely … this means … when I tell them it is hereditary … I remembered his sister … therefore … I tried to avoid this in order to have the strength to be with Baraa … so to engage with the past and ignore Baraa … or it will weaken my strength … I do not like it (Baraa's mother, Case 15).*

These mothers also described their experiences when they were admitted to the same hospital and the same room, as well as being treated by the same healthcare providers. Nagam's mother suffered very badly after being admitted to the room where her son had died several years before. This had an enormous effect on her:

> *It was shock … shock. His [her deceased son's] soul was around me … I did not know whether to cry about that [the first child who died from renal failure] or this [Nagam] … same hospital, same room. I hated people … I did not like to stay with them … I told them "please, let me get out from this room"… they were asking me "why?" I was telling them "I do not like it, I do not like it … no, no, I do not like it"… I was telling them "put me in any room except this one" (Nagam's mother, Case 3).*

Baraa's mother expected a similar sequence of events to happen to him when he was admitted to his room due to its associations with his sister, who had died few years before. She was sure that Baraa would be moved to dialysis as soon as he was admitted to the same room:

> *Baraa's mother: This is another story … this means the first time I entered with Baraa [to the dialysis room] I became sure that it is dialysis … it was a shock (Baraa's mother, Case 15).*

The mothers used several techniques to reduce the impact of their memories and postpone grief because they believed it important to remain strong so that they could face the current situation with their children. The mothers of Baraa, Qasim, and Nagam tried to detach themselves from any event connected with their dead children. The emotional pain Baraa's mother suffered because of the loss of her first daughter, Areej, affected her ability to care for Baraa. Her friends and relatives advised her to get rid of all things related to Areej to help her to forget her. However, she retained some photos and other mementos, such as Areej's games, in order to reminisce when she missed her daughter. Baraa's mother said that she never forgot her daughter, but she tried to reduce the painful feeling that she had when she remembered her.

Likewise, Nagam's mother removed her children's photos from her mobile phone as a way of forgetting. Qasim's mother, on the other hand, kept her children's photos, and was annoyed by one of her sons deleting some photos from her phone in an attempt to help her to forget her deceased children (she had been bereaved three times). Qasim's mother mentioned that she never forgot them and she greatly missed them, so she wanted to look at their photos when she felt like it.

After the death of her first child, Nagam's mother stopped breastfeeding her children, to try and avoid building a strong attachment with them, as she expected that they would eventually die. She thought that by doing this, she would keep her strength so as to be able to face the difficult situations when they arrived:

> *Psychologically, I became tired … after his death [the first child who died because of renal failure] … I did not breastfeed her nor Hosam [her son] … I do not want to breastfeed … that is it … as I was afraid they would die … so I did not breastfeed her [Nagam] (Nagam's mother, Case 3).*

Furthermore, she found that staying alone was much better than being visited by some of her relatives, such as her sisters, who could affect her own health:

> *What they will do … they will cry in front of me … they will make me collapse … instead … if I stay alone it is better than people coming … being alone is much better (Nagam's mother, Case 4).*

In summary, it seems that having previous experience of a child with the same disease gave some mothers additional resources to cope with the second situation, even if some of the techniques they deployed were stop-gaps at best, and were not likely to be conducive to good psychological health in the long term. However, when the mothers were undergo to situations that invoked memories regarding the death of other children, this undermined their ability to cope with the current situation. When the mothers were admitted to the same room where their previous children had died, they were exposed to an intensively painful experience that stimulated their wounded memories, and hampered their capabilities to face their current situations (and indeed to compose themselves for normal interactions). In addition, when they were asked to talk about their previous experiences by some students, they preferred to avoid discussing any painful memories that could drain the emotional resources they needed to face the current situation. The mothers stated that they needed to be as strong as possible, to be able to face the current situation and to transmit this strength to their children (and spouses, in some cases).

6.7. Insistence on accompanying the child

The mothers of Issa, Amjad, Firas, Qasim, Suha, and Baraa insisted on being with their children during any procedures or investigations they underwent. Moreover, they argued with any health care professionals who advised against their presence over concerns about the mothers' ability to cope with witnessing these emotionally-demanding procedures. The mothers described their intentions to accompany their children in several ways, as explained below.

6.7.1. Sharing suffering

The mothers of Issa, Qasim, Suha, and Baraa showed a dedicated commitment to being with their children at all moments of their illness. Despite having an extremely upsetting experience when they saw their children being exposed to some very painful procedures, most of them insisted on staying with them, forcing themselves to put up with watching them suffer. The mothers of Issa, Amjad, and Firas felt that they had an internal commitment to their children not to leave them fighting the disease alone. This was an innate instinct that they did not feel required to justify to anybody. The mothers of Latifa, Suha, Qasim, and Mousa wanted to transfer a sense of protection to their children during difficult situations to make them feel secure:

> *I want to be near you my daughter … "do not be scared … Do not worry, I'm your mum, do not be scared" (Suha's mother, Case 14).*

However, despite their undertaking to share their children's suffering, some mothers (Baraa, Mousa, and Rosol's) were unable to take as much of their children's suffering as they wished. Baraa's mother left the procedure room, being unable to watch the insertion of the cannula in the axillary area after several failures. She said that she was unable to tolerate witnessing the procedure, and preferred to wait outside the room. Mousa's mother fainted inside the emergency room when she attended one procedure on her son.

From the perspective of the health professionals, there was no agreement on whether it was desirable to let mothers attend their children's procedures (Table 27). Those who supported the mothers' presence with their children (such as Nurses Lana, Tagreed, and Shaima) thought that their presence was very helpful in terms of supporting the children and facilitating the procedure. Moreover, they noticed that the children felt more secure when one or both of their parents accompanied them. Other health professionals described negative experiences when they allowed mothers to accompany their children during these procedures. For example, Dr. Rami felt he needed to deal with Mousa's mother when she fainted during her child's tubing procedure. Because of incidents like this, he prefers mothers to wait for their children outside the procedure room. The nurses often felt stressed because of the presence of mothers during procedures.

They reported that they became less effective at performing procedures in front of the children's parents because they felt observed, and also because of the probability that the parents would reflect their inability to cope with these situations by blaming them and the other health professionals.

Some health professionals faced the problem of parents insisting that they accompany their children during any procedure, while others evaluated the situation based on the mother herself. For example, nurse Nancy may have allowed a mother to be present, based on her previous experience with her. If she knew that the mother would cope with the situation and her presence would not affect her emotional status or the progress of the procedure, she would usually allow her to attend. But if she knew that a mother was very sensitive to procedures being performed on her child, she would try to avoid her being in attendance.

6.7.2. Do not accept delegation of the child's care to other people

The mothers faced a dilemma concerning their own needs for rest and other commitments while their ill children wanted them to remain with them in the hospital for long-term treatment and care.

Table 27: The different perspectives of health professionals toward whether they agree with mothers' attending invasive procedures with their children

HCP's perspective	Reason	*Quote*
Agree	Supporting and comforting the child.	*If he is a young baby like Mousa, we let his mother stay with him because he usually keeps silent with her (Nurse Lana, Case 5).*
Disagree	Mother is not able to cope with attending the procedure.	*For me the majority of mothers, I asked them to wait outside … because I had one experience while I was taping for Mousa, his mother suddenly fainted and fell down … so now I'm afraid I was working for the child then I will work for the mother as well … now if she insists to attend I ask her to avoid looking, as she might not take it (Dr. Rami, Case 5).*
	Parents' presence might cause stress for the health professionals.	*[Issa's mother's] presence causes stress for me (Nurse Reem, Case 7).*
	Their presence might contribute to conflict.	*They do not accept having to go outside … when they enter to attend the procedure, they blame you and blame the doctor [if you failed or try several times] … whatever the trust relationship with them … therefore, I prefer to work professionally with them and to work alone (Nurse Nancy, Case 6).*
Situational	Situational, based on the mother's ability to tolerate.	*If the child is very connected to his mother … for example Firas … he cries a lot if you prohibit his mother from being with him … although I do not prefer mothers to attend the procedure, sometimes their presence is helpful (Nurse Asma, Case 11).*
	As a whole, the parents of chronic patients could be more able to tolerate difficult situations.	*but you can say that the chronic patients … such as Basil, parents understand … they adapt with the disease and with the procedure done for him (Nurse Khadija, Case 2).*

On one hand, their cognition was disturbed by thinking of their family issues and their other children, who felt emotionally deprived because of their mothers' long absences from home. They also felt that their presence was necessary in the hospital as they considered themselves to be the most expert people to take care of their sick children.

The mothers of Baraa, Firas, and Mousa said that they did not accept anybody taking care of their children other than themselves. Mousa's mother considered him to have a special condition, which meant that he needed more attention than her other two daughters:

> *Because of his condition … there are not many people who understand it … it is right that my husband takes care of him … and you know my other two daughters have good health … he is different … he should be considered as a special case (Mousa's mother, Case 5).*
>
> *I should stay with him … I did not leave him, I admit [to hospital] too much time … I did not leave him even for one time … although I have a sister who can take care of him … (Mousa's mother, Case 5).*

Similarly, Firas's mother described how she prioritised his care in her life and how she even left her youngest child, whom she was breast-feeding, to take care of him. However, not all mothers had the same ability to deal with the suffering that resulted from caring for their children. Rashad's mother felt burnt out from staying for long periods of hospitalisation. She mentioned that she felt exhausted, despite giving more attention to her son than her two daughters because of his disease, she felt that her home needed her presence. She was concerned about her daughters and how her hospitalisation significantly affected her social life and her relationship with her husband.

In summary, a high proportion of the mothers insisted on assuming the complete responsibility of accompanying their children during the whole period of hospitalisation. They felt unable to accept the assistance of their relatives with the care of their ill children and their homes during hospital stays. Despite the heavy physical and emotional burden the frequent hospitalisation of their children exerted on the mothers, they reported being more relaxed staying with their children in the hospital, and felt more anxiety and stress when they left their children with relatives and went home to support their families. Their sense of the impending loss of their children might have been the main motivator encouraging them to devote as much time as possible to them, while their other children could receive parental compassion later. However, because of the intrinsic difficulty of this role, some mothers struggled greatly with the commitment they undertook, and a few of them felt burnt out, explicitly stating a need to retrieve what was left of their families.

6.8. Conclusion

The mothers narrated different communication experiences, including adopting several stances when they interacted with their children during the care of their diseases. The perceived needs they had within the different care situations they faced determined the specific experiences they had when they interacted with their children and health professionals. There were several factors that affected the mothers when they interacted with their children, especially when they provided them with necessary care. For example, the mothers' realisation of the inevitability of death was an essential factor that made them change their targets from being focused on life-prolonging treatment towards facilitating a more comfortable life for them. The mothers evaluated any activities performed by their children in terms of the discomfort it caused, and they personalised the care of their children according to perceived benefits within the children's lifespan and capabilities. The next chapter presents findings related to the perceived challenges to effective communication in the hospital context, from the perspectives of the different study participant groups, including the health professionals.

CHAPTER 7: QUALITATIVE FINDINGS

CHALLENGES TO EFFECTIVE COMMUNICATION: THE PERCEPTIONS OF MOTHERS, PHYSICANS, AND NURSES

7.1. Introduction

This final findings chapter illustrates the study participants' perceptions of challenges to effective communication, and describes how these challenges impaired their ability to send or receive clear messages during the care process. Mothers regarded the lack of clarity in communications with health care staff as a key barrier to their understanding. They found themselves unable to understand some medical terms and some reported receiving mixed messages from different members of staff concerning their child's illness. The mothers described the challenge of finding the best way to care for their sick and sometimes irritable child, especially in situations of stress. They also found it difficult to respond to some of their children's questions. The health professionals had challenges of their own when interacting with parents and children with life-limiting and life-threatening diseases. They described certain challenging contexts, such as the initial diagnosis, when the child's health deteriorated, and when the child was approaching death. Some physicians felt that they got the blame for the failure of the treatment plan, and they perceived this to be one of their main struggles. Some nurses reported that work stress sometimes prevented them from being able to provide 'ideal' nursing care, including effective communication with children and families. Others were unprepared to provide families with emotional support. A few nurses believed that this role belonged to social workers or psychologists rather than themselves.

This chapter is composed of four sections: the first explores the challenges mothers experienced during hospitalisation, which stopped them from receiving clear messages about their children's conditions. The second section highlights how mothers described their own needs for emotional support alongside the medical care of their children. The third section focuses on the mothers' experiences of caring for their sick and sometimes irritable children.

The last section focuses on the challenges faced by health professionals in communicating with parents and children.

7.2. Lack of clarity

7.2.1. Using medical language

The use of medical language was perceived by parents to be a barrier to effective communication. Some mothers [24] received unclear messages from their medical team, as medical terms or sometimes English were used when they were discussing the children's condition. Amjad's mother felt too shy to ask Dr. Raed about the meaning of "albumin":

> *He told me that the albumin level was low; I don't know what he meant (Amjad's mother, case 9).*

Issa's mother made an effort to understand the medical language and concepts related to her child's illness. Although she did not initially understand it all, the experience of caring for her child long-term helped her:

> *With time, I became more able to understand English … I usually repeat … investigate the issue until I understand … sometimes they talk in Arabic and sometimes they talk in English (Issa's mother, Case 7)*

However, Rashad, Sewar, and Baraa's mothers said that they received clear messages about the condition of their children. Rashad's mother stated that although the health professionals used medical language, they clarified the English terms for her in Arabic:

> *They told me everything about it, and if they said in English, they tried to make me understand it in Arabic (Rashad's mother, case 10).*

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[24] The mothers of Asaad, Rosol, Mousa, Nagam, Firas, Qusai, Hala, Issa, and Suha.

Like Amjad’s mother, some parents felt too shy to ask for clarification. For example, Issa's father did not understand the medical language, and left the responsibility for communication with the health professionals to his wife:

> *Issa's mother: Some people, for example, do not understand the condition [Issa's condition] well … this means he does not understand sometimes … he referred to me to let him understand.*
>
> *I: you mean your husband?*
>
> *Issa’s mother: yes, my husband … some people do not know to talk English … some people do not know the classical language too much … he does not like to show that (Issa’s mother, Case 7)*

Some nurses [25] perceived that one of the factors in misunderstandings due to medical language arose from the clinical setting in an educational hospital. In the morning round, some specialists were accompanied by a large number of medical students when they came to see their patients. Naturally, specialists have a responsibility to educate students using medical terms. Because of this, some carers were shy or fearful about asking their specialists for explanations, and so they asked nurses to clarify what the doctors had said:

> *Now there is one thing, as an educational hospital. For example, today Dr. Raed entered Asaad’s room with four or five medical students … um … he discussed in English in order to teach his students … he gave orders in English and then he exited the room … Therefore, Asaad’s mother did not understand anything and she referred to me … [with compassion] she said: “I felt too shy to ask the doctor [as] he was busy … I did not understand anything of what he said … could you discuss what he said to me as you understand what he said?” (Nurse Nuha, Case 9).*

Nurse Najwa thought that some doctors used English because they found it difficult to translate into Arabic. Dr. Raji echoed this, explaining that doctors

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[25] Nurse Alaa, Najwa, Katia, Safaa, Aya, and Nuha

tried to use Arabic terms but had difficulty translating everything, especially terms outside their speciality:

> *Yes, this is our problem … we have a problem with terms … the majority of us [doctors] found difficulty in translating [from English to Arabic] … but nephritic people [specialists] know … I mean everyone in his specialty knows the Arabic equivalent … um … no no, we do not use English too much, no no (Dr. Raji, case 4).*

Most healthcare providers realised the importance of avoiding using a language that parents did not understand. However, some doctors did this because they needed to discuss medical topics with their students. For example, Dr. Khalid tried to balance the need to discuss medical issues with his colleagues and students, whilst also respecting Issa's mother's right to receive clear messages:

> *Now sometimes we, as doctors … need to talk in English with each other, because sometimes there are medical terms … but I always take care that when I talk with my team in English … you see that today … I was accompanied by students … I looked for Issa's mother and told her that we are talking about this and that … but I'm discussing with them because there are medical terms I want them [students] to know … so I reassured her that I'm talking like this … so after every two words [a few sentences] … I looked for her to tell her that we talk this and that … so it is important to respect the presence of a patient and his family and tell them in the Arabic language what is happening (Dr. Khalid, case 7).*

To summarise, parents asserted the importance of receiving clear messages from their healthcare providers. However, the use of medical terms or English when communicating with the parents was unhelpful. The clinical setting contributed to changing the focus from patients to students in some situations, and carers sought information from nurses, because they were more accessible than doctors. Most of the health care providers were aware of the importance of giving clear messages to parents, but despite this, some carers still reported misunderstandings because of the use of medical language.

7.2.2. Receiving mixed messages

The mothers of Issa, Rashad, Qusai, Rosol, Firas, Amjad, and Mousa reported receiving mixed messages from different health care providers. As discussed in chapter five, mothers preferred to receive information about their children directly from the specialist. However, there were several factors that prompted them to seek out other health care providers or people experiencing similar cases. A teaching hospital exposes parents to large numbers of health care providers presented by the assigned specialist doctor: a few residents and fellows, the assigned nurses who are exchanged in three shifts, and medical and nursing students from different universities. This means that one patient could encounter several healthcare providers, including students, on a daily basis, in addition to the parents of other children with the same disease. This increased the potential for receiving mixed messages from some of them:

> *It was 12:30 P.M., I was sitting with Qusai's mother. Two nursing students joined us in order to take some information about Qusai's condition. They mentioned that they had a clinical exam that day. Fifteen minutes later, Dr. Raed entered the room with another resident in order to see Qusai instead of Dr. Nihad, who is usually working in another hospital on the same day of every week. I took Doctor Raed's permission to stay to attend his consultation and instruction of the nursing students, which he welcomed. Qusai's mother asked several questions of Dr. Raed regarding her child's progression. He told her that he can give her limited information as he is not the assigned doctor for Qusai; however, he gave her some information about the probability for Qusai to need kidney transplantation and she needed to think about that after consulting Dr. Nihad about this issue. She mentioned that she is unable to decide as she does not have enough information regarding to this issue. Dr. Raed asked her to discuss that with her doctor and left the room. After that, Qusai's mother seemed to be distracted and hesitant, which was clear when she said "I do not know what to do … I'm very distracted". I kept silent, giving her the opportunity to express her feelings. However, one of the two nursing students told her "even if you do kidney transplantation for your child, it might not be efficient". Qusai's mother was shocked and started crying,*

> *complaining about the exaggeration of her son's problem. I tried to relieve her suffering, telling her about the importance of consulting her child's doctor for more accurate information (Fieldnote 5, case 12).*

On the other hand, the mothers of Baraa, Sewar, Latifa, and Qasim said that they were less likely to receive mixed messages, as they did not need to gain information from different sources. During my observations, it was very clear that the specialists had gained the trust of the majority of parents and children; more so than any other health care providers (see section 5.2). This might be fostered in a culture that places a higher degree of trust in specialists than in junior doctors and nurses. Sewar's mother, for example, mentioned that she relied solely on her child's primary doctor (Dr. Marwan) for information about her daughter:

> *In Hospital X I was asking Dr. Marwan for anything related to Sewar; he does not ask residents to examine her, he does everything for her … investigations, treatment, examination … um … he was simple and humble, he was telling me "anything Sewar needs, I will do for her" (Sewar's mother, case 6).*

In addition, I observed that the parents' differing levels of awareness might affect their tendency to seek health information from several health care providers. For example, Baraa's mother did not feel that she needed additional information about her son. This was supported by my observations, as I did not see her ask any health care providers, or me, about Baraa's condition throughout the whole observational period. She had several consultations with Dr. Raed, the only professional to whom she referred inside the hospital. However, she reported that she had previously sought a second opinion after the diagnosis of her deceased daughter (see the next section). In Baraa's case, she did not feel that she needed to do that again, as she already had enough information regarding his health. Moreover, she did not like to make comparisons with other children who had the same condition, as she understood the differences between them:

> *I do not like to know about other cases … I do not like … this means that I always say … you never know everyone … you never know anything inside him … about his case … his examinations … about his entity … his condition … no, I do not like it … I do not make comparison … for example … there could be several cases in this hospital on peritoneal dialysis like Baraa … but I do not make a comparison with my child's condition.*

To sum up, receiving mixed messages from different resources increases the probability of confusion amongst parents, owing to the fact that some information might not be specific to their children's case, or might simply be inaccurate. Therefore, parents with a high level of knowledge about their children’s disease (probably because they were comprehensively informed by their primary physician) might have more faith in the information they get. They would therefore be less prone to distress as a result of getting information from multiple sources. The opposite could also be true; many parents do not understand their child’s condition, and those who have less ability to read about the illness could be more liable to confusion from differing information sources. This could contribute to low feelings of confidence in what they know, and they are more likely to be influenced by the opinions of others with whom they feel personal trust.

7.2.3. Seeking a second opinion: mothers’ experiences

Some mothers [26] sought second opinions about their children’s conditions at certain stages of their children’s diseases, usually directly after the initial diagnosis, but also directly after receiving further bad news. Rashad’s mother, for example, took her child to another doctor to confirm his diagnosis:

> *When I came for the second time, he was one year old, and now he is one and three months. I said that I do not want to take him to this hospital … I took him to a private doctor and he told me that he wanted reports [his health records] … when I came to take the reports the doctor here told me he had no treatment [no cure for*

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[26] The mothers of Rosol, Nagam, Latifa, Issa, Hala, Amjad, Rashad, Firas, Qusai, Qasim, Suha, and Baraa.

> *this condition] … then I became distracted … this [one doctor] said there is no treatment and [said] that he [Rashad] needs complementary medicine and said he needs a biopsy in the muscle as well as in the spinal column (Rashad' mother, case 10).*

Hala's mother sought a second opinion after receiving bad news from her doctor. This was supported by my observations during informal conversations with her. She asked me to read the lab results for her daughter immediately after receiving very bad news from Dr. Nihad. She told me that she had been informed that Hala might soon need to be moved to peritoneal dialysis as her creatinine level was significantly high (around 97 mmol/L). Hala's mother planned to take Hala to another specialist as she had heard positive feedback from a friend (the mother of a same-case child) about the specialist. When I asked her if she had informed Dr. Nihad about it, she replied that she preferred not to share this with Dr. Nihad as she thought it would annoy her:

> *I'm afraid Dr. Nihad could be annoyed by hearing this …you know … I'm afraid she could think that I do not trust her … I'm concerned about her feelings … you know … we've together for three years … she is very kind … and she did her best … my thoughts are unorganized … I have no idea what to do (Hala's mother, Case 8)*

Dr. Nihad and Dr. Raed reported that some parents did not accept that their child's condition could not be cured, or could be difficult to improve. Dr. Nihad accepted their denial reactions, and understood their need to confirm the diagnosis. Because of this, she informed me, she would usually perform a proactive step with the families, believing that it would facilitate good communications with the parents in the future. The doctors usually give the patients the names of doctors in other hospitals so that they can seek second opinions. Dr. Nihad thinks that it is important for parents to be persuaded of her diagnosis when they return to receive her plan of treatment:

> *No, the issue is at the beginning of diagnosis we face problems … very much … do you know how … this means when the child is diagnosed we face a lot of problems ... this is by … um … many families come … this means even Hala's family … in the beginning, her family was questioning, questioning, questioning … then they*

> *went to Hospital X … this means they asked for discharge and took her file and she went there … so they went for two years and then they came back … do you know how … so they went and saw other doctors and returned back (Dr. Nihad, Case 8).*

> *No, no I usually tells them if you feel … go this is your investigations [lab tests related to Hala] … these are your papers … go and seek other opinions … sometimes I gives them the names of other colleagues in X or Y hospitals, I tell them to go wherever you want and when you feel that you are persuaded by the diagnosis I do not have a problem for you to return back … these are the families who are usually not persuaded (Dr. Nihad, Case 8)*

> *Sometimes if they have doubt you can ask [other opinions] … if you do not know who you can ask I'm telling you where you can ask [referring them to other colleagues] (Dr. Raed, case 9)*

Dr. Nihad, Dr. Raed, and Dr. Rawan realised that the tendency of some families to seek a second opinion accompanied a denial reaction that occurred after the initial diagnosis. Dr. Raed felt that some families tended to negate the disease if they were questioned about it by their relatives or friends:

> *Maybe they have 100% trust but their society tells them to ask another one maybe … see maybe if there is another thing … (Dr. Raed, Case 9)*

Moreover, Dr. Nihad indicated that some families claimed they did not know the nature of their children's disease although they were given complete information about it:

> *The most frequent thing is denial … they tell us that … we do not … um even if someone asks them they say we do not know what our daughter has … they usually say "it is not possible" or "is it really both kidneys injured?" (Dr. Niha, Case 8)*

The denial explained by Drs. Nihad and Raed could be explained by the social stigma connected with some diseases. The mothers of Qasim, Suha, Mousa, Sewar, and Rosol suffered from this, and it may have encouraged some of them to deny their children’s illness to others. Dr. Buthaina explained it:

> *The problem with the diagnosis is first of all the family will deny the disease … and if they have similar conditions in the family they could not admit to it, and if there is no similar condition they could deny the disease itself on the basis that there is no one in the family that has the same disease … and how they inform the family and relatives that their children have chronic diseases? … it is a shame for them to have these kinds of diseases (Dr. Buthaina, Case 3)*

This is supported by my observations. Although Hala has a chronic illness, having been diagnosed with nephrotic syndrome for several years, Hala’s mother told me during our initial conversations, that she didn't know what disease her daughter had. In the beginning, I thought she had not been well-enough informed. However, I realised later that she might want to deny the illness, especially when I discovered that she knew a lot about it, for example Hala’s lab investigations and the expected plan for her. Dr. Nihad also supported this, telling me that although she gave Hala’s mother comprehensive information about the condition, she hid her knowledge of the illness, especially in front of her relatives.

Dr. Rawan, Nurse Najwa, and Nurse Rania echoed Drs. Nihad and Raed in considering the tendency to seek a second opinion as the denial reaction of parents:

> *They try to find something different from reality … they are looking for a different thing (Dr. Rawan, Case 6)*

> *Some people like to refuse the real … no this is not the issue … it is not like this, let us have another one to be sure (Nurse Najwa, Case 14)*

> *They cry …”no it is impossible he will die … he will live … he will be cured … he will do this and that … so they hope, 90% they do not accept (Nurse Rania, Case15)*

The experience of some doctors regarding the parents' denial affected their interactions with them when they provided information about the progression of their children's diseases:

> *Not one word that your children will be taken for dialysis as they will not accept at that moment the disease itself … therefore, we give them little, little (Dr. Raed, Case 15)*

However, seeking a second opinion may not always indicate that the parents do not trust the doctors. Dr. Raed and Suha’s mother indicated that some parents were encouraged to seek a second opinion by their friends and relatives:

> *Suha’s mother: Everyone [around me] told me to take her to other doctors.*
>
> *I: who told you?*
>
> *Suha’s mother: my relatives, for example (Suha’s mother, Case 14)*

Another reason that some participants looked for a second opinion was uncertainty about the progression of their children’s diseases. Drs. Raed and Asaad often face the difficulty of expecting the future deterioration of some conditions, such as nephrotic syndrome:

> *I believe that the nephrotic disease is an unpredictable disease, which means that nobody knows what will happen with that child ... for example, some people could take long period till the deterioration of the kidney function. Of course, this is based on the type. The renal function could have some deterioration ... protein loss in a huge amount and this protein could affect the kidneys … now this type is not favourable for me and I know that after 10 -15 years they could have chronic kidney disease or end-stage kidney disease, they could need dialysis … to be honest, I usually tell them gradually.*
>
> *It is not from the beginning we tell them… to prepare them … so not from the beginning we tell them as I told you … we did not expect*

> *all patients … because the medicine is kind of proportional … not all patients will end up with a bad prognosis … no some of them, as I told you, could manage until 12 years … so we did not give the bad news from the beginning (Dr. Asaad, Case 11).*

Moreover, Dr. Majid mentioned that although he evaluated Suha’s condition as becoming worse from day to day, it is difficult to predict these deteriorations:

> *These conditions we do not know the development that happens to them … we do not have control (Dr. Majid, Case 14).*

Uncertainties about the progression of their child’s disease contributed to some parents being distracted about the future. Dr. Nihad adopts a gradual "step by step" approach to communication with parents that mainly focuses on short term outcomes, and avoids anticipating events. Moreover, she adopts a hesitant approach to disclosing future expectations regarding disease progression. This is related to the unexpected nature of children's diseases and the different responses for each case. However, Hala’s mother felt confused by the lack of certainty:

> *She told me that it could be difficult to anticipate what might happen … she could improve, but also, keep in mind that she could be moved to dialysis … I feel confused (Hala’s mother, Case 8)*

Having received the diagnosis, some families (e.g. Rashad, Nagam, Hala, and Amjad’s) transferred their children from the government hospital to a private hospital, thinking that it might provide better health services. However, they returned to the government hospital later:

> *We transferred Hala to another hospital for one year but we returned to this hospital again … that one is very expensive and it is far from our home (Hala’s mother, Case 8)*

Whatever the reasons behind seeking a second opinion, it was important to investigate doctors' attitudes towards it, and how it contributes to increasing the distance between health care providers and parents. Some doctors felt professionally undermined when they knew that the parents sought another consultation or second opinion without telling them, considering that they were not honest with them, or they did not trust them:

> *I am usually honest with them but they are not honest with me … but I usually give them excuse because this is dialysis … it is not a joke … transplantation is not a joke … because renal failure sometimes is more difficult than cancer (Dr. Raed, case 9).*

Dr. Raji mentioned that the most difficult issue he faced was the denial reaction of the families and their lack of trust in the doctor:

> *We say it is denial and the loss of trust … they could ask another specialist that is it real this has happened, why this has happened, how it has happened (Dr. Raji, case 4)*

On the other hand, Dr. Khalid mentioned that he considers a second opinion to be a patient's right, and that doctors should not take it personally:

> *This is his right, this is his right and … this does not disturb us … sometimes parents are clutching at straws so they ask other doctors in case they might find something else rather than this diagnosis … so I advise that if the parents say "are you sure doctor?"… to tell them "I have no problem if you ask other doctors, in order to confirm" of course … um … sure, I do not give them a view that I'm not sure about myself … I'm not telling them "I'm not sure you can be sure about my diagnosis" … no, "I'm sure but it is your right … if I was in your place I would go … if you would like me to write a report in order to go to see other doctors and if they like to confirm they can call me … I do not have any problem"… in my opinion, this is a patients' right and we should give them this right (Dr. Khalid, case 7).*

In addition to a second opinion, Drs. Rawan and Nihad found that some parents sought out other treatment options such as alternative medicines (e.g. herbal remedies). Dr. Nihad related these behaviours to the dominant culture that some parents have, which explains the parents' feeling of strong commitment toward their child's health. This commitment could be interpreted as them doing everything for their child in order to avoid self-blame in the future (see Section 6.5.1) in case there was a solution that they had not tried:

> *It is well known for us [in our culture] that we use the herbal treatment and these things … so one person does this … other person takes that … everyone you see they tell you to go for that [person who uses herbal treatment] … he did that and we heard about that [person] who gives herb … and he takes it and these things … Hala's mother is an example … um … she asked me several times about whether or not to give Hala some herbs from a spice dealer … the extended family puts pressure on some of them (Dr. Rawan, Case 6)*

Dr. Rawan was questioned by parents about whether to seek alternative medicine or not. She did not reject alternative medicine outright, perceiving that a refusal of the whole idea could lead to negative consequences, such as losing the trust of the parents. Some parents did not respond to doctors if they were advised strict prevention. Moreover, she respected the cultural background of the family as a foundation for building trust with them:

> *I usually tell the family "there should be neither harming nor reciprocating harm"* [27]*… you want to give him, give him … but the most important thing is not to harm him … the families accept … so there is something between us and them [middle way] … when you tell them it is prohibited you should not do it … he will not accept and he did not do … no … so when you do that as I told you. To be trustworthy you have to respect the cultural and family issues and feelings of guilt and all of that to keep trust (Dr. Rawan, Case 6)*

To sum up, making enquiries of various staff members was a very prominent phenomenon in the context of my study. Almost all of the parents in my study sought a second opinion about the condition of their children at certain stages of their children's disease. The responses of doctors toward this issue varied. A few of them considered this to indicate a loss of trust, which was supported by

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[27] From the prophetic tradition.

some parents, such as Hala's mother. However, the majority of health care providers considered it to be the right of parents. The doctors mentioned that they understood the parents' denial reaction and their attempts to search for any source of hope. The majority of them asserted the importance of being flexible and helping parents to understand that they are open minded and not annoyed if they ask for other opinions. This was perceived to be an important step because some parents had the preconceptions that seeking a second opinion might displease the doctors or that they might be encouraged by other people, circumventing the primary health service they are receiving. Therefore, they hide their actions and intentions from their doctor, which affects the trust between them.

7.3. Lack of emotional support: mothers' perceptions and staff responses

Some mothers [28] described a need to receive emotional support to relieve the distress they experienced. They wanted nurses to put themselves in their situation, so that they could feel and understand the suffering they live through. Several mothers criticised the focus of the majority of staff for devoting more attention to biomedical tasks and ignoring the emotional and supportive side that they strongly felt they needed.

> *All the nurses know me because this is my third time coming here … they help the patient [her child, Rashad] but I want them to feel with me … to help me as a patient … and feel with me as a mother … I want them when they feel I'm uncomfortable … help me to be patient … comforting me a little bit … some of them do not mind … it's not any difference to them (Rashad's mother, Case 10)*

> *We need to receive emotional support … this means to help us to tolerate our suffering … we need them to give us strength (Qusai's mother, Case 12).*

> *You need to deal with the patient and the carer … they [health professionals] should care about the condition of the carer … so to*

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[28] The mothers of Suha, Qusai, Rosol, Mousa, Issa, Rashad, and Baraa.

> *take care of the condition of the mother … for example the majority of mothers … carers … the emotional status … they do not tolerate (Suha's mother, Case 14)*

A few staff agreed with the mothers regarding emotional support for the parents of children with non-curative illnesses. For example, Dr. Rami echoed the aforementioned mothers [29] about the importance of providing special treatment for the parents of children with life-threatening diseases such as hydrocephalus:

> *With some children … I usually take care of their parents, especially the hydrocephalus … Rosol, for example, I feel compassion toward them [her parents] … as I know that she [Rosol] will not complete … she will die at the end … I usually take a longer time in the clinic with her [Rosol's mother] to … to give her the opportunity to talk (Dr. Rami, Case 1)*

Moreover, although Nurse Tagreed asserted the importance of treating parents equally, she mentioned that she made extra efforts to treat Rosol's mother in a compassionate way. She described how she considered the extra suffering of mothers of children with chronic diseases who are usually hospitalised with their children for longer periods:

> *Not always … sometimes I say this mother … Rosol's mother has admitted here for a long period … may God help her … and her daughter stayed here for more than one month … while she is in this room … so I say I will not admit another patient to her room … to make her feel comfortable [Rosol's mother] … that time there was a patient who admitted to the same room and he had a lot of visitors who disturbed her … so we tell her ok stay alone but if we need … we tell her please there is another condition … she need to admit for this room … so we need this room (Nurse Tagreed, Case 1)*

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[29] The mothers of Suha, Qusai, Rosol, Mousa, Issa, Rashad, and Baraa

However, other health professionals focused on providing physical health care but avoided any emotional support for children and their mothers, especially in cases with difficult conditions, such as those who participated in this study. Drawing on the perspectives of staff about this issue, we can see that there are several contributing factors to the apparent neglect of emotional issues. For example, Nurse Asma perceived herself to be lacking the knowledge and skills to provide this type of care for children and parents. She suggested educational courses to improve nurses’ skills in this area.

> *We need to take some courses related to improving the psychological status of patients (Nurse Asma, Case 11)*

Nurses Faten, Sajeda, Safaa, Nuha, and Khadija also felt themselves to be unprepared to provide families with suitable emotional support, while others (e.g. Dr. Majid, Nurse Reem, and Nurse Samia) felt that it was not their role, considering this to be the remit of a social worker or psychologist:

> *It is a difficult topic as you need to leave your issues [other tasks] and move toward the psychological status so you need to have time for psychological support … you need a psychiatric specialist for these conditions (Nurse Samia, case 15).*

> *Sometimes we do not know and sometimes there is no time … there is a significant shortage … not all know this thing and not all of us are eligible to perform psychological support for patients … if some people do psychological support for the patient they could destroy them instead (Nurse Najwa, Case 14)*

Furthermore, hospital policy seemed to encourage professionals to focus on undertaking physical tasks more than emotional ones. This policy limits accountability to the documentation of completed physical tasks, which could mean that more attention is given to accountable tasks and non-accountable ones are ignored, especially when the professionals were under significant work pressure. Some carers criticised nurses' behaviour when they focused on tasks for which they might be held accountable, while ignoring the children's significant needs:

> *She told me "I need to finish my work, I need to insert data into the computer to finish my work that will be observed … so I don't get blamed …" but this affected me, she was too late for my daughter [inserting cannula] and I kept silent … yes, I know that the cannula of my daughter is very difficult and it takes a long time to be inserted … if it is very difficult to insert, ask the anaesthesia [specialists], ask them to insert the cannula into her … as I heard that it stays for two months (Suha's mother, case 14).*

To conclude, health care providers mentioned several reasons behind being more inclined to perform purely physical tasks while being compelled to neglect the emotional support for children and their parents. For example, the pressure of their work made them unable to focus on additional issues such as providing emotional support. Furthermore they were not professionally credited for giving this support, but they were held accountable for not performing their routine physical tasks. Another reason given was that they felt unskilled in this area.

7.4. Communication with children

Mothers described facing some challenges with their children when managing their care. Mothers found it difficult to communicate with their children in some sensitive situations, such as when they became irritable as a result of their illness. Moreover, mothers answering their children's difficult questions related to their illnesses and their future challenging.

7.4.1. Caring for irritable children

A few carers complained of finding difficulties in treating their children, especially in terms of reacting to their irritable behaviours. The mothers of Basil, Sewar, Hala, Amjad, Firas, and Qusai described their children as "bad-tempered", and found themselves unprepared to talk to them or manage their care, especially if they suddenly became angry:

> *He [Qusai] does not like to eat the diet I do for him … usually I boil food for him but he does not like [that food] … if I insist that he eats that food, he becomes angry, shouting at me, then he goes*

> *outside and buys chips … he likes chips very much (Qusai's mother, case 12).*

Sewar's mother revealed that her child became irritable in some situations. In spite of being a sociable and friendly child, especially with her friends, nurses, students, and doctors, she had another side to her personality which was only revealed to people who were very close to her, like her mother and some close nurses. The mother described Sewar as stubborn, noting that she resisted any advice when she was angry:

> *When she gets annoyed by me or anyone … even sometimes you feel … she suddenly became angry … when she became angry it was very difficult to calm her down (Sewar's mother, Case 6).*

Likewise, Hala's mother reported that when Hala became angry, she would eat salty foods, which she was prohibited from:

> *One time she was out of sorts … she went to the supermarket and bought three buckets of chips and ate them … I was not at home at that time, he … her father asked her not to do that but [she] did not respond … then after one hour she took her pressure [hypertension] medication … she was trying to relieve her suffering (Hala's mother, case 8).*

7.4.2. Receiving difficult questions from children

The mothers of Amjad, Hala, Firas, Qusai, and Sewar reported that they were unprepared to answer difficult questions from their children. For example, Amjad's mother mentioned that when he had general oedema in his body, he asked his parents several difficult questions:

> *He usually had fears about it … he feels when he sees himself oedematous, he fears very very much he says "until when will I stay [like this]? When will I be cured? Until when will this disease be with me … um …Why me but not my friends?"… this means he asks questions like this (Amjad's mother, case 9).*

> *I told him "you are not alone … there are a lot of cases like you … thank God your condition is still better than others …" What to tell him? (Amjad's mother, case 9).*

The mother preferred to protect Amjad rather than talking to him in any depth about his disease. Hala's mother also reported difficulties answering her daughter's difficult questions, especially when she compared herself to her sisters and peers:

> *One day she noticed that her [younger] sister Lubna is significantly taller than her … you feel that Hala's clothes would not fit Lubna's size … so she usually asks me … "mum, why is Lubna growing and gaining weight but I'm not? … I feel that I'm like a boy" … When I help her during bathing … she tells me … "mum look at my body … why do all of my sisters have white skin but I have yellow?" … she keeps asking and asking … I swear sometimes I cry … I left her … yesterday she asked Dr. Nihad … "Doctor … I do not feel that I become older like other girls … this means that my sister Lubna … I feel that she is older than me although I'm older" … Dr. Nihad told her "I told you Hala … that your status is different … your disease is systematic … multiple things will be changed with you … as you have kidney disease" … she was very honest with her.*
>
> *I: So … what was Hala's reaction?*
>
> *Hala's mother: She cried excessively … then I knew that her blood pressure became very high … although it was not like this in Dr. Nihad's clinic … when Hala feels annoyed … her face becomes red and you feel that she is very despondent … I felt that she suffered (Hala's mother, case 8).*

Sewar's mother reported receiving similarly difficult questions from her daughter:

> *She was telling me "why am I not like my generation?" … she sees her niece she says "why I am like this while my niece is like this?" … I'm telling her of course "this is something from God, this is God's will and you will go to paradise … God wants to test you to*

> *see whether you are patient or not", and thank God she was not getting annoyed … when you ask her about her condition, she says "thank God" even when she is in the peak of her disease, she says "thank God" (Sewar's mother, case 6).*

Some children tried to protect their parents by avoiding discussing their anxieties and fears about the future (see protection by children, chapter five), but they were not able to sustain this. Instead, some of them (e.g. Hala, Sewar, Qusai, and Amjad) lost control in extremely painful situations and asked their parents questions as a way of relieving their suffering by gaining compassion. The majority of carers, however, preferred to sustain the protection approach, as they could not find suitable words to say. Sewar's mother was the exception, being more open with her daughter even when she tried to feign ignorance. She tried to be clear with her, although her responses were shaped by her traditional Islamic cultural support (see the role of culture, chapter five).

7.5. Work stressors faced by health professionals

Physicians and nurses faced challenges in certain situations while providing health care for children. These include the physicians being blamed by families for the failure of treatment, the dilemma surrounding the degree of emotional involvement faced by nurses, and other work stressors experienced by nurses.

7.5.1. Being blamed by families as a result of the failure of treatment: the perspectives of physicians

Drs. Asaad, Rasmi, Buthaina, and Raji revealed that they had been blamed by some families for the failure of the treatment. They perceived that some parents did not accept the nature of their children's disease, and this affected the manner of their communication with the health team. Dr. Rasmi mentioned that the families blamed him as though he had not done his job, or even as if he was the reason for their children's disease. Furthermore, some parents blamed doctors when their children's conditions deteriorated. For example, Dr. Buthaina felt upset for being blamed when Nagam was sent for dialysis:

> *When her child [Nagam's mother] was turned to dialysis … as she was not on dialysis before … you are not good … you are late on us*

> *… bad quality services … but we follow the case completely … we did not shorten at any time … but you know this is end stage renal disease … although she is educated [the mother] she did not accept the issue … although we expect them as a patient, the response to be better than this … although we provide good quality especially with nephrology (Dr. Buthaina, Case 3)*

The type of hospital could be another factor that affected the interaction of some parents with the health professionals. For example, Drs. Asaad and Rami mentioned that some parents had a negative view of government hospitals compared to private ones, thinking that the latter provided better health care services, due to being self-funded.

> *They think that the private sector provides a better quality service than the governmental sector, they usually go for a short period then they return when they know that there is no difference … and of course because of the high cost (Dr. Rami, Case 1)*

The reaction of families toward the failure of treatment was another challenge faced by health professionals. Some families blamed the health professionals after the death of their child. For example, Dr. Nihad felt upset after the death of a child she had worked with for five years, whose condition had significantly deteriorated after being given dialysis. The family blamed the health professionals for this perceived failure of treatment:

> *Sometimes we feel upset … for example in the last year … she was in renal failure … she was five years having treatment and in the end she did not respond to treatment … she became tired … so she finally died, we had [conflict] with parents, who asked how she died … why this happened (Dr. Nihad, Case 8).*

7.5.2. The dilemma of the degree of emotional involvement faced by nurses

Some nurses [30] indicated that they were emotionally affected by frequently interacting with children with life-limiting and life-threatening diseases. For

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[30] Samia, Rania, Alaa, Nancy, Aya, Katia, and Farah.

example, Nurse Rania described facing a moral dilemma as a result of this, finding it difficult to control her feelings toward the children. Caring for them while also having high expectations that they would die was emotionally harmful:

> *The first thing is the psychological effect … it is too much … it is abnormal … this means that I stayed for a long period having a depression … in this stage I have reached the stage of hating ICU … hating paediatric floor … because you are affected … there are people [children] you like … people you take care of … and you know they will die … I do not want any child to die during my shift … sometimes I ask God not to let him die during my shift … between my hands … in order not to see him dead (Nurse Rania, Case 15)*

However, the issue of how much health professionals should be emotionally involved with children and their parents was a dilemma among participants. A few nurses [31] thought that when children and nurses were emotionally connected, both of them might have significant distress after short-term separation (hospital discharge of the child) or long-term separation (death of the child, or the nurse leaving). Therefore, they recommended not getting into deep emotional relationships with the children in order to avoid the effects on their private life as well as emotional distress at the time of separation.

> *I discovered that actually all renal children [children with renal disease] … for me from my experience five years if you know the number of children with renal who were here how much they decreased … too much as a number decreased especially the re-admission … so those as I told you although we see them frequently … we treat them in friendly way but for me from inside … I do not involve myself with them too much … but I do not let them feel that (Nurse Katia, Case 4).*

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[31] Faten, Alaa, Katia, Mona, and Asma.

However, some nurses said that they were unable to control their feelings and found it difficult to separate their emotions from their work even when they intended to. Nurse Sajeda experienced difficulties with this, although she did not encourage the building of strong friendships with the children:

> *Sometimes a strong friendship [with children] is established because you see them two or three times per week … and you see all of their suffering … I think when you work with this child for a long time and then they suddenly die you are affected … I feel it has unintentionally happened … this friendship even if you try not to make it … it is out of your hands (Nurse Sajeda, Case 10).*

Nurse Rania mentioned that the children's diseases she works with in the hospital affected her private life. She described becoming wary about the health of her children as a result of her frequent contact with children with life-limiting illnesses. She also found it painful to imagine that her son could be in the same position as those children. In addition to fear and anxiety over her potentially transmitting these diseases to her children, she thought that the nature of her work affects her communication with her family, especially her children:

> *Nurse Rania: It makes you have psychological distress … ignore the physical tiredness … put it aside … this is another issue … the psychological suffering that you imagine your child … you imagine your child in the same position here … if you are in this place what will you do … all of this affects your psyche … so it affects how you deals with them.*
>
> *I: Could you tell me how this could affect your home … your family?*
>
> *Nurse Rania: you go home tired … you will arrive at a stage you do not want to do anything … this means you want to stay at home … you do not want to do anything … you do not want to go outside home … you do not want to see anyone … sometimes it affects my home … I become very nervous with my son … as I'm very pressured from work (Nurse Rania, Case 15).*

However, the work experience some nurses gained over time helped them to control their feelings, and this protected them from the emotional distress they might have had because of the frequent contact with the children. Nurses with past experience adapted their communication styles with the children to reduce the potential for emotional struggles at the time of loss. For example, Nurse Alaa reported that she separated her emotions from her work gradually. She reported a past experience of the death of one child who she was emotionally connected, and said that she had learned not to become emotionally involved with patients:

> *Nurse Alaa: Look, I have one bad experience … there was a child who was newly diagnosed with renal failure … when he went for the tencuf operation, I accompanied him to the operation department, I told him that it is a CT scan … I hid that it was a tencuf operation … um … I felt I needed to lie because I felt sad for him … however, when he discharged from the operation … he blamed me*
>
> *I : How old was he?*
>
> *Nurse Alaa: He was nine years old or something like this … he told me 'why you told me it is a CT scan … they opened my abdomen to insert the tencuf' … we were very close friends … we were joking together … laughing together … when he died, I was shocked … it was very difficult for me … now I'm friendly with children but … I have no real feeling toward them … I'm not so related to them (Nurse Alaa, Case 8)*

In addition to emotional distress at the time of loss, close relationships between nurses and children were perceived to erode the required assertiveness that enabled the nurses to perform their duties. Nurse Samia said that when the relationship with children crossed professional boundaries, children could receive a different message, viewing the nurse as a friend, which could negatively affect their behaviour. For example, children might not take the nurses' commands seriously because they perceive the nurses to be their close friends:

> *Nurse Samia: Look … the best thing … that the relationship between child and nurse should be friendly … when I see him … I smile to his*

> *face … he smile with me … but it is not appropriate to go beyond professionalism…*
>
> *I: should not go beyond professionalism … tell more about this issue please.*
>
> *Nurse Samia: Because … if it goes beyond professionalism … it will become negative … when the medication time comes … and nurse and child are a close friend … for example … what will happen … what will happen … child could postpone … he will run away … if you and him are close friends … you will not do your work … however … if I treat you very well … but with some boundaries between me and him … when the medication time comes … he will go alone to his bed … and he will receive his medication and we will stay friends … so he will take the medication … his medication will not be affected (Nurse Samia, Case 15).*

Nurse Samia’s perspective was supported by Nurse Alaa, who added that one of the disadvantages she experienced when she built a friendship with some children was that they did not respond to her when she tried to give them their treatment. For example, it was difficult to persuade Hala to take her medication when she was very busy with her friends. She ignored Nurse Alaa’s requests:

> *She [Hala] was always not in her bed … I stayed more than ten minutes looking for her … yesterday she made me tired before accepting to take her medication … she was playing with X and Y … you know…sometimes I feel that I play with those kids (Nurse Alaa, case 8).*

On the other hand, Nurse Katia did not have any problems treating Hala:

> *She is cooperative and good child … she might do that with other nurses … however … she did not do that with me … she knows the time of medication and she comes to me to take it and asks me whether she can go to enjoy with her friends … she knows her medication* time … *I always know where she is (Nurse Katia, Case 8).*

It is clear from the previous examples that Hala behaved in different ways depending on which nurse was treating her. Therefore, it might be concluded that it is the nurse who gives children the green light to behave in certain way, and children might behave as a respondent to the nurse's style of communication. Another explanation might be that some children are curious to test whether the nurse will remove the professional boundaries with them and move the relationship in a more social direction. In both explanations, however, the nurse has the essential role to control whether to allow the child to build up a social relationship with her or to insist on keeping some boundaries.

In addition to the issues of emotional distress at the time of separation and loss of assertiveness, there can also be harm if the child displays good commitment in the presence of certain healthcare providers and then avoids it if they leave the hospital. When the professional relationship is broken or shifted to a very social one, children can commit temporarily to good health habits, such as taking their medication, in order to satisfy the healthcare provider they are emotionally connected to. Therefore, if the healthcare providers protect certain boundaries when they treat children, it might help children to realise the importance of their compliance with the treatment itself, regardless of who provides it. Children could avoid connecting their compliance over treatment with the presence or absence of certain healthcare providers.

> *We have fun with them … we laugh with them … we joke with them … however, if it exceeds this, there is harm for me and for the child himself … for example, he does not want anybody except Dr. Rawan to come … just Dr. Rawan … please talk to her … to be honest this is neither practical nor applicable (Dr. Rawan, Case 6)*

This problem was very obvious with (Qusai, Case 12). His mother complained about him not being committed to his diet regimen, and his preference for prohibited foods. She tried to make boiled food but every time he refused, and if she insisted or forbade him he usually became angry and went to eat at other places. However, there was a nursing student who took Qusai as a case study for her paediatric clinical course who built a social relationship with him, and persuaded him to commit to his healthy diet. This helped him to reduce his bad habits for a while, but he resumed his negative behaviour after the student finished her course.

To conclude, the findings of the study showed that building social relationships with children might have several drawbacks for both nurses and children. In spite of short-term satisfaction, as illustrated by the children's preference to be cared for by nurses with strong social relationships, this satisfaction seems to wane after a period of time.

7.5.3. The work overload experienced by nurses

Work pressure is one of the greatest challenges nurses faced during their interaction with patients. Some nurses [32] said that the pressure they were under was an obstacle to effective communication with parents and families. For example, Nurse Alaa mentioned that she was assigned a high number of patients, which minimised her ability to provide good nursing care for them:

> *Sometimes we are assigned on A shift for 18 19 20 patients, today I'm assigned for 17 patients (Nurse Alaa, Case 8)*
>
> *I need to finish my work … I need to draw blood samples for Baraa … I need to make photos [MRI] for … [Silence] before the next shift's coming … I should finish before the next shift comes (Nurse Samia, case 15).*

Other nurses believed that it was important to achieve the international ratio between nurses and patients in order to achieve the best work. Nurses Rania and Nuha thought that the quality of care they provided was affected by the number of patients they were assigned. For example, a very high nurse-patient ratio could lead to a lower quality of work. Nurse Faten felt pressured when she was assigned to Latifa, who needed extensive work, in addition to other patients:

> *For example, Latifa wants dialysis every two hours. I clean for her at 8 and then I return at 10 and then when Dr. Raed saw her … he*

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[32] Alaa, Farah, Asma, Khadija, Nuha, Najwa, Rania, Reem, Safaa, Samah, and Tagreed.

> *started to change orders for her … he asked for blood pressure, he asked for weight, and for pressure and he ask me based on her weight to change the dialysis based on her weight and when we change he asked me for dialysis and when we change he ask me to do some investigations he asked me this … so Latifa needs one hour or one hour and a half alone … this is in addition to the other patients (Nurse Faten, Case 12)*

Nurse Rania felt that the high number of patients she is usually assigned negatively affected her way of treating them. She mentioned that she sometimes lost control because of the pressure she was under:

> *This could make me becoming very nervous to finish these tasks … sometimes I answer parents in hurry … as I'm very busy … but I do not want to treat them in this way (Nurse Rania, case 15)*

Nurse Asma faced the difficulty of time management in performing her tasks. Being a relatively junior nurse (eight months experience of working with children); she faced the problem of managing multiple tasks, especially when they needed a high level of skill, such as inserting a cannula for difficult cannulation children.

One of the most important factors contributing to the shortage of nurses was the high turnover of nursing staff, without the rapid compensation of new staff. Nurses Alaa and Farah mentioned that it took a long time to compensate for nurses who left. This increased their work pressure as they needed to deal with the same amount of work with fewer staff. In addition to turnover, maternity and sick leave exaggerated the problem, especially when there were difficulties compensating for this shortage with new nurses.

> *They usually compensate … but it takes time until they compensate … until they hire new staff … compensation for maternity no there is no compensation … nurses go for maternity and return without compensation (Nurse Alaa, case 8)*

As a result of this, Nurse Mona set priorities for her work, finishing the treatment of her assigned patients over spending time talking with patients or providing them with emotional support:

> *But not all nurse are free to do that … for example, I want to distribute treatment for 10 patients and sometimes I'm assigned to 16 patients … is it logical to leave all of their treatment for example and to set and start with that patient and forgetting the treatment of 15 patients … I will be honest with you I do not do that, I will not perform my work … it is better to leave her alone and give the medication for all (Nurse Mona, Case 10)*

Likewise, Nurse Asma used her time by finishing the basic requirement of her work tasks:

> *Why … because there is no time … this means to finish your [basic] work you have lots of tasks, this means the beginning of the shift you want to do bedding you want to change the blood you want to check on cannulas you need to check on lots of things (Nurse Asma, Case 11).*

7.5.4. Receiving many questions by families that are beyond nurses' responsibilities

Some nurses reported being exposed to further pressure by receiving many questions from mothers, which were beyond their responsibility to answer. Nurse Khadija stated that parents thought that nurses knew detailed information about their children's conditions:

> *Nurse Khadija: She [Basil's mother] asked me what the doctor was saying.*
>
> *I: could you describe it more for me?*
>
> *Nurse Khadija: she considers me to be closer to her … they like to ask us … in this stage, they consider the nurse as knowing many things about the patient especially when we are in the round [medical round] … therefore, she asks me what was the doctor saying about the condition of Basil ? (Nurse Khadija, Case 2).*

There are several reasons why the participants thought parents preferred to quiz nurses more than physicians. Hala, Firas, Suha, and Issa's mothers asked nurses to clarify the doctors' messages for several reasons. Firas's mother, for example, felt shy about asking doctors, especially when they were talking in English. As a result, she asked the nurse in the medical round to clarify some issues:

> *The nurse who comes to doctors, I asked her to open the computer on Firas's name if he has investigations, to read them for me and sometimes she told me "I'm busy" … [however] there are a lot of good nurses.*
>
> *I: do you ask doctors?*
>
> *Firas's mother: they were talking in English … I ask the nurse … I feel shy to ask them … I insist on the nurse and she answers me (Firas's mother, case 11).*

Some mothers felt that the nurses were more approachable than physicians. For example, Suha's mother preferred to ask nurse Rania to clarify the types of investigations the doctor intended to perform for Suha. She felt that nurse Rania was closer to her and appreciated that Rania simplified medical concepts for her. However, Nurse Nancy described how multiple questions from parents led to additional pressure:

> *The nurse enters a whirlpool … the nurse is always present, the doctor is not present … the nurse faces a problem … she usually has stress from families and visitors … (Nurse Nancy, Case 6)*

Nurses Mona, Alaa, Najwa, Rania, and Samia described how they tried to avoid answering questions from mothers, because they were aware of the risk of providing mothers with different or incorrect information about the doctors' treatment plans:

> *Sometimes they ask to have information from different resources … from here and there … then they go to the specialist and tell him "we know this and that [from nurses] you did not tell us this" … so the nurse will have a problem (Nurse Mona, Case 10).*

Furthermore, some health care providers [33] indicated that they were exposed to extreme pressure from visitors, usually second or third relatives of the child, who asked them many questions about the child's health. The medical team felt that the parents were the only people with the right to know all of the details about their child's health conditions (this appeared to be the policy of the hospital). Therefore, they were overburdened by interruptions from the patient's extended family:

> *Sometimes there are usually people who come to visit … um … and not too many relatives … this means they are not too close to patients … you see today how Asaad's uncle and grandfather came to ask me to tell them the whole story [everything about Asaad's health condition] … the problem is that they think that the person [the nurse] … the caregiver or this who comes to give treatment or wants to take a blood sample or give medication … is aware of the case completely … and [he or she] knows what was done for him [Asaad] and the investigations that are done for him … so they want us to tell them the whole story (Nurse Nuha, case 9).*

7.5.5. Other work stressors perceived by nurses

In addition to the problem of work pressure, night shift work is another stressor that some nurses [34] mentioned as a barrier to effective communication with parents and children. Nurse Reem described how her ability to work at night significantly decreased over time. It physically affected her ability to work effectively, especially after some years of working on C-shift:

> *Now after 5 years I cannot tolerate it [C-shift] … my body cannot tolerate the C- shift … I'm tired from C physically … that's it I cannot tolerate it … they should see other people different than us … we [seniors] they should give us opportunity … this means our circumstances change … our health changes we are no longer tolerant … in the past, we hurried up although we were given a*

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[33] E.g. Drs. Asaad and Rami, and Nurses Nuha, Rania, Farah, and Alaa.

[34] Nurses Asma, Alaa, Reem, Najwa and Samia

> *higher number but we did not use to become tired … now you work less than those and you feel always tired (Nurse Reem, Case 7).*

In spite of the challenges previously mentioned by nurses, some of them provided emotional support for mothers as much as they were able. Although it was not professionally planned or requested, Nurse Samah gave Rahma's mother support when she asked about her child's condition:

> *To tell you we go and talk to them no … for example I go to give her medication … sometimes she asked me Rahma's mother asked me for example, is there any hope sister? … so I give her ten minutes … as support … these cases one two three four with age [their diseases] will be systematic she will … um … have may God do not permit … this happens everything is in the hand of God … but the conditions that we receive or the conditions that we deal with like this or that … so I give her little hope with a little … to accept the situation so whatever happened with Rahma she will not be surprised (Nurse Samah, Case 1).*

Nurse Tagreed felt that some work conditions prevented her from doing her best work. For example, when she worked on holidays, she felt upset when she left her own children:

> *I left my children in the Eid days so this makes me uncomfortable when I come to work … but what to do our profession requires this … we needed to know this thing before so I should know that this profession is like this … if every nurse thinks that she should take time off because I have children, who will work? … honestly nobody will work … sometimes I say internally if the time could be turned back, I would not study nursing as we work intensively and our salary is not fair (Nurse Tagreed, case 1).*

> *Who among us do not wish to stay with her husband and children on Friday … this Friday is holiday is a weekend what to do if the holiday is on Thursday and my husband and children go for work (Nurse Najwa, Case 14).*

Nurses Aya, Lana, Safaa, Katia, and Samia mentioned a lack of motivation as another obstacle that affected their job satisfaction, indirectly perceiving it as affecting their communications. For example, Nurse Samia asserted the importance of positive motivation more than negative motivation to encourage nurses to communicate with children and families:

> *No, not always … to be honest we have more tendencies toward the negative side … if someone did many achievements we forget them quickly but if it is wrong it is extended the whole year (Nurse Samia, Case 15).*

Moreover, Nurses Farah, Nancy, Nuha, Rania, Reem, and Safaa felt unsatisfied because the families treated them differently to the doctors. Nurse Nuha criticised the way some families treated the nurses:

> *He could shout at the nurse but when the doctor comes he keeps silent (Nurse Nuha, Case 10).*

> *He could come and have fight with the nurse and things like this he talks in a nervous way … he was nervous originally from the doctor … then he fights with the nurses but when he goes to the doctor you do not hear any voice from him (Nurse Rania, Case 15).*

However, nurse Reem felt that not all people have the same perception:

> *Not all of them … some of them they come and talk sharply … my child has a temperature … the doctor did not see him; when the doctor comes his way is completely different and they say doctor sorry we disturb you, they talk to the doctor in a polite way (Dr. Reem, Case 7).*

Nurse Khadija talked about the challenge of dealing with the parents of children who are struggling with life-limiting illnesses. The suffering some parents felt as a result of their children's disease affected their manner of talking to the health professionals. Nurse Khadija encountered difficulties when she treated some irritable parents who preferred to be isolated because of their suffering:

> *Some parents they usually become more nervous as they are seeing their children like this … so they usually become like this … so they become nervous so you need to face this thing … they usually become resistant they do not want to talk to anybody from the health professionals … but they only focus on their medical treatment they do not accept the thing of what we are talking to her that could help their child (Nurse Khadija, Case 2)*

7.6. Conclusion

This chapter examined how the participants faced challenges when they communicated with each other regarding the care of the children. Mothers experienced difficulties, being unable to answer their children's questions about their disease, and when they compared themselves with their peers. Moreover, the use of medical language and English when discussing disease-related issues with parents was another barrier to effective communication, as it made the doctors' messages less clear.

Health professionals focused on providing physical medical tasks while ignoring the provision of psychological or emotional support for parents and children, signalling the entrenchment of the traditional biomedical paradigm, which remains a barrier to the development of healthcare in Jordan. Furthermore, hospital policy encourages staff to prioritise the performance of documented tasks for which they will be held accountable. This relegates psycho-social care to a coincidental occurrence in the course of other duties, for example answering patients' questions while monitoring symptoms during rounds. The effect of this is to undermine the efficiency of biomedical task completion and the quality of interpersonal care itself. Furthermore, the lack of value placed on psychosocial support means that busy nurses necessarily prioritise the tasks they are accountable for. Finally, many of them perceived themselves to be unable to provide this kind of support, and some of them said that this role should belong to social workers or psychiatric specialists.

The next chapter discusses the findings presented in chapter 5, 6 and 7 in conjunction with the current literature.

CHAPTER 8: DISCUSSION

8.1. Introduction

The findings of the current study suggest that the study participants adopted a protective approach when they communicated with each other. Children protected their parents from sadness by avoiding discussing their anxieties and concerns and likewise parents did not fully inform their children about illnesses. Sometimes they tried to isolate their children from any environment where sensitive illness-related topics might be discussed to avoid upsetting them. Physicians protected children from discussing sensitive topics regarding the progress of their diseases, but they also adopted a gradual way of communicating bad news to parents. Nurses learnt to maintain strict professional boundaries with children to avoid any emotional harm at the time of a child's death.

Furthermore, the study findings show that as a result of the extreme suffering mothers faced as a result of caring for their children, they were compelled to behave in certain ways that could be different from their pre-illness personalities. A mother's stance might therefore fluctuate significantly, ranging from a display of empathy to a display of 'toughness' when defending what they saw as their child's rights.

Finally, the study participants faced several challenges to effective communication during their children's treatment. For instance, mothers reported a lack of clarity in the messages they received from health professionals, especially when medical jargon was used. Health professionals reported challenges when they interacted with parents and children with life-limiting and life-threatening diseases. Some physicians felt upset as a result of being blamed by families when a child's condition deteriorated, despite feeling that they did their best to help. Nurses reported difficulties providing the best care possible for families, including communicating effectively with them. These difficulties stemmed from extreme work pressure and a lack of necessary supportive skills, which prevented them from behaving in an appropriate manner in some stressful situations.

This chapter discusses these key findings in conjunction with the relevant literature and theories. It is divided into four main sections. The first section discusses the degree of protection promoted by the study participants and the processes used to maintain this protection. Next, the role of staff regarding the amount of information provided is reviewed. Finally, the exchange of information between staff, mothers, and children is examined. The second section mainly sheds light on how staff tried to create a balance between promoting hope and disclosing honest information to parents. It also clarifies how the differences in perspectives between mothers and staff help to increase the tension between the maintenance of hope and acceptance of the reality of prognosis. The third section discusses the degree of parental participation in the treatment decision-making process, and the factors affecting their level of involvement. The children's participation in decision making and the parental perception of this are also considered in this section. The final section discusses the participants' perceptions of the challenges in maintaining effective communication. These challenges include a lack of clarity in the information provided for parents, the staff's lack of supportive skills, and the moral distress and compassion fatigue experienced by nurses as a result of caring for children with severe illnesses.

8.2. Mutual protection

In this section, the protection approaches adopted by the study participants are reviewed and discussed. Additionally, the issue of the amount of information parents require to know at the different stages of their children's diseases, and the optimal time such information should be given are also considered in the light of recent literature.

8.2.1. Factors that affected the maintenance of the protection approach

As highlighted in Section 5.2.4, there was a general tendency among mothers to avoid sensitive areas such as delivering bad news or talking about death with their children. This study added the new insight that some mothers used various different techniques to adopt a strict protection approach for their children. For example, the mothers of Latifa, Baraa, and Amjad isolated their children from being involved with other children and friends. This was to protect them from information that could increase their awareness of the difficulty of their health conditions, especially near the time of diagnosis. Furthermore, the uncertain nature of the children's illnesses meant that doctors were unable to confirm the long-term expectations of the prognosis. Another factor that promoted protection by the parents was their perceptions of the children's inability to understand death.

These findings substantiate previous qualitative studies in which the majority of parents did not initiate discussions with their children about death (Arabiat et al., 2011; Clarke et al., 2005; Gaab et al., 2013b; Price et al., 2013; Seth, 2010; Van Der Geest et al., 2015a). For instance, Clarke et al. (2005) interviewed 55 parents of children (36 boys and 19 girls) with newly-diagnosed acute lymphoblastic leukaemia in the UK to investigate the mothers' emotional and behavioural responses following diagnosis. The findings show that only 3 out of 55 mothers mentioned giving their children a full explanation about the possibility of death. This resonates with the protection approach demonstrated in the current study between parents and children, especially when discussing sensitive issues referring to death. However, in the Clarke et al. (2005) study parents were approached to participate four months after diagnosis, which could be considered proportionally to be at an early stage of illness. Therefore, this finding did not capture the effect of the changes in parental communication style on the behavioural and coping abilities of their children in the long run.

The current study has extended these findings, adding a new insight: some mothers changed their approach to communication with their children in response to certain situational changes or other factors during the extended period of their children's illnesses. As reported in Section 5.2.2, some children experienced the death of other children with the same condition. The mothers stated that they tried to hide this from their children, asking staff and other mothers to collaborate with them. However, the children knew anyway, because of such situations as being admitted in the same room as the deceased or knowing from information mistakenly leaked by visitors or friends. Therefore, mothers felt that they needed to become more open with their children – even though the refusal to discuss such issues came from the children rather than the mothers. Moreover, it was difficult for some parents such as those of Hala, Sewar, Amjad, and Qusai, to maintain this protection approach as their children became older. Additionally, some children were very sociaciable (such as Hala and Sewar) and very likely to be involved with other children and professionals.

Furthermore, the current study demonstrates that some mothers were also protected by the witholding of some significant information from them about their children’s health. As discussed in Section 5.2.5, some health care providers and relatives withheld information from mothers, although some of them picked up hints from non-verbal communication. This caused very severe consequences for mothers who realised that some information had been intentionally kept from them. This strategy was not without harm to the mothers, because being aware of such deceptions but not in possession of the full facts, the mothers often thought that the condition of their children was more serious than it actually was. For some mothers, the fear of the unknown could be more serious than knowing the reality itself. To our knowledge, this is the first study that highlights the issue of the protection of mothers and its possible consequences.

Although a few staff (such as Dr Raed, Dr Rawan, Nurse Alaa) indicated that the protective culture might have a significant role in increasing the tendency of some parents to adopt a protective approach with their children (see Sections 5.3.4 and Section 5.4.), the current study confirms current research by highlighting other issues that have a significant effect in promoting the protective approach for children. For example, as discussed in Section 7.4.2, the mothers of Hala and Amjad felt themselves to be lacking the skills to discuss such sensitive issues with their children. Additionally, the mothers of Amjad, Hala, Firas, Qusai, and Sewar reported that they found themselves unprepared to answer their children’s difficult questions. This chimes with a study by Van Der Geest et al. (2015a) that showed that parents felt a lack of confidence in their ability to convey the message that their child had a terminal illness.

In addition to lacking the skills and abilities to discuss sensitive issues with the children, the current study confirmed previous work (Dangel et al., 2000; Gaab et al., 2013b; Van Der Geest et al., 2015a; Zelcer et al., 2010), which found that parents aimed to protect their children from the emotional suffering they might undergo if they were given comprehensive details about their conditions. This was especially so when they thought that the children were not aware of their prognosis. The majority of health care professionals agreed with those mothers, believing that as long as the children were not aware of the possible complications of their illnesses, there would be no need to expose them to the extreme emotional suffering they might experience from knowing the nature and prognosis of their diseases. For instance, Dr. Rawan preferred not to inform children or even teenagers about end of life issues unless they asked for it themselves (see Section 5.3.4).

Moreover, as highlighted in Section 5.2.3, the findings of the current study have shown that some mothers (e.g. Hala, Sewar, Qusai, and Amjad's mothers) avoided open discussion with their children, as the children themselves did not want it. Similarly to previous work (Gaab et al., 2013b; Dangel et al., 2000; Van Der Geest et al., 2015a), parents and caregivers in the current study avoided discussion with their children about death, as the children themselves refused to talk about it. In Section 5.2.3, the present study added the finding that children used several techniques to express their refusal; some of them became angry and denied having anxieties or concerns (such as Hala, Sewar, and Qusai), or felt guilty, as evidenced by crying and isolation (such as Qusai and Amjad). Also, some children protected their family by being open to some relatives while adopting a close approach with others. For example, Sewar was open with her sister in law, sharing her concerns and anxieties with her, while strictly refusing any sensitive discussion with her mother. Likewise, Hala was more open with her father than her mother. Although a few mothers tried to initiate such discussions, the children's reactions prevented their parents from talking about such painful topics. Van Der Geest et al. (2015a) likewise affirm the children's reluctance to consider matters related to death despite using different approaches. For instance, one child in (Van Der Geest et al., 2015a) clearly mentioned his/her preferences to discuss positive things in their life, while another refused to answer their parents' sensitive questions.

The current study added another reason cited by mothers to hide significant information about the disease from their children. As described in Section 5.2.4 some mothers tried to protect their children from the stigma of illness. A few mothers mentioned that they withheld some information about the disease from their children to spare them from the emotional suffering they might experience because of having a disease of this type. Mothers wanted to protect their children from feeling different in front of their siblings. Furthermore, some health care providers confirmed the perceptions of mothers by reporting that they limited their discussion with children to the routine tasks to enable them to live a normal life like other children. Some nurses perceived that the child's feelings of difference could affect their enjoyment of their lives, and might also make them feel different to others.

This study has shown that the majority of parents viewed children to be cognitively unable to understand issues concerning death, which justified their tendency to avoid providing them with detailed information, especially about future progression or death, as discussed in Section 5.2.1. A few mothers (such as Nagam, Latifa, and Baraa) felt that their children were too young to understand such discussions. Previous studies showed that the children's age was one of the most important factors, and it significantly shaped the parent's interaction with their children, affecting the extent to which they were open when treating them (Arabiat et al., 2011; Clarke et al., 2005). This is consistent with other studies (Van Der Geest et al., 2015a; Dangel et al., 2000; Claflin and Barbarin, 1991), which found that some parents felt that their children were too young for this type of discussion.

Nevertheless, prior studies (Gaab et al., 2013a; Young et al., 2003) affirm that the parents' views of the accounts of communication with their children and those of the children themselves could be different. As they are considered the bearers of communication for their children, the perception of parents towards their children's maturity and information about the disease affected the information they transferred to their children. According to Gaab et al. (2013a), caregivers in New Zealand slightly misjudged exactly how clearly 5-7 year olds grasp the notion of biological death. When mothers use the protection approach for their children, whose awareness of death they underestimate, the distance between children and parents can increase. This in turn reduces their opportunity to have a mutual conversation. This barrier can heighten the suffering and anxiety of children with higher awareness, since they are not be able to express their concerns or share their worries with parents who underestimate their cognitive abilities.

In addition to age, the current study highlights that the majority of children gained an additional level of awareness due to having several admissions to hospital. The frequent reporting of children's health conditions in front of staff, students, and friends provided them with more information about their status. Also, children who were more sociable (such as Hala and Sewar) had a higher level of awareness than those who were protected by their families from interacting or making friends with children with the same diseases (such as Baraa).

Finally, as highlighted in Section 5.2.2, this study has extended our understanding of the experience of knowing about the death of a friend with the same illness, or attending their funeral, seems to be significant for providing the child with additional experience and awareness related to death. Similar findings were reported by studies that found that the children's knowledge of their status as dying could be increased by gaining additional experience through being treated in oncology wards. By this means, they could obtain supplementary information regarding their disease, including its seriousness, different details about their treatment, and information about death (Clarke et al., 2005; Goldman and Christie, 1993; Bluebond-Langner, 1978; Patenaude, 2005). This was probably related to the increased contact with the adult world as a result of several hospital visits (Clarke et al., 2005).

Finally, this study has also gained a new insight, in that mothers who perceived their children to have a high awareness of their upcoming death (such as Sewar and Hala) had more of a tendency to initiate an open discussion with them, although the refusal of these kinds of conversations also stemmed from the children themselves. As Hala and Sewar's mothers were sure that their children thought about issues related to the end of life, and death, they reported their attempts to initiate such discussions with their children to alleviate their suffering. This could imply that a mismatch between mothers and children about the level of awareness of their condition could be an obstacle that eliminated open discussion between parents and children. This would contribute to further protection by parents and children.

8.2.2. The role of staff in promoting the protection approach

The current study has shown that parents behaved as the primary gatekeepers of communication between health professionals and children, managing the exchange of communication between them and controlling how much information was provided for their children. Consequently, health care providers took the family's desire into considerations when/if they initiated any discussion with the children about their disease. This finding substantiates the previous work (Van Der Geest et al., 2015a), in which parents reported that they felt it was inappropriate for them to inform the child that they were likely to die, but they also thought that doctors should refrain from telling children this sensitive information as well.

Moreover, this study has shown that almost all participants, including staff, supported the notion that children only need to know partial information, which is appropriate to their age and their cognitive ability. Information should also be sufficient to ensure their cooperation with treatment, such as medication compliance and the performance of investigations, as well as ensuring good adaptation to symptoms in regard to life and school. The current study adds a new insight, finding that the majority of staff agreed with parents that discussing sensitive issues with children could be harmful to them, but that it could also result in negative psychological complications. However, this is contradictory to recent qualitative studies conducted in the UK and France, which showed that health professionals think that telling children the truth was the most appropriate strategy, as it helped them to alleviate any worries (Price et al., 2013; Sastre et al., 2012). Similarly, as alluded to by Price et al. (2013), there was disagreement between health professionals and parents.

This contradictory finding could be explained by the tendency of the majority of staff in this study to distance themselves from children during work, as highlighted in Sections 5.2.1 and Section 5.2.6, which resulted in less contact with children apart from routine tasks. Although the children became familiar to the staff as a result of being admitted to the same department several times during the period of their illnesses, this study shows that the interaction between children and staff was almost limited to routine tasks, or other general issues far removed from any sensitive topics related to their illnesses. It was clear that staff were very cautious about discussing such matters with the children so as to avoid conflicts with their families, especially if the child had an emotional crisis as a result of discussing such difficult topics. A low interaction between children and staff could greatly reduce the potential for staff to understand how the children think, what they know about their diseases, their awareness of their illness, and their worries and concerns. This could contribute to supporting the traditional view of the child as not being able to understand issues related to death. Therefore, the staff were more inclined towards an agreement with the parents to encourage the protective approach for their children.

8.2.3. Staff-mothers information exchange

This study found that the majority of mothers (such as Nagam, Sewar, Basil Latifa, Qasim, and Hala) wanted to receive complete, accurate, and honest information about the condition of their children. Moreover, a few mothers (e.g. of Baraa, Rosol, Issa, and Rashad) were disappointed when they knew that their doctors had withheld significant information from them, as discussed in Section 5.3.1. For instance, Rashad's mother mentioned that she experienced extreme shock when she learned that her child's consultant did not inform her that her son's condition (cerebral palsy) had no curative treatment.

In addition, the current study discovered that a few physicians (e.g. Dr.Rawan, Dr.Nihad, Dr.Asaad, Dr.Khalid, Dr.Badr, and Dr.Raed) asserted the importance of keeping parents informed, in order to avoid the shock they could otherwise experience as a result of being provided with sudden unfavourable information about their children's health. The initial shock parents could experience was perceived to lead to pathological grief, which could result in adverse reactions in the families. In line with these findings, several studies highlight the importance of always providing parents and children with honest and detailed information about their diseases (Gianinazzi et al., 2014; Ringner et al., 2011; Mack et al., 2006; Ferguson, 2007; Freeman et al., 2004; Steele, 2006). For instance, one mother in Hendricks-Ferguson (2007) study experienced a shock reaction by being abruptly informed that her son would die within two days to two weeks, without having been aware about his worsening condition. Moreover, as reported elsewhere (Hsiao et al., 2007), families described being devastated when they felt that physicians withheld information about treatment, as it left them unprepared for the outcomes.

Nonetheless, it is important to note that not all mothers in the current study preferred to be provided with detailed information about their child's condition at the point of diagnosis the diagnosis. A few mothers (e.g. Rosol and Suha's mothers) indicated the importance of gradually communicating bad news as a more appropriate strategy for the parents. As highlighted in Section 5.3.2, although Suha's mother asked for detailed information about her child's condition, particularly at the beginning of the diagnosis, she experienced extreme emotional suffering (she described it as relapse) later. This is consistent with prior studies (Kastel et al., 2011; Ringner et al., 2011; McGrath et al., 2007), which argued that parents who received information as soon as it was available perceived it as a positive experience. However, this was also problematic because they often needed more time to accept the information and preferred to be spared certain pieces of it. Moreover, some parents in the study by McGrath et al. (2007) felt that they got the information about relapse earlier than they wanted. They did not like to know much about it before it happened or before they sought the information from health professionals. Finally, as Seth (2010) reported, parents wanted information to be given to their children at a later time, after treatment had started, not before it commenced.

Additionally, a few physicians (e.g. Dr Rami, Dr Buthaina, Dr Raji, Dr Khalid) mentioned that many parents had a suffered trauma to receiving bad news in a blunt, direct manner. These reactions were perceived as temporarily limiting their cognitive abilities to understand complex information about their children's conditions. For instance, Dr. Buthaina did not provide Nagam's parents with full information at the point of diagnosis of diagnosis directly after giving them bad news, as she took their emotional reaction to the information into consideration. This study found that the amount of information to be provided for parents, and the appropriate time to communicate it is a challenging task for physicians, and other studies concur with this (Fallowfield and Jenkins, 2004). Additionally, according to Ringner et al. (2011), parents stated that health professionals adjusted to the parents' shock reaction by avoiding speaking about side effects and reactions to the treatment or the risk of relapse. For parents to be able to comprehend the information given to them, health professionals repeated it, and divulged it in small pieces.

8.3. Maintaining hope

This section discusses the following themes in the light of recent literature: creating a balance between disclosing honest information and promoting hope, and the tension between hope and acceptance of the reality of prognosis.

8.3.1. Creating a balance between disclosing honest information and promoting hope

As reported in section 5.3.4, the findings of the current study show that mothers' hope helped them to cope with the prolonged suffering they experienced as a result of their children's illness. The mothers saw hope as an essential component of life, and they found it challenging to handle their suffering without any glimmer of hope. Health care providers concurred with the mothers by asserting the importance of providing parents with a certain amount of hope. Additionally, although all mothers realised that the possibility of a cure for their children was very low, they perceived hope as essential to help them to continue their life and to cope with the suffering they faced.

The current study provides the new insight that while mothers acknowledged that physicians provided them with honest information regarding their children's conditions, they also wanted doctors to adopt a sensitive and gradual manner when communicating with them. As highlighted in Section 5.3.1 and Section 5.3.2, mothers changed their opinions regarding the information they preferred to be given. Although at the point of the diagnosis of their children they insisted on knowing all of the possible information related to the long-term expectations for their children, some of them regretted this after suffering extreme reactions as a result of being given the information in a blunt, direct manner.

Although these findings are supported by a few studies (Contro et al., 2002; Inglin et al., 2011), Folkman (2010) argues that it is still not easy to define the boundaries between information which offers false reassurance and information which promote hope. When there is no hope for a cure, health professionals experience a tension between promoting open and honest communication with parents and families on one side, and fostering hope that may be unrealistic on the other (Smith, 2014). Additionally, some health care providers worried that the preservation of hope that the parents insisted on could motivate them to argue for continued aggressive treatment, which in turn might cause the patient further suffering (Keene Reder and Serwint, 2009; Baergen, 2006). Baergen (2006) affirms that one of the consequences of unrealistic hope is that parents can think that a cessation of treatment means that their children will receive no care. This brings worries about misunderstanding the terms 'care' and 'treatment', which result from a tendency to refer to medical treatment as medical care.

The current study suggests that doctors should adopt a gradual approach when they disclose unfavourable information to parents, in response to parents' wishes. In interviews with the physicians, a few of them stated that they learned from personal experience that providing unfavourable information to parents in a direct manner was undesirable for the majority of them, and was also responsible for causing serious emotional reactions in parents (see Section 5.3.2). At the same time, all of the physicians warned other doctors against hiding significant information from parents so as to avoid the pathological grief they could experience if the child's health were to suddenly deteriorate. They perceive this to have extremely negative consequences on families who are not prepared for it. The perspectives of physicians were congruent with the perspectives of a few mothers in the current study. The mothers of Rosol, Suha, Mousa, Issa, and Qusai expressed a preference to receive unfavourable information in a gradual rather than a direct manner, agreeing with the physicians' experiences. However, they also asserted their rights to receive detailed information about their children's health.

Nevertheless, Mack et al. (2006) found that parents were more optimistic than physicians about the likelihood of a cure. They argue that doctors could be partially responsible for the unrealistic expectations that parents hold about the cure of their children. In contrast, another study conducted by Salmon et al. (2012) states that the majority of parents focus on hope as a short-term measure, giving the physician authoritative responsibility for the child's long-term survival. However, in this latter study, parents also wanted their doctors to give them positive information regarding short-term progress, and furthermore wanted their physicians to cushion them from long-term uncertainties. These contradictory findings counter the criticism of oncologists about fostering unrealistic hopes in patients and families (Salmon et al., 2012). Instead, they could respond to the parents' preferences by not giving unfavourable information in a direct manner and providing the parents with continuous doses of hope using a positive approach. Like the majority of parents in the Salmon et al. (2012) study, parents in Ringner et al. (2011) wanted to receive positive information from health care professionals that supported their hopes. Parents wanted to hear that everything was going to be fine, even though they understood that it could not be promised.

Some of the cases in the current study support these assertions. For instance, Suha's mother was extremely upset by Nurse Asma who provided her with information about the low possibility of her daughter's survival. As Suha's mother had been focused on the short-term improvement in her daughter's health, she felt extremely pained when she was given negative long-term information about her daughter's health. If we think of levels of hope metaphorically as steps on a staircase, being given negative long-term news bluntly is akin to tumbling dangerously from the top. On the other hand, maintaining a gradual decline down the ladder of hope would enable Suha's mother to use it as a tool that allowed her to keep standing on one step as long as possible before descending to the next. The temporary stability mothers gain from maintaining hope might make it easier to help them cope with the next step in the situation, allowing preparations to enable them to face change. Previous studies (Eliott and Olver, 2007; Sloan, 2015) demarcate hope from denial, finding that parents do not deny reality, but rather engage with the illness in a manner that affirms life rather than denies death.

8.3.2. The tension between hope and acceptance of the reality of prognosis

As highlighted in Section 5.4. , Jordanian culture is derived from the Arab-Islamic culture. As communication is significantly affected by culture, it was important to clarify how culture (specifically faith) affected the perspectives of the study participants to hope. This study added a new insight, that the beliefs of the majority of carers about the meaning of the disease gave them a greater level of acceptance of the illness, and also helped them to promote the hope that the future would be better. The majority of mothers reported believing that the disease was a test by God to measure their patience and acceptance of the destiny of God, and they realised that their patience and tolerance for this suffering was a good sign that shows their strong faith.

Moreover, some carers were sure that God would compensate them for their suffering in different ways. For instance, their suffering could be offset by having their own good health, a good relationship with their husband, and being provided with other healthy children. At the same time, the mothers were able to maintain hope because of their Islamic belief that asks people to avoid hopelessness even in the most challenging circumstances, since God has the absolute power to change this, especially if they ask him. This study shows that mothers create a balance of accepting the disease and promoting hope, and this originates from their faith. Mothers did not feel any contradiction between these two issues, which significantly affected how they coped with their children's illnesses as well as their interaction with the health care providers.

Similarly, recent literature showed that there is no contradiction between hope and acceptance of the reality of prognosis (O'Brien, 2014; Keene Reder and Serwint, 2009). Although the parents' hopes for a cure alongside their awareness of the poor prognosis could be difficult to understand, this phenomenon is evident in the literature (Van der Geest et al., 2015b). In addition, parents who lost a child and had been hopeful of a cure, did not appear to suffer from traumatic grief or plunge into depression (Van der Geest et al., 2015b). This demonstrates that there is no necessary link between hoping for a cure and being unable to cope with death. This fits in with other findings that parents use hope as a coping mechanism by which they resolve the extreme stress they experience as a result of their children suffering from serious illnesses (O'Brien, 2014; Zelcer et al., 2010; Folkman, 2010). Parents in Zelcer et al. (2010) acknowledged that hope gave them, and their children, strength to face the suffering.

Further studies (Keene Reder and Serwint, 2009; Van der Geest et al., 2015b) explain that the different experiences of health professionals and parents regarding hope resolve the tension between hope and acceptance of the prognosis. Researchers such as Keene Reder and Serwint (2009) argue that bereaved parents and health professionals alike see hope as a survival mechanism when faced with a serious illness. However, health professionals add that they experience stress when trying to weigh up a need to keep hoping with the reality of a prognosis, while parents view themselves as protecting their children but also having hope for them. This difference in perspectives between professionals and parents could increase the gap between them, especially when bad news was being communicated. Keene Reder and Serwint (2009) therefore concluded that the parents' understanding of hope could be different from the way that health professionals perceive it: as an innate humanity, and a parenthood role, which is not connected with the prognosis of diseases. This is congruent with the findings of the current study; the mothers of Baraa, Hala, Suha, Qasim, Qusai, and Rosol all acknowledged the importance of staying hopeful about their children's health even though they understood the low possibilities of their children being cured. Almost all of the mothers that participated in the current study knew the prognosis of their children's illness and remained hopeful about it.

Mishel's theory of uncertainty in illness could be used to explain the difference in the dynamic of hope between health professionals and parents. According to the theory, the uncertainty of diagnosis could be evaluated as positive and negative based on the value placed upon uncertainty by the patient, their social resources, and health care providers (Mishel, 1990). Parents tend to perceive uncertainty as an opportunity, especially when the possibility of a cure is minimal. It is usually perceived to be better than the negative certainty of non-cure, as it holds the potential for better outcomes. This could explain the tendency of some mothers (e.g. Mousa's) to try and avoid receiving negative information from relatives and health professionals. Mothers tended to maintain their state of uncertainty as they felt it presented an alternative to the painful reality. This also explains the tendency to seek a second opinion (Section 7.2.3) as a way of looking for hope from other sources. Parents who search for a second opinion tend to benefit from the uncertainty, considering it to be an opportunity to find something other than the stark reality.

As Mishel's theory indicates, this is the illusion that tries to use uncertainty as a buffering strategy to cope with chronic illnesses and adapt to the situation. The health professionals, on the other hand, tend to view uncertainty as a danger, probably of abrupt shock to the parents if the child's condition suddenly deteriorates, or of staff feelings of medical failure or inadequacy. This results in expectations of a harmful outcome, which leads them to generate a coping mechanism to reduce the uncertainty. In the current study, health professionals such as Dr Raed, Dr Nihad, and Dr Asaad viewed uncertainty as a problem they faced when they communicated information about the prognosis of children’s health. The study findings show that a lack of confidence affects the physicians’ desire to provide parents with prognostic information. For example, Dr.Nihad and Dr Raed used a hesitant approach when they gave Hala and Amjad prognostic information so as to avoid providing their parents with false expectations that would affect the trusting relationship with them negatively (see Section 5.3.2).

Several doctors adapted to prognostic uncertainty by preparing parents for the worst, in order to avoid the sudden shock they would recieve if they were not prepared for unfavourable information. However, a few parents maintained the status quo by living with their children in the present and avoiding looking to the future, focusing on achieving short-term, rather than long-term, goals. In this way they considered prognostic uncertainty as an opportunity to live in the present without being disturbed by the painful certainty. In Kars et al. (2011) parents expressed this through their attempts to postpone grief as a way of living in the current moment with their children.

8.4. The degree of parental involvement in decision making

It is evident that physicians played significant roles in the process of decision making, even more than other parties, including parents (McKenna et al., 2010; Higgins, 2001). In the current study, a group of mothers (the mothers of Basil, Latifa, Sewar, Issa, Hala, Suha and Amjad) preferred to give the doctor the greater responsibility for determining major treatment options for their children. On the other hand, the mothers of Baraa and Qusai did not accept the doctors’ opinions in all situations; instead, they sought out other resources to get more information about some of the major decisions to decide the best course of action for their children. This was especially so when they had other children who had experienced treatment-related suffering. The rest of the mothers (Nagam, Rashad, Rosol, Mousa, Firas, and Qasim) reported mixed approaches ranging from adopting a passive role when deciding certain decisions to playing a major role in others.

Relatively similar findings were found by Higgins (2001), who described parents’ preferences for their roles in decision making related to cardiac transplantation. A few parents preferred being completely guided by physicians’ recommendations; one example was the father of an infant with hypoplastic left heart symptom. Considering the decision of leaving the infant without treatment (which indicates leaving the child to die within a few days) was difficult for him and his wife until the cardiologist helped them make the decision. However, some parents in the study also adopted autonomous decision-making behaviours, actively seeking participation in treatment decisions for their children. They had a logical mode of decision making, characterised by seeking information from several resources, weighing alternatives, trying to make the best decision for their children's status, and finally evaluating their decisions.

8.4.1.1. Factors that affected the degree of parental participation in decision-making

This study shows that there are several factors affecting the extent of parental involvement in the health decision of their children. Although these decisions are ultimately the responsibility of parents, as they are considered legally responsible for decisions related to their children's health, the parents displayed significant variability in the degree of their preferences for being involved in them (see Figure 14). A few mothers (e.g. Basil, Latifa, Sewar, Issa, Hala, Suha, and Amjad) gave the doctor a greater responsibility in the decision-making process. As highlighted in Section 6.3.1, the mothers of Qusai, Firas, Qasim, Asaad, Suha, and Issa trusted the doctor, as the main expert, to make these types of decisions. They also perceived themselves as lacking in the required medical knowledge to decide the best course for their children without the help of a doctor. This is supported by previous studies (Kilicarslan-Toruner and Akgun-Citak, 2013; Zwaanswijk et al., 2007). For instance, parents in Zwaanswijk et al. (2007) reported several factors that affected parental involvement such as the lack of knowledge about the illness and treatment, trusting physicians' experiences, practical circumstances, and having a certain condition, such as being very ill or depressed, that prohibited parents from being able to decide.

The current study adds that some parents reported that the feelings of guilt mothers might have as a result of taking certain decisions made the decision-making process more complicated. As reported in Section 6.3.1, to some extent, parents preferred to agree with doctors' opinions regarding the treatment options, so as to avoid the additional burden they might experience if the decisions had negative outcomes. Similar to previous work (Caeymaex et al., 2013; Caeymaex et al., 2011), this was especially so if the decisions were major and contrary to the physicians' opinions.

The parents who participated in the current study considered all treatment options that they thought might prolong their children's lives. The general principle the parents adopted was 'trying whatever is possible to preserve a child's life is better than nothing'. The literature reports similar findings (Carnevale et al., 2006; Kars et al., 2011; Kilicarslan-Toruner and Akgun-Citak, 2013; Young et al., 2002; Bluebond-Langner et al., 2007; Gurková et al., 2015). Gurková et al. (2015) found that parents and doctors did not hesitate to try experimental treatment when conventional treatments failed. One parent in this study asserted the importance of ensuring that they tried everything that could be done for their child. Moreover, Bluebond-Langner et al. (2007) found that none of the parents in their study (17 US, 17 UK) discontinued any supportive therapies, cancer therapies, or symptom-directed therapies. Parents in Bluebond-Langner et al. (2007) study felt that questioning the oncologists and asking for further scanning and treatment, as well as being in continuous contact with the oncologist, were essential parental roles they should perform. This is supported by the findings of Mack et al. (2008), in which several bereaved parents did not recommend the treatment of incurable cancer for other families despite their insistence that it be done for their children.

In addition to trusting the physician, it seems that the severity of the child's illnesses affected parental decision-making roles. As highlighted in Section 6.3.2, the mothers of Nagam, Mousa, Sewar, Qasim, Suha, and Baraa found themselves being compelled to choose some options related to certain treatments for their children as they did not have several alternatives. A few of them felt that if they refused care for their children it was as if they had left their children to die. Similar findings were shown in previous works (Carnevale et al., 2006; Gross and Howard, 2001; Kilicarslan-Toruner and Akgun-Citak, 2013; Pyke-Grimm et al., 2006), which demonstrated that the severity of the children's illnesses affected parental decision-making roles.

Moreover, the relationship with the doctor seemed to affect parental involvement in health-related decisions about their children. In (2006) , for example, (Pyke-Grimm et al.) investigated the views of 36 parents, whose children were suffering from cancer, in order to isolate what influenced the parents in making decisions about their children’s care. They discovered that the parents’ relationship with the doctor or doctors treating their children was key, as was the collaboration that existed between them. However, the findings of this study did not clarify the nature of the relationship between trusting the doctor and the extent of parental involvement in the decision-making process. In another study, Mack et al. (2011) found that where physicians supplied parents with good quality information and clear communication, this encourage parents to take the active role in decision making which they originally wanted to play. Where parents did not trust their physicians’ judgement, they were less likely to become involved in decision making than parents whose involvement in decision-making reflected their own wishes.

However, the current study showed contrary findings to this: mothers who trusted in their doctors’ ability participated less in the process of decision-making. For example, Firas’s mother agreed with the majority of the physician's decisions related to her son’s health as long as her child's condition was improving. However, she mentioned that if his condition did not improve, then she would take her child to another physician or seek another institution. Another example is Suha’s mother; she trusted her daughter's doctor, agreeing with almost all decisions regarding her daughter’s condition. She perceived Dr Majid to have the medical knowledge and experience, and did not trust in her own ability to decide in such situations. One explanation for these contradictory findings could be that mothers who did not trust their own knowledge tended to adopt a passive approach, preferring to leave the bulk of the responsibility to the doctors.On the other hand, parents who trusted their knowledge and who were aware of their role in the decision-making process were more likely to be involved in the decision-making process. Further studies are required to investigate this issue in further depth.

Financial considerations seemed to slightly affect parents’ decisions in regard to some treatment options and procedures. In the current study, although all children that participated in the study were covered by the health insurance policy that covers all Jordanian children, some parents felt unable to transfer their children to the private sector where they thought their children could receive a higher quality of health care. Some physicians (e.g. Drs Asaad and Nihad) reported that some parents went to the private sector for several months, but returned to the public sector because of the very high cost of going private. Similar findings are reported by (Kilicarslan-Toruner and Akgun-Citak, 2013); some health insurance policies covered certain health procedures but not others. This concerned parents when they were making decisions, as they considered some procedures and techniques to be based on the ability of the health insurance to pay.

8.4.1.2. Children's involvement in decision-making

The current study agrees with previous studies (Coyne, 2008; Coyne et al., 2014) that children are rarely involved in decision making, and also that they appear to be marginalised in health care decisions. During the observation period, it was clear that children were not involved in their own care, especially regarding the most important health decisions, such as major operations or main procedures. Both parents and health professionals in the current study perceived children to be unable to decide for themselves especially when the decision was considered to be life-saving or end of life. This is supported by (Vrakking et al., 2005; Coyne et al., 2014). In Coyne's et al. (2014) work, the indications were that children were not involved in major decisions including investigations, the decision to treat, and the administration of cancer therapy, as they were not able to refuse the treatment. However, they were involved in minor decisions (e.g. choices about care delivery), which helped in gaining their cooperation, building a trust relationship with them, making treatment more agreeable, and giving them a sense of control.

The current study had further shown that parents agreed with health professionals that children could not be involved with the major decisions. Children were perceived to lack the maturity to make these decisions. Coyne et al. (2014) found that children trusted the adults' decisions as they perceived their parents to be acting in their best interests and also felt that the health professionals were the experts. However, although adolescents accepted and trusted the adults' decisions, they stated preferences to be involved in the information sharing and the decision-making process. Nevertheless, in (Coyne et al., 2014) the children and parents were interviewed within a year of diagnosis, which limits our understanding of changes in the decision-making process over time. Therefore, a longitudinal study which examines shared decision-making and how it varies with time and different children's developmental stages could provide an extensive understanding of this process.

8.5. The effect of the uncertainty nature of non-malignant illnesses

In the current study, some mothers were unable to prepare for their children's death because of the uncertainty of their health conditions. The mothers of Baraa and Qasim had lost other children: Baraa's sister and three of Qasim's brothers died suddenly, and so their mothers were not able to spend their last days with them. The mothers did not prepare themselves or their children for death. Although some mothers became less strict with their children when they felt that they were no longer going to get better (such as Sewar and Qusai's mothers), other mothers (such as Baraa's mother) kept their children strictly to the treatment restrictions and diet regimen until the moment of death. For example, Areej (Baraa's sister) was not allowed to eat protein-containing foods even when she could see other children eating them.

Similar to these findings, Bužgová and Páleníková (2015) found that the carers of patients with non-cancer diseases could not identify a precise moment to make the final decision to terminate curative treatment. It took years until the final decision was made (Carnevale et al., 2006). However, contradictory findings were found in Kars et al. (2011), who investigated the experience of parenting a child with cancer throughout the end of life stage. Their findings showed that parents who were informed about the inevitability of the death of their children were more able to help their children to enjoy their lives. Evaluating enjoying life was based on positive normal activities such as cooking together, play time with friends and any specific activities which made each child feel happy. These contradictory findings could be explained by the nature of cancer illnesses having a more predictive nature than other life-limiting conditions. Because of this, parents could have a more precise estimation about their children's health progression, particularly in the end of life stage.

Bužgová and Páleníková (2015) point out that long-term illness with an unknown prognosis can make huge demands on families, who have to adapt to every change in the child’s condition and every deterioration. Diseases which are non-malignant do not run a predictable course, so parents’ reactions vary from optimism to slow acceptance that the disease is both progressive and incurable (Bužgová and Páleníková, 2015). The current study showed that a few mothers (e.g. Suha, Baraa, and Rashad’s mothers) were optimistic at the beginning of their children’s diagnosis especially when they were not provided with complete information regarding the severity of their children’s illnesses. However, they gradually came to understand the incurable nature of the diseases.

8.6. Challenges to effective communication

In this section, a few challenges to effective communication are discussed: the lack of clarity in the medical information that the mothers received from health professionals, the lack of supportive skills reported by nurses, and the moral distress and compassion fatigue experienced by nurses.

8.6.1. Lack of clarity

The current study shows that the medical jargon used by some physicians obfuscated the information on progress that parents received from health professionals. This is congruent with other studies (El Halal et al., 2013; Majdalani et al., 2014), in which parents reported that they had access to health professionals to question them about the condition of their children, but the medical language used by the staff affected their ability to understand. The current study expands this finding, showing that using medical jargon led some parents to retreat from active participation in medical decisions concerning their children. As some parents felt shy about asking their children’s physicians for further clarification of some concepts, they left the decision making to the other partner who had a better understanding of the jargon (see Section 7.2.1).

The current study also showed that the clinical setting in which the study was conducted significantly affected the nature of communication. Being an educational hospital, more attention could be given to students, which could have an indirect impact on the parents’ chances of receiving clear information from the health professionals. As discussed in Section 7.2.1, Nurse Nuha felt compassion toward Asaad's mother because she felt shy about asking the physician for further clarification during his discussion with medical students about the health of her son. Therefore, she asked the nurse later for further clarification.

This study has also found that all of the participants reported preferring to receive medical information from the specialist, who gained the trust of the majority of parents more than any other of the professionals. Some physicians and mothers thought that sensitive information should be given to the head of the medical team to communicate, because they had the authoritative responsibility. This might be encouraged by the prevailing culture that trusts specialists more than junior doctors and nurses. This chimes with prior studies in which physicians were perceived to be the preferred professionals to break bad news (Kastel et al., 2011; Soanes et al., 2009; Ringner et al., 2011; Seth, 2010), while the nurse has the role of interpreting (Ringner et al., 2011; Kastel et al., 2011; McGrath et al., 2007).

The current study also added that mothers preferred to receive sensitive information from the specialist responsible for their children's treatment, yet there were several factors that made them more likely to approach nurses rather than doctors. Nurses were more present than doctors and were also perceived to be more approachable and less aloof (due to their more frequent human contact with patients and families). As a result of this, nurses were exposed to the further pressure of questions from families.

The current study also revealed that parents faced the problem of receiving mixed messages from different health care professionals. This is congruent with (Contro et al., 2004), who found that families reported a desire to receive information, especially bad news, from familiar health professionals who would provide them with honest and clear information. In the current study, some of the parents reported receiving mixed messages from professionals, which increased their distress and confusion. The nature of the health setting could explain the increase in the delivery of mixed messages. A major educational teaching centre exposes parents to a large number of health care providers who are presented by the assigned specialist doctor, a few residents, fellows and the assigned nurses who are exchanged in three shifts, as well as a few medical and nursing students from more than one university. This means that one patient could encounter several healthcare providers, including students, on a daily basis. This is in addition to the parents of other children with the same disease.

Furthermore, this study has discovered that parents with a high level of trust in their knowledge about the illness of their children were less likely to be affected by receiving mixed messages, or to search for information from different resources. The opposite could also be true: many parents do not understand their child's condition, and those who are less able to read about the illness could be more easily confused by the multiple information strands they receive. This could contribute to their low trust in their own knowledge, and in turn they are likely to be more affected by the opinions of others they trust.

8.6.2. Moral distress experienced by nurses

The current study found that nurses were exposed to moral distress as a result of the extreme pressures they worked under. Nurses suffer moral distress when they are expected to act in a way which runs contrary to their beliefs (Jameton, 1984; Morgan, 2009). Another concept related to moral distress is moral dilemma. This refers to a situation in which important moral values are in conflict, and deciding on one option rules out the others (Jameton, 1984). As highlighted in Section 7.5.3, a few nurses stated that the high number of patients they are usually assigned negatively affected their way of communicating with them. This affected their ability to interact with parents according to what they believed to be ideal, thus intensifying their feeling of moral distress. Some other studies showed similar findings, reporting the effect of staffing levels on the quality of care for dying children and their families (Chen et al., 2013; Costello and Trinder-Brook, 2000; Davies et al., 2008; Kain, 2011; Papadatou et al., 2001). Some nurses felt frustrated as they did not find enough time to spend with the children and their families because they had too much work in their department (Costello and Trinder-Brook, 2000; Kain, 2011). However, other nurses appreciated ward work as a means of escape from what they considered to be a very stressful (bedside) situation (Costello and Trinder-Brook, 2000).

The current study found that some nurses experienced moral distress from becoming emotionally involved with children and families despite their belief that they should not do so. In spite of their realisation of the negative consequences of the emotional involvement of nurses, children, and parents at the time of separation, it was difficult for some of them to avoid their feelings towards the children. One issue that contributed to this emotional attachment between nurses and children was that the children, being chronic patients, were admitted to the same department on many occasions, thus allowing a connection to develop. As reported in Section 7.5.2, the nurses Faten, Alaa, Katia, Mona, and Asma found it difficult to avoid emotional distress over the death or deterioration of some children, and this affected their personal lives.

This finding is supported by Citak et al. (2013) who show that the second reason for conflict reported by nurses was their inability to maintain professional boundaries, due to the extended period that patients and their families stayed in the hospital. Consequently, the relationship between nurses and families, particularly the children's mothers, tended to shift in a non-professional direction. The current study extended these findings by revealing that work experience could have a significant effect on the nurses’ ability to adapt to emotional involvement with patients. Some nurses in the current study reported that they learned from experience how to become emotionally detached from the child and its family.

The study also revealed that the ability to control their feelings varied among nurses. Some of them felt unable to take control in this way, while others perceived themselves to more able. However, work experience seems to have a significant effect in either case. As reported in Section 5.2.6, a few nurses stated that their ability to keep professional boundaries developed over time. They described themselves as being fragile and significantly involved with children’s suffering at the start of their nursing career, but as they gained more experience, they perceived themselves to be better at controlling their feelings.

The current study added a new insight, showing a difference in the perspective of nurses and mothers regarding the degree of professional boundaries. On the one hand nurses thought that emotional detachment with children and parents was necessary to avoid involvement with children, and would therefore protect them from emotional distress. On the other hand, the mothers devalued this manner, considering it to be a mechanical way of interacting with their children. As highlighted in Section 7.3. , the mothers reported that they appreciated nurses who displayed sensitivity toward the suffering of parents and children and showed empathetic attitudes towards them. Baraa's mother indicated it to be important that nurses ask about their personal life in addition to the nursing care that they usually provide. The majority of mothers in this study stated a significant need to be heard and supported by health professionals. They criticised some nurses who focused only on their nursing tasks and avoided any other interactions with them.

It could also important to mention that while the complete detachment that some nurses tried to adopt with the children was undesirable for the parents and children; it was also undesirable for the nurses themselves. Although some nurses mentioned that they preferred to set strict professional boundaries with children in order to protect their private lives, other nurses criticised this approach, feeling that they should have a reasonable degree of emotional involvement with the children. Some nurses felt that complete detachment from the children made them guilty of having an indifferent attitude towards the children's suffering. The majority of them thought that a middle way was best.

8.6.3. Compassion fatigue experienced by nurses

According to Meadors and Lamson (2008), compassion fatigue is a concept that is directly related to nurses' engagements with individuals who have experienced trauma. The literature expresses the concept of compassion fatigue using synonyms such as secondary traumatic stress, vicarious traumatisation, or post-traumatic stress disorder. According to Robins et al. (2009), working with vulnerable people such as traumatically injured and dying children is a predisposing factor for secondary trauma[35] to be experienced by health care providers. The literature identifies several work-related triggers for compassion fatigue, for example, lack of support from management and work overload (Maytum et al., 2004). Personal triggers of

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[35] Secondary trauma is symptoms or emotional responses resulting from working with a traumatised person or persons.

compassion fatigue include crossing professional boundaries and having unrealistic expectations (Maytum et al., 2004).

The findings of the current study show that a few nurses (Samia, Rania, Alaa, Nancy, Aya, Katia, and Farah) reported that they emotionally struggled because of the frequent contact with children suffering from severe illnesses. The current study also supports the previous literature (Borhani et al., 2013; Contro et al., 2004; Costello and Trinder-Brook, 2000; Davies et al., 2008; Morgan, 2009; Papadatou et al., 2001; Patenaude, 2005; Price et al., 2013; Yam et al., 2001); as nurses felt themselves unable to help the children, feelings of helplessness and guilt, sadness and ambivalence were heightened. Nurses struggled to overcome the emotional suffering that resulted from the termination of the relationship with the infant and its parents after the infant’s death, so they tried to distance themselves emotionally from the parents and children. For example, they would try to keep themselves busy with physical care to minimise any social interaction or discussion about the infant’s condition with the parents.

The theory of the nurse as wounded healer (Conti-O'Hare, 2002) could provide a framework to explain the compassion fatigue experienced by nurses who work with children with life-limiting and life-threatening illnesses. The assumptions of this theory can also be used to resolve personal and/or professional pain resulting from such work. According to the theory, all human beings experience trauma in their lives. This trauma stems from recent events, and it can be sustained if the issues that stem from it are not resolved in an efficient manner; the trauma does not automatically resolve itself without intervention. However, if the previous trauma is dealt with effectively, the pain resulting from it will be consciously understood and processed and will not affect the care provided for others (Zerubavel and Wright, 2012). The previous trauma can be transformed efficiently through engaging in steps of reflection, which could help to understand its meaning. Eventually, these traumas can be transcended and transformed into something less harmful, which can lead to the therapeutic use of self in resolving the trauma. The process of healing involves moving from being 'walking wounded' [36] towards 'wounded healer' [37] (Conti-O'Hare, 2002). However, if the strategies employed to cope with the trauma are ineffective, the previous trauma could negatively affect the person's ability to provide optimal care for others.

This theory was used to explain some of the findings of the present study. Nurse Rania, for instance, has worked in the paediatric ICU for several years. She mentioned that her work with dying children negatively affected her private life. She reported becoming more suspicious about the health of her children as a result of her frequent contact with children with life-limiting illnesses. In the context of wounded healer theory, because she had been exposed to the previous trauma of caring for children who eventually died in the ICU department, nurse Rania had psychological trauma that seemed to be unresolved (walking wounded). Because she coped ineffectively with these traumas, she expressed negative reactions that were manifested by her extreme emotional distress, and which affected her personal life. Her work experiences affected her communication with her family, especially with her children; imagining that her son could be in the same position as the children on the ward was painful for her.

Additionally, being suspicious about transmitting these diseases to her children made her extremely fearful and anxious. Several triggers made Rania walking wounded rather than wounded healer: the extreme work pressure she was exposed in the ICU department and the loss of motivation from the administration. Her extremely high job dissatisfaction was exaggerated by the absence of self-reflection practice or peer support in the department – it could have been helpful for staff to share their experiences, and in turn this could help to eliminate their suffering. All of these triggers prevented nurse Rania from being able to recognise her previous trauma pain and then go on to transform and transcend it. This could have helped her to move from walking

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[36] Walking wounded: the nurse suffers a trauma and is unable to deal with it correctly; this destabilises nurses and weakens their coping mechanism, so they find themselves unable to cope well with the situation they are in (Conti-O'Hare, 2002).

[37] Wounded healer: the nurse uses self-examination and spiritual tools to process the trauma and learn from it. The healing process begins, and the nurse takes on board the experience of trauma and pain, in order to better help others going through the same emotions (Conti-O'Hare, 2002).

wounded to wounded healer. Other nurses who had severe trauma because of the death of children they were emotionally involved with also had the predisposition to be walking wounded, as they too lacked departmental support and were unable to express their emotions in the work environment. Like Rania, they were also exposed to extreme work pressures, which undermined their ability to provide the best health care they were capable of.

8.6.4. Lack of supportive skills

The majority of nurses paid significant attention to physical health care, but seemed to ignore emotional support for children and their mothers, especially for patients with difficult conditions, such as those who participated in this study. Some nurses perceived themselves to be lacking the knowledge and skills to provide this type of care for their patients. They suggested the provision of educational courses that would improve their skills in providing this kind of support. Additionally, some staff thought that the role of providing emotional support belongs to other health professionals, such as social workers.

Several studies report communication skills education needs for nurses working with children with palliative care needs and their families (Amery et al., 2010; Chen et al., 2013; Contro et al., 2004; Lee and Dupree, 2008; Papadatou and Bellali, 2002; Papadatou et al., 2001; Peng et al., 2013; Tubbs-Cooley et al., 2011). Nurses faced several challenges regarding communication with patients or their families, and in many situations found themselves being unprepared to act or behave in a proper manner. Nurses reported being at a loss for words especially when discussing prognosis issues with dying children and their families (Papadatou et al., 2001). They also described challenges responding to difficult questions by children, and conflicts with families.

A few studies highlighted a desire to acquire additional communication skills in order to help them to deal appropriately with situations such as informing families of sudden death, transition from curative to palliative care, and discussing ‘don’t resuscitate’ status (Citak et al., 2013; Papadatou et al., 2001; Patenaude, 2005; Yam et al., 2001). Nurses reported that they had inadequate helping skills, especially with terminally ill, depressed, and desperate patients, particularly because they did not know how to give hope to them. They felt de-motivated when children withdrew themselves from communication because of their depressed mood and avoided contact with health care providers (Citak et al., 2013). This finding has important implications for nurses' education, especially in difficult circumferences. The conclusion will expand upon this in further depth.

8.7. Conclusion

This study has found that there was a general tendency amongst all participants to exhibit mutual protection when they interacted with each other in the caring of children. There were several factors that promoted the maintenance of protection approach employed by the study participants. The uncertainty around children's illnesses prevented doctors from confirming the future progress of the conditions. Another factor that promoted protection was the parents' perceptions that their children were not cognitively able to understand issues related to death. The protective approach adopted by children and parents toward each other had adverse consequences on children as they were unable to discuss their anxieties and suffering.

Hope was important for mothers, who used it as a coping mechanism to adapt themselves to suffering. The mothers asserted their need to receive positive messages from the health professionals and avoid information which negatively affected their emotions. However, the perspective shifted from hope of a complete cure at the beginning of the diagnosis to that of having a high quality of life at the end of life stage. The difference in viewpoint between health professionals and parents about hope could contribute to the persistent tension between communicating honest information and hopeful information. While health professionals felt the inherent conflict in achieving this balance, the mothers felt that there was no contradiction between honesty and hope, considering hope to be important at any stage of the disease.

There were several factors that prevented parents from being involved in the process of decision making: the fear of future guilt, the severity of their children's disease, and the degree of trust in physicians. As much as parents trusted their children's doctor, they were passive about decisions concerning their children's treatments.

CHAPTER 9: CONCLUSION

9.1. Introduction

This chapter summarises the major findings of this study and demonstrates its contribution to the field of communication with children with palliative care needs. It is divided into three sections. The first section highlights the key contributions of the three study findings. The second outlines the study's implications for clinical practice, education, and future research. The last section focuses on the strengths and weaknesses of the study.

The aim of this study was to explore the experience of communication in the care of children with palliative care needs, from the perspective of family carers, physicians, and nurses and to identify the implications for interdisciplinary palliative care education and practice.

The study addresses the following research objectives:

- To investigate how nurses, family carers, and physicians communicate with each other in the context of the care of children with palliative care needs.
- To investigate what the participants perceive to be the elements of effective communication.
- To explore their experiences and respective roles in the communication process, both in terms of communication between one another and in relation to the children in their care.
- To explore the facilitators and challenges they describe in relation to achieving effective communication both in terms of communication between one another and with the children in their care.
- To identify the implications of the study for the education of nurses and physicians, and interdisciplinary palliative care practice.

This study was undertaken in a Jordanian hospital and focussed on three paediatric units. It uses a qualitative case study methodology. Each case study includes the child with palliative care needs, the most engaged family carer, and the physician and nurses. Data was collected in two ways: participant observation and semi-structured interviews with the family member, physician, and nurses. There were 15 cases in total. I conducted 60 interviews (with 15 mothers, 12 physicians and 21 nurses) over 197 observational hours. During the field work, I recorded field notes that included verbal and non-verbal interactions and conversations with study participants as well as the contextual components of the research settings.

Moreover, I was concerned with developing a reflexive analysis of my role in data collection and interpretation, and considered that as a part of the data. Analysis of the observational notes was ongoing, as this ensured that the subsequent interviews were used to best effect in addition to providing helpful directions related to the observations that followed. During the observations, I had naturally-occurring conversations with the mothers and the health care staff that participated in the study. This helped me to build rapport with the research participants and other hospital staff members, and provided me with essential background information on the hospital's policies.

The conversational field notes were taken directly after the conversation, and were maintained in a diary format for each case. Although unplanned, some joint interviews were conducted in addition to the individual interviews, as I sometimes faced unexpected events. For example, a few mothers wanted to conduct the interviews in the presence of their ill children or relatives such as husbands or other children. However, I asked for another individual interview when I felt that they had something that they were unable to say in the presence of their husbands and relatives. The participants were recruited after consideration of the well-established ethical issues of autonomy, beneficence, non-maleficence, justice, and self-determination.

Within-case and cross-case analysis was undertaken in accordance with Stake's (2006) recommendations. The within-case analysis focused on establishing the contextual background for every case; this was significant to protect the uniqueness of each case within its context and to be consistent with the case study approach. The within-case analysis was presented narratively for every case (see Appendix H). Then, cross-case analysis was undertaken to systematically extract the themes and subthemes of each case to identify similarities, differences, and contradictions. The cross-case analysis is summarised in chapters 5, 6, and 7.

9.2. Major contribution to existing research

The principal contributions of the study are summed up in the current chapter. The first area concerns the issue of mutual protection. The second area summarises the different stances and roles adopted by mothers as highlighted in Chapter 6. The third area summarises the main conclusions extracted from the challenges to effective communication as perceived by the study's participants.

9.2.1. The key contribution related to mutual protection

9.2.1.1. Mutual protection

The parents and health care providers adopted a protective approach when they communicated with each other about the children's care. The parents avoided disclosing information to the children about the severity of their illness to protect their feelings. This happened particularly in the initial stages of their illnesses as the parents wanted their children to resume their lives like other children. The health professionals maintained some professional boundaries when they cared for children to protect themselves any from emotionally demanding situations. The mothers described their children as feeling guilty and considering themselves responsible for their parents suffering. This was revealed by their crying when they saw their parents were upset. Some children protected their parents by avoiding any discussion of their conditions and diseases, while others tried to protect their parents by being more open with their friends and relatives and closed with their parents, especially their mothers.

This study supports the conclusions of previous research (Bluebond-Langner, 1978; Clarke et al., 2005; Goldman and Christie, 1993; Patenaude, 2005), which showed that some children had higher awareness about their illness than their parents expected. This was affected by several factors such as age, environment, their intelligence level, their hospital experience (from repeated admissions), and the level of socialisation.

9.2.1.2. Communicating bad news

All mothers stressed the importance of being provided with honest information about their children's health status. However, they also said that it was important for the health professionals to adopt a sensitive approach when delivering unfavourable news. The health professionals adopted a gradual manner when they informed the parents of bad news, to try and avoid the risk of anger or denial reactions. The study reveals the different techniques adopted by physicians to gradually inform parents of bad news: starting with the results of lab tests, which could reduce the emotional burden on the doctor and the parents; using a hesitant approach, especially when informing the parents of their future expectations of the child's health; focussing on short-term outcomes and avoiding long-term outcomes, especially when the disease was in the early stages with an unclear prognosis.

Some physicians adopted the depersonalisation technique; (see Section 5.3.3) as they thought that it could relieve the emotional suffering of the parents. However, other doctors warned that such techniques were harmful to the parents as they could mislead them or encourage denial and illusions regarding their child's health. To our knowledge, this is the first study to illustrate the phenomenon of depersonalisation and mention the possible advantages and disadvantages for parents.

9.2.1.3. Maintaining a balance between hope and honesty

The mothers employed hope as a coping mechanism when adapting to their children's illnesses. In their view, hope was critical to treatment as it helped them to stay committed to the treatment and protected them to some extent from the extreme emotional suffering that would occur if they lost hope. This study finds that using negative terms has extremely adverse effects on the parents' emotions. Hence, although the mothers asked the doctors to be as honest as they could, they still wanted the physicians to provide them with a positive message by communicating this information in a sensitive manner. The doctors tried to balance this by providing the mothers with short-term outcomes and not giving them too many details about their children's long-term prospects, especially when they had uncertain expectations about the progression of the children's diseases.

9.2.2. The key contributions related to mothers' communication experiences

9.2.2.1. Decision making

It was noted that the mothers who felt less confident about their knowledge of their children's health gave the physicians the main role in determining major treatment options. The underlying trust in physicians could play a significant role in the mothers adopting a passive role in decision making. However, some mothers played an active role in deciding which procedures their children would undergo by gathering comprehensive information from different resources and evaluating its suitability. Mothers who had previous experience, such as having had other children with the same condition, were more involved in the decision making, and their decisions were significantly affected by their previous experiences with their deceased children. Some mothers reported the difficulty of treatment decisions as another factor that made them defer to the doctor's suggestions. Some decisions could not be rejected as the other option was perceived as leaving the child to die. The feeling of 'future guilt' also reduced parental courage to independently make decisions for their children. Therefore, the parents accepted all medical procedures that could help the child to survive even if they knew it could not be helpful.

9.2.2.2. Giving a higher priority to the ill child

Most of the mothers insisted on accompanying their children for the majority of their time in hospital, especially when they were exposed to painful, invasive procedures. Some of them wanted to support their children with their presence, wanting to make their children feel that they were not alone. Other mothers felt selfish if they escaped from observing their children's suffering when they were exposed to intensive procedures. In addition, they refused the assistance of their relatives despite the heavy emotional and physical burden of the hospitalisation. The mothers prioritised caring for their ill children over their other responsibilities because of their fundamental need to care for children they perceived to be especially vulnerable. Some of them were afraid of future guilt, and wanted to do their best to help and relax their ill children.

9.2.2.3. The experience of having a second child with the same illness

Some mothers who had a second child with the same disease were stronger because the experience increased their ability to adapt themselves to the second situation. However, these mothers reported enormously painful experiences if they were admitted to the same room in which their previous child had been cared for. In addition, the second child was often treated by the same health professionals who had treated the deceased child. The mothers who had more than one child with the same illness had a tendency to dredge up unhappy memories, and some of them refused to talk with students who they expected to ask them to review the family history. The mothers avoided these kinds of discussions because of these painful memories, and also as a means of maintaining their strength in the face of the current situation. To our knowledge, this is the first study that examines the experience of having more than one child with a serious life-limiting illness and explains the negative and positive consequences of it.

9.2.3. The key contributions related to the challenges to effective communication:

9.2.3.1. Lack of clarity

As reported in Section 7.2. , there was a lack of clarity when communicating prognostic information between parents and health professionals. Several factors contributed to this, such as the staff using medical jargon or English. This study added a new insight; this problem may have caused some parents (e.g. Issa's father) to leave the responsibility of communicating with staff to other family members (such as mothers) because of their low confidence. This contributed to the adoption of a passive role in medical decision making about their children. Another factor that contributed to the lack of clarity shown in this study was the nature of the clinical setting in an educational hospital, which was perceived to change the focus from patients to students in some situations.

The lack of clarity led to frequent interruptions of the nurses' work by mothers asking questions. The nurses felt that answering the mother's questions was not their responsibility. This study suggests a new reason for the nurses' avoidance of mothers' questioning: their awareness of the risk of providing the mothers with an incorrect message about the doctors' treatment plans. Although all of the mothers preferred to receive prognostic information from the assigned specialist, they reported feeling that the nurses were more approachable than the doctors and tended to simplify medical concepts for them more than the doctors did. Therefore, they had the tendency to ask nurses more questions than doctors. In addition, the nurses reported being put under pressure by the questions they received from second or third-degree relatives of the children, who did not have the right to know any medical information about the child’s health. Another factor that contributed to the lack of clarity between parents and professionals was receiving mixed messages from different health care providers.

The frankness and flow of information between parents and physicians was hindered by some parents wanting to seek a second opinion and hiding it from the treating physician because they thought that it might offend or annoy them. Some doctors considered the desire for a second opinion to be a result of the denial reaction, while others felt disregarded by those families, with low trust. Some doctors gave the parents the names of other physicians in the same field in order to reduce their anxiety and to ensure the accuracy of the information they received. To our knowledge, this is the first time the issue of seeking second opinions was discussed and explained in a comprehensive manner (see Section 7.2.3).

9.2.3.2. Communication with children

The mothers reported facing some challenges as they cared for their children. They found themselves being unable to behave suitably when they faced difficult situations such as caring for their children when they were irritable from their illnesses or when they were found themselves unable to answer their children’s questions. This study expands on previous research findings that the majority of children who protected their parents by avoiding discussing sensitive issues were unable to consistently maintain this protection. Some of them lost their protective abilities in tough situations, and probably needed to discharge in this manner to relieve their suffering.

9.2.3.3. The perspectives of health professionals

A few physicians reported being blamed by some families for the failure of treatment, even though they said that they did their best to help the child to survive. The nurses reported enormous work pressure, which affected their ability to communicate effectively with children and parents. This pressure was attributable to the high number of patients assigned to each nurse, and the high turnover rate of nurses who were not replaced with new staff quickly enough. As well as this, some nurses reported the problem of working the night shift and holidays as another obstacle to effective communication with children and parents. They felt upset when they left their own children crying as they left their homes to come and work during the time they should have been spending with their families. A lack of motivation was another obstacle affecting the nurses' satisfaction. Finally, some nurses reported negative feelings when they felt that the families treated them differently to the doctors.

9.3. Practical implications

The findings of this study have several implications for clinical practice, education, and future research. This section will discuss several issues concerning talking about death, communicating bad news, decision making, providing emotional support for families, improving the work conditions of the health professionals, and the experience of having second children with the same illness.

9.3.1. Mutual protection

This study revealed that children were unable to communicate their intense feelings and hidden pain related to end of life issues because of their desire to protect their parents. The health care providers and some parents did not know about the children's suffering, which meant that many of them struggled to deal with the practical and psychosocial problems affecting the children. There was no emotional support or counselling service for either children or parents. The services provided for parents were also limited for the families who had socioeconomic problems. These findings therefore have several implications.

In the first instance, investigating the reasoning behind parents' decisions to talk (or not) to their children about death is a substantial issue. The findings of the current study indicate that while open and honest communication between parents and children is crucial, not all mothers agree with open communication about death with their children. Therefore, any future intervention planned for them should respect their autonomy and decisions. However, the role of health professionals could be significant, especially for parents who do not understand their children's level of awareness. Increasing the parents' awareness of their children’s protective approach and its consequences on their mental and psychological health could be one of the most important interventions to improve mutual communication between parents and children.

Second, as reported in Section 7.4.2, some mothers found themselves unable to answer their children’s difficult questions. Consequently, they preferred to protect their children instead of discussing their anxieties. This could indicate that the mothers’ lack of knowledge of how to act in such situations precipitated a flight response in order to avoid an emotional discussion. Professionals could play a significant role in supporting parents during the process of communicating sensitive issues to them. Parents should be prepared for the children’s emotional responses after discussing their situation. In Van Der Geest et al. (2015a), some parents regretted talking to their children about death as they found themselves unable to cope with their child’s reaction.

Third, the findings have significant implications for education. As several of the health professionals in this study underestimated the children’s ability to understand death, as discussed in Section 5.2.1, they supported the parents’ avoidance of such discussions with their children. This increased the parents’ tendency to avoid initiating open discussions with their children. The findings of the current study can inform the education of health professionals about the ability of children to understand death even if they prefer not to show it to their parents. In addition, health professionals reported a lack of supporting skills for parents during difficult situations, such as when they receive difficult questions from their children. Although a few health care providers said they had taken a course on how to improve communication with parents and families, they also mentioned that this course is not specific to children and parents with life-threatening and life-limiting conditions. They also reported needing more practical advice on how to deal with some difficult situations.

Finally, the study demonstrated that some mothers were being protected by their husbands and some medical professionals, who concealed significant information about their children’s progression, as discussed in Section 5.2.5. Some mothers experienced extreme suffering when they understood the non-verbal communications between the health professional and their husband. Knowing the reality of the situation was much easier for mothers than having the child’s condition hidden from them. Therefore, it could be significant to increase the fathers’ and professionals’ awareness of the probable negative consequences of concealing information from mothers.

9.3.2. Communicating bad news

The findings could inform education. Since physicians experience difficulty in balancing hope and honesty (Roberts et al., 2005), it could be crucial for the health professionals to distinguish between their perspective of hope and the parental perspective of hope. The findings show that while parents typically insist that they need to know all of the relevant information when their child is diagnosed, some regret knowing this painful information all at once and wish that it had been revealed gradually. This study shows that parent needs and information preferences can change over time, and this underlines the importance of continuously assessing their preferences for how much information they receive. This study suggests that consultants distinguish between their perspective of how much information parents should know and what parents actually prefer to know and their individual variations. This study suggests that consultants explicitly clarify parental preferences of the amount of information they wish to know, as well as a suitable time to receive this information.

9.3.3. Decision making

The findings of chapter six have significant implications for clinical practice. The parents’ experiences should be taken into consideration when the medical teams establish the children’s treatment plans. The parents’ experiences of their children’s care should be given more attention. Although the mothers had significant amounts of information relating to their children’s conditions, some of them had less confidence in independently deciding about their care. Therefore, health professionals could facilitate greater parental involvement in the decision-making process. Although the findings show that a few mothers preferred to give the responsibility for decision making to the physician, it is the responsibility of professionals to encourage parents to be an essential part of this process. This could be achieved by providing them with clear and comprehensive information about the health status of their children. In addition, nurses and physicians have a significant role to play in raising parental awareness of involving their children in the decision-making. The child's degree of involvement in the decision making process may vary due to several factors, such as the stage and seriousness of their illnesses and the types of decision being made. Therefore, the assessment of the level of their involvement should be an ongoing process (Coyne and Harder, 2011).

9.3.4. Providing emotional support for families

The mothers in the study talked about the intense emotional pain they experienced and the importance of emotional release such as crying and finding specialised professionals to give them support. The children who participated in the current study were treated in general paediatric wards, and this could undermine the health professionals' attention to the continuous emotional support parents and children need. The enormous amount of pressure that physicians and nurses are under, and the administrative focus on the physical part of medical care hindered the provision of emotional support to the mothers. Less attention was given to the emotional aspects of child illness and the suffering parents were exposed to.

As mentioned previously, palliative care in Jordan is only given to children with oncological diseases. However, families of children with life-limiting and life-threatening illnesses represent an important group which would benefit from the provisions of palliative care for many reasons. The chronic and unpredictable nature of their illnesses and the process of the families' adaptation is never finished (Bužgová and Páleníková, 2015). This could result in them being exposed to a severe crisis without a support system.

For the change to be effective, it should be on an organisational level rather than an individual one. The following suggestions are thought to improve the quality of care provided for these parents: continuous education for professionals, which provides staff with specialised communication skills and emotional support for children and parents; the hiring of other health professionals (such as social workers, clerks, and chaplains) who can provide emotional and spiritual support for parents in the different stages of the child's illness.

9.3.5. The experience of having a second child with the same illness

As reported in Section 6.6.2, the study found that mothers who had a deceased child with the same disease had an enormously negative emotional experience when they discovered that a second child also suffered from it. This negative experience was stimulated by being admitted to the same room in the hospital and/or being exposed to questioning by students and health professionals. Therefore, clinical practice could benefit from this finding by avoiding stimulating the painful memories of parents who had deceased children by avoiding admitting them to the same room as their previous child. This could help the parents to adapt to their children's illness. However, it is important to assess parental preferences before such intervention to account for individual differences among parents. Therefore, a clear discussion with parents who have a second child with the same illness, in order to understand their preferences regarding the medical environment and the medical teams they would like to treat their second child could significantly improve parental satisfaction with hospitalisation.

9.4. Future Research

The findings suggest further research on the following key areas would be beneficial: (1) the issue of children's awareness of death; (2) Follow up parental experiences after the children's death; (3) involving the fathers' experiences.

9.4.1. Children's awareness of death

The issue of children's awareness of death requires further investigation. Although the previous discussion about children's awareness of disease and end of life issues gives background information that explains the ways parents and health care providers communicate with the children, this knowledge was gained from secondary sources (mothers and HCPs). Interviewing the children themselves was beyond the scope of this study; I was unable to interview the children for several reasons, such as reducing the expected harm to them, especially if I was to discuss sensitive issues with them. The lack of clear ethical laws related to conducting research with children in Jordan prohibited me from giving further attention to this issue. I recommend research where the children are the primary resource, to collect more credible information on their awareness of death.

9.4.2. Follow up parental experiences after the death of the children.

A few studies (Kreicbergs et al., 2004; Van Der Geest et al., 2015a) investigated bereaved parents retrospectively to examine whether or not they talked/regretted talking with their children about death. This research provides us with some information about whether parents regret their decision to talk to their children about death, a long time after their children's death. The aforementioned studies, however, reflected contradictory findings. Kreicbergs et al. (2004) noted that the majority of parents who discussed death with their child believed it was a good decision. In contrast, 69 of the 258 parents questioned, who chose not to talk about death, subsequently regretted their decision. In the (Van Der Geest et al., 2015a) study, however, some parents did not feel positive about the conversation with their children about death. The parents mentioned that they experienced this negative feeling because of their children's emotional reactions. This contradictory finding calls for further qualitative studies (probably longitudinal in design) to investigate in depth the long-term parental effects resulting from their decision to talk or not to their children about death.

9.4.3. Involving fathers' experiences

The current study explored the communication phenomena from the perspectives of the mothers and health care providers. This was because of the mothers' availability as they were the ones that mainly accompanied their children in hospital. According to hospital policy, fathers are prohibited from accompanying their children in the hospital to protect the other mothers' privacy. Nevertheless, the fathers' experiences of communication with their children would triangulate the findings, and could provide other dimensions that expand on what is already known from this study. Hence, other studies that involve fathers could enrich the analysis of communication and complement the findings of this study.

9.5. Methodological Issues

9.5.1. Study strengths

The study is built on a qualitative case-study approach, which involved the study of cases within a real-life contemporary context or setting (Yin, 2009). Relying on only one source of data collection is not sufficient to develop an in-depth understanding (Creswell, 2013a). As this study employed observation in addition to the semi-structured interview, it accomplished an in-depth understanding of the communication phenomenon being studied. The contextual description of each case (see Appendix H) significantly enriched the analysis, which improved the understanding of each individual case (Creswell, 2007; Merriam, 1998).

This study has several strengths. Although it was conducted in one hospital, it is one of Jordan's major referral centres, and covers a wide area, even outside the capital city where it is located. Therefore, as reported in the methodology chapter, the children recruited in the study came from different geographical regions in Jordan. This improves the transferability of the findings to another setting. However, this hospital represents only one sector of the Jordanian health care system, which has four health care systems, as addressed in Section 3.4. The nature of the interaction is significantly different between the private sector and the public sector, due to the high cost of the private sector, which affects the socioeconomic level of the customers who seek its services. This limits the transferability of the findings to these health care sectors.

While other studies addressed the experiences of parents at certain stages of their children's illness, they did not address parental insight into their children's experiences in the long run. This study recruited children who were at different stages of their illnesses, as highlighted in the methodology section. Therefore, the study participants' experiences varied according to the different stages of the children's illnesses. Moreover, this study captured the different experiences of mothers in the long run as it recruited mothers with more than one child with the same illness. This gives further depth to their experiences and how their perceptions change over time.

Finally, the variability of the participants' ages, education, and socioeconomic levels resulted in more findings. In addition, the condition of the children was varied. Unlike previous studies that tended to investigate the experience of one class of disease, the cross-case analysis in this study depicts the shared experiences among different classes of children's diseases.

9.5.2. Study limitations

This study had several limitations that should be acknowledged. The period of observation varied significantly for each case study. I spent several weeks performing data collection for some cases (e.g. Rosol, Mousa, Sewar, Hala, Suha, and Baraa), which enabled me to collect rich information. However, in other case studies (e.g. Basil, Nagam, and Latifa) I spent a relatively short period observing them (a few hours) because of the difficulty of predicting the exact time of discharge, as well as some unexpected events, such as the death of Nagam (Case 3). Therefore, more attention was given to some case studies (e.g. Hala, Sewar, and Baraa) than others, which might result in shedding more light on some issues while neglecting others.

In addition, as participation in the study was voluntary, some participants may have contributed more than others due to their greater interest in it. Of the 20 mothers who were recruited, five refused to participate, and they could have different perspectives, which were not depicted in the study (see Section 3.6.1).

Moreover, I noted that some participants were uneasy about the presence of the recorder. Some of them mentioned issues after the recorder was turned off and I did not document this information, according to their requests. However, although I recognised that some participants were anxious about the presence of the recorder, it is hard to not record the interviews because of the need to give the participants my attention particularly to get their non-verbal communications. As the nature of the study requires me to ask questions based on the participants’ answers rather than a standardised structured interview, I needed to devote all of my attention to the participants, so as to ask the proper question in the proper manner.

Another limitation was that the observational data and interview data were sometimes contradictory. While the analysis stage was difficult for me because my interpretation and observations differed from the participants’ experience, I attempted to solve this problem by prioritising the participants themselves, as the aim of this study is to explore their experiences. However, I tried to acknowledge the contradictory findings by referring to the evidence and leaving the reader to accept whatever they think is more credible. Another problem was the differing perspectives between mothers and professionals on certain issues. Again, I acknowledge both perspectives leaving the reader to accept the interpretation they think is more comprehensive. This is congruent with the philosophical approach of interpretative constructivism I adopted for the current study, which acknowledges the presence of more than one reality based on different views and perspectives.

The participants, especially the doctors and the head nurse significantly changed some of their behaviours because they were being observed. Despite using several techniques to reduce the effect of my presence on the findings (Section 3.12.), this influence could not be completely eliminated. However, I felt that it did not significantly affect the findings, as I felt that the participants (especially the nurses and carers) behaved in a very natural way, particularly during the middle and end of the study, which indicates that trust had been built up with them.

Although the information was only collected by me, I tried to avoid transferring information between mothers and professionals to protect its confidentiality. I avoided discussing the experiences of mothers with professionals openly and investigated some aspects of their experiences in a general manner. Although this could prevent some participants being affected by the opinions of others, it could be regarded as a limitation that restricted my ability to investigate the individual cases with the professionals. I tried to solve this problem by investigating some aspects based on the aggregated analysis from the previous interviews that were conducted with the previous case studies.

Another limitation of the study was that I was unable to follow up with parents after the death of their children. Although one of the strengths of this study is using participant observation that captures current life events as well as the historical experiences gathered by interviewing participants, it did not capture the effect of the parents' decisions in the long run. However, the presence of some mothers who had more than one child with the same illness (such as Baraa and Qasim's mothers) facilitated the investigation of their experiences of their deceased children and thus their change of perception was examined. This was especially so when they compared how they were before the disease struck their children and their condition with the current children.

Finally, the study adopted a multiple case-study approach, aiming to provide a thorough understanding of profound experiences (Merriam, 1998; Stake, 1995; Stake, 2006; Yin, 2014). Consequently, the experiences gained from this study were not generalisable beyond the group of study participants from which the information was collected. However, using a collective case-study approach in which information was gathered from several sources of evidence (mothers and professionals) and using different ways of collecting data (participant observation, individual interviews, and joint interviews) allows the findings to be transferred to other mothers and professionals who care for ill children in the same context (see Transferability). In addition, although the sampling strategy adopted in this study was purposeful on the admission of children to the paediatric department, which limited my ability to use a maximum variability sampling technique, the analysis of the sample showed that the sample was diverse in several aspects, as the children's illnesses, ages, and the stage of their illnesses were all significantly varied. In addition, the mothers and professionals had diverse demographic characteristics, socio-economic status, age, education, and experiences. This improves the transferability to other settings with the same context.

9.6. Conclusion

To conclude, this study focuses on children who need palliative care and considers how physicians, nurses, and families communicate in these circumstances. The aim was to identify exemplars that can be used across a number of disciplines and improve palliative care and education. Communication is a spontaneous and continuous social interaction that needs to be observed as a process in the field rather than in isolated individual experiences. The existing literature addresses only one aspect of communication, such as the challenges of communication reported by nurses. Other studies address the parental perspectives of initial end of life care communication.

This study is unique as it applies a qualitative collective case-study approach that yields a rich and in-depth understanding of the experiences of communication from more than one perspective. It was underpinned by the interpretative constructivist approach that guided the analysis, and accepts more than one interpretation of reality as viewed by the participants.

Communication between the health care providers, parents, and children who participated in this study was dominated by mutual protection. It would also be helpful to include children's views, to get a clearer understanding of their perspectives and set these against a cultural and environmental backdrop. Disseminating these findings through their presentation in national and international conferences in addition to publication in a high-ranking journal will inform the healthcare system to change policies and health practices and education. The findings of this study will also inform the education of health professionals to increase the awareness of families to improve communication with their children.

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APPENDICES

Appendix A: Letter of ethical approval

وزارة الصحة
مستشفى الأمير حمزة بن الحسين

الرقم م ح٣/٣٢/٣٦١٢
التاريخ ....
الموافق ١٤/١٢/٢٠١٤

مديرة دائرة التمريض
مدير الدائرة الطبية

تحية طيبة وبعد ،،،

إشارة لاجتماع لجنة اخلاقيات المهنة في مستشفى الامير حمزة والمنعقد بتاريخ 14/ 12/ 2014 م فقد اطلعت اللجنة على البحث المقدم من طالبة دكتوراه : مها محمد وهبي يوسف عطعوط دراسه بعنوان :

Exploring the Process and Experience of Communication in the Care of Children with Palliative Care Needs: The Perspectives of Nurses , family carers and Physicians in Jordan

وبعد الدراسة المستفيضة حول هذا البحث قررت اللجنة الموافقة على إجراء الدراسة مع إطلاع اللجنة على النتائج قبل النشر .

للتكرم بالاطلاع وتسهيل مهمة الباحثين في إجراء البحث اعلاه .

وتفضلوا بقبول فائق الإحترام

مديرعام مستشفى الأمير حمزه

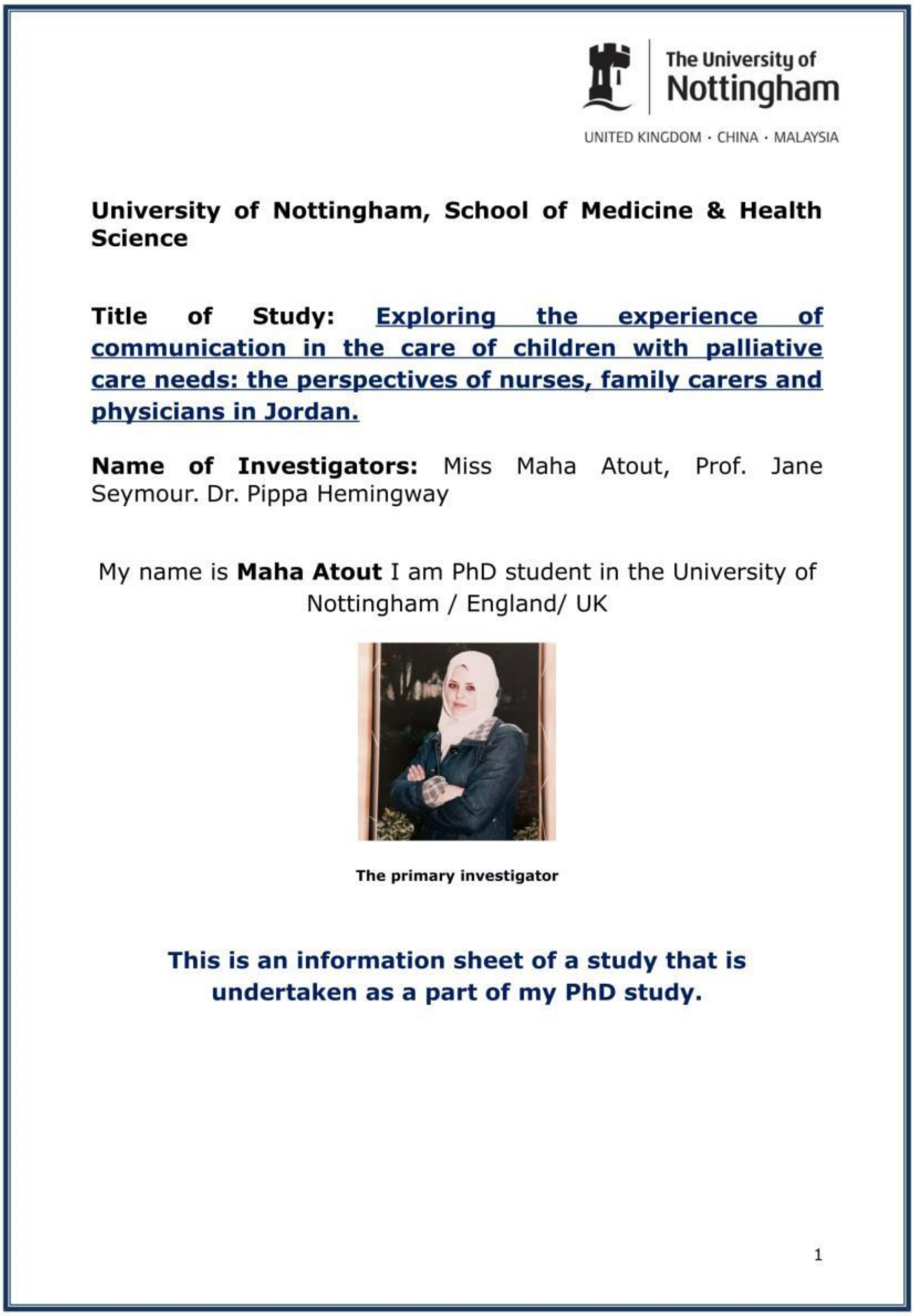
الدكتور مازن تقوى

د. [illegible] حمزة
[illegible]

نسخه :-
- عطوفة مكتب مدير عام
- الملف العام .
م.ا
14/ 12/ 2014

المملكة الأردنية الهاشمية
هاتف ٠٠٩٦٢٦٥٠٥٣٨٢٦ فاكس : ٠٠٩٦٢٦٥٠٥٣٧٩٠ الموقع الإلكتروني www.phh.gov.jo

Appendix B: Information sheet for family carer



The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

University of Nottingham, School of Medicine & Health Science

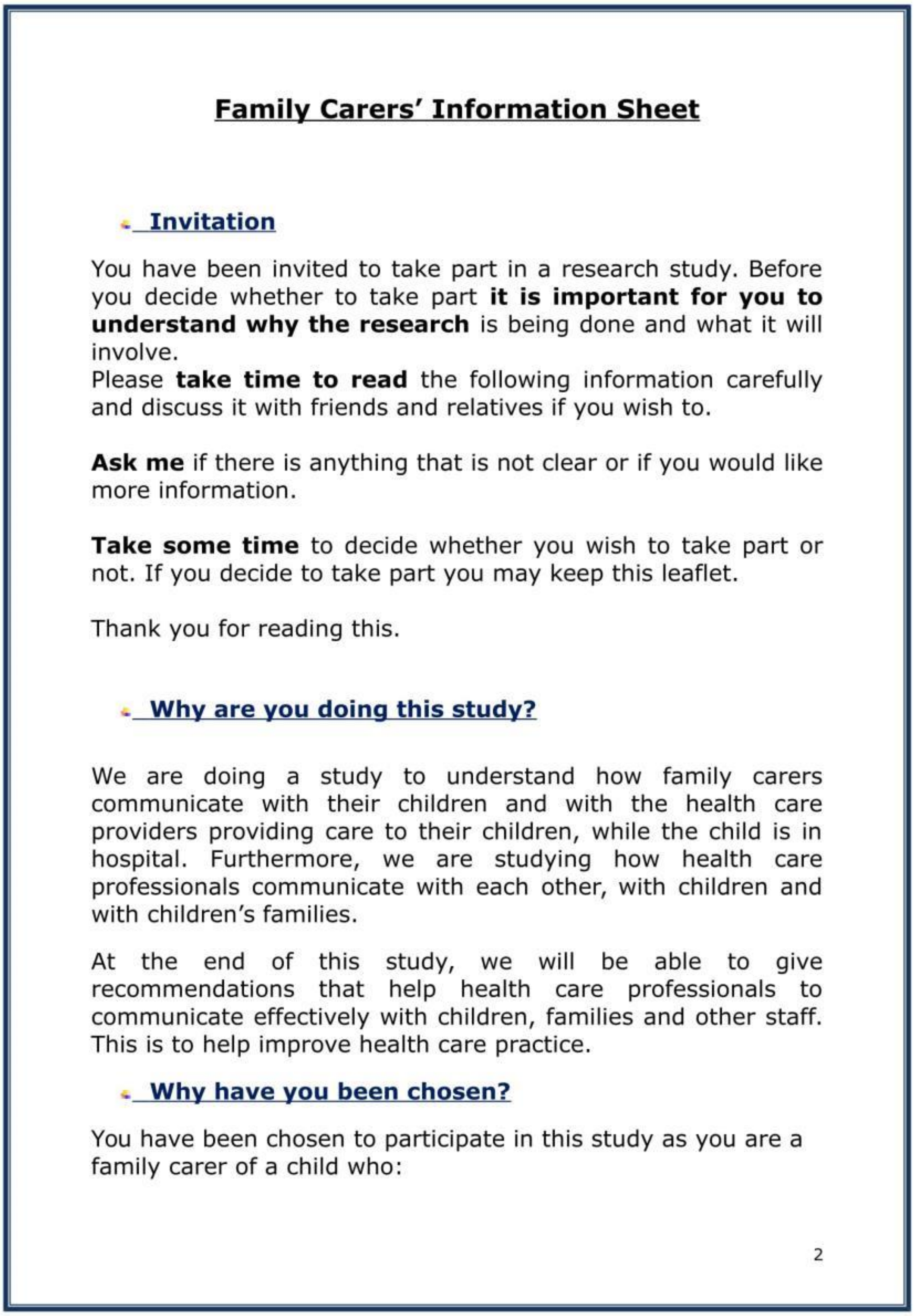
Title of Study: **Exploring the experience of communication in the care of children with palliative care needs: the perspectives of nurses, family carers and physicians in Jordan.**

Name of Investigators: Miss Maha Atout, Prof. Jane Seymour. Dr. Pippa Hemingway

My name is **Maha Atout** I am PhD student in the University of Nottingham / England/ UK

The primary investigator

This is an information sheet of a study that is undertaken as a part of my PhD study.



Family Carers' Information Sheet

Invitation

You have been invited to take part in a research study. Before you decide whether to take part **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 friends and relatives if you wish to.

Ask me if there is anything that is not clear or if you would like more information.

Take some time to decide whether you wish to take part or not. If you decide to take part you may keep this leaflet.

Thank you for reading this.

Why are you doing this study?

We are doing a study to understand how family carers communicate with their children and with the health care providers providing care to their children, while the child is in hospital. Furthermore, we are studying how health care professionals communicate with each other, with children and with children's families.

At the end of this study, we will be able to give recommendations that help health care professionals to communicate effectively with children, families and other staff. This is to help improve health care practice.

Why have you been chosen?

You have been chosen to participate in this study as you are a family carer of a child who:

2

• Aged between 1 – 12 years old
• Admitted to the University hospital as diagnosed with a condition that need for palliative care.

What is the meaning of palliative care?

Palliative care is a concept includes **providing total care** for patients who have condition that **could threaten their lives** or are chronic in nature, in order to **improve their quality of life**.

It includes giving support **for families** of the patients as well.

It focuses on treatment of **pain** and other **physical symptoms**, **psychosocial issues** (like worry and anxiety) and **spiritual** problems. .

What does this study involve?

This study focuses on **you as family carer** of a child patient who is in need for palliative care, and also on **nurses** and **physicians** who are responsible for providing care for your child.

We will **watch and observe** how you communicate with health care professionals who are involved in his/ her care.

We will also watch how health care professionals (nurses and physicians) who are responsible on the care of your child communicate with you and your child as well as how they communicate with each others.

In the beginning, I (Maha Atout) will start with a short period of observation in order to be familiar with you and your child's care and with the floor, and then I will start a longer period of observation which is likely to last between 1 to 4 weeks.

During observation, I will spend some times **talking and asking** questions for you and for your child's nurses and physicians and I will **take some notes** relating to the study.

At the end of the observation period or shortly afterwards, I will ask your permission to interview you about your experiences of care and communication in hospital using **recording device** to register the interview.

Note: I will not observe any personal care for your child and you have the right to ask me to leave the room or to stop doing the observation permanently without giving any reasons for that.

Where will the research take place?

The research will take place **in this hospital**. The researcher will **spend time with** you and your child as an observer while you are stay to hospital. And she wants to observe **nurses** and **physicians** during their work with you.

The **interviews** will be held in the hospital as well. You can choose the suitable place to be interviewed.

Do you have to take part?

No. It is up to you to decide whether or not to take part and this **will not affect** the treatment of your children at all.

If you decide to take part you are still free to withdraw at any time and without giving a reason.

What do I have to do?

If you accept taking part in the study, you will be asked to complete **a consent form** and to return it to the head nurse or to me.

Your **child's agreement** to being observed is important as well and they will be asked to provide this if they are old enough to do so, i.e. if their age is between 6- 12 years old.

At the end of observation, the researcher invite you to take part in an interview and will ask you for a suitable **appointment** and place for conducting individual interview, however, your child could be present during the interview.

You will be asked a few questions related to the main objective of the study (**see the discussion guide**) in order to be discussed during the session.

You could answer **what you think**; therefore, there is **no wrong or right answer**. The session will be recorded by recorder machine for the study purposes only.

What are the possible disadvantages and risks of taking part?

- In the beginning, you could be disturbed because of my presence. **If you do not like my presence**, you can ask me to stop observing me without giving any reasons.

- The interview could induce **painful experiences** and memories for you.

  If this happened, please ask the researcher to stop the interview. You can then think about whether you wish to continue or not.

What are the possible benefits of taking part?

No direct benefits for you by taking part in the study.

However, the result of this research will improve the quality of health practice regarding to improving communication between children patients, family carers and health care providers.

What if something goes wrong? / Who can I complain to?

In case you have any concerns of anything, you can initially approach the researcher **Maha Atout**, Phone No.
0798041583.
Email: ntxma15@nottingham.ac.uk

However, if you have further questions or complain, please contact **my main advisor** Professor Jane Seymour. (Do not worry about language, you can write in Arabic).

The following is her email address:

Email**:** Jane.seymour@nottingham.ac.uk

or you can contact the head nurse of paediatric units (sister Thanaa) as well.

Will my taking part in this study be kept confidential?

Yes. The confidentiality will be kept through:

- During observation and interview, I **will never** share your information with anybody except with my advisors for educational purposes. However, your identifying information will be removed and pseudonyms will be added instead.

- I will keep all information collected about you during research only on my personal computer and I will put password to protect them from being accessed by another persons.

- I will not write names of you or your family members on my notes

What happens if I want to stop participating in the study?

You are free to stop participating at any time without giving any reasons for that.

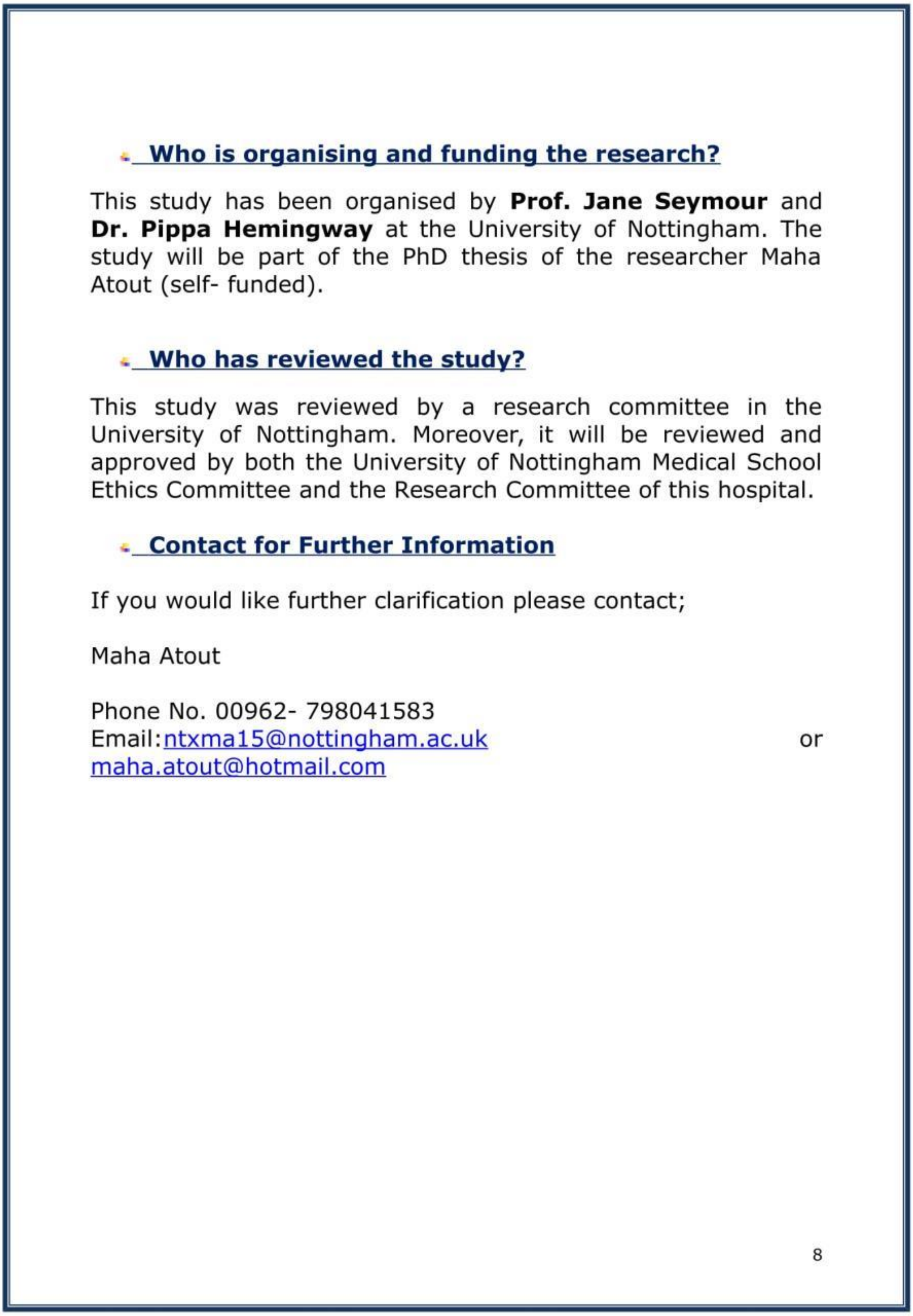
But it is difficult to remove the observational data that you have already been involved, and this could be used in the final analysis.
You can inform the researcher to stop from being observed in the future.

What will happen to the results of the research study?

- The research team intends to disseminate the results through presentations at **conferences** and through **publication.**

- The results of the study will also be made available to the **ethical committee in this hospital** in order to provide them with these data.

- If you like to **receive summary of the report**, you need to give the primary researcher (Maha Atout) your address details to send that to you when we finish the study.



Who is organising and funding the research?

This study has been organised by **Prof. Jane Seymour** and **Dr. Pippa Hemingway** at the University of Nottingham. The study will be part of the PhD thesis of the researcher Maha Atout (self- funded).

Who has reviewed the study?

This study was reviewed by a research committee in the University of Nottingham. Moreover, it will be reviewed and approved by both the University of Nottingham Medical School Ethics Committee and the Research Committee of this hospital.

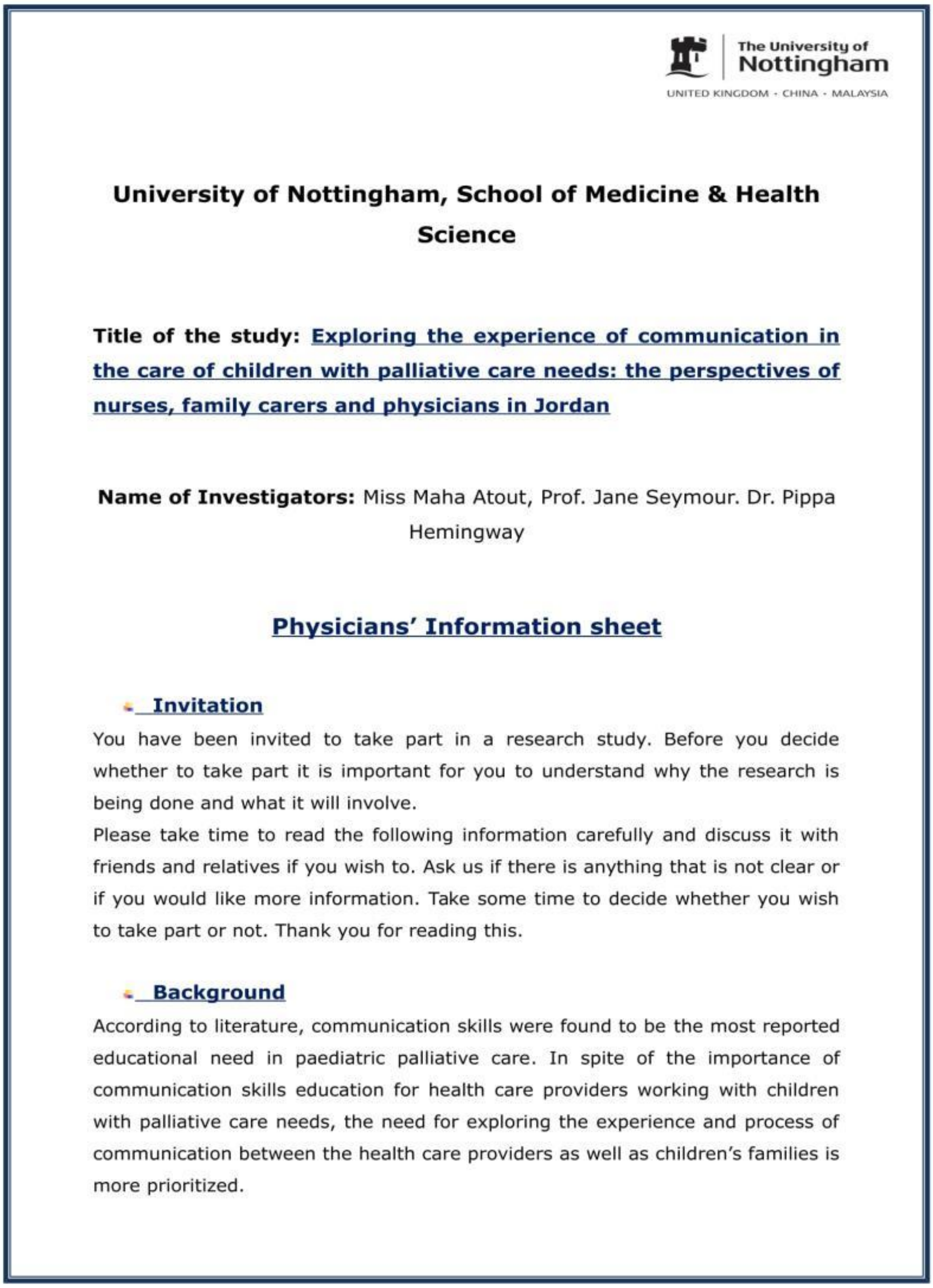
Contact for Further Information

If you would like further clarification please contact;

Maha Atout

Phone No. 00962- 798041583
Email:ntxma15@nottingham.ac.uk or
maha.atout@hotmail.com

Appendix C: Information sheet for physicians



The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

University of Nottingham, School of Medicine & Health Science

Title of the study: **Exploring the experience of communication in the care of children with palliative care needs: the perspectives of nurses, family carers and physicians in Jordan**

Name of Investigators: Miss Maha Atout, Prof. Jane Seymour. Dr. Pippa Hemingway

Physicians' Information sheet

Invitation

You have been invited to take part in a research study. Before you decide whether to take part 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 friends and relatives if you wish to. Ask us if there is anything that is not clear or if you would like more information. Take some time to decide whether you wish to take part or not. Thank you for reading this.

Background

According to literature, communication skills were found to be the most reported educational need in paediatric palliative care. In spite of the importance of communication skills education for health care providers working with children with palliative care needs, the need for exploring the experience and process of communication between the health care providers as well as children's families is more prioritized.

It is important to investigate phenomena related to communication within hospitals from multiple perspectives, due to the fact that modern care is provided by multidisciplinary teams of health care providers, and it also involves patients themselves and their relatives. However, there has been little research into the experience of communication from different perspectives. This study will be the first to shed light on communication experience from the perspectives of Jordanian nurses, physicians and family carers, which supports the need for the current study.

What does the study involve?

You are being asked to take part in this study which will be started with a preliminary period of observation for child with palliative care needs, his/ her family carer, the most involved physician and you as the most involved nurse perceived by parents of the child.

The observation will focus on the communication phenomena in paediatric palliative care which includes your communication with your colleagues and other health care professionals as well as your communication with the child who has palliative care needs and his/ her family. The observation period could last a period of (1- 4) weeks for every case.

The researcher could attend some of your interviews and consultations with patients. During the observation, there will be some informal conversations which will be documented as a part of field notes (not compulsory). At the end of the observation period for every case or shortly afterwards, tape recorded interviews will be arranged in order to undertake a more formal semi-structured interview with you.

Why have you been chosen?

You have been identified by the parents of children who have palliative care needs as you are the most involved physician with the care of their children.

Do you have to take part?

It is up to you to decide whether or not to take part. You are under no obligation to take part. Your participation/non-participation will not affect your profession state in any way. If you do decide to take part you will be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. Any data collected from you will be anonymized and coded before analysis.

What do I have to do?

- If you agree to take part in the study, you will be asked in the first instance to complete **a consent form**.
- Furthermore, at the end of the observational period (1-4 weeks), the researcher will invite you to take part in **an interview** and will ask you for a suitable appointment and place for conducting individual interview. You will be asked a few questions related to the main objective of the study (see the discussion guide) in order to be discussed during the session. You could answer what you think and discuss other opinions with the groups. There is no wrong or right answer. The session will be recorded by recorder machine for the study purposes only.

What are the possible benefits of taking part?

No direct benefits for you by taking part in the study.

However, the result of this research will improve the quality of health practice regarding to improving communication between children patients, family carers and health care providers.

What are the possible disadvantages and risks of taking part?

- In the beginning, you could be disturbed because of my presence. If you do not like my presence, you can ask me to stop observing you without giving any reasons.
- The interview could induce painful experience and memories that stimulate pain and sadness feeling for you, you could ask the researcher to stop the interview to find possible solutions to relief your pain such as giving you proper time to regain your control and keep in touch with you through calls or refer them to a suitable counselling service.
- It is important to note that this study does not focus on making assessments of your clinical practice but it focuses on communication with child patient and his/ her family.

What happens if I don't want to carry on with the study?

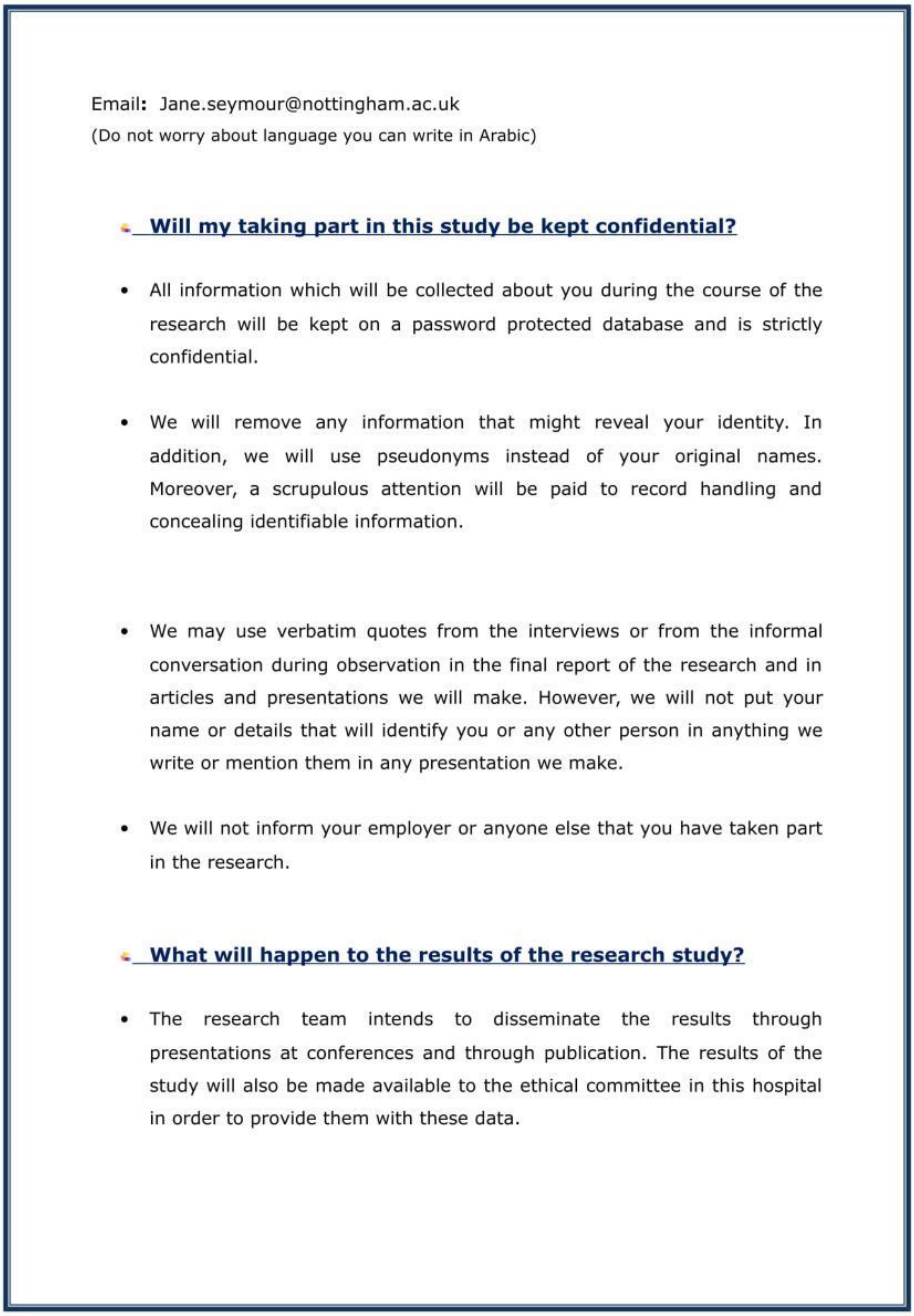
Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your professional status being affected. However, **it is difficult to remove the data that you have already been involved, and this could be used in the final analysis.**

You can inform the researcher to stop from being observed **in the future.**

What if something goes wrong? / Who can I complain to?

In case you have any concerns about anything to do with the study, you can initially approach the researcher Maha Atout, Phone No. 00962- 798041583
Email: ntxma15@nottingham.ac.uk

However, if you have further questions or complain, please contact my main advisor Professor Jane Seymour.
The following is her email address:



Email: Jane.seymour@nottingham.ac.uk
(Do not worry about language you can write in Arabic)

Will my taking part in this study be kept confidential?

- All information which will be collected about you during the course of the research will be kept on a password protected database and is strictly confidential.
- We will remove any information that might reveal your identity. In addition, we will use pseudonyms instead of your original names. Moreover, a scrupulous attention will be paid to record handling and concealing identifiable information.
- We may use verbatim quotes from the interviews or from the informal conversation during observation in the final report of the research and in articles and presentations we will make. However, we will not put your name or details that will identify you or any other person in anything we write or mention them in any presentation we make.
- We will not inform your employer or anyone else that you have taken part in the research.

What will happen to the results of the research study?

- The research team intends to disseminate the results through presentations at conferences and through publication. The results of the study will also be made available to the ethical committee in this hospital in order to provide them with these data.

- If you like to receive summary of the report, you need to give the primary researcher (Maha Atout) your address details to send that to you when we finish the study.

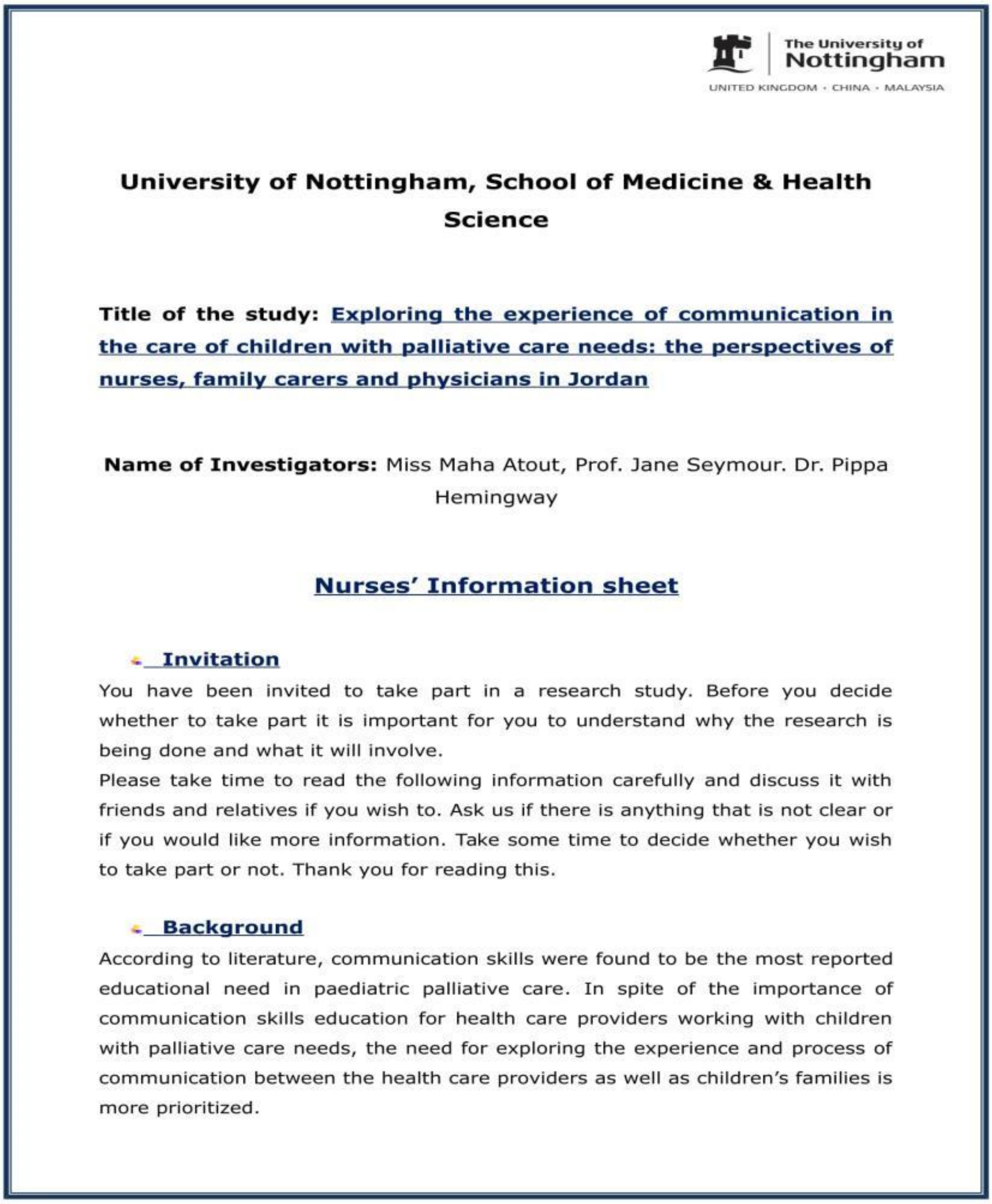
Who is organising and funding the research?

This study has been organised by Prof. Jane Seymour and Dr. Pippa Hemingway at the University of Nottingham. The study will be part of the PhD thesis of the researcher Maha Atout (self- funded).

Who has reviewed the study?

This study was reviewed by a research committee in the University of Nottingham. Moreover, it will be reviewed and approved by both the University of Nottingham Medical School Ethics Committee and the Research Committee of this Hospital.

Appendix D: Information sheet for nurses



The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

University of Nottingham, School of Medicine & Health Science

Title of the study: **Exploring the experience of communication in the care of children with palliative care needs: the perspectives of nurses, family carers and physicians in Jordan**

Name of Investigators: Miss Maha Atout, Prof. Jane Seymour. Dr. Pippa Hemingway

Nurses' Information sheet

Invitation

You have been invited to take part in a research study. Before you decide whether to take part 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 friends and relatives if you wish to. Ask us if there is anything that is not clear or if you would like more information. Take some time to decide whether you wish to take part or not. Thank you for reading this.

Background

According to literature, communication skills were found to be the most reported educational need in paediatric palliative care. In spite of the importance of communication skills education for health care providers working with children with palliative care needs, the need for exploring the experience and process of communication between the health care providers as well as children's families is more prioritized.

It is important to investigate phenomena related to communication within hospitals from multiple perspectives, due to the fact that modern care is provided by multidisciplinary teams of health care providers, and it also involves patients themselves and their relatives. However, there has been little research into the experience of communication from different perspectives. This study will be the first to shed light on communication experience from the perspectives of Jordanian nurses, physicians and family carers, which supports the need for the current study.

What does the study involve?

You are being asked to take part in this study which will be started with a preliminary period of observation for child with palliative care needs, his/ her family carer, the most involved physician and you as the most involved nurse perceived by parents of the child.

The observation will focus on the communication phenomena in paediatric palliative care which includes your communication with your colleagues and other health care professionals as well as your communication with the child who has palliative care needs and his/ her family. The observation period could last a period of (1- 4) weeks for every case.

I will help you through participating in simple nursing assistant activities such as bed making (i.e. assuming the role of an aide nurse) as well as through accompanying the assigned nurse while you provide nursing care.

During the observation, there will be some informal conversations which will be documented as a part of field notes (not compulsory). At the end of the observation period I will invite you to take part in an individual interview and will ask you for a suitable appointment and place for conducting tape recorded interview.

Why have you been chosen?

You have been identified by the parents of children with palliative care needs as you are the most included nurse with the care of their children.

Do you have to take part?

It is up to you to decide whether or not to take part. You are under no obligation to take part. Your participation/non-participation will not affect your profession state in any way. If you do decide to take part you will be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. Any data collected from you will be anonymized and coded before analysis.

What do I have to do?

- If you agree to take part in the study, you will be asked in the first instance to complete **a consent form**.
- The researcher will participate in simple nursing assistant activities such as bed making (i.e. assuming the role of an aide nurse) as well as **through accompanying you** while you provide nursing care.
- Furthermore, at the end of the observational period (1-4 weeks), the researcher will invite you to take part in **an interview** and will ask you for a suitable appointment and place for conducting individual interview. You will be asked a few questions related to the main objective of the study (see the discussion guide) in order to be discussed during the session. You could answer what you think and discuss other opinions with the groups. There is no wrong or right answer. The session will be recorded by recorder machine for the study purposes only.

What are the possible benefits of taking part?

No direct benefits for you by taking part in the study.

However, the result of this research will improve the quality of health practice regarding to improving communication between children patients, family carers and health care providers.

What are the possible disadvantages and risks of taking part?

- In the beginning, you could be disturbed because of my presence. If you do not like my presence, you can ask me to stop observing you without giving any reasons.
- The interview could induce painful experience and memories that stimulate pain and sadness feeling for you, you could ask the researcher to stop the interview to find possible solutions to relief your pain such as giving you proper time to regain your control and keep in touch with you through calls or refer them to a suitable counselling service.
- It is important to note that this study does not focus on making assessments of your clinical practice but it focuses on communication with child patient and his/ her family. **However, the researcher still has the duty to report any poor practice she observes to the head nurse.**

What happens if I don't want to carry on with the study?

Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your professional status being affected. However, **it is difficult to remove the data that you have already been involved, and this could be used in the final analysis.**

You can inform the researcher to stop from being observed **in the future.**

What if something goes wrong? / Who can I complain to?

In case you have any concerns about anything to do with the study, you can initially approach the researcher Maha Atout, Phone No. 00962- 798041583
Email: ntxma15@nottingham.ac.uk

However, if you have further questions or complain, please contact my main advisor Professor Jane Seymour.

The following is her email address:

Email**:** Jane.seymour@nottingham.ac.uk

(do not worry about language you can write in Arabic)

Will my taking part in this study be kept confidential?

- All information which will be collected about you during the course of the research will be kept on a password protected database and is strictly confidential.

- We will remove any information that might reveal your identity. In addition, we will use pseudonyms instead of your original names. Moreover, a scrupulous attention will be paid to record handling and concealing identifiable information.

- We may use verbatim quotes from the interviews or from the informal conversation during observation in the final report of the research and in articles and presentations we will make. However, we will not put your name or details that will identify you or any other person in anything we write or mention them in any presentation we make.

- We will not inform your employer or anyone else that you have taken part in the research.

What will happen to the results of the research study?

- The research team intends to disseminate the results through presentations at conferences and through publication. The results of the study will also be made available to the ethical committee in this hospital in order to provide them with these data.

- If you like to receive summary of the report, you need to give the primary researcher (Maha Atout) your address details to send that to you when we finish the study.

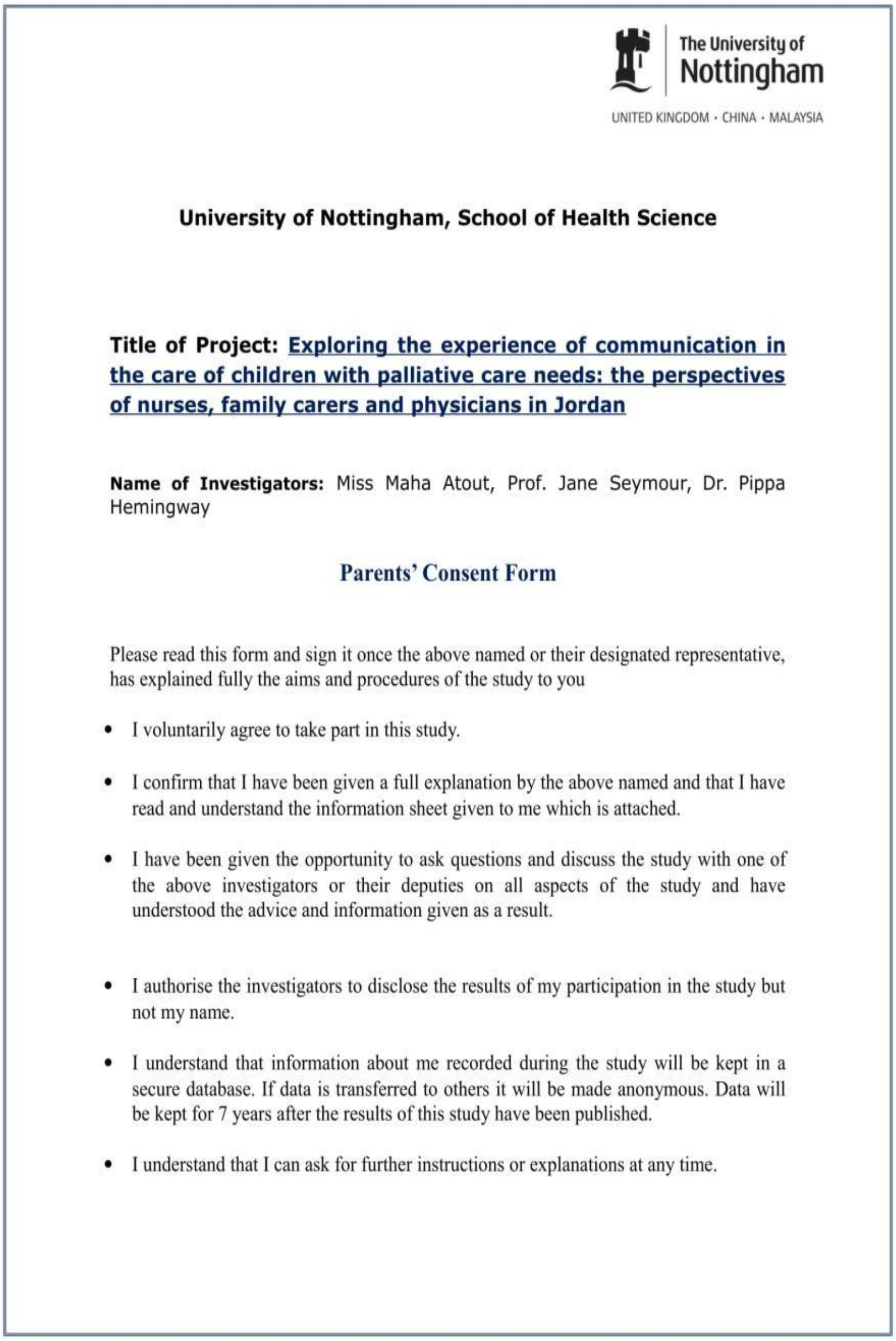
Who is organising and funding the research?

This study has been organised by Prof. Jane Seymour and Dr. Pippa Hemingway at the University of Nottingham. The study will be part of the PhD thesis of the researcher Maha Atout (self- funded).

Who has reviewed the study?

This study was reviewed by a research committee in the University of Nottingham. Moreover, it will be reviewed and approved by both the University of Nottingham Medical School Ethics Committee and the Research Committee of this Hospital.

Appendix E: Parents’ consent form



The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

University of Nottingham, School of Health Science

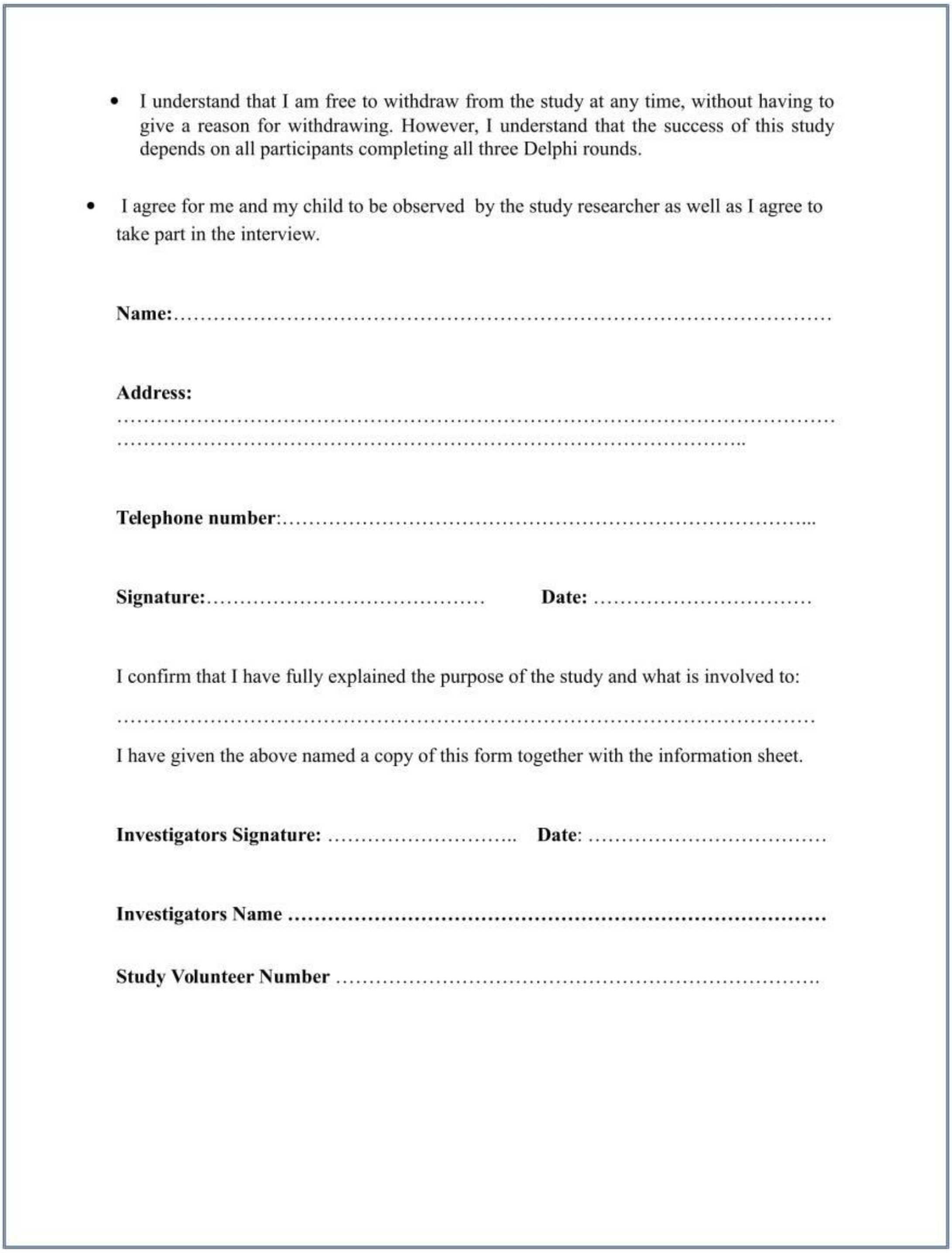
Title of Project: Exploring the experience of communication in the care of children with palliative care needs: the perspectives of nurses, family carers and physicians in Jordan

Name of Investigators: Miss Maha Atout, Prof. Jane Seymour, Dr. Pippa Hemingway

Parents’ Consent Form

Please read this form and sign it once the above named or their designated representative, has explained fully the aims and procedures of the study to you

- I voluntarily agree to take part in this study.
- I confirm that I have been given a full explanation by the above named and that I have read and understand the information sheet given to me which is attached.
- I have been given the opportunity to ask questions and discuss the study with one of the above investigators or their deputies on all aspects of the study and have understood the advice and information given as a result.
- I authorise the investigators to disclose the results of my participation in the study but not my name.
- I understand that information about me recorded during the study will be kept in a secure database. If data is transferred to others it will be made anonymous. Data will be kept for 7 years after the results of this study have been published.
- I understand that I can ask for further instructions or explanations at any time.



- I understand that I am free to withdraw from the study at any time, without having to give a reason for withdrawing. However, I understand that the success of this study depends on all participants completing all three Delphi rounds.

- I agree for me and my child to be observed by the study researcher as well as I agree to take part in the interview.

Name:……………………………………………………………………………………

Address:
………………………………………………………………………………………………
……………………………………………………………………………………..

Telephone number:…………………………………………………………………...

Signature:…………………………………… **Date:** ……………………………

I confirm that I have fully explained the purpose of the study and what is involved to:

………………………………………………………………………………………………

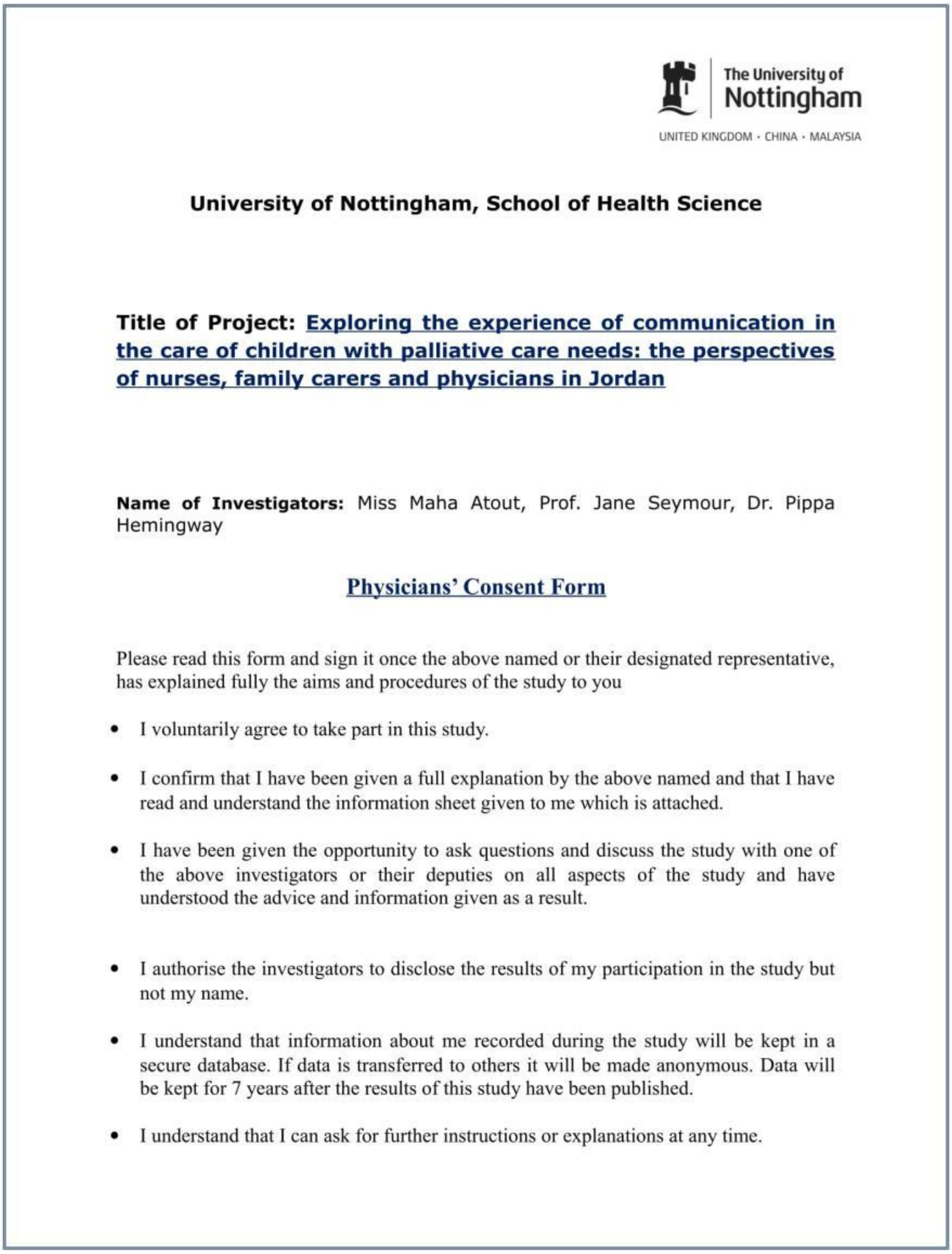
I have given the above named a copy of this form together with the information sheet.

Investigators Signature: ……………………….. **Date**: ………………………………

Investigators Name ……………………………………………………………………

Study Volunteer Number ……………………………………………………………

Appendix F: Physicians' Consent Form



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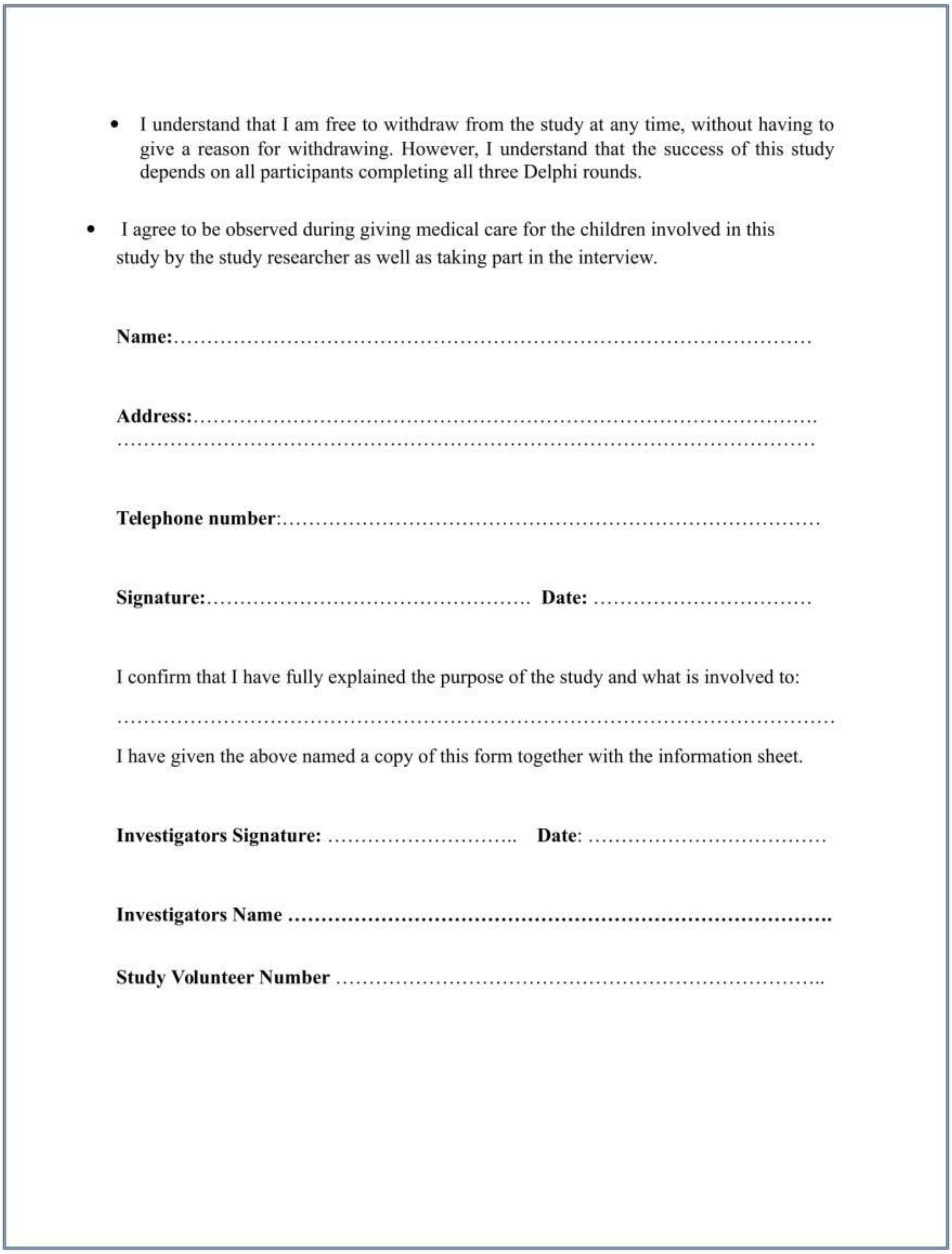
Title of Project: Exploring the experience of communication in the care of children with palliative care needs: the perspectives of nurses, family carers and physicians in Jordan

Name of Investigators: Miss Maha Atout, Prof. Jane Seymour, Dr. Pippa Hemingway

Physicians' Consent Form

Please read this form and sign it once the above named or their designated representative, has explained fully the aims and procedures of the study to you

- I voluntarily agree to take part in this study.
- I confirm that I have been given a full explanation by the above named and that I have read and understand the information sheet given to me which is attached.
- I have been given the opportunity to ask questions and discuss the study with one of the above investigators or their deputies on all aspects of the study and have understood the advice and information given as a result.
- I authorise the investigators to disclose the results of my participation in the study but not my name.
- I understand that information about me recorded during the study will be kept in a secure database. If data is transferred to others it will be made anonymous. Data will be kept for 7 years after the results of this study have been published.
- I understand that I can ask for further instructions or explanations at any time.



- I understand that I am free to withdraw from the study at any time, without having to give a reason for withdrawing. However, I understand that the success of this study depends on all participants completing all three Delphi rounds.

- I agree to be observed during giving medical care for the children involved in this study by the study researcher as well as taking part in the interview.

Name:……………………………………………………………………………………

Address:…………………………………………………………………………………….
…………………………………………………………………………………………………

Telephone number:………………………………………………………………………

Signature:…………………………………………. **Date:** ……………………………

I confirm that I have fully explained the purpose of the study and what is involved to:

…………………………………………………………………………………………………

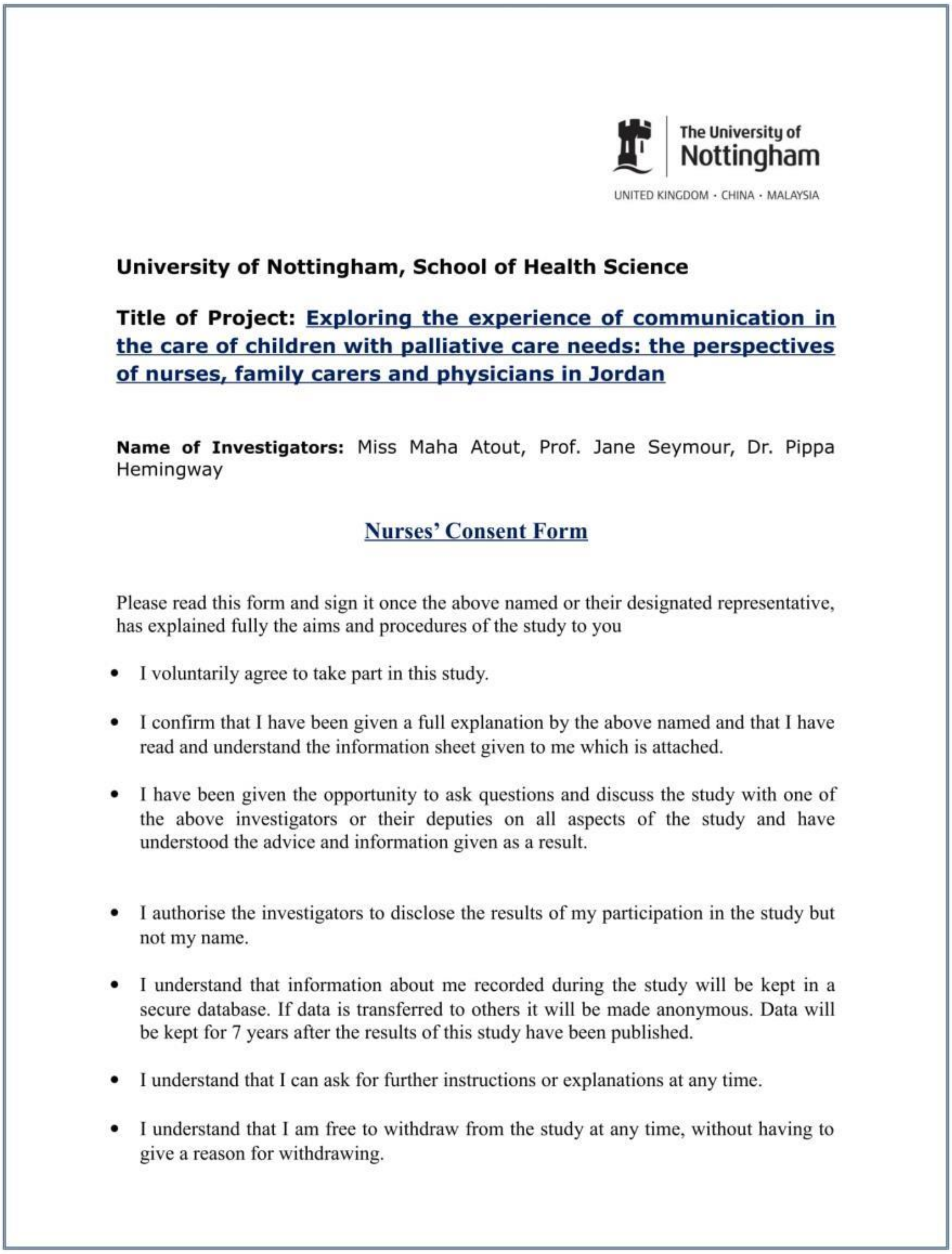
I have given the above named a copy of this form together with the information sheet.

Investigators Signature: ……………………….. **Date**: ………………………………

Investigators Name ……………………………………………………………………….

Study Volunteer Number ………………………………………………………………..

Appendix G: Nurses' consent form



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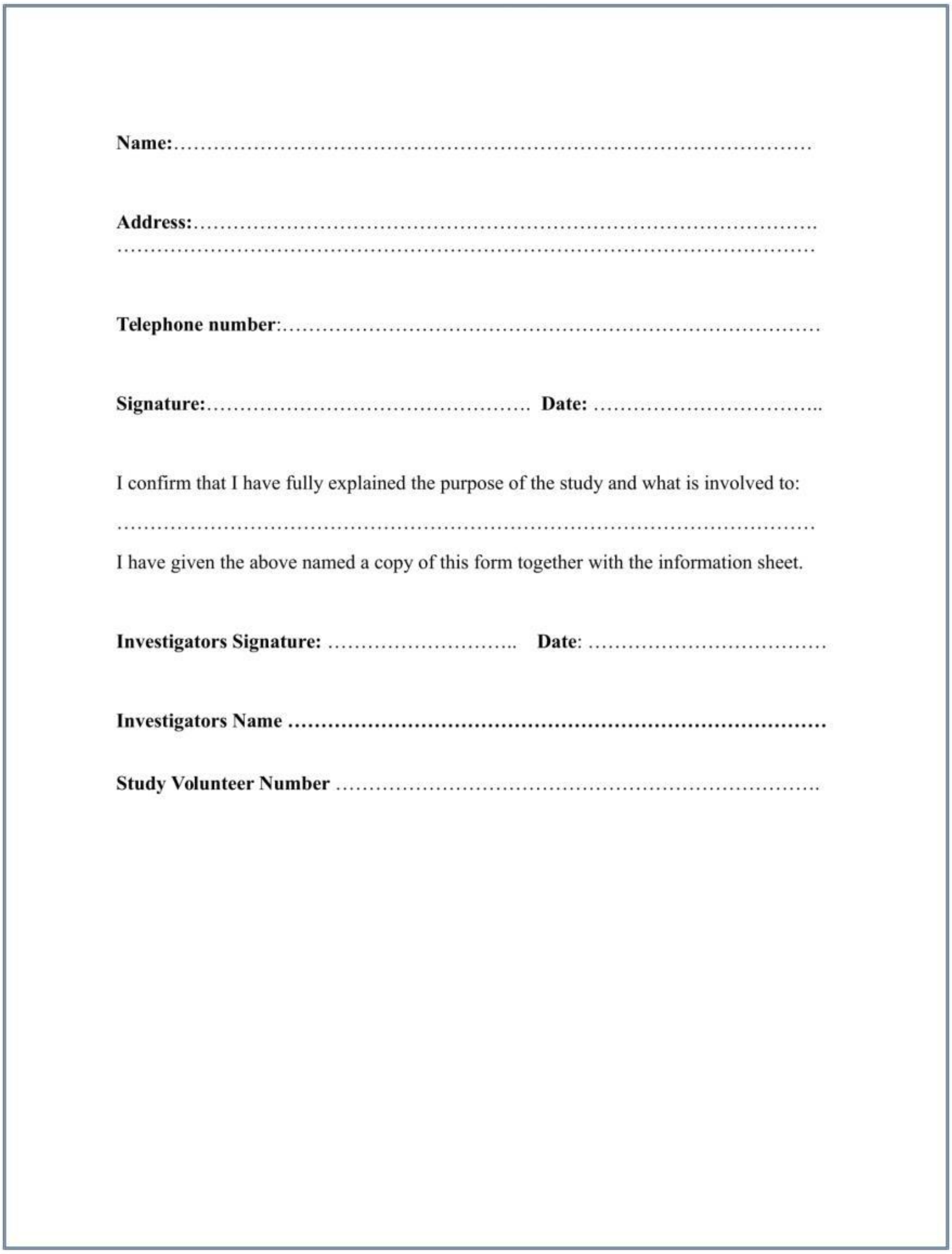
Title of Project: Exploring the experience of communication in the care of children with palliative care needs: the perspectives of nurses, family carers and physicians in Jordan

Name of Investigators: Miss Maha Atout, Prof. Jane Seymour, Dr. Pippa Hemingway

Nurses' Consent Form

Please read this form and sign it once the above named or their designated representative, has explained fully the aims and procedures of the study to you

- I voluntarily agree to take part in this study.
- I confirm that I have been given a full explanation by the above named and that I have read and understand the information sheet given to me which is attached.
- I have been given the opportunity to ask questions and discuss the study with one of the above investigators or their deputies on all aspects of the study and have understood the advice and information given as a result.
- I authorise the investigators to disclose the results of my participation in the study but not my name.
- I understand that information about me recorded during the study will be kept in a secure database. If data is transferred to others it will be made anonymous. Data will be kept for 7 years after the results of this study have been published.
- I understand that I can ask for further instructions or explanations at any time.
- I understand that I am free to withdraw from the study at any time, without having to give a reason for withdrawing.



Name:………………………………………………………………………………………

Address:……………………………………………………………………………………….
…………………………………………………………………………………………………

Telephone number:…………………………………………………………………………

Signature:…………………………………………. **Date:** ……………………………..

I confirm that I have fully explained the purpose of the study and what is involved to:

…………………………………………………………………………………………………

I have given the above named a copy of this form together with the information sheet.

Investigators Signature: ……………………….. **Date**: ………………………………

Investigators Name ………………………………………………………………………

Study Volunteer Number ………………………………………………………………….

Appendix H: An example on narrative within case analysis

Hala: Case Study eight

Hala was 12-year-old female patient diagnosed with nephrotic syndrome at the age of 8. Her mother said that Hala did not suffer from any complaints before discovering her condition and that to her knowledge there was no historical background in the family.

After exposure to severe psychological pressure because of a family problem, Hala spent a whole night crying. In the morning, the mother noticed a significant edema around her eyes. In the beginning, she thought that this was normal and could have been stimulated by her crying. However, she later felt that it might be something abnormal as it stayed for two days. The mother and grandmother took her to the nearby health centre, and the doctor transferred her to hospital after finding that her dipstick urine protein level was +3.

Hala’s father has a severe chronic illness, which prevents him from working. Hala’s immediate family comprises her parents, five sisters, and one brother. The family suffers from financial hardship because of the father’s disease. They live in a two-room basement in one camp of a Jordanian city. They are supported by the Ministry of Social Development with a pittance of money (around 180 JD/month) from which they need to pay 75 / month JD rent.

It was very difficult to get consent from the mother, who needed to go to another hospital to visit her husband in the morning, and then come to her daughter in the hospital where the study was carried out. This was in addition to her home responsibilities, which included preparing her children to go to school, cooking, and cleaning the home. The mother got no support from her family who live far away from her, in the south of Jordan.

I did a participant observation for Hala for 25 hrs. This included taking notes on informal conversations with her mother. I conducted three separate interviews (with separate consent) towards the end of the observation period. The reason for conducting more than one interview was to talk to the mother alone, as sometimes Hala joined in, which prevented the mother from talking freely. I also interviewed her physician (a specialist), as well as one nurse who had frequent contact with her and agreed to participate in the study. I reported on data from two other nurses who referred to Hala during our discussions about different cases.

The key themes in this case are:

Dr. Nihad told me about her experience of informing Hala's parents about their daughter's initial diagnosis. She reported that she informed them of the lab results as a starting point. She insisted on the importance of clearly and honestly informing parents from the beginning about the diagnosis and probable complications, as well as not giving them any false reassurances, by stressing the disease's deteriorating nature. Furthermore, she discussed the proposed treatment plan with them, which included delaying the complications that could lead to renal failure in order for Hala to live longer without the need for dialysis.

> *In the beginning, I told them that the result of the biopsy is like this … you know, the result of biopsy shows that her kidney has fibrosis … this fibrosis will increase with time … it will not decrease with time … you know … therefore … it has some complications that could lead to renal failure in the end … so I tell them that it could lead to renal failure in the end … if we do not control blood pressure … if we do not control the renal functions … if they lose their continuous follow up with me … you know, so I tell them that they need to be informed … I put them in the situation that this child … one day … could have renal failure … but all that we can do is to postpone this failure and let her live without dialysis as long as possible, as much as we can postpone dialysis … it will be better for her .*

Dr. Nihad adopted a gradual, step-by-step, approach to communication with the parents, which mainly focused on the short-term outcomes and avoided anticipating events. Moreover, she also adopted a hesitant approach when she disclosed future expectations of the disease's progression. This could be related to the unpredictable nature of children's diseases and the different responses for each case. However, Hala's mother felt confused by the lack of certainty:

> *She told me that it could be difficult to anticipate what could happen, she could improve, but also, keep in mind that she could be moved to dialysis … I feel confused.*

Dr. Nihad refused to use the word 'death' when she communicated bad news to Hala's parents. She insisted that providing hope for parents is essential when disclosing bad news to them:

> *I try to let them know where we are in the treatment plan … step by step … for example this Thursday … her kidney functions elevated … so I showed the mother how the kidney function is going upward … but today I told them that they are better … however, the overall things are going to the worst … the worst does not mean that she is going to die … the worst means that one day she could go on dialysis … one day she could find a kidney donor and she could get a transplant.*

The stage of the disease could have a significant effect on how to communicate bad news to parents. For example, disclosing bad news at the initial diagnosis could be significantly different from disclosing it at the end of life period, as highlighted by Nurse Alaa:

> *During the different stages of the disease … the majority of our talk with parents focuses on how to improve healing, how the child's health might be improved … how to minimise the complications of the disease … the majority of discussions usually concentrate on the issues of improvement … however, if the child enters the last stages … for example … the lab results got significantly worse … then … the manner of talking with the family could be different … with more indications to death.*

Nurse Alaa viewed hope as essential for parents, who could be very sensitive when they found out about the nature of their child's disease. She thought that it could be very painful for them to receive bad news unsupported by any source of hope. She perceived that Jordanian culture has a significant role in people not accepting the hope-less nature of certain diseases:

> *Based on our culture … when you put yourself in the parents' place … it is very difficult to accept a doctor telling you … to your face … that your child is a hopeless case … and that death is coming … you could not accept the doctor himself … I have seen similar situations … when the doctor was very direct with parents … they came and said … we do not want this doctor to be responsible for treating our child.*

Dr. Nihad reported facing some challenges related to the parents' reactions to Hala's initial diagnosis. She said that their first reaction after the diagnosis was denial. She received a lot of questions from both parents about the diagnosis. These questions included whether the disease affected both kidneys or not, the time it would take to arrange transplantation, whether and when she might be moved on to dialysis, how they could help her and if she could recommend any other doctor or hospital to go to for other solutions. She added that they asked her to write a note to transfer Hala to a military hospital [38] where they went for two years before returning because of transportation difficulties and financial issues.

Dr. Nihad supported nurse Alaa's perspective that parents did not accept the non-curative nature of the disease (or the idea of it being difficult to improve). She said that she accepted their denial reaction and she understood their need to be sure about the diagnosis, therefore, she said that she gave them the names of doctors in other hospitals in order for them to seek other opinions. She mentioned that she had no problem about their seeking second opinions as she thought that it was important for them to be persuaded when they returned to receive her plan of treatment, and she claimed that she had no problem hearing second opinions from her colleagues.

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[38] The military sector is a health sector in Jordan. The others are the public, private, and university hospital sectors (see section 3.4. for further details). Some lay people think that the military sector provides a better quality health service than the public sector, although there is no evidence for this. The study hospital is classified as a public hospital.

What Dr. Nihad said about the tendency of parents to seek second opinions was supported by my observations during informal conversations with Hala's mother. I noticed that she sought a second opinion immediately after hearing bad news from Dr. Nihad, by asking me to read the lab results for her daughter. She told me that she had been informed that Hala needed to be moved to peritoneal dialysis as her Creatinine level was significantly high (around 97 mmol/L). The mother told me that she had thought of taking her daughter to another specialist as she had heard from her friend (the mother of a same-case child) that he was a perfect doctor who had completely cured one nephrotic case. I asked her whether she had told Dr. Nihad about this, and she replied that she had not, as she was afraid the doctor would be annoyed:

> *I'm afraid Dr. Nihad could be annoyed by hearing this … you know … I'm afraid she could think that I do not trust her … I'm concerned about her feeling … you know … we've together for three years … she is very kind … and she did her best … my thoughts are disorganised … I have no idea what to do.*

In addition to being confused after hearing her friend's advice, the mother complained about being unable to pay for that particular doctor as he worked in a private hospital [39] that she did not have health insurance for.

Nurse Alaa mentioned that she was asked several questions by Hala's parents after the daily morning rounds, when the doctor had left the room, as they wanted her to explain some points that they did not understand. She said that they sometimes felt shy about asking the doctor questions and they found the nurse an easier person to communicate with. As they were in an educational hospital, Nurse Alaa concluded that the parents' hesitancy to ask their doctor questions could have been motivated by the presence of a number of medical students who usually came along with the consultant on his morning rounds. It should be noted, however, that the doctor returned alone later on in order to check Hala's progression. Nurse Alaa mentioned that she was asked questions

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[39] In Jordan, the private health sector is not supported by the government and treatment is usually paid for by the clients themselves. It is more expensive and there is a widespread perception that it provides better health services, although there is actually no evidence of this.

by the parents about the progression of Hala’s disease. She felt unable to talk about any future plans, perceiving that it was the specialist’s role to do so. She was afraid of giving a different message to the doctor’s regarding the overall plan. Nurse Alaa clarified that she did not have all of the details about Hala’s plan of treatment in any case, as she did not attend all of the consultations made by the doctor, which could be performed in the office or paediatric clinics.

In spite of her insisting on the importance of being honest and clear with the parents, Dr. Nihad used a protection approach with Hala when she discussed bad news with her. She was afraid that Hala could stop taking her medication, perceiving that hope was an essential factor in obtaining her compliance for treatment. Dr. Nihad reported that Hala’s CA++ level was significantly low and she suspected that she had intentionally stopped taking her medication, especially as she was starting to approach adolescence, which is a difficult age to deal with:

> *I: Could you tell me, Dr. Nihad, about how you communicate with Hala regarding her condition and what difficulties you have found (if there were any) in talking to her about her condition?*
>
> *Dr. Nihad: It is difficult to give Hala complete information or even talk about painful things … of course I do not talk about death … because Hala is still a child … she is approaching adolescence age … those usually do not take their medication … she has a very low Ca++ level … I suspect sometimes that she intentionally does not take her medication … I do not tell her anything that makes her frustrated as I depend on her to take her medication … she feels that she want to live a normal lifestyle like any child … she does not like to live alone, differently from other children … she could ask herself why me … why me? … in this sensitive age, they become aware of this … she does not want to be sick … she does not want to be admitted to hospital for seven days … she does not want to be absent from school for two weeks … she does not want to have general weakness … she does not want to have growth retardation … she does not want to lose her menstruation … all of these things are challenges for her … do you understand?*

Dr. Nihad was not the only one to adopt a protection approach with Hala. It seems that a *multisource protection* was employed with her. The mother also believed that Hala only needed to have partial knowledge about her condition and its treatment. This could have had an important function in encouraging her to commit to her treatment plan. Her mother used comparisons with other children who had the same condition in order to encourage her daughter to keep taking her medication and stick to her diet regimen:

> *For example, I told her that X is moved to dialysis because her kidney function has deteriorated as she has some bad habits … for example … she drinks the milk her grandmother brings to her … she takes some herbs from the spice dealer … but you are not like her … you have a good kidney function … because you take your treatment regularly and you try to keep your health; as well you are on a healthy diet.*

Nurse Alaa indicated that parents' wishes regarding the amount of information that should be disclosed to the child are usually taken into consideration. She mentioned that the majority of families she works with do not want to be given negative information that completely lacks hope for their children, especially mentioning or indicating death. She feels that health care providers should behave in accordance with the families' wishes. Moreover, she believes that while some children could have some idea about life and death, others could not understand the concept of death.

> *I: From your experience, how much information is usually disclosed to children about their conditions … diseases … and are there any indications of death?*
>
> *Nurse Alaa: No … no … this is not present … it is rejected … it is rejected … the family itself refuses this idea … this is the first reason … the second thing is that … the majority of children … in spite of finding some of them have an idea about death and life … the majority of them do not understand death well … the majority of them do not talk about death.*

However, it was difficult to prevent Hala from getting information from the various different sources available to her. It was very difficult to isolate her from the environment in which she lived, and almost impossible to segregate her from the fast, information-rich highly-technological world around her. Indeed, I would argue that Hala had several resources that would have enabled her to get a complete picture of her disease and its treatment. The following is a brief discussion of some of these resources.

Hala was a very social child. She might be one of the most social children I have ever met. The first time I met her, she was sitting near the main door of the medical paediatric department with a security employee. It seemed that they were close friends, as I saw them several times together. Moreover, Hala had a very good relationship with the nurses on that floor. Her relationship with them went beyond her being a sick child who needed some nursing care. It was very clear that she knew all of their names; she preferred some of them to provide care for her over the others. One day she told a nurse who came to ask her to go to the procedure room in order to insert an I.V line that she preferred a certain nurse to insert the cannula for her. In addition, she usually went to the nursing station and sat talking to the nurses about different things such as news and the weather. The mother told me that she went several times with some friends to the cafeteria to have dinner.

Hala was very friendly with the other children as well. She acted as a leader of the children in the department. During my observations, I noticed her come to her room with some other child patients from the same floor several times in order to take something from her mother. She was also friendly with the infant on the bed beside hers. I saw her carrying him and he would smile at her as if they knew each other. From her discussions with his mother, it seemed that she knew about his disease. It seemed that Hala usually tried to identify the new admissions and strike up a social relationship with them, also, finding out some details of their disease.

Hala had a smart phone connected to the internet. She spent hours and hours reading, playing, and listening to music. She was very active and experienced in the use of social media, for example using WhatsApp to communicate with her friends. She was also very competent with Facebook. One day she asked me to play ‘Happy Farm’ with her, a familiar game that people invite their friends to join using their Facebook accounts. I declined, saying that I did not know the rules of the game. My reason behind this was to avoid building a deep social relationship with her that could hurt our feelings when we separated.

Hala also acted as an information provider for nursing students. One day, during one of my visits, a few students entered her room with their clinical instructor for one of them to perform a clinical exam. I got the instructor's permission to attend. It was Hala, rather than her mother, who was informative about her case. It seems that she had met the student who was to be examined beforehand. Hala was sitting on her bed, with her hands clasped, as if she was to take the exam and was fully prepared. Her mother was on the chair near the bed and the group of students and the instructor were around them. I was surprised about the level of awareness this child had about her condition. Indeed, she corrected the student several times about the values of her lab tests.

Dr. Nihad confirmed that Hala could have higher awareness because of her long stays in hospital. She could see and meet other kidney patients, which could increase her knowledge of the disease and the probability of death.

Hala's mother told me about her daughter's reaction toward the death of her best friend Sami, who she had got to know in the hospital. Sami was ten years old, the same as her, and had End Stage Renal Disease (ESRD). His health condition had deteriorated very fast and he had entered PICU several times. After he had entered PICU, he would not accept feeding by anyone except Hala, who was concerned about his health. [40] When milk was given to him, he refused to drink any with the help of his mother or Nurse Rania. One day her mother said that Hala had asked her 'Am I going to be like him, Mum?' After Sami's death, his mother phoned Hala's mother, but unfortunately Hala answered, and was informed about Sami's death. Hala's mother told me that Hala gave the phone to her mother, went quickly to the bathroom and closed the door. The mother said:

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[40] This is supported by nurse Rania, another participant in this study, who worked in the ICU department and was the nurse assigned to Sami.

> *When she gave the phone to me, she entered the bathroom quickly and kept crying … her father asked her to come out, but she did not respond … she kept crying … honestly, this is the first time I saw her suffer … suffer … suffer like this … really … as a result of her suffering … I admitted her to the hospital immediately.*

Hala's mother complained that she faced difficulties asking the doctor questions about her daughter's condition in front of her. Hala's mother described her as a very clever girl, and she wanted to protect her from hearing any painful information about her condition. She experienced the presence of her child as a barrier to her communications with the doctor.

However, either Hala was not as open as people around her thought, or she became more closed in on herself as a response to the environment in which she lived. She was afraid of harming people around her by complaining about her disease, and was afraid of harming her parents and doctors. She probably played the role required of her (being a kind girl who comes with her mum to hospital, taking her medication on time, having excellent commitment to her low-protein diet, and not asking many questions, as she does not understand the progression of her disease). In spite of being a very social child who was able to form very good relations with many people, it seems that she still had a dark side to her life. This side, which she tried to hide from her friends, the nurses, and probably her doctor, was obvious to her mother, who accompanied her most of the time. The mother stated:

> *I said to her … tell me what's hurting you … she tells me … nothing – I do not have pain … she has great dignity … she hides her pain … her doctor, Nihad, told me that she had never met a child with this degree of awareness before … she felt that she is like very old women … she is very aware but she prefers to hide … she does not like to show her pain.*

The fear and suffering that Hala was unable to express in words was communicated by describing her dreams. Hala's mother told me that sometimes she disclosed her suffering to her father:

> *Hala is more open with her father; one time she told him about her night dreams … she saw her dead grandmother come to take her and fly into the sky … in the sky … she saw her friends Hosam*[41] *and Raed … they were very happy and played together using stars … when she told him … her father … started crying.*

Hala did not like to see her parents being sad because of her sickness, and did not like to complain to her mother. However, her mother believed that Hala was completely aware of her condition, in spite of being very protective of disclosing her feelings:

> *I'm sure a million percent that she knows everything about her disease … but she does not like to show it … imagine …one day she brought a science book as if she had a science exam … she discussed with her father her exact problem … she told him that this is the kidney and this is the grains that I have fiber in … she wanted to discuss about her condition for her father because he is not educated.*

Nurse Alaa reported that she started to separate her emotions from work. She told me about a past experience concerning the death of a child who she liked very much, saying that their relationship had developed to the extent of them becoming close friends. When he died, Nurse Alaa was very shocked, and she decided not to become emotionally involved with any patients from then on:

> *Nurse Alaa: Look, I had one bad experience … there was a child who was newly diagnosed with renal failure … when he went for the tencuf*[42] *operation, I accompanied him to the operation department, I told him that it was a CT-scan … I hid that it was a tencuf operation … I felt I needed to lie because I felt sad for him …*

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[41] Hosam and Raed were two close friends of Hala's who had died from the same condition as her.

[42] A tencuf is a tube that is usually inserted in the abdominal cavity to facilitate peritoneal dialysis.

> *however … when he was discharged from the operation … he blamed me.*
>
> *I: How old was he?*
>
> *Nurse Alaa: He was nine years old or something like this … he told me 'why you told me it is a CT-scan? … they opened my abdomen to insert the tencuf' … we were very close friends … we were joking together … laughing together … when he died, I was shocked … it was very difficult for me to believe this … now I'm friendly with children but … I have no real feeling toward them … I'm not so related to them.*

However, having high awareness was also seen as negative by some health care professionals. Nurse Alaa reported the problem that some nurses faced with Hala as she asked for certain nurses to insert the cannula for her. Nurse Alaa explained that Hala wanted one attempt at insertion of the cannula, and she perceived that certain nurses could be highly skillful, which could reduce her suffering with the insertion. Nurse Alaa said that it was difficult for this to be offered to her, as it was impossible to get the same nurse for Hala for a whole 24 hour period.

Nurse Asma found the same challenge in communicating with Hala, after she had had a successful first-time procedure. Nurse Asma was a junior nurse who had worked in the hospital for eight months. She found inserting an I.V cannula for children was a significant challenge because of their tiny veins, which could be difficult to find. As well as this, the long periods that some children stay in the hospital contributes to consuming the majority of the veins, and they rupture:

> *The most frequent challenge I face with Hala is inserting the cannula for her. Of course, she used to have a nurse that could insert the cannula for her from the first trial … when a new nurse comes to insert her cannula … she could need at least two or three attempts … she refuses this … she wants a nurse that can insert it at the first attempt … she already suffers from the disease itself … she needs to enter the hospital frequently … she does not want to*

> *have pain from the several attempts … I understand her feeling … she wants the cannula to be inserted the first time.*

In spite of being seen as a very strong girl in comparison with the other same-condition children, her strength was not constant. It could peak with her being a strong friendly girl who liked to make good relationships, and then decline very sharply, especially when she had acute pain because of her disease. Hala used to get up at night crying, shouting, and screaming because of the severe pain she felt. As her mother put it:

> *Sometimes she wakes us from our sleep … shouting … screaming from the severity of pain … she shouts to relax … she wants us to support her throughout her suffering.*

Moreover, Hala was not viewed as a very kind child by everyone. She lost control sometimes, became angry in some situations, and could also behave in a selfish manner at other times. Her mother, who was the closest person to her, and the one who accompanied her most of the time, experienced this. She told me, for example, that Hala asked her to buy her expensive fast-food dinners. The mother said that she tried to offer her what she wanted, but, this food was very expensive and she was not always able to afford it. She got annoyed when Hala did not eat it all, but instead took one bite and left the rest:

> *Yesterday, on our way to the hospital, Hala called me and told me that she wants Shawarma sandwich … l returned to the bus station in order to buy it … the last week … she cried a lot in order for me to buy a cafeteria dinner for her … I hope she eats it … she eats one small bite and leaves the rest … it is not fair … I paid one JD for it … and Hala did not eat it … I became angry with her … I do not have money … I told her that I cook for your sisters a soup without meat or chicken to find something to eat when they return from school … feel with others … what you like for yourself … like it for your siblings … she told me … you do not want to feed me … you do not like me.*

Finally, Hala’s mother reported problems answering Hala’s difficult questions, especially when she compared herself to her sisters and peers:

> *One day she noticed that her sister Lubna* [43] *has breast enlargement … she is significantly taller than her … you feel that Hala’s clothes do not fit on Lubna’s size … so she usually asks me … ‘mum why do I feel Lubna grows and gains weight but I’m not … I feel that I’m like a boy’ … when I help her during bathing … she tells me … ‘mum look at my body … why do all of my sisters have white skin but I have yellow?’… she keeps asking and asking … I swear sometimes I cry … I left her … yesterday she asked Dr. Nihad … ‘Doctor … I do not feel that I become older like other girls … this means that my sister Lubna … I feel that she is older than me although I’m the older one’ … Dr. Nihad told her ‘I told you Hala … that your status is different … your disease is systematic … multiple things will be changed with you … as you have kidney disease’ … she was very honest with her.*
>
> *I: So … what was Hala’s reaction?*
>
> *Hala’s mother: She cried excessively … then I knew that her blood pressure became very high … although it was not like this in Dr. Nihad’s clinic … when Hala feels annoyed … her face becomes red and you feel that she is very defeated … I felt that she suffered.*

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[43] Hala is older than Lubna, Lubna is ten years old.

Appendix I: An example on the coding technique adopted for one interview

Transcript	**Code**
Me: Hello Dr. Raed.	
Dr. Raed: Hello...You told me Maha?	
Me: yes...Maha...Just a reminder that these registrations will only be used for the objectives of this study; all information will be kept confidential. We will use pseudonyms instead of real names and there is no right or wrong answers, the questions depend on your experience.	
Dr. Raed: ok...You can begin	
Me: you are pediatric nephrologist and as we discussed before that I'm interested in studying communication phenomenon in the field of pediatric who have palliative care needs, therefore, I worked with two cases you are treating them; one of them is nephrotic...Firas... and the other is end stage renal disease ..Latifa...	
Dr. Raed: who said that the nephrotic syndrome has no treatment or is it hopeless case?	**Resentful/ displeased**
Me: I did not say that it is hopeless case, but based on the Royal college of pediatric and child health in the UK, when life-threatening conditions for which curative treatment may be feasible but can fail, where access to palliative are may be necessary alongside attempts to curative treatment and/ or if the treatment fail... that patient is in need for palliative care which starts from diagnosis of that disease.	
Dr. Raed: Ok, that's fine.	

Transcript	**Code**
Me: could you tell me please, how you communicate bad news for your patient's parents or children?	
Dr. Raed: the information we give based on what I usually expect for them as a doctor who work with patient who have kidney disease. It depends on the underline cause or the background of the nephrotic patient has…the nephrotic syndrome is not only one type, instead, it is several types; there is something that usually called steroid sensitive and something called steroid resistant and based on the type of nephrotic I could expect what will happen for that child ..There could be something called benign cases which respond to cortisone …yes it has many relapses but the outcome could be better than those which did not respond with steroid. Now the problem that usually happens in nephrotic syndrome those cases which initially express no response to steroids …those may indicate other pathophysiology. They usually need for renal biopsy till knowing what is the exact the histopathology that does not respond to steroid…as I said; we have more than one type...Around four. Based on which type I can know the long run of it.	**Expectation** **Not standardized** **Not- standardized**
Me: Oh, that's interesting and probably important to know the underline cause of the nephrotic syndrome in order to expect what could be happened later. In case the long run was not favorable, how you communicate this for the child's parents? Do you face any challenges regarding this issue?	
Dr. Raed : As I believe that the nephrotic disease is unpredictable disease which means that nobody	**Uncertainly**

Transcript	Code
know what will be happened with that child...for example, some people could take long period till the deterioration for the kidney function. Of course this is based on the type. The renal function could have some deterioration. Protein loss in a huge amount and this protein could affect kidney...now if this type is not favorable for me and I know that after 10 -15 years they could have chronic kidney disease, or end stage kidney disease, they could need dialysis...to be honest, I usually tell them gradually... (Um) because honestly they should know what will be happened, of course, as I expect...but not in one word. Your child will need dialysis...as at that moment, they could not accept, you know, some of them do not accept the disease itself....we told them that there are some cases that take long period while ... some of them get better or they take long time till arrive the adulthood and the science says that this type could affect kidneys and they could have ...you know. But after dialysis there is something called kidney transplantation and the science is more developing.. you know, you relive their pain ....not if he has kidney failure this means life is finished means the death is coming ..!! Things like those issues do you know how is it... they accept it if you give it as this...but they usually usually the main objective for them from the first day that...doctor does he want to make dialysis?...so we told them that God is responsible for this issues and science talks like this ... but even if he need dialysis he will not make it now, instead he will make dialysis after 10, 15, 20 years...and all of this depends on the types I told you about...so usually breaking bad news needs certain way ...does that right?	**Not- standardized** **'Gradual'** **Should know** **Uncertainty** **Gradual** **Denial** **Giving example** **Hope** **Protection** **Avoid talking about death** **Denial** **Fear from dialysis** **God control** **Protection** **Maintaining hope** **Not- standardized**

Transcript	**Code**
Me: yep	
Dr. Raed: So you need to tell them little little this means not to make it one shot that your son will need dialysis because you cannot decide it...does that right or not?	**Gradual** **Uncertainty**
Me: agree by moving my head	
Dr. Raed: The nature of disease and because it of unknown etiology, no one knows because all of what you have said could be not true.	**Uncertainty**
Me: you've said that some families do not accept the disease itself, could you tell me more about this issue. I mean what challenges could you face regarding to the families who are not accepted the disease of their children?	
Dr. Raed: Sometimes we face some problems related to the fear of families from this type of disease, because sometimes there could be certain kind of denial for the diagnosis…they do not accept…, therefore, they usually ask anyone walking in the street…they hope to find something which could be better that what the consultant told them…so based on this, some people give them hope while others not and some of them could mix things and make it really complicated.	**Fear** **'Denial'** **Double check** **Seeking hope** **Receive mixed message**
Me: Um…could you give me an example from your experience while working with Latifa or Firas cases?	
Dr. Raed: Um…no I do not remember an example about those two case specifically, but I can remember one	**Receiving mixed**

Transcript	Code
family who has a child with nephrotic syndrome… someone gave them the information sheet which is related to the end stage renal failure … nutrition… nutritionist …the second day the family "Doctor, why you do not tell us that he has renal failure?" I told them. He has not …and if he has, I would tell you little little that he has …but he has not! they said that the nutritionist and she gave us an information sheet…they spent two days suffering from this accident…you know something could be happened like that …you know…because they do not want another one to confirm the disease…they could find someone who give them some hope..!!!	message Clarify misunderstanding Gradual Mixed message Suffering Seeking hope
Me: Oh really, I'd never thought of that. Although I'm a nurse, but I did not have certain experience as you know it is mainly the consultant task to give these types of information for the family.	
Dr. Raed: I would add one more thing regarding to the nature of people here… you can add it as a note or something else…that for example the chronic disease or regarding to big procedures or even dialysis or even transplant…Um…they hide on you … they do not say everything for physician and they go to ask outside…	Seeking second opinion Hide information
Me: they go to ask outside…	
Dr. Raed: yes, they ask other physicians…they ask a few ones in order to ensure…this means I'm honest with	Double check Resentful/ displeased

Transcript	**Code**
them...but they are not honest with me...and I know sometimes...sometimes from one word he says...I know that he went and asked outside because this word is not for him...and he should not know it...do you know how?	**Discovering**
Me: yep	
Dr. Raed: Um...but I give them excuse...because it is dialysis...it is not joking...because kidney failure could be sometimes more difficult than cancer.	**Giving excuse/retreat**
Me: This is the first time I know this...!	
Dr. Raed: they could have 100% trust, but their society tells them ask another one...there could be another thing... and for several times during our meeting... we...pediatric nephrologists...every month we have a meeting...we have exams and so on...we talks about the same patients who came to all of us they went to Maha and the came to me and they went to x and y..Do you know how?	**Social encouragement** **Double check** **Looking for hope** **Discovering**
Me: Um...	
Dr. Raed: they try to take other information about the disease of them in order to make double check ...but they do not tell their physician that they went and asked.	**'Double check'** **Hiding/ fear from displeasing doctor**
Me: In case you know that one parent ask other physician/ physicians in order to (as you said) make double check, how you behave in this situation?	

Transcript	Code
Dr. Raed: I usually tell my patients if you are not sure or if you have any doubt you can ask...you can do whatever you want...and if you do not like to return here you can...I will not be annoyed by that...this is what I have and I know what I say and I'm responsible of my words...I'm not a fresh graduate consultant...I have my special training and I have started kidney transplantation here in prince Hamza...	**'Having doubt'** **Refer to another doctor** **Resentful/ displeased** **Defense/ showing trust**
and anything I say I usually make double check...I could make consultation from more than one consultant outside Jordan if I have any difficulty...so	**'Double check'**
I'm not so much annoyed by him...I tell him go and ask and if you not persuaded ...you can stay there...to	**Resentful/ displeased**
me if he told me that I went there and asked that consultant and came back to here...this is better for me because he did not persuaded and that is why he returned back to me..I will not be annoyed. They	**Being honest/** **Returning back**
think do not tell doctor that I asked Maha as they afraid from being annoyed...and more than one time I	**Hiding/ Fear from displeasing doctor**
found them by chance...one of them put his file with me in order to read it, he wrote names of two consultants nephrologists outside outside in the private sector...so he did not see that he wrote the name of two of my colleagues...he consulted them	**Discovering**
and went there and returned here...here Arabs are not honest and they swear oath...unfortunately here especially the serious things or the chronic they	**Stereotyping** **Double check**
usually ask several ones and they do not told the doctor who treat them...doctor I went to that doctor and that doctor and consulted them...	**Hiding/ Fear from displeasing doctor**
unfortunately we ...the Arab in general are not honest	**Stereotyping**
...for example I have one patient ....I see that there is an upnormality in the results...if you ask here for	**Not honest with doctor**

Transcript	**Code**
example whether she takes her medication in regular way she swear oath one hundred times that she takes ...and you feel sometimes that there is something upnormal but they do not say...English people say sorry doctor I did not take my medication. I forgot he did not feel shy...but this is really helpful regarding to make an explanation why this is happened...does that true or not?	
Me: Um... (around 3 seconds of pause)...Dr. Sael, I'm interested in understanding your way of communication with children who have nephrotic syndrome or end stage renal failure...I would like to understand the way you communicate to them about their disease and what challenges (if any) do you have when you communicate to them?	
Dr. Raed: we said Maha?	
Me: Yes... Maha	
Dr. Raed: Maha...I have my own way of communication with those...usually I do not take to families alone...I want child to be sit with them because at the end he is the patient not his family is the patient...but this means we should (um)...whatever the age of the child...he should be present when I talk to them about the disease...	**Involving child**
many times I feel that he do not understand ...he do not know the meaning of nephrotic ... nephrotic in Arabic means التناذر الكلوي (fibrosis) ...I do not understand the meaning of تناذر !	**Child does not understand disease**
We tries to simplify things by saying there is smuggling of albumen or smuggling of protein from urine.	**Simplify concepts**
So he does not know what is the meaning of	**Careless to know**

Transcript	**Code**
smuggling and careless to know the meaning of smuggling...so he did not know even when we told him after number of years, the renal function could be diminished and these things he will not understand it ...but my own special way I do not tell the family anything while the child is not present...I talk little little in order he knows that he has something else...in order to know that he has something especially when they give him his medication ...you know the bad taste medication ...to know that this is important to him...but if I talk to family only and give him medication ..he could ask himself why they give me this medication...what they want from me...nobody told me..I was not informed or something like that...to be honest I like the child to be involved whatever the age of him.	**about disease** **Doesn't understand** **Involving child** **Gradual** **Compliance to medication** **Involving child**

Codebook for the selected codes

Code	**Description**
Resentful/ displeased	When doctor feels displeased from parents who hide information.
Expectation	The expectation of doctor regarding to the long run of disease
Not standardized	When the treatment of certain disease is not standardized, instead, it depends on the underline cause of it.
Should know	When doctor believes that parents should know about the progress of the disease of their children.
Uncertainty	The doctor is not sure about the long run of the disease
Gradual	Doctor uses gradual approach when breaking bad news for parents
Honest	Doctor is honest with parents regarding to the information related to the disease of their children.
Denial	Parents do not accept the disease of their children especially when it is initially diagnosed
Giving examples	Doctor gives examples about other cases when he/ she gives bad news about certain disease.

Code	**Description**
Hope	Doctor gives hope for family about the future of the disease of their children
Protection	Avoid talking about negative sides of disease to protect the other
God control	The belief that God control the cure of the disease
Maintaining hope	When doctor tries to provide hope even when the possibility of cure is very limited, e.g. when doctor tries to prolong life without the initiation of dialysis.
Fear	Fear of families from these types of diseases
Double check	Families seek other opinions when they receive unfavorable information about the disease of their children
Receiving mixed message	When parents receive contrast information from HCPs.
Social encouragement	Society encourage parents to seek second opinion
Fear from displeasing doctor	When parents hesitate to tell doctor that they seek other doctors' opinion
Refer to another doctor	Refer parents to other doctors in order to reassure them about the information of disease of their children
Double check	When someone want to check certain information about the condition of patient
Compliance	Child's compliance on medication
Giving excuse	When doctor gives an excuse for families who hide some information to him/her.