Concerns and Needs of Chronically Ill Hospitalised Children and Carers in a Saudi Public Hospital

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A thesis in fulfilment of the requirements for the degree of Doctor of Philosophy

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Sydney, Australia

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Chronic paediatric diseases have been on the rise in Saudi Arabia. However, information on the experience of carers of hospitalised chronically ill children is lacking. This study set out to explore the needs and concerns for wellbeing of carers of chronically ill children in a Saudi public hospital.

The research was conducted in two phases. The quantitative phase employed a cross-sectional survey design using the satisfaction questionnaire and the sf12-v2 health survey. A total of 78 and 71 participants completed the satisfaction survey and the wellbeing survey respectively. The qualitative phase involved semi-structured interviews with carers, healthcare providers, managerial and administrative staff as well as 6 months of observations and analysis of hospital documents.

The surveys showed satisfaction level of carers ranged from satisfied to highly satisfied. Carers of chronically ill children had double the risk for screening positive for depression compared to the norm (p < 0.0001). The qualitative phase highlighted some novel findings. First, the hospitalisation of the chronically ill children had an indirect effect on the education of their sisters. Second, this research identified the need for providing holistic family-centred care in Saudi Arabia tailored to the needs of the patient, carer and family. The findings also highlighted concerns relating to children’s role in the management of their chronic condition, an area that requires further research.

Examination of the findings through the family-centred lens highlighted priorities for Saudi Arabia including the importance of advocating for FCC, increasing the knowledge of all involved parties about the FCC model, building staff capacity to support FCC, creating supportive environments and enhancing the physical layout of the hospital. The findings of this study provide a foundation for Saudi Arabia, and other countries with similar cultural and social contexts to draw on in tailoring medical and mental services.
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Dedication

To my husband Nawaf Sayedakram for his endless love and support

To my children Deema, Rital and Abdulaziz for their understanding, love and patience

To my parents Abdulsalam Yousef and Ahlam Dashash for their everyday prayers and unconditional love
Acknowledgements

I would like to start by praising Allah, the almighty, for guiding me through the toughest times and helping me complete this PhD study. I thank him for giving me strength, health, love, family and the determination that kept me going.

Achieving this dream of completing my PhD studies would not have been possible without the help and support of many individuals to whom I am forever grateful.

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Pursuing a PhD in a foreign country so far away for my own culture, family and friends was very hard. However, I was very fortunate to have met the nicest group of friends who made my time here not only bearable but enjoyable. For that I am truly grateful. I would like to thank you all for the girl’s nights out, park barbecues, talks about school and for literally being there for me.

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Abstract

Chronic paediatric diseases have been on the rise in Saudi Arabia. However, information on the experience of carers of hospitalised chronically ill children is lacking. This study set out to explore the needs and concerns for wellbeing of carers of chronically-ill children in a Saudi public hospital.

The Research was conducted in two phases. The quantitative phase employed a cross-sectional survey design using the satisfaction questionnaire and the sf12-v2 health survey. A total of 78 and 71 participants completed the satisfaction survey and the wellbeing survey respectively. The qualitative phase involved semi-structured interviews with carers, healthcare providers, managerial and administrative staff as well as 6 months of observations and analysis of hospital documents.

The surveys showed satisfaction level of carers ranged from satisfied to highly satisfied. Carers of chronically-ill children had double the risk for screening positive for depression compared to the norm ($p < 0.0001$). The qualitative phase highlighted some novel findings. First, the hospitalisation of the chronically ill children had an indirect effect on the education of their sisters. Second, this research identified the need for providing holistic family-centred care in Saudi Arabia tailored to the needs of the patient, carer and family. The findings also highlighted concerns relating to children’s role in the management of their chronic condition, an area that requires further research.

Examination of the findings through the family-centred lens highlighted priorities for Saudi Arabia including the importance of advocating for FCC, increasing the knowledge of all involved parties about the FCC model, building staff capacity to support FCC, creating supportive environments and enhancing the physical layout of the hospital. The findings of this study provides a foundation for Saudi Arabia, and other countries with similar cultural and social contexts to draw on in tailoring medical and mental services.
### List of Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
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<tbody>
<tr>
<td>AIHW</td>
<td>Australian Institute of Health and Welfare</td>
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<td>AUD</td>
<td>Australian dollar</td>
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<tr>
<td>BP</td>
<td>Bodily Pain</td>
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<td>ECG</td>
<td>Electrocardiography</td>
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<td>FCC</td>
<td>Family-Centred Care</td>
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<td>GDP</td>
<td>Gross Domestic Product</td>
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<td>GH</td>
<td>General Health</td>
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<tr>
<td>HREC</td>
<td>Human Research Ethics Committee</td>
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<td>ICU</td>
<td>Intensive Care Unit</td>
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<td>KFHU</td>
<td>King Fahad Hospital of the University</td>
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<td>KSA</td>
<td>Kingdom of Saudi Arabia</td>
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<tr>
<td>MCS</td>
<td>Mental Component Summary</td>
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<td>MH</td>
<td>Mental Health</td>
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<td>MOH</td>
<td>Ministry of Health</td>
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<td>PCC</td>
<td>Patient-Centred Care</td>
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<td>PCS</td>
<td>Physical Component Summary</td>
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<td>PF</td>
<td>Physical Functioning</td>
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<td>RE</td>
<td>Role-Emotional</td>
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<td>RP</td>
<td>Role-Physical</td>
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<td>SF</td>
<td>Social Functioning</td>
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<td>SNMHS</td>
<td>The Saudi National Mental Health Survey</td>
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<td>Vitality</td>
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<td>WHO</td>
<td>World Health Organization</td>
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<td>WMH</td>
<td>World Mental Health Survey</td>
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Chapter 1

Introduction

“I hate my life because of my son... I don’t desire life anymore.”

(Rihab, carer)

Rihab is a Yemeni woman living in Saudi Arabia and is the mother and carer for 8-year old Adam, who suffers from severe asthma. Rihab is exhausted and overwhelmed by her son’s disease. Sometimes when Adam had an asthma episode, he had difficulty breathing. On a couple of occasions he almost died. For Rihab, this was torture and she was left feeling like she hated her own life and often wished she could die. It pained Rihab to see her son go through these episodes and this has had an impact on her own physical and mental health.

Rihab was aware of the negative psychological effects that her son’s chronic disease had on her. Her above words sounded like a call for help. Which begs the question: was her call being answered? Even yet, was anyone aware of that call?

Rihab’s case brings up more questions for me. What are the effects of caring for a chronically ill child on the carer? How are these effects assessed or addressed in Saudi Arabia? What roles do carers play in the care of their children? What needs to be done to make their experience with the chronic disease and the hospitalisations easier? What are the facilitators of the health and wellbeing of carers? What are the barriers to the health and wellbeing of these carers? Is caring for the carer part of the care delivered at hospitals in Saudi? If not, how can care of the carer be incorporated into the care that is delivered? I address these questions in this PhD study.

The focus of this PhD thesis is to explore the experience of carers of chronically ill hospitalised children in Saudi Arabia. I focused on assessing the carers’ level of satisfaction and wellbeing. I also tried to identify the different roles that carers play. In addition, this study explored the facilitators and barriers to the wellbeing of carers. My hope is to give voice to my participants, listening to them and understanding the individualities of their experiences.
1.1 Background

The World Health Organization (WHO) has defined chronic diseases as conditions that are long-term and of slow progression that are not communicable (World Health Organization, 2018). They have also identified chronic diseases as a major challenge for sustainable development. Chronic diseases have distressing and long-lasting effects on individuals, communities and healthcare systems which include: the complexities of managing these diseases, lifestyles changes, direct and indirect financial burdens and social isolation (Barlow & Ellard, 2006; Brown et al., 2008; Hopia, Paavilainen, & Åstedt-Kurki, 2004).

Today, more children are being diagnosed with chronic medical conditions than ever before (McManus & White, 2017; Perrin, Anderson, & Van Cleave, 2014). Asthma, type 1 diabetes and cancer are examples of chronic diseases that have severe impacts on the health of children, on individuals, as well as the communities (Australian Institute of Health and Welfare, 2012).

In Australia, 11% of children were diagnosed with asthma in the year 2014-2015 (AIHW, 2016). In the United States, the prevalence of asthma amongst children has been increasing, with an average annual increase of 0.06% between 2001 and 2013 (Akinbami, Simon, & Schoendorf, 2016). In Canada, asthma incidence increased by 30% from 1996 to 2005 and the prevalence increased by 55.1% (Gershon, Guan, Wang, & To, 2010).

Type 1 diabetes is another chronic disease that affects children. According to Patterson et al. (2014), it is estimated that 79,000 children globally are diagnosed with type 1 diabetes annually. In 2014, type 1 diabetes in children was diagnosed in Australia at a rate of 25 cases per 100,000 population (AIHW, 2016). In the United States, the prevalence of type 1 diabetes was estimated to be 1.93 per 1,000 (Dabelea et al., 2014). The incidence rate of type 1 diabetes is also increasing in Finland, Norway, Sweden, Britain and Germany (Patterson et al., 2014).

The prevalence of chronic paediatric conditions such as hypertension, diabetes, childhood obesity, cancer, heart diseases and genetic blood disorders have increased in Saudi Arabia in the last 20 years (Ministry of Health, 2011). Type 1 diabetes is a common chronic paediatric condition in Saudi Arabia. A study conducted from 2001 to 2008 in Saudi Arabia estimated the prevalence of type 1 diabetes in children under 19 years to be 109.5
Anecdotally, asthma is also very common among children in Saudi Arabia, but there is a lack of empirical studies documenting its incidence or prevalence in Saudi Arabia.

Chronic paediatric conditions affect the patient (the child) as well as other family members especially the carers. Caring for a child with chronic illness can have significant emotional and social burdens on the carer. These carers need to endure several challenges that include managing the strong emotions of stress, anxiety, vulnerability, social isolation and repeated hospitalisations (Barlow & Ellard, 2006; Brown et al., 2008; Hopia et al., 2004; Katooa, Shahwan-Akl, Reece, & Jones, 2015; Kratz, Uding, Trahms, Villareale, & Kieckhefer, 2009; Youngblut, Brady, Brooten, & Thomas, 2000). For example, in the United States, the majority of the paediatric hospital days are due to chronic illness (Simon, et al. 2010). In Australia, children accounted for 8% of all hospitalisations in 2004-05 (AIHW, 2005). Such hospitalisations affect the whole family and require a long-lasting partnership with the healthcare providers. (Nuutila & Salantera, 2006). At home, parents are usually the primary carers. On the one hand, society recognises parents’ responsibility and autonomy in caring for their children and exercising control over almost all aspects of their lives (Tong, Lowe, Sainsbury, & Craig, 2010). But on the other hand, at the hospital, they are expected to surrender control and power to the hospital staff, while they may also be required to ask for permission to take part in the care of their child (Tong et al., 2010). The power that parents have outside of the hospital is therefore handed over to the nurses. (Ames et al, 2011; Bourke, 1997).

The change in their parental roles is a major contributor to their emotional distress as they are uncertain of their roles in caring for their hospitalised child (Moorey, 2010; Uhl, Fisher, Docherty, & Brandon, 2013). Other sources of carer stress include being in an unfamiliar environment and the uncertainty about their child’s condition and the information they are receiving (Board & Ryan-Wenger, 2002; Colville et al., 2009; Hallström, Runesson, & Elander, 2002; Pai, Bhaduri, Jain, Kumar, & Sethi, 2008; Uhl et al., 2013). While the literature documents the contributors to the emotional burden of the carers, most of this literature is from Western countries and there is very little known about the situation in Saudi Arabia.

The increase in chronic paediatric conditions around the world and the associated increase in morbidity and mortality marks chronic paediatric conditions as a public health
problem. The literature reviewed for this thesis (see Chapter 2) indicates that globally a significant number of children suffer from chronic conditions. In addition, the carers of the chronically ill children frequently suffer from a myriad of stressors and effects that disrupt family functioning. The literature also indicates that chronic paediatric conditions have increased in Saudi Arabia. However, information about the experience of carers of chronically ill children in Saudi Arabia is lacking. We do not yet know the level of satisfaction of carers of chronically ill children in Saudi Arabia, the roles they occupy in care provision, or what is required to maintain their health and wellbeing. To fill this gap, this study explored the experience of carers supporting their chronically ill children during their hospital stay.

1.2 The family-centred care model

The family-centred care (FCC) model has been widely recognised by many medical societies as a fundamental part of paediatric healthcare to achieve the best possible care and patient and family satisfaction (Alabdulaziz, Moss, & Copnell, 2017; Dennis, Baxter, Ploeg, & Blatz, 2017; Kuo et al., 2012; Zarubi, Reiley, & McCarter, 2008). The Institute for Patient- and Family-Centered Care (n.d., para.1) defines family-centred care as “an approach to the planning, delivery, and evaluation of healthcare that is grounded in mutually beneficial partnerships among healthcare providers, patients, and families.”

The model emphasises the dynamic relationship that exists between the family, patient and healthcare providers (Alabdulaziz et al., 2017; Kuo et al., 2012; Shields, 2010). It calls for assessing the family and patient needs, listening to their concerns, involving them in healthcare delivery and decision making, and improving the care that is delivered to the entire family (Abdulbaki, Gaafar, & Waziry, 2011; Bourke, 1997; Smith & Conant, 2000). FCC practice can lead to improved health results, increased healthcare provider and family satisfaction, increased family awareness about care provision and effective utilisation of health services (Alabdulaziz et al., 2017). Therefore, the model provides an opportunity for effective interactions between the patient, family and the healthcare providers.

There is limited literature about FCC in non-Western countries. A thorough literature review revealed the paucity of FCC literature in Saudi Arabia. The information from this thesis will add to the global body of knowledge and help to better understand how the FCC model can also be applied to the developing country settings like Saudi Arabia and
other Middle Eastern countries with similar cultural backgrounds. More information and details on FCC will be discussed in Chapters 2 and 7.

### 1.3 Significance of the study

As indicated earlier, many children live with chronic conditions that involve frequent hospitalisations (AIHW, 2005; Simon et al., 2010). There is an increase in the hospitalisations for some of these chronic conditions. Frequent hospitalisations have impacts on the carers of these hospitalised children (Ames, Rennick, & Baillargeon, 2011; Nuutila & Salanterä, 2006; Tong et al., 2010). Such impacts include social isolation, family separation, and feelings of lack of control, stress, and anxiety (Barlow & Ellard, 2006; Brown et al., 2008; Hopia et al., 2004; Katooa et al., 2015; Kratz et al., 2009; Uhl et al., 2013; Youngblut et al., 2000).

To ensure the wellbeing of these carers, it is important to reduce the impact of the caring role on the carers. Therefore, it is important to identify what contributes to the carers’ wellbeing. The literature shows that carers need to establish good communication with the healthcare staff and to receive adequate information regarding their child’s condition (Ames et al., 2011; Hummelinck & Pollock, 2006; Lee & Lau, 2013; Söderbäck & Christensson, 2008; Uhl et al., 2013). The carers also need support from healthcare staff to ensure that they have the option to participate in healthcare delivery and decision making regarding their hospitalised child (Uhl et al., 2013).

However, what is known about the burden of care and its impact on the carers is mainly from western countries. There is very limited literature on the Saudi context discussing the hospitalisation experiences of carers of chronically ill children. The available literature is discussed in Chapter 2, Section 2.3.2. To the best of my knowledge there have been no studies carried out in Saudi Arabia to examine the experience of carers and their needs and concerns when caring for their chronically ill hospitalised children. This study addresses this gap. An assessment of the carers’ health and wellbeing in Saudi Arabia could help in addressing their physical, social, and psychological needs and therefore may help enhance paediatric care and reduce the burden of care through:

1) providing information on the level of carers’ satisfaction with physician communication skills and with overall satisfaction. Such information is valuable
in determining what contributes to carers’ satisfaction and what might be done to enhance their experience of hospitalisations,

2) exploring the roles that carers of chronically ill children occupy at the hospital. Providing such information is valuable in determining whether carers have the option to be active participants in their child’s care provision and in identifying opportunities for improvement by establishing an effective relationship with carers, and

3) providing information on the carers’ level of wellbeing and what contributes to their health. By examining the social and cultural context in Saudi Arabia, this thesis adds to the body of knowledge concerning how carers in Saudi Arabia deal with health and disease and what hinders their mental healthcare.

1.4 Purpose of the study

This study examined the experience of carers of chronically ill hospitalised children in a Saudi public hospital. The purpose of the study was to understand the needs and concerns for wellbeing of carers of chronically ill children during their child’s hospital stay.

1.5 The research questions and objectives

This study addressed the following research questions:

1) How satisfied are the carers with the care provided by the hospital for their chronically ill child?

2) What roles do carers play in caring for a chronically ill child in the hospital?

3) How does caring for a hospitalised chronically ill child affect the wellbeing of carers?

3.1) What factors facilitate the health and wellbeing of carers of chronically ill children?

3.2) What barriers do carers face in ensuring their own health and wellbeing?
The objectives of the study were to:

1) explore carers’ experiences of hospitalisation of their ill child,
2) assess the satisfaction of carers with physician communication skills and with the overall care provided for their hospitalised child,
3) explore the roles of carers in the hospital,
4) assess the level of wellbeing of carers, and
5) explore the facilitators and barriers to the wellbeing of carers of chronically ill children during the child’s hospital stay.

1.6 Organisation of the thesis

The thesis is organised according to the following structure: In this first chapter, I began with a brief background about chronic diseases in children and the burden they have on families and communities globally as well as in Saudi Arabia. I then summarised what has been done previously in the literature, thereby demonstrating the gap that this study is trying to fill. Following this, I moved on to the significance of the study together with the aims and the research questions and in this section I outline how this thesis is organized.

In Chapter 2, I go into more detail about chronic diseases, establishing the burden of chronic paediatric conditions, the impact on the child’s and the carer’s wellbeing, and what is currently known about the needs and concerns of carers of hospitalised children. Next, I discuss the roles of carers in paediatric hospitalisations and the different needs they require to maintain their wellbeing. I also present the different emotional, psychological, financial, social and developmental effects that chronic diseases have on the sick child and the family members. Finally, I move on to discussing and critically analysing family-centred care as the model that is relevant to understanding current practices in addressing the needs of the carer and the chronically ill child in providing care for the hospitalised child.

In Chapter 3, I present relevant information about Saudi Arabia that will help to contextualise the research findings. This includes demographic information, an overview of the health system and the health situation, including the mental health system, and an overview of mental illnesses in Saudi Arabia. Finally, the chapter concludes with a brief overview of the Saudi Arabian social and cultural context of disease and illness.
In Chapter 4, I explain and discuss the research design, including the methodologies underpinning the research. I explain in detail how both the quantitative and qualitative phases were designed, along with the process of data collection and data analysis. I provide a brief background to my personal and professional life so that the readers are then able to determine to what extent my background may have influenced and shaped the research. Finally, I discuss how I ensured rigour in the research, particularly in the qualitative phase of the study.

In Chapter 5, I present the results of the quantitative study. The surveys were used to respond to the first and second research questions. First, I used the satisfaction questionnaire to measure the carer’s satisfaction with the physician’s communication skills, as well as overall satisfaction. Second, I used the wellbeing questionnaire to measure the health and wellbeing of the carers from their perspective. The two questionnaires were also used to compare the satisfaction and wellbeing between carers of chronically ill and acutely ill children.

In Chapter 6, I present the findings of the qualitative study aimed at identifying the needs and concerns of carers of chronically ill hospitalised children.

In Chapter 7, I interpret the findings through the lens of the family-centred care model. Finally, in Chapter 8, I provide a general discussion that connects the dots and brings together results from the quantitative and qualitative phases. The thesis concludes by discussing the strengths and limitations faced in this research and the implications of the research for Saudi Arabia.
Chapter 2

Literature Review

The main aim of this chapter is to establish the burden of chronic paediatric conditions, their impact on children and their carers’ wellbeing, and what is currently known about the needs and concerns of carers of hospitalised children. This chapter begins by examining chronic diseases and their significance as a public health problem. This is followed by a discussion of the global burden of chronic paediatric diseases. Next, the chapter discusses the roles of primary caregivers in paediatric hospitalisations and the different requirements for maintaining their wellbeing. Finally, the different emotional, psychological, financial, social and developmental effects that chronic diseases have on the sick child and the family members are presented.

There are several variations in the available definitions for chronic diseases. These variations include not only classifying different diseases under the “chronic diseases” umbrella but also variations in the time that a disease must be present for it to be classified as a chronic disease (Bernell & Howard, 2016). The World Health Organization (2018, para. 1) defines chronic diseases as “Diseases that are not passed from person to person, of long duration and generally slow progression.” This definition excludes HIV as a chronic disease as it is “passed from person to person.” The Australian Institute of Health and Welfare (2017, para. 1) defines chronic diseases as “long-lasting with persistent effects ranging from mild to severe” and specifies some common features amongst chronic diseases which include: “complex causality with multiple factors leading to their onset, a long developmental period for which there may be no symptoms, a prolonged course of illness that could lead to other health complications, and are associated with functional impairment or disability.” For the purpose of this study, this definition will be used, as it encompasses more diseases and conditions within the term “chronic disease” and highlights some common features of chronic diseases.

A person may have more than one chronic disease at once. Chronic diseases typically have no curative treatment or effective vaccination and have varying trajectories – for instance, there may be little or slow progression over years, with episodes of often unpredictable acute exacerbations. Others may lead to complex chronic conditions that require long-term hospitalisation and carry a high risk of mortality. In general, chronic
conditions require long-term management which limits the functioning of the individual and necessitates special adaptation (AIHW, 2014; Barlow & Ellard, 2006; Charron-Prochownik, 2002). Furthermore, chronic diseases may influence a person’s quality of life by affecting his/her social life and causing an economic burden (AIHW, 2005; Halpin, Morales-Suarez-Varela, & Martin-Moreno, 2010).

2.1 Literature search strategy

The search strategy involved reviewing pertinent literature around topics on chronic diseases in developed and developing countries, chronic diseases in children, effects of caring for a chronically ill children, the family centred care model, the health situation in Saudi Arabia and the cultural and societal context of Saudi Arabia. The aim of this literature review was to critically review existing literature to better understand what is currently known about the burden of chronic paediatric conditions, their impact on children and their carers’ wellbeing, and the needs and concerns of carers of hospitalised children globally and in Saudi Arabia.

The literature was searched throughout the study period to gather relevant articles by using a variety of electronic databases such as PUBMED, CINAHL, EMBASE, PopLine and Cochrane Library. The search was conducted on relevant articles dating back to 1944 till 2018 to shed the light on how the practice of caring for hospitalised children has changed throughout the years which eventually led to the development of different caring models. The researcher used a variety of search terms such as ‘chronically ill children’, ‘family centred care model’, ‘care of chronically ill children’. ‘Saudi Arabia’s health system’, ‘paediatric chronic diseases’, ‘the Platt report’, amongst many others.

2.2 Global response to chronic diseases

In response to the overwhelming social, economic and public health impacts of chronic diseases (these impacts will be discussed in Sections 2.4 and 2.8), the World Health Organization adopted the Global Non-Communicable Diseases Action Plan in addition to regional plans (WHO, 2013b). This is articulated in the New Public Health approach, which is an integration of evidence-based measures at national and regional levels that focuses on surveillance and research and promotes the health of the individuals and populations (Halpin et al., 2010; Tulchinsky & Varavikova, 2010). Moreover, the National Heart, Lung, and Blood Institute has developed Centres of Excellence in chronic
disease management in low and middle-income countries (Halpin et al., 2010). Additionally, the magnitude of chronic diseases was the focus of a United Nations High Level meeting in 2011, which called for a system of indicators and targets to monitor progress against chronic diseases (Alleyne et al., 2013; AIHW, 2014; Byfield & Moodie, 2013). After that, the target of a 25% reduction in premature mortality from chronic disease by 2025 was set and adopted by countries around the world (Alleyne et al., 2013; AIHW, 2014; Byfield & Moodie, 2013).

2.3 Chronic diseases in children

There are many types of chronic paediatric diseases. Some are present at time of birth, while others develop at later stages of childhood. Although some children may eventually recover from chronic diseases, in many cases, chronic diseases persist into adulthood and affect the person throughout their life (AIHW, 2005). Therefore, these diseases may challenge the normal trajectory of childhood by disrupting the physical, social, cognitive and emotional development of the child (AIHW, 2005). Globally, the prevalence and impact of chronic paediatric conditions has steadily continued to escalate (McManus & White, 2017; Perrin et al., 2014), with 1.2 million deaths in children due to chronic diseases in 2002 (Proimos & Klein, 2012).

Asthma, type 1 diabetes and cancer are examples of chronic diseases that have severe impacts on the health of children – for both individuals and their communities (AIHW, 2012). Diabetes mellitus is characterised by the body’s inability to control glucose, which is the main source of energy. This is caused by a deficiency of insulin in the body or an inability to make use of the available insulin, or both. As a result, the blood-glucose level increases, which can have serious consequences on health including blindness, kidney failure, disability and death (AIHW, 2012). Care for type 1 diabetes in a child is often complex and treatment entails long-lasting relationships with professionals. It also requires the child to learn how to manage his/her diseases by monitoring energy intake, checking glucose levels and learning how to inject insulin (AIHW, 2005).

Trends in paediatric hospitalisations suggest that the number of overall children’s admissions and deaths have declined. However, chronic conditions currently account for most hospitalisations and deaths in children (Wijlaars, Gilbert, & Hardelid, 2016). Trends in paediatric hospitalisations also suggest that most children without a chronic condition are less likely to be hospitalised for a serious illness. Therefore, as clearly indicated by
Wijlaars and colleagues (2016), it appears that the relatively small portion of children with chronic diseases accounts for most of the healthcare expenditure. Wijlaars’s argument about the significant health expenditure incurred by chronic paediatric conditions is supported by an earlier study by Berry and colleagues (2014). In their study, Berry and colleagues attempted to describe the medical expenditure of paediatric patient with complex chronic conditions in the year 2011. They used two databases; Truven Marketscan Medicaid Database and the Kids’ Inpatient Database (KID) for their study (Berry et al., 2014). The former database contained the medical claims of more than 3 million children. The KID is the largest multistate database in the US that at the time of the study included information on admissions from the year 2000 through to 2009. The datasets for each year of the KID database includes more than 3.4 million hospitalisations of children aged 0-18 across more than 4000 hospitals in the US. With the use of these large datasets, the estimates of the study was likely to be highly reliable. The study estimated that children with complex medical conditions accounted for 34% ($1.4 billion) of the total medical expenditure on children with Medicaid. Not only is this consistent with the findings of Wijlaars and colleagues mentioned earlier, the study design was robust as explained below and therefore, I would argue is a clear indication of the economic impact of the hospitalisation of even a small proportion of chronically ill children. Berry and colleagues (2014) started off by identifying the diseases that are considered complex chronic conditions by using the International Classification of Diseases, ninth edition, Clinical Modification (ICD-9-CM). They then accounted for how the use of different medical services could vary across and between different groups of complex chronic conditions. Finally, they took into account how there could be variations in spending in unplanned hospital readmission, the use of outpatient services and any other services that are not part of the hospital admission.

Further evidence for the economic impact of the hospitalisation of children with chronic conditions is provided by Simon and colleagues who undertook a retrospective observation of nationally representative data in the United States. They examined inpatient paediatric admissions for the years 1997, 2000, 2003 and 2006 for children under 18 years of age. They found that hospital admissions for complex chronic diseases increased from 8.9% of admissions in 1997 to 10.1% in 2006. These admissions utilised 22.7 – 26.1% of bed days and consumed a significant amount of health services (Simon et al., 2010). Similar results were also noted by Cohen et al. (2012) in a Canadian study.
They used hospital admission data for the years 2005 – 2007 and included more than 15 thousand admissions for chronic complex conditions which corresponds to 0.67% of children in the study area. The study cohorts were identified through the use of the Discharge Abstract Database, The National Ambulatory Care Reporting System and the Ontario Health Insurance Plan data sets. All of these datasets are monitored for quality by the Canadian Institute for Health Information and therefore adds to the reliability of their findings. The study examined each child’s usage of the healthcare system and the associated costs throughout the two year study period. Usage of healthcare system included admissions to the hospital, consultations by specialists, surgeries, emergency room visits and homecare expenses. Costs of medications, physician visits and homecare were calculated by summing up the fees directly paid to providers. The remaining costs for other services were estimated by using patient-specific case weights indices multiplied by the provisional average cost. The case weights were obtained from the individual patient records and the average costs were obtained from the Ministry of Health. The study concluded that children with complex chronic diseases, although comprising only a small percentage of the population, accounted for one-third of expenditure on paediatric healthcare. Despite a number of positive aspects of the design of this study, especially in terms of how the costs were calculated, this study only included paediatric patients who have complex medical conditions and were hospitalised for more than 2 years; those who were hospitalised with complex chronic condition for less than two years were not included. Thus, the prevalence of complex chronic conditions and overall costs may have been underestimated as a result of excluding a significant proportion of paediatric patients.

It is evident from the literature reviewed above that complex chronic conditions in children are responsible for most of the paediatric hospitalisations and a substantial amount of healthcare spending. Such patterns have important implications for healthcare delivery such as identifying and implementing best practice for children with these conditions to provide the best possible and efficient care.

2.3.1 Chronic diseases in Western countries

Type 1 diabetes is a significant public health issue in both Australia and the United States. In Australia, in 2016, the prevalence of the disease was 6,400 children with type 1 diabetes under 15 years of age (AIHW, 2018a). The incidence of the disease in 2016 was 2,600 cases which equated to 12 cases/100,000 population (AIHW, 2018a). Similarly, in
the United States, annual incidence of type 1 diabetes in children in the years 2007-2008 exceeded 20 cases per 100,000 population (Dabelea et al., 2007). In Europe, reliable, up-to-date information on type 1 diabetes is available, with nationwide registries in most countries (Patterson et al., 2014). A study by Patterson et al. (2012) using these registries estimated the annual increase in incidence of type 1 diabetes in Europe to be 3-4%. A comparison of the increase rates showed that the escalation was predominantly in Austria, Hungary, Lithuania and in some parts of Germany, while there were decreases in Poland, UK and other parts of Germany. Another study by Marigliano et al. (2015) assessed the incidence and prevalence of type 1 diabetes in children under 15 years of age in Italy from 2008-2013. The study estimates the average percentage increase in incidence rate during the study period to be 3.6% per year. The average prevalence during the study period was estimated to be 1.26 cases per 1000 persons. Both studies by Patterson et al. (2012) and Marigliano et al. (2015) show a similar incidence rate of diabetes and have used the same method of estimating the incidence rate from the reported prevalence with the use of Poisson regression. Similar results were obtained in the Netherlands in which the prevalence of type 1 diabetes in children under 15 years during the study period (2009-2011) was observed to be 144/100,000 children (Spaans et al., 2015).

Allergic diseases are also common chronic conditions in children. The prevalence of allergic diseases in Western countries is estimated to be 41% compared to other chronic diseases (Al Frayh, Shakoor, ElRab, & Hasnain, 2001; Warner et al., 2006). Of the different types of allergic diseases, bronchial asthma is particularly serious, contributing to most of the morbidity and mortality (Al Frayh et al., 2001). In some instances, asthma can restrict some children’s lives and the lives of their families (AIHW, 2012). In spite of latest improvements in understanding the pathogenesis of asthma and developing new treatments, the prevalence of asthma is still rising in different countries (Al Frayh et al., 2001; Chiou & Hsieh, 2008). In Australian children, although deaths due to asthma are not common, asthma was responsible for most of the disease burden in children in 2003 (AIHW, 2005; AIHW, 2012). More recent data show that asthma was responsible for most of the disease burden in Australian children aged 5-14 years with asthma ranking first in as the leading disease burden for males and second for females in that age group (AIHW, 2018b). In the United States, the prevalence of asthma in 2009 was 8.2%, affecting a total of 24.6 million people, of which 7.1 million were children (Akinbami, Moorman, & Liu, 2011; Moorman et al., 2011). In Canada, incidence of asthma in
children increased by 30% from 1996 to 2005, and the reduction in overall mortality, contributed to a 55.1% increase in asthma prevalence during the study period (Gershon et al., 2010). The authors used a validated registry of all residents of the city with asthma, utilising an asthma case definition that was validated and employed in previous studies.

Cancer is another chronic disease that affects some children, although it is less common. In Australia in 2003, 16% of deaths among children were due to cancer. In Switzerland, a study by Spycher et al. (2011) estimated incidence of leukaemia in children under 14 years of age to be 4.51 per 100,000 person-years and 13.85 for all other cancers.

### 2.3.2 Chronic diseases in Saudi Arabian context

As discussed in Chapter 1, over the past 20 years, the prevalence of chronic paediatric conditions has also increased in Saudi Arabia, with conditions such as asthma, diabetes, childhood obesity, cancer, heart diseases and genetic blood disorders (MOH, 2011). However, the literature in the Saudi context has tended to focus on diabetes, with other chronic paediatric diseases being underreported. For example, several studies concluded that sickle cell disease is relatively common in Saudi Arabia (Al-Qurashi, El-Mouzan, Al-Herbish, Al-Salloum, & Al-Omar, 2008; AlHamdan, AlMazrou, AlSwaidi, & Choudhry, 2007; Jastaniah, 2011); however, information on the prevalence of sickle cell diseases in Saudi is inconsistent (Jastaniah, 2011). Studies have estimated that 2 – 27% of the population carries the gene and up to 1.4% have sickle cell disease (Al-Qurashi et al., 2008; AlHamdan et al., 2007). However, these estimates probably underestimate the frequency of the disease as they are not derived from newborn screening (Jastaniah, 2011). Moreover, data in Al-Qurashi et al’s (2008) and AlHamdan et al’s (2007) studies were based on data for the period 2004-2005. It is likely that the current situation would be very different given that mandatory premarital screening for sickle cell disease started in Saudi Arabia in 2004. The aim of the screening was to identify couples at risk of having children with sickle cell disease and provide counselling to reduce the occurrence of these marriages and therefore the birth of children with sickle cell disease (Alswaidi et al., 2012).

The problem of type 1 diabetes is a significant issue in Saudi Arabia, and this might be a reason that it has received most of the attention. A study investigating the incidence of type 1 diabetes in children under 15 years of age in a sub-population in Dhahran city in the eastern province of Saudi Arabia in the years 1990-2007 concluded that the incidence
rate continued to rise alarmingly over the study period, exceeding those of other Arab countries (Abduljabbar, Aljubeh, Amalraj, & Cherian, 2010). The average incidence was 27.52/100,000/year. The study collected data from the paediatric diabetes registry that was developed in 1994 and included all children diagnosed with new-onset type 1 diabetes from 1994 till 2007. The results seem to be reliable as the data collected were further verified from the electronic records of the computerised registry of all children admitted to this hospital with a diagnosis of diabetes mellitus during the study period. Data were collected on the admission date, gender, diagnosis and age of all newly diagnosed children for the 18-year study period.

The Saudi literature indicates that the incidence and prevalence of asthma is very common; however, much of this literature is outdated. The highly cited study by Al Frayh et al. (2001) used an internationally designed protocol and provided important reliable information on the prevalence of asthma in Saudi Arabia. The study investigated the change in asthma prevalence in school-aged children between the age of 8 and 16 years over a nine-year period, showing an increase in prevalence from 8% in 1986 to 23% in 1995. More recent information is not available for Saudi Arabia. The above evidence establishes that chronic paediatric conditions are a growing concern in Saudi Arabia. However, this data needs to be interpreted cautiously as the current evidence is outdated. There is an urgent need for updating the evidence to better reflect the current situation. The prevalent chronic disease in Saudi Arabian children will be further discussed in Chapter 3.

### 2.4 Caring for a chronically ill child

Having a child with a chronic disease affects the family differently than an acute illness. Although acute illness disrupts the usual life of the family and their way of functioning for a relatively short time, once the patient has received treatment, it is expected that life will go back to normal (Marin, Chen, Munch, & Miller, 2009). However, with chronic conditions, there is no such expectation, with prolonged effects requiring the family to adjust to the sickness and to continuously accommodate the needs of the sick family member (Marin et al., 2009). Moreover, advances in technology and improvements in providing medical care have led to an increase in the life expectancy of children with chronic illnesses. This prolonged lifespan in chronically ill children comes with an increase in medical expenditure as well as continued burden and stress on the parents and
the families (Balling & McCubbin, 2001; Boling, 2005; Broger & Zeni, 2011; Janse et al., 2004). Additionally, according to Balling and McCubbin (2001) children with chronic conditions are often susceptible to acquiring acute illnesses. This adds to their burden and requires hospitalisation for both diseases, thus increasing their healthcare expenditure. The susceptibility of children with chronic diseases to acute illnesses was demonstrated in a study by Dosa, Boeing, and Kanter (2001), who reviewed all of the charts of unscheduled ICU admissions relating to chronic conditions to examine the events that increased the risk of developing acute illnesses. The study was conducted in the United States in a region of 17 counties with a total population of 472 thousand children under 18 years of age. This study revealed that children with chronic conditions have a threefold excessive risk of developing an acute illness that is directly attributable to the chronic condition and that requires hospitalisation compared to other healthy children.

The above-cited literature clearly demonstrates that parenting a child with chronic illness can have significant emotional and social burdens on the parent. Over the past few years, many scholars have reviewed the possible impacts of having a child with a chronic illness (Barlow & Ellard, 2006; Brown et al., 2008; Hopia et al., 2004; Katooa et al., 2015; Kratz et al., 2009; Youngblut et al., 2000). For example, in their review of the literature, Barlow and Ellard (2006) examined ten published systematic reviews to provide an assessment of the psychological wellbeing of children with chronic disease, their parents and siblings. The authors reported that these systematic reviews in general showed that chronically ill children are at an elevated risk of psychological distress although that risk differs according to the specific chronic disease. However, according to Barlow and Ellard (2006) only two of the studies they included in their review investigated the effects of the chronic disease on the parents. They noted that these two studies had inconsistent findings with one revealing that parents of children with cancer suffered from stress – especially after diagnosis and the other reported that parents of children with sickle cell disease showed no difference in their wellbeing and mental health compared to controls (Barlow & Ellard, 2006). These inconsistencies suggest that the precise extent of parental stress and psychological wellbeing may vary depending on their child’s disease condition or how the study was done.

A more recent quantitative study involving 1567 parents of a chronically ill and/or disabled children and paediatric nurses in Germany by Vonneilich, Lüdecke, and Kofahl (2016) reported similar stressors associated with having a chronically ill child. The study
looked at how the burden of care affected the health-related quality of life of carers of children with different diseases. The authors reported that parents of the hospitalised children experienced a heavy emotional burden as a result of the hospitalisation of their child. They often felt insecure and helpless in the hospital with no idea about what was required of them. The parents also needed help, information, support, encouragement, and counselling in order for them to cope with the disease. The burden of care seemed to have impacted the parent’s mental and physical health. An earlier study by Kratz and colleagues (2009) in the United States also reported similar findings. This 2009 study used a randomised controlled trial to examine the effectiveness of a curriculum called “building on family strengths,” and was complemented by qualitative data collected from 83 participants in the intervention groups. The study reported that parents were left managing the strong emotions of stress, anxiety, vulnerability and social isolation. Families in the study also reported that support systems can become drained, resulting in the family feeling lonely.

Therefore as discussed above, there is strong evidence in the literature about negative impacts on the family when there is a child with a chronic illness irrespective of where the research has been carried out (Brown et al., 2008; Katooa et al., 2015; Lukemeyer, Meyers, & Smeeding, 2000; Youngblut et al., 2000). In summary, the literature discussed above has identified a myriad of stressors that may affect the family and their different needs. These stressors include financial burdens, changing lifestyles, interruptions of daily routines, adjustments required by the medical conditions, role strains, general uncertainty over the child’s future, and the prognosis of the disease (Brown et al., 2008; Katooa et al., 2015; Lukemeyer et al., 2000; Youngblut et al., 2000). All of these sources of stress alone or collectively may lead to anxiety, depression, loss of control and post-traumatic stress (Brown et al., 2008).

In Saudi Arabia, studies discussing the experience of carers of hospitalised children have focused on carers of children with disabilities only. A prospective study conducted in the Saudi city of Riyadh compared between mood symptoms of 75 mothers of children with sensory, physical and mental problems (cases) and 35 mothers with healthy children (controls) using the hospital Anxiety and Depression scale (Al-Eithan, Robert, & Al-Saeed, 2010). The scale is used extensively in clinical settings in Saudi Arabia and was assessed to have high validity and reliability (Al Aseri et al., 2015). The study found that these carers had higher scores of anxiety and depression compared to the control group.
(Al-Eithan, Robert, & Al-Saeed, 2010). Another retrospective cohort study conducted in Saudi Arabia in 2011 used the same Anxiety and Depression scale and recruited carers of a child with autism as cases and carers of a normally developed child as controls (Almansour, Alateeq, Alzahrani, Algeffari, & Alhomaidan, 2013). Similar to the above mentioned study, Almansour and colleagues found that the average depression score and the average anxiety score were significantly higher in cases compared to controls. They concluded that the burden of care for a child with autism on carers is associated with an increased risk for anxiety and depression (Almansour et al., 2013). The above mentioned studies by Al-Eithan et al. (2010) and Almansour, Alateeq, Alzahrani, Algeffari, and Alhomaidan (2013) used highly reliable and valid measures and therefore it could be concluded that the demand placed on the mother caring for a child with disability contributes to high levels of stress and anxiety for these mothers.

The comprehensive literature search carried out as part of this literature review did not find any Saudi studies discussing the effects of caring for a chronically ill child on the carer. The lack of studies may be an indication of how this issue is overlooked in Saudi Arabia. Based on the studies from other countries presented in the above sections, chronic conditions are also highly likely to negatively affect Saudi families in different social, behavioural and personal ways. The social and cultural norms practised in Saudi Arabia affect the ways in which they respond or function in the event of a disease. These different effects will be further discussed in Chapter 3.

2.5 Partnership between the parents and healthcare team

The importance of developing a truly effective partnership between the parents and the healthcare team has been noted in the literature (Fisher, 2001; MacKean, Thurston, & Scott, 2005; Nuutila & Salanterä, 2006; Swallow & Jacoby, 2001). While there have been differing views about the parent-healthcare staff partnership, there is a consensus that the development of a true effective partnership is generally beneficial for healthcare provision (Espezel & Canam, 2003; O'Haire & Blackford, 2005; Swallow & Jacoby, 2001).

Qualitative studies in Canada exploring family centred care (FCC) through the experience of families with hospitalised children have shown that parents of a chronically ill child value the healthcare team when the team appears to care about the parents, understand that each family is different and negotiate the roles of each partner as part of an effective
Partnership (Espezel & Canam, 2003; MacKean et al., 2005). Parents value the rapport that is established with the nurse. A key factor in establishing that rapport from the parents’ perspective occurs when the nurse demonstrates that she/he is familiar with the child and his/her condition. Another important aspect in maintaining rapport between the parent and the nurse is sharing of information (Espezel & Canam, 2003).

The development of a true partnership between the parents and the healthcare staff is characterised by mutual trust between both partners, transparency and open communication, which enables partners to negotiate the roles that each of them will play (MacKean et al., 2005; McPherson, Jefferson, Kissoon, Kwong, & Rasmussen, 2011; Nuutila & Salanterä, 2006; O’Haire & Blackford, 2005; Swallow & Jacoby, 2001). Factors such as the uniqueness of the child, his/her family, the disease and the evolving parent-healthcare staff partnership are also taken into consideration and accommodated for (MacKean et al., 2005; Nuutila & Salanterä, 2006). For example, Nuutila and Salanterä (2006) conducted a study in Finland which involved interviews with nine families who had a child that was diagnosed with a long-term illness. While this study was based on a small sample, the study elicited rich information from a diverse range of participants. Moreover, the study design incorporated various measures such as providing study participants the opportunity to give feedback on the findings and researchers’ interpretations. Thus, although the sample size is small the study findings can be considered trustworthy and credible (Liamputtong, 2009). The study found that an effective partnership between the parents and the healthcare staff had a profound impact on the ability of parents to cope with the disease. The effective partnership helped the parents at the early stages of diagnosis when they needed explicit uncomplicated information to be shared with them about the child’s disease. To establish trust, it was important to the parents that they perceive the healthcare staff to have the knowledge required to care for their child. At a later stage, when their child was discharged, the parents needed to learn homecare. In the Finnish study the researchers concluded that the following factors were essential for an effective and collaborative partnership between healthcare providers and parents as well as to avoid conflict:

1) Parents need to be provided with information and advice relevant to managing their child’s condition.

2) Healthcare staff needed to listen to the parents and their viewpoints

3) Healthcare staff needed to get to know the family and their everyday life
4) The manner in which information is shared between the healthcare staff and the family of the child was important. Communication needed to be clear and expectations clearly articulated from the start. Healthcare needs should be identified through mutual discussion while ensuring that the information communicated had been understood by both sides of the partnership.

The attitude of the healthcare staff toward the parents may present a problem in the development of an effective partnership. When the staff do not show their respect to the knowledge and skill the parents have gained through caring for their chronically ill child, the partnership may be hindered (Nuutila & Salanterä, 2006). For example, a grounded theory study by Coyne and Cowley (2007) conducted in two hospitals in England found that some nurses in the study misinterpreted the partnership with the parents as providing the nurse with assistance. The parents in the study were unofficially viewed as an extra set of hands rather than partners who can determine the extent of their involvement. The nurses in the study assumed that parents were going to help in taking care of the child and did not ask the parents if they wanted to be involved. They took the help of parents for granted.

The attitude of the carer and how he/she is willing to enter this partnership and make it work is also important for developing an effective partnership (Thorne, Nyhlin, & Paterson, 2000). When carers are passive toward their child’s care, the extent of their involvement is limited to understanding what is going on with his/her care, and they are not expected to be actively involved in the care of the child, then a true partnership with the healthcare staff will not be possible (Simons, Franck, & Roberson, 2001).

In summary, evidence from the literature consistently shows that effective partnerships between parents and the healthcare staff can help parents to cope with their child’s diseases (Coyne & Cowley, 2007; Espezel & Canam, 2003; Fisher, 2001; MacKean et al., 2005; Newton, 2000; Nuutila & Salanterä, 2006; O'Haire & Blackford, 2005). The partnership needs to be based on mutual respect and open communication. The success of the partnership may be affected by the attitude of both partners and their desire to collaborate with each other (Espezel & Canam, 2003; Nuutila & Salanterä, 2006; O'Haire & Blackford, 2005).

Most of the studies about partnership in care discussed in this section were undertaken in developed countries, and there were very few studies from developing countries. This
literature review identified only one study in Saudi Arabia discussing parent-professional collaboration. In their study exploring the perception of FCC from the perspective of families and paediatric nurses, Alabdulaziz et al. (2017) found that the paediatric nurses scored low in the quantitative data on their perception and practice of the parent-staff relationship. The authors compared the mean scores of the perception and practice of nurses for all FCC elements. For the parent-staff relationship element, the mean practice scores were lower than the perception score (3.53 and 3.95, respectively) and the difference was statistically significant. This meant that nurses probably believed that this relationship was important but were less likely to incorporate it into their practice. However, while the qualitative findings revealed that nurses knew the importance of involving the parents in the care process and the need to work in collaboration with them, the quantitative data contradicted these findings. The observations made by the researchers determined that the nurses involved the parents by assigning them caring, hygiene or medication roles. However, it might be the case that the nurses were trying to involve the parents in the care process but did not necessarily establish an effective partnership that enabled them to make decisions and negotiate roles, which are essential elements of an effective partnership. It is likely that, although the nurses were familiar with the concept of partnership they might not necessarily be familiar of ways to put it into practice or were practicing a very superficial form of this partnership. Whether this applies to other healthcare facilities in Saudi Arabia is unknown due to limited studies. My own experiences in Saudi Arabia’s healthcare facilities leads me to agree with the Alabulaziz et al.’s (2017) findings. Carers are viewed as helping hands that lessen the burden of the healthcare staff and rarely as partners in the care of their children in Saudi Arabia. This might be as a result of the limited knowledge of ways to partner with carers and limited support from upper management. In reviewing the available literature, it is hard to draw a firm conclusion on this issue. It is essential to explore the nature of the relationship between carers and healthcare staff further and examine the factors that influence the extent of this relationship in Saudi Arabia.

2.6 Parental roles

The essential roles that parents occupy when their child is hospitalised have been well documented in studies mostly from developed countries, with a few from developing countries. These roles include being a source of comfort and support for their children
the role of a learner and a teacher, provider of physical care (Affram et al., 2008; Gasquoine, 2005; Söderbäck & Christensson, 2008) and, in some instances, provider of technical care (Affram et al., 2008). These roles will be discussed in detail in Sections 2.5.1, 2.5.2, and 2.5.3.

These roles differ from parent to parent and from one country to another. For example, Shields and Nixon (2004) looked at the hospital care of children in four countries – two developed (Australia and Britain) and two developing (Thailand and Indonesia). The authors found that although there were no rules in the hospital that require parents to stay with their children, in both developed and developing countries, the parents themselves thought that they should stay with their children and did that. Although parents were not obligated to stay, the parents were expected to participate in providing basic care to the child. However, fewer parents in developing countries thought that they should be expected to be involved in the care. Parents in Indonesia were paying for the care of their children at the hospital and, therefore, some of them felt that they should not be doing the care themselves. This study shows the roles of parents and what is expected of them is not the same in all countries. In addition the study demonstrated how culture plays a major role in dictating what is accepted of carers and healthcare providers and what roles they occupy. While the study provides a useful comparison of the perception of care and roles in developed and developing countries, it would be useful if the study is replicated in Arab and Middle Eastern countries to examine the influence of culture in these regions.

Just as the role of the parents in delivering care differs from one country to another, the extent of the involvement also differs from parent to parent within one country or even culture. In general, it seems that parents are now expected to be actively involved in providing care for their hospitalised child. However, the extent to which each parent wants to participate is not clear (Coyne, 2015). Balling and McCubbin (2001) in their study of the relationship between primary caregivers of chronically ill children and hospital staff in Canada, noted that parents of a chronically ill hospitalised child have a strong desire to be involved in the delivery of the technical aspects of care as well as the routine aspects of care. According to the authors, the caregivers of chronically ill children accumulate a wealth of knowledge and experience in dealing with their hospitalised child’s condition, leading them to think that they are experts in delivering technical care and thus desire that kind of involvement. However, it is unknown whether this attitude is also common amongst caregivers of chronically ill children in other locations. There is a
gap in the literature about the degree of involvement that caregivers in developing countries – particularly Saudi Arabia – desire.

2.6.1 Provider of nurture, support and comfort
The role that parents undertake to support and comfort their child while hospitalised has been well documented through reliable and rigorous qualitative studies in both developing and developed countries (Affram et al., 2008; Lam, Chang, & Morrissey, 2006; Roden, 2005). These studies showed that many parents regarded supporting and comforting their children as the most crucial role they can provide for their children. Lam et al.’s (2006) study in Hong Kong revealed that parents believed their presence is really important to provide emotional love and support. They felt that, with their absence, an important aspect of the child’s care would be missing that cannot be replaced by the nurses’ care (Affram et al., 2008).

The presence of the parent when the child is about to undergo a certain procedure can help ease the child’s concerns and lessen their fear. Ames et al. (2011) and Lam et al. (2006) both demonstrated that parents occupy the important role of explaining what is happening to their child and reassuring him/her about their health. When the child is undergoing a difficult or painful technical procedure such as drawing blood, parents can provide the child with a sense of security and reassurance.

While parents agree to and undertake their role as supporter and comforter, fulfilling this role may have a negative impact on their own health, raising issues around the needs and concerns of the parents themselves (Ames et al., 2011). These negative impacts are discussed in Section 2.8, while needs and concerns are considered in Section 2.7.

2.6.2 A teacher and a learner
Parents are sometimes expected to teach the healthcare team about their child’s usual behaviours and activities and whether or not a child has deviated from their usual selves (James et al., 2002). At other times, parents might learn from the healthcare staff about their child’s medical care and how they can participate in it. However, parental participation is affected by the willingness of the staff to involve the parents in caring for the children and teaching parents the skills they need in caring for the child. The more informative and clear the information parents receive from the staff the more likely it is that they will contribute to the care of their child and have a positive experience of hospitalisation (James et al., 2002). It is therefore important that good communication is
established between the parents and the staff, involving policies and routines (Newton, 2000). Kirk and Glendinning (2004) and Coyne and Cowley (2007) found that when the child is ready for discharge from the hospital but needs technical care to be carried out at home, the parents were ready to learn if they were shown how to do it, were observed doing it, and were confident in their ability to carry on doing it at home. The parents in both studies were eager to have their child at home and that motivated them to learn the technical care required (Coyne & Cowley, 2007; Kirk & Glendinning, 2004).

2.6.3 Provider of physical and technical care
Qualitative studies conducted in both developed and developing countries have shown consistently that most parents choose to stay in the hospital and provide their usual physical care for their children (Affram et al., 2008; Coyne & Cowley, 2007; Gasquoine, 2005). Basic physical care includes bathing, changing diapers, feeding and dressing (Affram et al., 2008; Gasquoine, 2005).

Qualitative studies conducted in Ghana, New Zealand and Portugal have shown that parents were sometimes responsible for providing technical care for the child, especially when the child has a chronic disease and the carer has become an expert in caring for the child (Affram et al., 2008; Coyne & Cowley, 2007; Melo, Ferreira, Lima, & Mello, 2014). This involved advanced nursing care such as maintaining intravenous lines, administering medication, and reporting unusual findings to the healthcare team (Affram et al., 2008; Coyne & Cowley, 2007; Melo et al., 2014). For example, in their grounded theory study, Coyne and Cowley (2007) undertook a one-year observation in two hospitals in England. The study involved 11 children with a range of acute and chronic diseases, 8 mothers, 2 fathers and 12 nurses. They found that parents generally were willing to provide basic care for their children but were reluctant to provide technical care, which was viewed as part of the nurses’ job and parents feared that if they became involved in technical care they could harm their children. However, in the case of chronically ill children, parents had become experts in caring for their children and were, therefore, confident in their ability to provide such care. Based on these findings, Coyne and Cowley (2007) and Balling and McCubbin (2001) argued that parents of chronically ill children are different from other parents due to the expertise parents develop through the constant care they provide for their chronically ill children. Therefore, such parents were more comfortable than other parents in providing technical care. However, whether the parents of chronically ill children wanted to be involved in providing technical care or felt compelled...
to do so as it was expected of them is not known. It is also possible that the parents feared
that not complying with what was expected of them would affect the quality of care
provided to their children.

### 2.7 Parental needs during hospitalisation of child

Different studies have delineated several needs that the caregiver and/or the chronically
ill child require to promote their wellbeing during the hospitalisation of their child. These
needs include the need for recognising the parents’ expertise, the need for partnership
with the healthcare team, the need for normalisation, the need for information, the need
for participation in delivering care, the need for self-efficacy, the need for certainty, the
need for a listening ear and the need for care (Balling & McCubbin, 2001; Hopia et al.,
2004; Hummelinck & Pollock, 2006; Katooa et al., 2015; Kratz et al., 2009).

Reliable and rigorous qualitative studies and systematic reviews in developed and
developing countries have consistently demonstrated that the presence of the mothers in
the hospital is closely related to the physical, social and emotional wellbeing of the sick
child (Hopia, Paavilainen, & Åstedt-Kurki, 2004; Pai, Bhaduri, Jain, Kumar, & Sethi,
2008; Power & Franck, 2008). Pai et al. (2008) in their grounded theory study in India
found that parents are regarded as experts on their child and his/her behaviour and
therefore can make a valuable contribution to his/her care. Parental participation also
benefits the child by imposing a sense of security. The separation anxiety that may occur
due to hospitalisation is therefore avoided, and the parent-child relationship is preserved
and probably even strengthened (Hopia et al., 2004; Power & Franck, 2008). However,
during the child’s hospitalisation, parents need to be supported by the healthcare team to
help them cope emotionally and physically with their child’s illness and hospitalisation.
It is important that parents receive such necessary support to help them avoid becoming
mentally and physically exhausted (Hopia et al., 2004; Sarajärvi, Haapamäki, &
Paavilainen, 2006). In fact, many parents regarded the nurses’ role in their child’s illness
as providing emotional support (Pai et al., 2008).

### 2.7.1 Need for recognising the parents’ expertise

Parents of chronically ill children are different from parents of children with acute
illnesses (Marin et al., 2009). A retrospective cross-sectional quantitative study by Balling
and McCubbin (2001) looked at the degree that parental expertise was valued by
healthcare providers. They found that due to the nature of chronic diseases and the
requirement for long-term care, these parents have developed expertise in caring for their children. When the child is hospitalised, they expect that their knowledge and status as the ones who know the child best will be recognised by the healthcare team. This recognition means listening to the parents, taking their advice, updating them on the child’s illness and involving them in decision making. When even one of these needs is not fulfilled, these parents can feel isolated, stressed, dissatisfied and lose trust in the capabilities of the healthcare team (Balling & McCubbin, 2001). Healthcare providers should recognise these parent’s needs. Allowing time for a trusting relationship to build between the nurses and the parents is crucial. Nurses should recognise that each parent is different and, therefore, negotiate to what extent the parent wants to be involved in the care of the child and take their expertise into consideration when developing a healthcare plan for these children (Balling & McCubbin, 2001). However, the result of the study should be viewed with caution since the internal validity of the survey instrument was considered low.

2.7.2 Need for partnership with the healthcare team

Nowadays, the parents are considered a valued member of the care of the child’s health, especially if the child has a chronic condition which requires ongoing care (Balling & McCubbin, 2001; Kratz et al., 2009). Parents of children with chronic illnesses anticipate that a partnership will develop between them and the healthcare team. Therefore, effective partnership between the parents and the healthcare team is necessary to achieve the best possible care for chronically ill children (Balling & McCubbin, 2001; Kratz et al., 2009). A study by Kratz, Uding, Trahms, Villareale, and Kieckhefer (2009) recruited parents who care for a child who is chronically ill in a randomised control trial for two years to help come up with a curriculum that would help these parents build up their confidence in their ability to manage their children’s complex medical conditions. The study used sound and rigorous techniques and reported on qualitative data from focus groups discussions in the intervention group. According to the study, to be successful, this partnership needs to be built on mutual respect between both parties, and values what each party brings to the relationship. This includes sharing of accurate, comprehensive information, valuing the parent’s participation in the child’s health, and the ability to be involved in mutual decision making (Kratz et al., 2009).

The relationship that forms between the healthcare team and the caregiver is one that evolves and progresses. The parent may initially put all of her/his trust in the competence
of the healthcare team. However, because parents of chronically ill children have expertise about their child’s illness (as mentioned in Sections 2.6.3 and 2.7.1), they may be able to detect whether some kind of mistake was made in caring for the child. This may lead to mistrust in the healthcare provider’s ability to care for the child and parents may try to take greater vigilance over the responsibility of monitoring the child’s illness and progress (Balling & McCubbin, 2001; Kratz et al., 2009). In addition, when the healthcare team fails to involve the parents in making decisions about the child, the parents understandably feel isolated, while also feeling anger, stress and worry. When a relationship is successful, it can have many benefits for the child, the parent and the healthcare team, leading to better quality of care (Balling & McCubbin, 2001; Kratz et al., 2009).

2.7.3 Need for normalisation

One of the main needs of the caregiver for a chronically ill child is the need for normalisation (Coyne & Cowley, 2007; Fisher, 2001; Nuutila & Salanterä, 2006). As the child has a long-lasting requirement for medical treatment and requires frequent hospitalisations, admission to the hospital is viewed as a normal event by parents of chronically ill children, as shown in a study by Knafl and Deatrick (2002). The study by Knafl and Deatrick (2002) compared the results of 59 families’ responses to childhood chronic conditions through two interviews conducted with each family a year apart. Interestingly, the authors found that not all families normalised their experiences or seek normalisation. As described by the parents, normalisation refers to familiarity with the hospital setting, the child’s healthcare needs and how to be involved in caring for the child and making medical decisions for him/her. The study revealed that normalisation isn’t always achievable and that families could have reached varying degrees of it. Additionally, the normalisation achieved can fade when the chronic disease of the child was changing or new developments were happening (Knafl & Deatrick, 2002). This is when the healthcare providers can reassure the parents and normalise their experience, giving them a much-needed source of comfort and support, acknowledging the difficult time they are going through and how it might affect the family. This reassurance can make the parents experience so much better (Balling & McCubbin, 2001; Knafl & Deatrick, 2002).

A quantitative study conducted in Saudi Arabia examined the coping patterns of carers of chronically ill children. The study found that mothers of chronically ill children strive to
normalise their lives as much as possible (Katooa et al., 2015). To reach this normalisation, the mothers rely on various forms of support such as respite help from family and friends, as well as from governmental associations and the hospital, to help them cope with the difficulties that come with having a chronically ill child. Coping strategies are extremely helpful in achieving resilience and managing the chronic illness in a healthy manner (Katooa et al., 2015). Although the study provides important insights into the self-efficacy, social support and quality of life of carers of chronically ill children in Saudi Arabia, the study was only conducted on Saudi participants and excluded the carers of chronically ill children of non-Saudi backgrounds. This is problematic, as the Saudi population is made up of almost 38% of people of non-Saudi background (General Authority for Statistics, 2016). Thus this only provides a partial picture of the quality of life of chronically ill children in Saudi Arabia.

2.7.4 Need for information

Quantitative and qualitative research has demonstrated that one of the most important needs of the parents during their child’s hospitalisation is being kept informed (Balling & McCubbin, 2001; Hopia et al., 2004; Hummelinck & Pollock, 2006). According to Balling and McCubbin’s (2001) quantitative study, parents of children with chronic diseases have to share the role of caring for the child with the healthcare team. One of the ways in which the healthcare team can value their developed expertise (Sections 2.6.3 and 2.7.1) is to keep them informed about the child’s condition and treatment. The authors add that having accurate, timely information is one of the ways in which the parents can maintain their role as carers of their children in an otherwise stressful situation. When healthcare teams withhold the information, parents may distrust them, which often leads to dissatisfaction (Balling & McCubbin, 2001).

A study by Taanila (2002) revealed that when a parent is unhappy with the amount of information they receive about how to deal with their sick child, they felt five times more insecure and helpless than other parents with adequate information. Adequate, well-presented information specific to the family and the child’s disease and advice on how to handle the condition have a positive protective influence on the wellbeing of the parents and child, helping them make informed decisions (Taanila, 2002). Although parents require updated information about the condition of their child, that information needs to be tailored to each family’s specific circumstances to ensure the wellbeing of the family (Hopia et al., 2004; Hummelinck & Pollock, 2006). For example, Hopia et al. (2004)
found in their qualitative study that some families could not handle knowing all of the relevant information about the sickness of their child but, for other families, having sufficient information is necessary for them to cope.

While it is important to tailor the information to the specific needs of each family, Hummelinck and Pollock (2006) highlight the practical difficulties in tailoring the information while considering variations in parental needs not just between parents but that informational needs for an individual parent can also change over time. The qualitative study involved semi-structured interviews with 20 sets of parents of 21 hospitalised chronically ill children. The findings showed that at the initial stage of diagnosis, parents may feel overwhelmed by the amount of information shared with them about their child’s chronic condition. Later on, as parents grow more confident with the medical condition their child has, they will therefore require information to care for the child on a day-to-day basis. The authors also highlight that the reasons parents had for wanting information were so that they could be involved in making decisions and providing care to the child, to re-establish their sense of control, and to be able to answer the child’s questions about his/her illness. Interestingly, the study revealed that parents of children with complex chronic conditions that require multidisciplinary care like leukaemia often felt overwhelmed with information. On the other hand, parents with children with a less severe chronic condition that can be managed at the primary care level, like asthma and epilepsy, reported a deficit in information regardless of how severe their child’s condition was. The study concluded that, overall, the parental and patient information needs are not being met. Thus, the task of providing individually tailored information is challenging for a variety of reasons. First, each individual family has its own needs for information that changes over time. Second, it is difficult to identify opportunities to respond to the specific information needs and provide information to parents in such a way that does not add to their anxiety. The literature reviewed in this section raises the question of the practicality of responding to parental informational needs when the needs are constantly changing. Children with chronic diseases require long-term hospitalisations and I would argue that during this period the informational needs would change. Thus, it is necessary to establish an effective strategy to understand the changing needs on a regular basis and to respond to these needs.

Although mothers staying at their child’s bedside wanted to be kept informed about their child’s condition, they were often passive in approaching healthcare staff to seek
information or support (Lee & Lau, 2013; Pai et al., 2008; Ygge & Arnetz, 2004). As a result, these mothers often felt negative emotions such as loneliness, helplessness and hurt. Some mothers also felt that, because the nursing staff were so busy, the level of care provided was not up to the mothers’ expectations. Several studies also found that mothers often developed coping strategies such as monitoring their child’s health conditions (Melnyk, Feinstein, Moldenhouer, & Small, 2001; Melo et al., 2014; Murphy, Christian, Caplin, & Young, 2007; Nuutila & Salanterä, 2006; Pai et al., 2008). The constant monitoring was a coping mechanism to lessen mothers’ feelings of helplessness and anxiety (Pai et al., 2008). A study in Portugal echoed these findings and revealed that when communication between the healthcare team and the parents are adequate, anxiety levels experienced by parents drop and they become more motivated to participate. This, in turn, has a positive effect on parents’ adherence to treatment and coping mechanisms. The parents also benefit from the orientation and information provided to them by the nurses, which reassures parents of their capabilities in providing care for their sick child (Melo et al., 2014). The passiveness of parents in approaching the healthcare team for information is likely to add to the difficulties in responding to the parental informational needs. Healthcare staff may need to actively engage with the parents and empower them to approach health care staff for information.

2.7.5 Need for participation in delivering care

Parents of children with chronic illnesses participate in caring for their child on a day-to-day basis. Therefore, when the child is hospitalised, they need to be involved in providing care for the child. Studies have reported that nurses at that hospital encouraged the participation of parents, but they often restricted their participation to physical care such as bathing, feeding and diapering (Affram et al., 2008; Coyne & Cowley, 2007; Gasquoine, 2005). Participation in the medical care of the child – such as learning how to give the medication, how to manage the machines, or to perform certain medical tasks – might be important to parents of children with chronic diseases, as it helps them in decision-making (Balling & McCubbin, 2001). When parents are excluded from participating in providing medical care for the child and learning how to manage his/her care, these parents may lose the ability to make informed decisions (Ballinger & McCubbin, 2001).

Additionally, several qualitative and quantitative studies have looked at the needs of parents of chronically ill children and have identified decision making as highly important
(Balling & McCubbin, 2001; Espezel & Canam, 2003; Hopia et al., 2004; Hummelinck & Pollock, 2006). These studies suggest that parents of chronically ill children go through different stages of decision making; from surrendering all control to the healthcare team at the initial diagnosis of the child (Balling & McCubbin, 2001; Hummelinck & Pollock, 2006; Kratz et al., 2009), to needing to be involved in making the decisions (Balling & McCubbin, 2001; Hummelinck & Pollock, 2006), to challenging the medical decisions made by the healthcare team. The final stage is reaching a partnership with the healthcare team on making decisions for the child (Balling & McCubbin, 2001; Hummelinck & Pollock, 2006).

2.7.6 Needs for self-efficacy and certainty about their role

With the ongoing care of the chronically ill child, parents can become skilled and knowledgeable about their child’s condition. Parents of children with chronic conditions need to feel confident in their skills and capabilities to carry out the required care for their child (Hopia et al., 2004; Kratz et al., 2009). Confidence in their ability to manage and care for their child positively affects them and their child. Parental self-efficacy is, therefore, an important need of parents of chronically ill children. Self-efficacy is defined as the “belief in one’s capability to successfully execute the recommended courses of action” (Conner, 2010, p. 22). Self-efficacy is important for parents in order to establish an effective partnership with the healthcare team that benefits the ill child (Hopia et al., 2004; Kratz et al., 2009). Parents with a sense of self-efficacy tend to be more involved and active in caring for their child and adjust more easily to their child’s illness and be more satisfied with the care provided to their child.

Several studies have revealed that parents accompanying their child at the hospital adopt a new identity with greater self-confidence (Kratz et al., 2009). However, they might need the hospital staff to encourage them in developing such confidence and accepting their new roles as parents of a sick child (Hopia et al., 2004). In addition, although parents are eager to be involved in delivering the care to their child and making decisions on his/her behalf, some parents were uncertain of their exact role in the care of their hospitalised child. They find themselves in an unfamiliar environment feeling helpless and isolated (Hopia et al., 2004). With the ongoing relationship with the healthcare team due to the chronic illness that such children have, healthcare teams have the opportunity to support, guide and help parents manage the care of their children, while increasing their feelings of competence and confidence (Hopia et al., 2004; Kratz et al., 2009).
2.7.7 The carer’s need for care

Evidence suggests that lifelong care for a chronically ill child is associated with poor emotional and physical health in the carer (Brehaut et al., 2004; Murphy et al., 2007; Raina et al., 2005). Mothers experience a lot of difficulties when involved in caring for their chronically ill children and, as a consequence, need care themselves. When burdened by the hospital stay and care, mothers often seek support from family members. Sometimes, they get the fathers to substitute for them, and when this is not possible because of the financial cost of fathers leaving work, they made different arrangements (Brehaut et al., 2004; Murphy et al., 2007; Raina et al., 2005).

As aforementioned, parents of a chronically ill child feel anxious, stressed and vulnerable (Brown et al., 2008; Halpin et al., 2010; Katooa et al., 2015; Lukemeyer et al., 2000). Therefore, they need to confide in someone outside of the family who will listen to them and to their experiences, acknowledge their feelings, and support and guide them (Hopia et al., 2004). Hopia et al. (2004) report that the families in their study did not find it easy to offload their feelings and expected the nurses to take the initiative to encourage the families to talk and share their feelings. However, studies had conflicting findings on the response of the nurses when confronted with the parents need for care (Bruce et al., 2002; Hopia et al., 2004; Sarajärvi et al., 2006). Sarajärvi et al. (2006) and Bruce et al. (2002) found that nurses recognised when the caregivers were in need of physical or emotional care. However, that knowledge did not always translate into providing care for the caregiver or supporting him/her. In their studies, the majority of the parents felt that they lacked the needed support and care from the nurses (Bruce et al., 2002; Sarajärvi et al., 2006). Hopia et al. (2004) found that nurses used selective family nursing that was situation-specific, in which nurses provided care to the parent according to the situation and when they felt that the parent had expressed a need for care. Perhaps the absence of clear guidelines on the extent of care that nurses should provide to the parents as part of their job is a reason behind the conflict in the above-mentioned studies.

My own experiences in Saudi Arabia leads me to agree with Hopia et al.’s study (2004) findings that parents might find it easier to be passive in sharing their feelings and expect the healthcare staff to reach out. In a country like Saudi Arabia sharing your feelings, emotions and complaining to somebody else is relatively uncommon unless it was a close member of the family. Therefore, if the healthcare team did not identify when these
parents were in need and actively sought to find out their experiences and what they were going through as carers, these carers would not receive the help they need.

2.8 Effects of the chronic illness on the wellbeing of the child and the family

There is a wealth of information in the literature consistently documenting the undeniable impacts that chronic paediatric illnesses can have on family members. These impacts include difficult regular caregiving needs, the complexities of managing these diseases, lifestyles changes, financial burdens, social isolation and school absenteeism (Barlow & Ellard, 2006; Brown et al., 2008; Hopia et al., 2004). The child may also be affected by the disease pathology and side effects of the medication and by the required adaptation to his/her lifestyle because of the chronic illness (Brown et al., 2008). Therefore, feelings of tiredness, pain and fatigue from the illness as well as the need for constant care may present obstacles for living a normal life for all members of the family (Barlow & Ellard, 2006; Brown et al., 2008; Hopia et al., 2004).

2.8.1 Effects on the family members

A qualitative study by Hopia et al. (2004) and documented comprehensive literature reviews (Barlow & Ellard, 2006; Brown et al., 2008) have reported that after the child is diagnosed, the family members may be required to adjust their lives, redistribute roles and responsibilities and change their family functioning to accommodate the care that is required for the chronic condition. Depending on the degree of the severity of the chronic condition, the family may have to be intensely involved in caring for the sick child (Brown et al., 2008). Complex treatment routines or advanced restrictions caused by chronic conditions can limit family activities and social interactions (Brown et al., 2008). As a result of minimal family outings, family members can feel isolated from regular life. This can lead to psychological impacts on the wellbeing of the whole family (Hopia et al., 2004).

Siblings of a chronically ill child may feel isolated and neglected, trying to grab what is left of their parents’ attention and care (Barlow & Ellard, 2006; Brown et al., 2008; Vermaes, van Susante, & van Bakel, 2012). The siblings might in time learn that their parent’s help is not particularly effective since they are preoccupied with the chronic disease (Vermaes et al., 2012). In addition, Vermaes et al. (2012) in their meta analysis strongly argue that the siblings of a chronically ill child not only hide their negative feelings from their overwhelmed parents but they might also be less inclined to share any
positive news. This might affect the parents’ ability to recognise their well child’s competencies and achievements. Moreover, parents experience a lot of stress from negotiating their parental roles and observing the ups and downs of their child’s health. Research conducted by Hopia and colleagues (2004) found that parents find themselves trying to balance the required medical care for the chronically ill child along with the other family and work commitments, which leads to parents struggling with emotional strains. Moreover, parents may have a difficult time coming to terms with their child’s medical condition, the expected outcome, and the future wellbeing of the child (Barlow & Ellard, 2006). The degree of severity of the chronic condition and the need to manage symptoms and administer some complex treatments can take its toll on the parent’s psychological and emotional wellbeing (Hopia et al., 2004). The enormous responsibility that parents feel can overwhelm them and leave them anxious, not knowing how to respond to their child’s condition or what to do for him/her (Hopia et al., 2004). These results are in agreement with the findings of a study carried out in Egypt that assessed the quality of life in parents of children with chronic heart disease. It indicated that, of several factors that affected the parents’ quality of life, the most important was the severity of the illness (Arafa, Zaher, El-Dowaty, & Moneeb, 2008). In addition, hospitalisation of the sick child stirs up negative emotions in parents, such as feeling concerned and anxious, grief, guilt and fear (Burton, Lethbridge, & Phipps, 2008; Hopia et al., 2004; Landsman, 2008).

A study by Board and Ryan-Wenger (2002) revealed that the effects of hospitalisation of the child on the parents remain visible in the parents even after six months of hospitalisation. Pinto, Ribeiro, and Pettengill (2010) echoed these findings and revealed that families that had a child discharged from a hospital suffered from the change in their family routine as a result of having to make follow up visits to the hospital. The emotional disturbance suffered by the parent can spread to the child leaving him/her feeling stressed too (Vermaes et al., 2012).

Katooa et al. (2015) argue that while having a chronically ill child worries both parents, the majority of the burden usually falls on one parent – typically the mother (Katooa et al., 2015). The authors further emphasise that the mother is commonly the primary caregiver of the child, she is the one responsible for making doctors’ appointments, giving medication and monitoring the condition of the child, in addition to carrying out the regular household cleaning and cooking. The study was conducted in the Saudi city of
Jeddah, which might explain why the author claimed that the majority of the caring burden falls on the mother. In Saudi Arabia, it is a common practice that, when a child is hospitalised, the mother will accompany him/her and care for the sick child. In addition, it is a requirement of the hospitals in Saudi Arabia that the carers of paediatric patients be females. Hence, the burden of care is likely to fall more on the mother of the child in such a context.

Some parents cope with their child’s illness by becoming overprotective, monitoring the child’s symptoms and losing trust in healthcare providers. That can lead to anxiety, depression and exhaustion (Katooa et al., 2015).

Brennan, Hugh-Jones, and Aldridge (2013) in their longitudinal mixed methods study suggest that siblings and families try to normalise their life as much as possible by living in the moment – the here and now – and try to avoid thinking about the future or the prognosis of the disease. This seems like a coping mechanism to buffer the effects of living with a chronic disease and, according to the authors, it helps minimise feelings of sadness. In addition to the effects on the family members, hospitalisation can affect the sick child psychologically, causing feelings of anger, fear and insecurity, which may consequently alter the behaviour of a child in the hospital (Hopia et al., 2004). In addition, if the child experiences pain, his/her mood may change, leading to a relapse of the illness (Hopia et al., 2004).

School-aged children with chronic illness may be forced to be absent from school for long periods because of the need for treatment that sometimes requires hospitalisation. The child’s education could therefore be disrupted, and the child may feel isolated and depressed as result of losing touch with his/her peers (Barlow & Ellard, 2006). The child also may become overwhelmed with the amount of academic work he/she needs to catch up on (Barlow & Ellard, 2006).

It is clear that chronic paediatric diseases and the repeated hospitalisations impose significant burdens on the family as it disrupts the family’s stability and threaten its usual functioning. It is therefore important that healthcare delivery supports families in dealing with these hospitalisations, and in maintaining family stability and function as much as possible.
2.8.2 Financial effects

In addition to the above-mentioned psychological and social impacts, having a child with a chronic disease can impose extensive private costs on families. These costs include direct costs such as treatment equipment, educational services, medication, transportation and other special needs that constitute a heavy financial burden on families (Brown et al., 2008). In Saudi Arabia, the direct costs on families are probably minimal since there are public hospitals and clinics free of cost for every citizen. Non-Saudis in governmental jobs are also eligible for treatment in the public hospitals. Those with private jobs can receive medical care through their insurance. The hospital also lends the family any equipment they may need for care at home. Hence, families caring for chronically ill children may not have significant direct costs in Saudi Arabia.

A comprehensive literature review by Brown et al. (2008) and a quantitative study by Lukemeyer, Meyers, and Smeeding (2000) have suggested that the high cost or limited availability of special child care could make it necessary for the parent to care for the child. The literature review study was conducted by searching all relevant studies in a variety of medical search engines as well as reviewing evidence from books (Brown et al., 2008). The quantitative study’s methods also seemed reliable as they used a sample of 2,214 families randomly selected from a sample of 3,824 families used in a previous study (Lukemeyer et al., 2000). The study also had a 60% response rate which has been used by some and gained acceptance as the minimum goal for quantitative research (Fincham, 2008). Both mentioned studies found that the necessity of caring for the chronically ill child may lead to indirect costs incurred through reduced opportunities for the parent to undertake paid work or a reduction in the amount of hours a parent is available to work, thereby reducing their salary (Brown et al., 2008; Lukemeyer et al., 2000).

A study conducted in the United States argued that, for women who typically are the primary caregivers, the more caregiving responsibilities they have, the less likely it is that they will participate in paid labour (Lukemeyer et al., 2000). However, that does not necessarily apply to women in those countries where females do not usually participate in paid labour outside of the household. For example, in the Middle East, women are more underrepresented in the workforce than in any other region of the world (Ross, 2008). Therefore, a mother caring for a chronically ill child in this region may not necessarily witness a reduced opportunity for paid employment.
Nevertheless, chronic diseases impose substantial financial burdens on the individual and the community. With the high associated healthcare costs, loss of employment due to illness and premature death, it is estimated that the most costly disease groups are chronic conditions such as cardiovascular diseases, mental illness, oral health and musculoskeletal diseases (AIHW, 2014).

2.9 Conclusions

The literature reviewed above identifies chronic diseases as an important public health problem of global proportions. There is sufficient evidence to conclude that a considerable number of children around the world suffer the consequences of having a chronic disease. In addition, the family of the chronically ill child suffer from a myriad of stressors and effects that disrupt family functioning. The literature also shows that chronic paediatric diseases are on the rise in Saudi Arabia. However, information on the experience of hospitalisation of chronically ill children and their primary carers in Saudi Arabia is lacking. For Saudi Arabia, we do not yet know what is required to ensure the wellbeing of chronically ill children and their parents during the child’s hospital stay. To fill this gap, this study seeks to address the experience of carers supporting their chronically ill children during their hospital stay. Listening to the carers will help to identify the different needs they and their children require to maintain their wellbeing, the barriers they face, and the facilitators that help them. Gaining this knowledge will form the basis for improving the quality of services offered for hospitalised children and their carers.

2.10 Models of Care

Several models of care have been implemented and carried out in paediatric nursing in general and with chronic conditions specifically. In most hospitals, nurses are responsible for the day-to-day provision of healthcare. This means that they often have the most contact with the patients and their families and have the greatest input in the delivery of care. Therefore, the majority of the documented models of care come from the nursing discipline (Alsop-Shields, 2002; Shields, 2010). Nurses’ models are important because they articulate important concepts essential to nursing, which helps to inform teaching, assessment, practice, management, and research (Alsop-Shields, 2002).
To guide my research, I will examine the family-centred care (FCC) model. This model was chosen because of the comprehensive approach it uses to welcome the child and the family as a whole into the care that is provided. It provides a framework for understanding the needs and concerns of hospitalised children and their carers, which is the focus of this thesis. FCC acknowledges the stressful emotions that can arise from the hospitalisations and the different needs that the family requires to ensure their wellbeing. FCC will be examined and studied within the Saudi context, and several recommendations will be made on how the model should be adjusted or modified to make it suitable to meet the challenges of chronically ill, hospitalised children and their carers in Saudi Arabia. These points will be discussed in Chapters 7 and 8.

2.10.1 Family-centred care

Family-centred care (FCC) has been acknowledged by the Healthy People Act 2020, Institute of Medicine, American Academy of Pediatrics, Joint Commission, and many other medical societies as a fundamental part of healthcare delivery to achieve quality care and patient satisfaction (Kuo et al., 2012; Zarubi et al., 2008). However, as Kuo and colleagues (2012) rightly point out, there is still some ambiguity surrounding FCC, what it is, how it should be planned and implemented, and whether or not hospitals are ready for it. Thus, it is important that FCC is understood and planned correctly by healthcare providers in order to achieve its goals.

Family-centred care (FCC) is a model of care that ensures that care is planned and delivered around the whole family. In a sense, FCC means that health professionals are partnering with the family in caring for the child (Kuo et al., 2012). FCC challenges us to improve the hospital environment in a way that reflects better health outcomes. It involves assessing the health needs of the entire family, detecting factors that impact their wellbeing, listening to their concerns and empowering them, involving them in decision making and improving health service delivery to the whole family (Abdulbaki et al., 2011; Bourke, 1997; Smith & Conant, 2000).

Parental participation in the provision of care to their hospitalised children is an essential element of FCC. It involves the active involvement of parents in the provision of care to their children (Abdulbaki et al., 2011). In addition, parental participation in nursing care benefits both the parents and children (Abdulbaki et al., 2011). Parental involvement in caring for their children reduces their stress and anxiety. It also helps parents to learn a
lot about their child’s condition and improves their ability to deal with their child’s illness. For children, parental involvement helps in maintaining their routine. It provides the children with the opportunity to ask for clarity about their medical conditions from staff. Therefore, it assists them to better cope with their hospitalisation and sickness (Abdulbaki et al., 2011).

2.10.1.1 The development of FCC

To fully understand FCC, we need to look back at the journey of its development. In 1802, the L’Hospital des Enfants-Malades in Paris was the first hospital to care solely for children. After that, in the United States, in 1855, the Children’s hospital in Philadelphia was also developed. During that time, families of hospitalised children were considered visitors and were not permitted to stay overnight with their children.

Studies by Jolley and Shields (2009) and Darbyshire (1995) explored the concept and history of FCC in the meaning it holds in practice. The authors agree that the model was largely influenced and shaped by previous terms and models of care such as the parental participation which refers to the involvement of the parent in the care delivery (Darbyshire, 1995; Jolley & Shields, 2009), care-by-parent in which parents live in a specially designed facility that seems like a home with their hospitalised child and the partnership-in-care where the parents and the healthcare professionals are partners that are responsible for the hospitalised child’s care (Jolley & Shields, 2009). All of these models proceeded the FCC model and paved the way for its development.

According to Jolley and Shields (2009), prior to World War 1 (before the 1920s) the emotional and psychological needs of children were taken into account by nurses and health care delivery emphasized that in their practice. However, by the 1920s that way of practice slowly changed to be more suited for the health care staff than the parents and staff assumed most of the control for the child’s care (Jolley, 2007).

The western practice of children’s hospitalisation in the middle years of the 20th century involved the hospitalisation of children without their parents. In addition, parents visitations were heavily restricted (Jolley & Shields, 2009). This era witnessed the fight against infectious diseases which might explain why parents were prohibited from staying with their hospitalised children; to prevent transmission of infectious diseases (Lomax, 1996). During that time period, children hospitalised for chronic diseases such as
tuberculosis could spend a long period at the hospital even up to two years (Jolley & Shields, 2009). The separation from the parents had enduring and serious emotional and psychological impact on the children (Robertson, 1970). Not only were children separated from their parents, but according to Jolley and Shields (2009), the health care providers’ approach to providing care to the children was affectionless. That was largely due to the fact that the focus at that time was on the child’s physical and medical needs and nurses were unfamiliar of the emotional or psychological needs of hospitalised children (Gofman, Buckman, & Schade, 1957).

By the end of World War II, psychologists started realizing the importance of the psychological needs of adults and children. The war was seen by many as the driving force of change in the care of hospitalised children that eventually led to the development of FCC (Bradley, 2001; Jolley, 2007; Jolley & Shields, 2009). The change in paediatric practices in that time period was largely accredited to the work of British theorists John Bowlby and James Robertson (Alsop-Shields & Mohay, 2001; Bowlby, 1944a, 1944b; Jolley & Shields, 2009). The two theorists extremely influenced the care of hospitalised children through their scientific work and advocacy (Alsop-Shields & Mohay, 2001). Bowlby is widely recognized as the expert who explained the effects that the separation from the mother had on the child (Alsop-Shields & Mohay, 2001). The first study done by Bowlby that brought his theories about family separation into light was conducted on 44 children who were being psychologically assessed after stealing. The study compared these children to controls who were brought to the same clinic for different reasons. The study group had been separated from their mothers in an early stage in life due to hospital admissions and therefore, Bowlby suggested that it played a role in their ‘affectionless character’ (Alsop-Shields & Mohay, 2001; Bowlby, 1944a, 1944b). While working as Bowlby’s assistant, Robertson’s own child got hospitalised without her parents and he witnessed the changes in her behaviour due to the separation (Alsop-Shields & Mohay, 2001). From that point on, he decided to focus his work on the effects of the separation from the mother on the hospitalised child (Alsop-Shields & Mohay, 2001). Robertson took Bowlby’s theories and applied them with the help of his wife. The two documented films on the effects of mother separation on the child due to hospitalisations. These films were filmed in the United States and Australia. Robertson was recognized internationally for spreading the word on the need for parents to be with their hospitalised children (Alsop-Shields & Mohay, 2001). The two theorists and investigators were instrumental
in changing the paediatric practices with Bowlby’s theories forming the basis for what is known today as FCC (Alsop-Shields & Mohay, 2001; Jolley & Shields, 2009). Influenced by the work of Bowlby and Robertson, community groups that called for admitting parents with their children started to develop (Alsop-Shields & Mohay, 2001).

According to Kuo et al. (2012) with increased awareness of the trauma of family separation when a child is hospitalised, new policies were developed to allow for rooming-in to happen, allowing visitation for siblings and parents escorting children into surgeries. These changes in hospital practices regarding the rights of children who are hospitalised and their families facilitated parental participation in paediatric departments. By the 1980s, parents were permitted to get involved in the care of their children. They were helping in some of the physical aspects of care, such as bathing, feeding and diapering. Parents were also involved in improving the children’s psychological status. That involved allowing siblings to visit, encouraging children to take pictures with their families, and permitting them to make telephone calls (Abdulbaki et al., 2011).

In the mid-1980s several general national conferences on children with special needs were conducted in the United States at which family advocates were invited to speak (Kuo et al., 2012). They spoke about their experience of having a child that is hospitalised, the importance of developing a partnership between parents and healthcare team, and the importance of involving the parents in decisions made about the health of their children (Kuo et al., 2012).

Following these conferences in 1987, the United States Surgeon General recommended the introduction of “coordinated, family-centred, community-based care for children with special healthcare needs and their families.” (Surgeon General’s Report, 1987, p. p. 23) In 2001, FCC was considered essential for the provision of quality healthcare by the Institute of Medicine. By 2003, the American Academy of Pediatrics declared FCC to be the standard of healthcare for children. They also changed several policies to incorporate FCC. Family-centred care and patient-centred care are now a key part of the Healthy People 2020 initiative (Kuo et al., 2012).

2.10.1.2 Theoretical underpinnings of FCC

The trend toward the use of FCC started as early as 1950, but there seems to have been disagreement around what exactly FCC should include (Newton, 2000). The focus and
vision of FCC has always been on supporting the developmental and emotional needs of the child (Abdulbaki et al., 2011; Newton, 2000). To achieve this vision, different strategies have been put in place, such as family visits to the hospital prior to the hospitalisation taking place, preparing for the surgery with education and information, open visitation for families and siblings, and establishing homecare services. As Newton (2000) points out, it is now common practice for all of that to happen as part of FCC and the transition is slowly happening to place the family at the centre of the child’s health and healthcare plan (Newton, 2000).

Abdulbaki et al. (2011) and Newton (2000) emphasise the need for the nurses to recognise family members as an important part of the child’s health and respect and value their input in caring for the child to make FCC effective. If the family members were absent from the child’s bedside, the nurse should maintain the routines and practices that were put in place by the family. When family members are present, the nurse, family and child should negotiate the care process. The negotiation of roles and establishment of this relationship are necessary for the child’s health. It is through these negotiations that nurses establish the parent’s role as the expert on the child and his/her health, and parents learn to turn to nurses for expert advice, information and care for their child. FCC also helps in encouraging family networking and support and recognising available coping strategies (Abdulbaki, Gaafar, & Waziry, 2011; Bourke, 1997; Newton, 2000; Shields, Pratt, & Hunter, 2006; Smith & Conant, 2000)

As Brathwaite (2003) points out, using a theoretical framework is important in a number of ways: to guide the study as it is developing, help design the appropriate intervention, describe the intervention, and consider the facilitators and barriers to its effectiveness. Therefore, this study will draw on the FCC model to understand the needs and concerns of carers of chronically ill children.

2.10.1.3 Applying family-centred-care

Newton (2000) and Shields (2010) strongly argue that the biggest obstacle to implementing FCC is the ambiguity that continues to surround it. On the provider’s side, some consider FCC as delegating responsibilities to the families of patients. They might even delegate more responsibilities than families can handle or want. Families want to partner with healthcare staff in decision making, but that does not necessarily mean that they desire the increased responsibility. On the caregiver’s side, there is no common
definition or agreement of what exactly parental participation encapsulates. Families do not really know the extent of responsibilities that should come with partnership. In addition, language, ethnic and racial differences may sometimes complicate the communication between those partners (Kuo et al., 2012).

Additionally, FCC is difficult to translate into practice. Darbyshire’s (1994) PhD research identified a number of reasons behind this. The study took place in Scotland and looked into the experience of parents who ‘live in’ the hospital with their hospitalised children. The qualitative study used a combination of phenomenology and grounded theory to formulate a detailed account of the experiences of nurses and parents and to bring in the perspective of families and nurses about the frustrations that occur when practicing FCC. The study identifies several parent themes which were ‘adapting to the hospital’, ‘being a good parent’ and ‘parenting in public’. Nurses’ themes included ‘nurse expectations of parents’ and ‘nurses perceptions when working with parents’. The author suggested that the paediatric literature underestimates how difficult it is to apply FCC into practice and concluded that FCC is an ideal that is difficult to translate into practice. This is due to the judgmental behaviour of nurses towards the parents which leaves them with the feeling of ‘parenting in public’ and the difficulties of leaving the other children without care at home.

Some key points that Darbyshire’s study discussed above established were that FCC is subjective to the perspective of the families and healthcare staff, the difficulties parents face when parenting in public and the difficulties that are associated with performing what are considered as easy to perform parenting tasks at the hospital, the importance of the little things in nursing practice when it comes to FCC and finally the importance of advocating for FCC between families and healthcare staff. The study seems to suggest that for FCC to succeed, it is necessary for nurses and healthcare staff to clearly articulate their expectations from carers. As Darbyshire (1994) rightly emphasized, it is necessary for staff and carers to have honest clear communication as FCC has the possibility of transforming nursing care practice for the better. The information gathered from this work helped shed light on the difficulties that parents experience as a result of the hospitalisations of their children.

The literature also identifies other difficulties in implementing FCC, including requiring staff and family education, in addition to FCC being labour intensive and costly (Newton,
2000; Shields, 2010). For example, healthcare staff must be taught conflict resolution, communication skills and family dynamics as part of their FCC education (Newton, 2000; Shields, 2010). Family and primary caregivers must also be educated about FCC. Shields (2010) suggests that information about FCC can be handed to families and children as part of the admission process. Finally, the model requires a high staff-parent ratio. As Shields (2010) points out, FCC encourages family involvement and, therefore, the model needs a large contingent of staff to be able to effectively partner with caregivers and negotiate with them, which is also costly. Another study by Shields et al.’s (2006) mentioned earlier also reported a sub-theme of the cost of FCC. Interestingly, the cost of FCC was not relevant only for the hospital or its staff. The families were also subject to both financial costs which included lost employment as well as the emotional costs that manifested in the need to ask for relatives to look after their other children.

Although the implementation of FCC has its difficulties, a Cochrane review of randomised controlled trials of FCC by Shields, Zhou, Pratt, et al. (2012) revealed that FCC could have benefits for the hospitalised children’s clinical care, carer’s satisfaction and cost. However, the review had strict inclusion criteria that only one randomised control trial met. Therefore, the review had limited evidence of the effectiveness of FCC. Another related review of quasi-experimental studies of FCC had the same small number of studies that met their criteria (Shields, Zhou, Taylor, et al., 2012). The included study compared three interventions and two outcomes between the experimental group (FCC group) and the control group. The study found that after 5 days of intervention, the satisfaction with nursing care and the self-efficacy of parents was significantly higher in the experimental group than the control group. Given the limitations in the number of studies included in both reviews (Shields, Zhou, Pratt, et al., 2012; Shields, Zhou, Taylor, et al., 2012) no firm conclusion can be drawn.

After examining family-centred care, I would argue that it incorporates families in every aspect of the child’s care. Family-centred care is a comprehensive model that can be applied to clinical intervention, research and education. The model puts the family and the chronically ill child at the centre of the care provided and helps carers to take responsibility, make informed decisions, thereby maximising their wellbeing and that of their child, as well as the quality of care provided. Hence, the effective application of the model represents an opportunity for a true partnership to be established between the family of the chronically ill child and the healthcare staff. However, for the model to
reach its full potential, healthcare staff and caregivers must be educated about it. In addition, as Shields (2010) strongly emphasises, the hospital must have the financial and human resources that are needed for the successful implantation of the model.

2.10.1.4 Applying FCC in Saudi Arabia

FCC is a model of care that has been developed primarily for western contexts. Hence, its applicability to non-western contexts and the degree of required adjustment to the model is unclear (Alabdulaziz et al., 2017). Limited literature is available in African and South East Asian contexts (Alabdulaziz et al., 2017; Shields & Nixon, 2004; Söderbäck & Christensson, 2008). Only one study was found in Saudi Arabia, which examined the nurses’ perspectives, beliefs and practices of FCC in the Saudi context (Alabdulaziz et al., 2017). The authors found that the concepts of FCC were generally accepted in the Saudi context. However, they argue that there appeared to be a deficit in the knowledge amongst nurses of the theoretical underpinnings of the FCC model. Although there appeared to be a general acceptance of FCC, observations revealed that the core concepts and principals of FCC had not been implemented in practice.

Alabdulaziz et al. (2017) was the only study found to examine FCC in Saudi Arabia. The study was conducted in the Western Province of Saudi Arabia. Whether other parts of Saudi Arabia would generate similar or different findings is not known.

2.10.2 Summary and conclusion

The above section has attempted to examine the FCC model and determine its relevance to the needs and concerns of chronically ill hospitalised children and carers that can help guide interventions to provide a better quality care.

Chronic paediatric conditions affect the whole family and require the participation and involvement of the primary carers. FCC is designed to be a comprehensive approach to care, and thus it is important that its breadth and depth is not undermined when it is applied in guiding decisions on clinical interventions, research and education. FCC concepts welcome the patient and the family into the care provided, thus bridging physical, psychological and social needs. The immediate and extended family are very important in Saudi culture (this is further discussed in Chapter 3 Section 3.6.1). Therefore, the FCC model is especially relevant to the Saudi context, as it extends beyond the patient and acknowledges the family in the care provided.
In relation to chronic diseases, studies have shown that FCC can increase carers’ engagement, increase carers’ and healthcare staff satisfaction, reduce anxiety and improve quality of life (Abdulbaki et al., 2011; Bourke, 1997; Newton, 2000; Smith & Conant, 2000). However, the practical difficulties of implementing FCC must be pointed out. As Shields (2010) emphasises, for successful implementation of FCC in paediatric healthcare settings, parents and staff must be educated about FCC. In addition, the expenses that are associated with implementing the model must be acknowledged. For example, the hospital managers must realise that the model requires more staff to effectively negotiate with the parents and for the extra time that is required to implement the model. On the other hand, Shields (2010) has concerns about FCC because she claims it is better for developed countries and is challenging for implementation in developing countries with low resources. Although Saudi Arabia is considered a developing country, the country is a high-income country and healthcare is provided free of charge for both Saudis and immigrants. Therefore, implementation of FCC may be more feasible in Saudi Arabia than other developing countries that are low on resources.

In conclusion, to explore the experiences of primary carers and their chronically ill children during the child’s hospitalisation, and to understand the facilitators and barriers of wellbeing to primary carers, this study drew on the family-centred care model in developing the interview questions, using it as a lens to interpret findings and to make recommendations for further research and practice.
Chapter 3

About Saudi Arabia

In this chapter, an overview of the Saudi context is provided to help understand the crucial role of the social and cultural context of the country. In particular, it looks at how Saudi society deals with health and disease as well as its relevance to service delivery for hospitalised children. The chapter begins by providing some general and demographic information about Saudi Arabia, then presents key statistics about the health situation in the country. This is followed by an examination of the health system along with a description of mental illnesses and the mental health system in Saudi Arabia. Finally, the chapter concludes with a brief overview of the cultural and societal context.

3.1 General and demographic information

The Kingdom of Saudi Arabia (KSA) is the largest country in the Arabian Peninsula, occupying an estimated 2.15 million square kilometres. The General Authority for Statistics (2017) report estimates the population of Saudi Arabia to be 33.4 million with 2.52% population growth per year. The report notes that Saudis make up an estimated 20.7 million (62%) of the population with a further 12.6 million (38%) residents. Women and children make up 27% and 32% of the population, respectively (General Authority for Statistics, 2017).
Saudi Arabia was established in 1932 by King Abdulaziz AL-Saud who ruled KSA for 30 years. After King Abdulaziz died, his sons took over the ruling of the kingdom one after the other. Saudi Arabia holds an especially important place in the Muslim world as the custodian of the two holy mosques and the birthplace of Islam. The country abides by Islamic rules which are apparent in almost every aspect of Saudi lives (Halligan, 2006). From an economic perspective, Saudi Arabia has the largest oil reservoirs in the world. The economic prosperity of the country has resulted in a high standard of living, free medical services, free education, development of hospitals and universities. Yet, with little economic diversification and a lack of foreign investments, the kingdom’s economy is highly dependent on oil prices (Central Intelligence Agency, 2016). While KSA is considered to be a high-income country, it is also regarded as a developing country (United Nations, 2012a). The classification is based on the Human Development Index, which is comprised of three indices that measure a country’s progress in education, longevity and education (Nielsen, 2011).

The Human Development Index for Saudi Arabia is estimated at 0.847 and, therefore, the country ranks 38th out of 188 countries (United Nations Development Programme, 2016). The study estimates the literacy rate for Saudis 15 years and older at 94.7%, life expectancy at birth is 74.4 years and Gross National Income per capita is 50,284 US
dollars. The significant gap between the Gross National Income per capita (50,284) and the Human Development Index (0.847) indicates that the level of development in the country is below what is expected of its GDP (Fadaak, 2010).

Poverty is still evident in the country in some regions that have not benefited from the country’s high national GDP (United Nations, 2012b). According to the Millennium Development Goals report for Saudi Arabia by the Ministry of Economy and Planning (2011), the country has limited poverty to small areas, with the provision of educational, health and social services to those in need. However, there have been few studies on poverty in Gulf Cooperation Countries except for the country of Bahrain (United Nations, 2005). In Saudi Arabia, no national agreed-upon poverty line currently exists in the kingdom. In addition, the Saudi General Authority for Statistics in the kingdom has no national or regional data about the characteristics or estimates of poverty in Saudi Arabia. Therefore, information remains unclear on the exact areas affected by poverty in Saudi Arabia.

A report by the King Khalid Foundation (2013) was the only official report I found that attempted to measure the relative poverty line and sufficiency line in the kingdom. The poverty line is an indication of the minimum income that a person or a family can live on, whereas the sufficiency line indicates the minimum income on which a person or a family can live comfortably. The report argues that the relative poverty line provides a more suitable indicator to use in Saudi Arabia than the absolute poverty line. The absolute poverty line – used by developing countries – uses the cost of the most essential food items to measure the indicator. The relative poverty line, on the other hand, compares the lowest earning households with the average of the rest of the households in a country. The authors justify their claim of the suitability of the relative poverty line for Saudi Arabia by arguing that the country has a developed economy and therefore would benefit more by using the relative poverty line as an estimate – similar to developed countries (King Khalid Foundation, 2013).

The average Saudi family consists of seven family members. Therefore, the report estimates the sufficiency line for a seven–member family to be SR12,496 which is approximately equivalent to AUD$4,511 per month. The report generates four relative poverty line estimates based on the different ways used internationally to determine that value. For the purpose of this study, I will refer to the method used in the United Kingdom
and other European countries, which uses 60% of the average household income to determine the poverty threshold. For Saudi Arabia, the average income in households per month is SR10,723 (AUD$3,870) and therefore the relative poverty line is 10,723*0.6 = 6,433.8 (AUD$2,322) (King Khalid Foundation, 2013).

According to the King Khalid Foundation (2013), identifying these two indicators provides a vital step forward in helping policymakers to determine the shortcomings and expand the beneficiary group for subsidy program aid to include those that are categorised as middle income.

Fadaak (2010) estimated the total number of poor people in Saudi Arabia, with the results shown in Table 3.1. The study identified the poor as the individuals who “relied upon the income support system for the social security pension in all provinces in the kingdom between 2004 and 2005” (Fadaak, 2010, p. 691)
Table 3.1: Number of the poor in Saudi Arabia according to their province (Fadaak, 2010)

<table>
<thead>
<tr>
<th>Province</th>
<th>Total number of poor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Al-Riyadh</td>
<td>47,433</td>
</tr>
<tr>
<td>Mecca</td>
<td>65,286</td>
</tr>
<tr>
<td>Al-Madinah</td>
<td>26,330</td>
</tr>
<tr>
<td>Al-Qasim</td>
<td>13,457</td>
</tr>
<tr>
<td>Eastern Province</td>
<td>33,173</td>
</tr>
<tr>
<td>Asir</td>
<td>53,183</td>
</tr>
<tr>
<td>Ha’il</td>
<td>15,679</td>
</tr>
<tr>
<td>Tabuk</td>
<td>10,875</td>
</tr>
<tr>
<td>Al-Baha</td>
<td>12,830</td>
</tr>
<tr>
<td>Northern Borders Province</td>
<td>5,024</td>
</tr>
<tr>
<td>Al-Jouf</td>
<td>6,603</td>
</tr>
<tr>
<td>Jizan</td>
<td>35,116</td>
</tr>
<tr>
<td>Najran</td>
<td>10,147</td>
</tr>
<tr>
<td>Total</td>
<td>335,137</td>
</tr>
</tbody>
</table>

3.2 Health situation in Saudi Arabia

Almalki, FitzGerald, and Clark (2011a) note that Saudi Arabia has achieved substantial strides in healthcare in recent years. A report by the Institute for Health Metrics and Evaluation (2017) showed that male life expectancy has increased from 70.67 years in 1990 to 76 years in 2016, and female life expectancy from 73.5 to 78.7 years. The report adds that during the same time period, under-5 mortality rate has declined from 46.8
deaths per 1,000 live births to 6.6 deaths per 1,000 live births. Infant mortality rate also declined from 37.1 deaths per 1,000 live births to 5.4 deaths per 1,000 live births (Institute for Health Metrics and Evaluation, 2017).

Saudi Arabia introduced a compulsory vaccination program in the 1980’s which helped in controlling infectious diseases (Memish et al., 2014). Since then, the health profile of the country has changed, with chronic diseases such as ischemic heart disease, cerebrovascular disease, chronic kidney disease, Alzheimer’s disease, diabetes, congenital defects and liver cancer causing most of the deaths in all ages in 2016 (Institute for Health Metrics and Evaluation, 2017). Other causes of deaths included road injuries, lower respiratory tract infections and falls (Institute for Health Metrics and Evaluation, 2017). The rising burden of chronic diseases, road traffic incidents and mental health problems is an indication of how Saudi Arabia has been able to control the spread of infectious diseases (Memish et al., 2014). However, they also point to the new challenge of chronic diseases that the kingdom now faces.

Saudi Arabia has a young population with at least 25% of the total population under 15 years old (General Authority for Statistics, 2016). This group also faces the significant burden of chronic diseases (Moradi-Lakeh et al., 2016). A study by Al Frayh et al. (2001) identified bronchial asthma as the most prevalent childhood chronic disease in Saudi Arabia at that time. Although the disease has been identified by scholars as a significant problem in Saudi, no recent studies have been done to determine its prevalence in Saudi Arabia.

Sickle cell disease also contributes to the chronic disease burden in children in Saudi Arabia. A two-year nationwide study in Saudi Arabia used multistage random probability sampling with a cross-sectional survey of the Saudi households in all 13 regions of the country (Al-Qurashi et al., 2008). The study reported that sickle cell disease was prevalent in 108 children (under 19 years of age) out of 45,682 surveyed, with a prevalence of 24 cases per 10,000. The study concluded that sickle cell disease was most prominent in the Eastern Province (this study’s location) with 145 cases per 10,000.

Diabetes is also a significant issue in Saudi Arabian children with the incidence rate of the disease amongst children under 15 years of age estimated at 31.4 per 100,000 population (Patterson et al., 2014). Other paediatric chronic diseases that have increased in Saudi Arabia include cancer, heart diseases and genetic blood disorders (MOH, 2011).
3.3 Health system in Saudi Arabia (1925- today)

Before oil was discovered, the people of Saudi Arabia were traditional and poor. There was no official healthcare system and health services were dependant on traditional medicine (Albejaidi, 2010).

The first public health department was established by King Abdulaziz in Mecca in 1925 while he was controlling the areas of Najd and Hejaz, before the kingdom was established (Almalki, FitzGerald, & Clark, 2011b). The department provided curative health services free of charge for the population and pilgrims, but with the limited national income at that time, the department was unable to achieve major improvements in healthcare services. Therefore, the majority of the population were dependent on the health services provided by traditional healers (Almalki et al., 2011b). In my own experience and observation as a Saudi national born, raised and educated in Saudi, it is not that common today for Saudis to go to traditional healers. However, these practices have not completely disappeared, with some people still dependant on traditional medicine. Such practices may result in people not seeking professional help or delaying seeking such help (discussed further in Section 3.6.5.2).

Today, the Ministry of Health (MOH) is the main provider of healthcare in Saudi Arabia, with 244 hospitals (33,277 beds) and 2037 primary health care centres (Aldossary, While, & Barriball, 2008; Almalki et al., 2011b). These services from MOH comprise almost 60-70% of healthcare provided in Saudi Arabia and are free of charge to citizens and immigrants (Aldossary et al., 2008; Almalki et al., 2011b; Berhie, 1991). The healthcare services provided by MOH operate at three levels: primary, secondary and tertiary. The primary health care centres supply preventive and curative primary care and refer cases that need more advanced care to public hospitals, which is the secondary level of care. Patients that require care from a specialist, such as patients with chronic diseases, are referred to specialised hospitals which provide the tertiary level of care (Almalki et al., 2011b). These hospitals have the most experienced health personnel with the advanced medical equipment and have the ability to deal with complex health problems (Albejaidi, 2010). The remaining 30-40% of healthcare services in Saudi Arabia are provided by the private sector (medical care cost is paid by the patient or his/her insurance), with 125 hospitals (11,833 beds), and other governmental agencies, with 39 hospitals (10,822 beds) (Aldossary et al., 2008). The availability of free health services from all levels of
healthcare means that the financial burden on families is minimal. In addition, even when a patient requires homecare, these services are also provided for free and the machines required are loaned to that person free of charge.

Saudi Arabia welcomes more than 2 million people each year for pilgrimage which is a compulsory trip to Makkah city in Saudi Arabia in the month of Dhu al-Hijjah for all Muslims who are capable physically and financially to make the journey in which people are required to do certain tasks (Mirza et al., 2018). The high number of visitors carries with it a range of different health risks such as infectious diseases, skin diseases and injuries. Therefore, MOH has allocated a substantial budget for healthcare throughout the country and developed many hospitals to be prepared for the high volume of patients and to ensure the quality of care provided (Royal Embassy of Saudi Arabia, 2016; WHO, 2013a). The budget for healthcare for the year 2016 was approximately SR59 billion, (AUD$21 billion) (MOH, 2018). However, evidence from MOH statistics suggests that health service delivery throughout the country is less than optimal, with uneven accessibility to health services and unequal distribution of healthcare facilities and hospitals (MOH, 2011). For example, there are long waiting lists in some regions for people to gain access to healthcare services. In addition, there is a shortage of services for elderly patients, adolescents and special needs patients, especially in rural areas (Walston, Al-Harbi, & Al-Omar, 2008). The unequal distribution of healthcare services and healthcare personnel may mean that not all children who are chronically ill and require hospitalisation receive the care they need.

Although the official language in Saudi Arabia is Arabic, healthcare providers and nurses mostly communicate in English. The nursing workforce in Saudi Arabia is comprised primarily of expatriates who speak English as their second language and are recruited from India and the Philippines (Aldossary et al., 2008; Tumulty, 2001). Other nurses in Saudi also come from Australia, Britain, South Africa, Malaysia and Middle Eastern countries (Aboul-Enein, 2002; Aldossary et al., 2008). Statistics by the Ministry of Health show that the total number of nurses in 2016 was 180,821, with Saudi nurses constituting only 36.5% of the total (MOH, 2016).

The high numbers of expatriate nurses produces several challenges, such as a high turnover rate as they move back to their countries (Almalki et al., 2011a). Another major challenge of having expatriate nurses is the language barrier. As public hospitals in Saudi
Arabia serve people of all socio-economic status – including everyone from people with low socio-economic class to the Royal Family – it is common to have patients who are unfamiliar with the English language. At the same time, most expatriate nurses are also unfamiliar with the Arabic language. A study by Halligan (2006) about expatriate nurses’ experiences of caring for Muslim patients in Saudi Arabia found that language was a major communication barrier. At the time of employment, these nurses were required to know English language as a first or second language. However, lack of familiarity with Arabic language proved to be challenging, as patients and carers did not know how to communicate with them. Consequently, the carers used a combination of gestures that included finger clicking, which was considered rude by the nurses (Halligan, 2006). Other issues included the problem that expatriate nurses mostly have different beliefs and values from Saudi society. In addition, as Almalki et al. (2011a) argue that these nurses might not have sufficient knowledge about the Saudi culture and the way Islamic religion is embedded in their patients’ lives and, therefore, respecting Islamic values might be absent from their practice. Hence, it is the Saudi nurses who have been found to deliver care that is more aligned with the needs of the local population (Almalki et al., 2011a).

3.4 Mental health system in Saudi Arabia

According to Bohlmeijer, Prenger, Taal, and Cuijpers (2010), people with chronic diseases in general are at an increased risk of developing mental health issues. In addition, the child’s chronic disease can have impacts on the carer, the child and the siblings (Barlow & Ellard, 2006). Therefore, the availability of good mental health services is essential.

In Saudi Arabia, mental health services are integrated into primary care centres in accordance with recommendations from the World Health Organization (World Health Organization, 2001). A mental health policy was introduced in 2006 that aimed to increase the number of specialised mental healthcare providers, raise the quality of provided mental healthcare, improve services to people with addiction, develop advanced professional development programmes in mental health, enhance research, establish national quality indicators, develop and increase social services units, and improve mental health throughout Saudi Arabia (Al-Habeeb & Qureshi, 2010; Koenig, Al Zaben, Sehlo, Khalifa, & Al Ahwal, 2013; Koenig et al., 2014).
According to Koenig et al. (2013), the current practice at primary care centres in Saudi Arabia involves identifying patients who require mental healthcare or evaluation, conducting an assessment, treating them, and referring only those requiring more specialised care to psychiatric clinic, psychiatric ward at a general hospital or to a specialised psychiatric hospital. Such referred patients receive treatment at either private or public psychiatric hospitals with well-developed inpatient and outpatient services. Patients needing psychiatric consultations can also go directly to a psychiatric hospital or to the emergency department of public or private hospitals without needing a referral (Koenig et al., 2014). Some wealthier patients prefer to see the psychiatrists through private consultations in private hospitals and pay themselves to avoid or reduce the stigma of seeking care (Koenig et al., 2014). This will be further explained in Section 3.6.6.

Saudi Arabia still lacks a well-developed community mental health system. Efforts are now being made to train healthcare providers to identify mental health symptoms and to overcome the low detection rates of mental health problems in Saudi Arabia (Becker, 2004; Koenig et al., 2014). The low detection rate may be due to the fact that psychiatric symptoms are presented from patients in Saudi Arabia as physical symptoms or are associated with supernatural causes (see Sections 3.6.5 and 3.6.6), which contributes to the difficulty of making a correct diagnosis. It is therefore important for healthcare providers to differentiate between somatic symptoms that have no medical explanations and those that are psychological in nature (Koenig et al., 2014).

Moreover, the focus in Saudi Arabia seems to be on psychiatric illnesses, while the promotion of mental wellbeing is left out. According to Turkistani et al. (2014), despite the growing evidence of the effect of chronic diseases on the mental wellbeing of patients and carers, the problem is yet to be addressed or acknowledged in Saudi Arabia. Hence, as the mental wellbeing of Saudis continues to attract low priority, those affected – such as chronically ill children and their carers – continue to suffer in silence with limited help.

### 3.5 Mental illness in Saudi Arabia

In order to determine the adequacy of current mental healthcare in Saudi Arabia, and to determine if it is meeting the current needs of Saudi society, information on the prevalence of mental health issues is of critical importance (Koenig et al., 2014). However, as Koenig et al. (2014) indicate, there are no statistics of the overall prevalence
of mental health issues and the only available information comes from studies on specific populations or regions.

Becker, Al Zaid, and Al Faris (2002) and colleagues’ study at King Khalid University Hospital in Riyadh examined 431 outpatient visits and reported a 20% prevalence of symptoms of depression amongst the sample. Similarly, a study by Al-Khathami and Ogbeide (2002) in the same area of central Saudi Arabia and in the same time period consistently reported that, out of 609 primary care patients, 18% had mental health problems. AbuMadini and Rahim (2002) investigated the diagnoses of 1,366 admissions to the psychiatric wards between 1988-1998 and reported that 19.5% had schizophrenia, 15.2% bipolar disorder, 10% depressive disorder, 9% transient and acute psychotic disorder, 8% adjustment disorder, 8% dissociative disorder and 28.3% were re-admissions. The authors also reported that males in the study were more frequently admitted for schizophrenia, whereas females were admitted more for anxiety and depression.

The Saudi National Mental Health Survey (SNMHS) was launched in 2011 and is the first national epidemiological survey of mental illnesses in Saudi Arabia. It is part of the World Mental Health (WMH) survey initiative by the World Health Organization to increase awareness of mental health issues in governments, to assist in gathering information on its prevalence and treatment, and determine if there was disparity between the existing needs and the available mental health services (Shahab et al., 2017). A pilot of the SNMHS was carried out in 2011 to identify the challenges of carrying out the main study in Saudi Arabia and the best practices to meet the challenges (Shahab et al., 2017). The main survey is being performed on a representative sample from rural and urban areas of the 13 regions of Saudi Arabia on approximately 6,000 individuals of both genders who are above 15 years of age. Face-to-face interviews will be carried out by qualified WMH team members (University of Michigan Survey Research Center, 2018). This study is important as it may help to fill the current gap on prevalence of psychological disorders, risk factors, and available services and outcomes (Koenig et al., 2014).

3.6 Cultural and societal context

Although Saudi Arabia went through rapid changes through industrialisation and modernisation, it remains a country that is governed by traditions, tribal customs and
religion (Luna, 2002). It is crucial to understand the interplay between different factors in Saudi culture, such as religion, coping mechanisms and the ways in which they influence the Saudi approach to chronic illnesses. Understanding the coping mechanisms that Saudis need and use, for example, could assist healthcare providers to support these families.

3.6.1 Family dynamics

As a Saudi woman born, raised and educated in Saudi Arabia, I cannot overemphasise the role of the family in all aspects of life. As Almutairi and McCarthy (2012) also note, family plays a central role. For the Saudi context, family is not just the nuclear family of the parents and children, but includes the extended family of grandparents, uncles, aunts and cousins. The central role of the family has links to Islamic principles which emphasise the importance of keeping strong ties and relations with family members and promise rewards to those who do that (Almutairi & McCarthy, 2012). This includes family visits, aiding those in need of financial aid, celebrating religious holidays together, and visiting the sick members of the family (Al-Saggaf, 2004). In addition, in large cities, relatives sometimes live next to each other (Mustapha Achoui, 2006), which confirms the strong ties that exist between the immediate and extended family members (Almutairi & McCarthy, 2012).

In my experience, it is quite common in Saudi for extended family members to live in the same household with the nuclear family. When married, the oldest son or in rare cases oldest daughter sometimes lives with his wife and children with the grandparents. In some cases, this is to take care of the grandparents – especially when their health becomes fragile. The burden of caring for ill grandparents usually falls on the daughter-in-law, particularly if she is a stay-at-home wife. This means that if this family also has a child who is chronically ill, the burden of care for the woman can be extremely high. In other cases, the grandparents let the son and the family stay with them to help the son start his life without the added expense of rent. In such cases, staying at the grandparent’s house and having a child that is chronically ill will actually benefit the family by ensuring access to a strong support system. This support will help the carer stay at the hospital when necessary without worrying about her other children or household responsibilities.

Additionally, grandparents are held in high respect in Saudi culture and can control – to a large extent – their entire family (al-Shahri, 2002). Grandparents are quite likely to
influence decisions and expect their views to be respected and carried out without question. This has implications for healthcare delivery. As Almutairi and McCarthy (2012) argue, when the grandparents are present at the hospital, they expect that they will be treated with respect and compassion. In addition, they also might expect to be involved in the medical management of the hospitalised child’s care.

3.6.2 Gender roles in Saudi Arabia

Gender inequity exists to a varying degree in every community, but this changes over time and across different groups (Vo & Park, 2008). Women are disproportionately impacted by such disparities (Climo, 2000). In the following section, I explore gender roles in Saudi Arabia and how these influence women’s lives. Understanding the structure of Saudi families and the roles that men and women play in Saudi society is important for healthcare providers who are caring for a chronically ill child and his/her carer.

3.6.2.1 Socially accepted roles of women

Saudi Arabia adheres to Islamic religion and its law – known as Sharia – guides all facets of life in the country. While Islam does not forbid women’s participation in politics or pursuit of a career outside the household, Sharia laws can often be interpreted in ways that restrict women and reinforce gender stereotypes (Al-Asfour, Tlaiss, Khan, & Rajasekar, 2017). Thus, Saudi women face difficulties in pursuing a career outside of their households, with societal norms and gender stereotypes valuing their role as a homemaker, wife and mother (Al-Asfour & Khan, 2014). These cultural expectations limit what women are able to do and delay their career development.

In Saudi Arabia, more than half of college degrees are earned by women; however, only 20% of women join the labour force (Al-Ahmadi, 2011; Vogelstein, 2018). Societal expectations might be a major reason for this, as individuals are expected to adjust their aspirations and adhere to the norms, and women who choose to pursue a career or challenge accepted behaviours are often labelled as a deviant (Tlaiss, 2014). Hence, a third of the country’s economic potential is left untapped (Vogelstein, 2018). Those who choose to work tend to cluster in culturally acceptable and traditionally “feminine” roles that are considered less shameful, such as in the sectors of education, art, health services and healthcare (Tlaiss & Elamin, 2016). Therefore, as Al-Asfour et al. (2017) argue that female participation remains modest due to confusion between the teachings of Islam and the conservative cultural interpretations of it. This has implications for the health sector.
where, in the absence of qualified Saudi females available to join the nursing workforce, expatriates are employed to deliver health services. As noted in Section 3.3, 63.5% of the nursing force are expatriates.

While in the past, women’s roles have been restricted to the home front and the private sphere, the country is currently embarking on a new direction and is seeking to recruit qualified females for senior positions in both the public and private sectors (Al-Ahmadi, 2011). The advancement of women’s leadership roles was strongly influenced by the announcement of late King Abdullah in 2009, in which he encouraged women to assume leadership roles in Saudi Arabia (Alsubaie & Jones, 2017). According to Alsubaie and Jones (2017), this announcement was followed by the appointment of the first female Deputy of Minister of Education. Soon after, the Shura Council appointed 30 females as Shura consultants. Al-Sudairy (2017) notes that another major advancement for women in Saudi Arabia was declaring the right for women to run for municipal elections in 2015. This led to 900 women running in the elections with 37 being elected. Women now hold 19.9% of parliamentary seats (Al-Asfour et al., 2017). The situation is not significantly different in the private sector, with more females joining the business world and entrepreneurship is seen as a positive role for females (Danish & Smith, 2012).

However, Saudi females remain quite underrepresented in these leadership roles, accounting for 17% of executive positions (World Economic Forum, 2017). In addition, although females in Saudi Arabia are graduating with more than half of the higher education qualifications in the country, they represent only 3.1% of university presidents and directors (Alsubaie & Jones, 2017). Nevertheless, as Alsaleh (2009) points out, appointing women to such leadership positions is a major advancement for women in a country as conservative as Saudi Arabia. In addition, these leadership roles are outside the traditionally accepted sectors for women, such as health, education and family services.

Another significant advancement for women in Saudi Arabia was lifting of the ban on women driving on June 24th 2018. This provides an indication that the country is serious about change. However, the pace of change is very slow, and many other significant issues remain unaddressed. For example, the existing guardianship system requires male approval for women to open bank accounts, travel, get a passport, and start some
businesses. Unless this system is addressed, women will continue to be accorded a lower position in society and the existing gender inequalities cannot truly be addressed.

A major challenge for working women in Saudi Arabia is achieving balance between their responsibilities at home and work. Al-Ahmadi (2011) argues that, although most Saudi families employ domestic helpers, domestic responsibilities and child rearing remain the responsibility of women. The kitchen, the house and the children are considered a woman’s territory. It is frowned upon in society that a man would assume such roles or help his wife in these matters. In my experience, a man that is helpful around the house would usually not talk about it with others as it is considered not manly. Therefore, Saudi society expects women to balance both responsibilities at home and work – and do that well – which puts pressure on women and has implications for their health. When one of these women has a chronically ill child that requires hospitalisation, in most cases societal expectations dictate that a woman’s first responsibility is to care for her chronically ill child; if she chooses her job, she is most likely to be subjected to criticism or attack from her family and society at large.

3.6.2.2 Socially accepted roles of men

Saudi Arabia is a patriarchal male-dominated society (Ahmad, 2011). The men are seen as competitive, independent leaders (Elamin & Omair, 2010). Moreover, a man’s role is mainly outside of the household with the obligation to provide for the family (Mobaraki & Söderfeldt, 2010). As the breadwinner of the family and the person in total control and authority at the top of the family hierarchy (Katooa, 2014; Mobaraki & Söderfeldt, 2010), the father has the final say in all family decisions and is in control of his wife and children. A good example of the patriarchal system in Saudi Arabia is the existing male guardianship system (mentioned in Section 3.6.2.1) with unmarried women being under their father’s control, married women under their husband’s control and widowed women under their son’s control (Aldosari, 2017; Mobaraki & Söderfeldt, 2010). Women are required to obtain their male guardian’s approval for education, travel, marriage, employment and, in some cases, for receiving medical procedures (Aldosari, 2017). Although a decision by the Ministry of Health in 2012 stated that women 18 years and older are not required to get male approval for medical care except for abortions, that decision is yet to be implemented (Aldosari, 2017). As hospital policies in Saudi Arabia mandate the carer of a hospitalised child be a female, the male guardian system might be
problematic if the father needs to sign approval for any medical procedures. Male dominance can also have implications for a woman’s health in situations where male guardians may sometimes choose to withhold care from a female relative if the healthcare provider is a male (Aldosari, 2017). Therefore, women’s health may also be compromised by the guardianship system and the segregation of sexes.

3.6.3 Gender segregation

During my entire life, living in Saudi Arabia, I have seen gender segregation as the social norm, especially in government spaces and within education facilities. Gender segregation has shaped Saudi society and is supported socially through cultural practices and politically through policy and regulation that enforces gender segregation (Aldosari, 2017; Alhazmi & Nyland, 2013). For example, growing up in Saudi Arabia, you become accustomed to gender segregation being enforced not only in schools but in restaurants, which have family sections and male-only sections. In addition, some shopping malls limit access to females and families only, allowing males to shop only on certain days of the week. Waiting rooms in hospitals are also separated according to gender. Additionally, most working facilities are also segregated as much as possible.

Enforcing gender segregation in healthcare facilities is difficult. So, other measures are adopted, such as having a female nurse or a relative of the female patient present when she is examined by a male healthcare provider (al-Shahri, 2002; Aldosari, 2017). In addition, there are women-only wards in hospitals which are only accessible to females – including visiting relatives (Aldosari, 2017; Mebrouk, 2008). The existing practice of gender segregation makes it challenging for female Saudi nurses to provide care for male patients. A study by Mebrouk (2008) exploring the perception of Saudi female nurses revealed that, although Saudi nurses do take care of male patients, they preferred the segregated working conditions. These nurses also often helped their female patients to stay properly covered as required by Islamic religion – even when they were unconscious. Another study by Alotaibi, Paliadelis, and Valenzuela (2016) similarly reported that both the female nurses and their families found it upsetting for female nurses to provide care for male patients in male-only wards. The nurses in the study who were influenced by their faith preferred sex-segregated working conditions, although that was not possible in the modern healthcare facilities. This situation also contributes to the high percentage of expatriate nurses working in hospitals.
In an emergency situation, gender segregation might become an obstacle, and emergency workers can find it difficult to provide care to female patients (Aldosari, 2017; Kotlyar & Arnold, 2006). According to Aldosari (2017), male paramedics are sometimes not allowed access to female university campuses even when the life of a female student is at stake. A quantitative study in the city of Jeddah, Saudi Arabia confirms this claim. Participants in the study were opposed to the idea of male paramedics entering a home to save female patients when there was no male relative present (Hamam, Bagis, AlJohani, & Tashkandi, 2015). Male paramedics have an Islamic licence in Saudi Arabia that allows them to enter a home to respond to a female medical emergency. Yet, in the above-mentioned study, participants objected to help from a male paramedic. This is therefore not a case of Islamic law but rather, such perceptions and practices arise from prevailing social and cultural beliefs and misinterpretations or misunderstandings of Islamic principles. According to Islam, for medical purposes, it is permitted for a female to be examined by a male – even in the absence of a male relative (Hamam et al., 2015). In these instances, what is usually prohibited becomes permitted due to necessity.

From the above discussion, it is clear that gender segregation is important to Saudi patients, carers and healthcare providers and might, in some instances, interfere with the provision of healthcare. Understanding these aspects in regard to the Saudi society is important – especially as expatriates make up a significant percentage of the healthcare workforce and are involved in providing care to chronically ill children.

3.6.4 Influence of religion on healthcare seeking and healthcare provision

Saudi Arabia is a 100% Muslim country and the religious principles of Islam and the life of the Prophet Muhammad strongly influence their lives. Muslims believe that whatever happens in their lives and whatever diseases or hardship they endure is God’s will and under God’s control (Jazieh et al., 2012). Muslim patients often view suffering and disease as a test from God and the atonement of sins and death is viewed as part of the passage to meet God (Rassool, 2004). They also believe that, regardless of the reasons for their illness (scientific or cultural), their health and illness are from God and cures and treatment are under God’s will (Jazieh et al., 2012). A collaborative inquiry study on cultural beliefs about pain in Saudi Arabia by Lovering (2006) found that Saudi participants believed in predestination and that God was inflicting disease and pain as an opportunity for them to earn good rewards. The participants also believed that pain could
be the result of an evil eye which is a malevolent glare that causes bad things to happen to someone.

Religious beliefs have a significant influence on Saudi society and this, therefore, has implications for healthcare delivery. For example, Halligan’s (2006) phenomenological study in a hospital in Saudi Arabia showed that Islam influenced every aspect of the patients’ lives. The nurses in the study were stressed by the patient’s faith and left feeling powerless. The nurses were experiencing what the author called emotional labour due to dealing with the strong religious and cultural beliefs of patients and families. For example, the belief that sickness and death was part of God’s plan frustrated the nurses and left them feeling powerless because they were doing their jobs to the best of their ability; however, patients remained convinced that whatever happens is up to God. Since most of the nurses in the study were expatriates, these beliefs were different than their own, and it was therefore challenging for them to deal with them (Halligan, 2006). Moreover, cultural and religious interpretations of health and illness influence patient adherence to a healthcare professional’s advice and treatment. Therefore, as George (2001) emphasises, it is crucial that the healthcare professional has a good understanding of the cultural and religious beliefs pertinent to Saudi Arabia so that they are better able to provide culturally sensitive care.

3.6.4.1 Ramadan and fasting

During the month of Ramadan, adult Muslims and children who have reached puberty are obligated to fast from sunrise to sunset. During their fasts, people are expected to abstain from eating, drinking, smoking and sexual intercourse, or taking anything into the body orally or through injections. However, Islam makes concessions, and patients, travellers, and pregnant, lactating or menstruating women are not obligated to fast. But, they are supposed to fast later to make up, once their situation has changed (Almutairi & McCarthy, 2012). For chronically ill children, Islam excuses the sick from fasting, even if the child has reached puberty. The child is permitted not to fast and continue taking his/her medication as usual. Islamic fatwa- which is Islamic laws extracted by Muslim scholars from Quran or Prophet Mohammed’s (peace be upon him) Hadith- allows for a person who is chronically ill and cannot fast at all to be excused from fasting and the person can donate to a charity or feed the poor instead. Hence, their condition is not affected by fasting. Some people who are exempt from fasting still choose to fast for
personal or social reasons (Leiper & Molla, 2003). For example, although travellers are exempt from fasting, they commonly keep on fasting – especially if the travel time is short. However, the usual norm for the sick in Saudi Arabia and other Muslim countries is to break the fast whenever someone is sick, as it might bring him/her more harm to continue fasting and not take their medication. In addition, the development of protocols that emphasise the importance of nutrition and treatment for critically ill children reduces fasting amongst sick children (Jimison et al., 2008).

3.6.4.2 Organ and blood donation

Most Muslim scholars agree that organ donations are permissible under Islamic law (Albar, 2012; Ghannam & Ismail, 2012; Sharif, 2012; Van Den Branden & Broeckaert, 2011). Although a study by Aldawood, Al Qahtani, Dabbagh, and Al-Sayyari (2007) demonstrates that the rate of organs donated by Saudis is low due to religious misconceptions about the meaning of brain death, a recent report by the Saudi Center for Organ Transplantation (2016) shows that organ donation appears to be increasing amongst the Saudi population. The report indicates an increase of consent for organ donations and for transplants to be performed compared to the previous year. Additionally, the number of patients on the waitlist for kidney transplants seems to be decreasing, with 2,708 patients in 2016 compared to 4,200 in 2005. This might indicate that more people are consenting to organ donation.

The increase in organ donation implies an increase in the general population’s awareness of the importance of organ donations and of its permittance under Islam. The increase in organ donations can help many people in need of organ transplants including people with chronic health problems, such as chronic kidney failure, chronic liver infections, chronic artery disease and emphysema (Moscalu, Smith, & Sharma, 2015).

After the mufti (the Islamic scholar in charge of extracting Islamic fatwa from Quran or Hadith) of Saudi Arabia released a fatwa stating that donating blood to save life is a duty for every Muslim, many donors were eager to donate blood as an act of charity (Alfouzan, 2014). Studies conducted on Saudi patients have shown that blood donation is a common practice amongst the Saudi population (Abolfotouh et al., 2014; Alam, 2007; Alfouzan, 2014). The practice seems to be more acceptable than organ donation, and there seem to be no misconceptions surrounding blood donations. This is crucial for chronically ill children undergoing operations or requiring blood transfusions.
3.6.5 Belief in the supernatural

3.6.5.1 Causes of illness

The belief that diseases are the result of supernatural causes is highly prevalent in Saudi society (Jazieh et al., 2012; Obeid, Abulaban, Al-Ghatani, Al-Malki, & Al-Ghamdi, 2012). Such beliefs include the evil eye (Lovering, 2006), jinn possession (a supernatural being that could possess a human) (Obeid et al., 2012), and black magic (Dardas & Simmons, 2015). Treatment is through prayer and faith healing (Dardas & Simmons, 2015).

Some Muslims associate any mental health issues they might be experiencing with these supernatural forces (Dardas & Simmons, 2015). Therefore, a common practice is to seek help from the Imam (a Muslim who leads Muslims during prayer) or Sheikh (a Muslim who is knowledgeable about Islam) instead of healthcare providers (Dardas & Simmons, 2015). The Imam or Sheikh then performs some practices that are believed to remove the effects of the supernatural forces, jinni, evil eye or black magic. While these practices are rooted in culture and connected to religious beliefs, these practices do not actually cure the individual from his/her mental health problems and, therefore, they continue on suffering from mental health issues (Dardas & Simmons, 2015). As previously mentioned, others consider the psychological symptoms as a test from God or an absolution for their sins (Dardas & Simmons, 2015; Jazieh et al., 2012). Such beliefs and practices may delay or interfere with the treatment of chronically ill children, and this can be detrimental to their health. Similarly, such beliefs can also delay carers from seeking professional help.

3.6.5.2 Help-seeking behaviour

Studies involving interviews with cancer patients (Jazieh et al., 2012), university educated students and teachers (Obeid et al., 2012) and women and housewives (Elolemy & AlBedah, 2012) have shown that the use of traditional ways of treating medical conditions is quite common. These include use of prayer, cupping (alternative therapy that uses section cups on the body to relieve tension), and the use of Zamzam water (holy water for Muslims), water that has been blessed by The Quran, honey, black seed and other methods. In these studies, the researchers found that participants strongly believed that even conditions such as epilepsy – which participants believed to be a result of Jinn possession (Obeid et al., 2012) – could be cured with traditional and faith healing.
The stigma of mental illness and beliefs on help-seeking

The World Health Organization (2014) has identified stigma as one of the obstacles to promoting mental health and providing effective treatment. Studies have shown that stigma prevents individuals from seeking mental healthcare and, as a result, their conditions were more likely to worsen (Barney, Griffiths, Jorm, & Christensen, 2006; Wang, Fick, Adair, & Lai, 2007). In Saudi Arabia, mental health issues are highly stigmatised and this hampers help-seeking behaviour (Gearing et al., 2015). Al-Krenawi, Graham, Dean, and Eltaiba (2004) reported that Arab societies often somatise their mental health symptoms in an attempt to avoid the stigma that is associated with mental health issues. When people somatise their illness, they usually present their psychological distress as physical symptoms or mix the two together (Ali et al., 2010; Koenig et al., 2014). The somatisation of psychological symptoms might make it difficult for physicians to recognise mental health problems and differentiate medically unexplained physical symptoms from psychological symptoms that are manifested physically (Koenig et al., 2014). This suggests that mental health problems might potentially go undiagnosed and therefore the appropriate treatment might not be offered.

Although Islamic teachings direct Muslims to seek help and find treatment when they are sick (Dardas & Simmons, 2015), as Gearing et al. (2015) argue, the existing stigma in Arab societies around mental health issues often leads to delays or not seeking professional help. Help-seeking is related not just to stigma but also to beliefs around what causes mental illness, as discussed in Section 3.6.5.1. Therefore, mental health services tend to be underutilised in Saudi Arabia. In addition, it is also possible that there is insufficient awareness of the existence of mental health services (Nasir & Al-Qutob, 2005).

The stigma associated with mental health issues in Saudi society, and the way it can negatively affect the trajectory of mental illness and prevent individuals from seeking mental health has implications for carers of chronically ill patients. Studies show that long-term care of a chronically ill child can negatively impact the mental wellbeing of carers (Barlow & Ellard, 2006). Fear of mental health stigma can negatively affect these carers and influence them not to seek help. These issues should be acknowledged when designing and carrying out mental health interventions that could improve diagnosis and treatment of mental illnesses (Dardas & Simmons, 2015).
3.6.7 Cultural competence

Cultural competence is the ability of a person to competently provide culturally appropriate and sensitive care for a diverse group of people (Burchum, 2002; Cowan & Norman, 2006; Garity, 2000). The social and cultural context discussed in the above sections clearly point to the need for cultural competence in the provision of care, and this is especially important given that a significant proportion of the health workforce are expatriates. For healthcare to be culturally competent, it is important for healthcare providers to understand the religious beliefs that Saudis hold. Among the factors that might delay or affect their adherence to medical treatment are Saudi family dynamics, gender relations, the supernatural causes of illness, and the cultural beliefs on traditional medicine, and food and medicinal supplements. In the case of a chronically ill child with asthma for example, the use of herbal therapies and teas is common in many cultures. Understanding and soliciting this information by a healthcare professional is important for counselling the carers about the potential risks that may be associated with such herbal therapies (George, 2001).

In addition, in the Saudi culture, the society is family-oriented and the family is the cornerstone of care provision. This involvement is not only limited to the immediate family but often extends to extended family members and, in some cases, even the tribe (Luna, 2002). The nurses in Halligan's (2006) study found it difficult to deal with the families of Saudi patients that are so involved in the care of the hospitalised patient and visited the patient frequently. Therefore, the healthcare provider needs to recognize the importance of family within the Saudi social context and that for the care process to be culturally competent, the healthcare plan needs to be developed in a way that includes family.

3.6.8 Summary and reflection

As discussed in this chapter, Islamic religion is dominant in Saudi life and affects people, their beliefs and how they approach treatment. This includes, for example, the religious beliefs that Saudis hold – as discussed in Section 3.6.5 – the supernatural causes of illness, and the value of traditional medicine. As these practices are common in Saudi Arabia, it is important that healthcare providers discuss these issues with patients and their carers and educate them about the possible risks associated with such practices to ensure that they deliver culturally competent care. Other issues to take into consideration include the
stigma associated with mental health issues and how this might affect seeking professional help.
Chapter 4

Doing The Research

This study set out to examine the experience of carers of chronically ill hospitalised children in a Saudi public hospital. The purpose of the study is to understand the needs and concerns for wellbeing of carers of chronically ill children during their child’s hospital stay. The study consisted of two phases. A quantitative phase that aimed at understanding the carers’ satisfaction levels with care provided by physicians and assessing to what extent the hospitalisation of the chronically ill children affected the health and wellbeing of the carer. Two surveys were conducted – the first was designed to measure the overall satisfaction of the carer with the care provided with the physician communication skills; the second survey was intended to assess the wellbeing of the carer. The qualitative phase sought to develop a deeper understanding of the experience of carers and the facilitators and barriers to health and wellbeing.

This chapter is divided into two main sections: firstly, Section 4.1 describes the quantitative phase of the study, the study design, aspects of the quantitative phase and details of how the data were collected and analysed. Section 4.2 explains the qualitative phase of the study and describes the research methodology and theoretical framework relevant to the qualitative phase as well as how the data were collected and analysed. The researcher’s stance is acknowledged in this chapter along with the steps taken to ensure the quality of the qualitative research. The research questions and the methods used to address them are outlined in the following table:

Table 4.1: Research questions and methods used to address them

<table>
<thead>
<tr>
<th>Research questions</th>
<th>Methods</th>
<th>Chapter</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) How satisfied are the carers with the care provided by the hospital for their chronically ill child?</td>
<td>Satisfaction survey as the main source of data</td>
<td>Chapter 5</td>
</tr>
<tr>
<td>2) What roles do carers play in caring for a chronically ill child in the hospital?</td>
<td>Qualitative study to explore the roles of carers</td>
<td>Chapters 6, 7, and 8</td>
</tr>
</tbody>
</table>
3) How does caring for a hospitalised chronically ill child affect the wellbeing of carers?

Wellbeing survey to measure the effects of hospitalisation on the carer’s wellbeing - Chapter 5

3.1) What factors facilitate the health and wellbeing of carers of chronically ill children?

Qualitative study to explore facilitating factors and barriers to wellbeing - Chapters 6, 7, and 8

3.2) What barriers do carers face in ensuring their own health and wellbeing?

4.1 Phase 1: The quantitative study

4.1.1 Study design

As outlined in Table 4.1, the quantitative study aimed to address the following two research questions:

1. How satisfied are carers with the care provided by the hospital for their chronically ill child?
2. How does caring for a hospitalised chronically ill child affect the wellbeing of carers?

The quantitative study employed a cross-sectional design that aimed to examine the demographic characteristics of the carers and determine if they have significant unmet needs as determined by two measures: their level of overall satisfaction with the communication by the physicians and, secondly, their level of wellbeing. As demonstrated in Chapter 2, Sections 2.5, 2.6.2 and 2.7.4, the literature clearly shows that communication with health providers is a key component affecting patient’s satisfaction with the care they receive (Espezel & Canam, 2003; MacKean et al., 2005; Nuutila & Salanterä, 2006; Swallow & Jacoby, 2001). Therefore, this PhD study included a survey to determine the extent to which the physicians’ communication skills affected carers’ satisfaction with the services provided.

Previous research has also shown that hospitalisation of a child can place a heavy emotional burden on the carer, which may then be associated with poor psychological...
health and reduced wellbeing of the carer (Hopia et al., 2004). Therefore, it was important to determine how the hospitalisation of their child affected the wellbeing of their carer. Thus, a wellbeing survey was also included in the quantitative phase. By measuring both the satisfaction and wellbeing of the carer, we can get a partial picture of how they experienced the hospitalisation of their children and identify any unmet needs. As mentioned earlier, previous research has established that the burden of caring for a chronically ill child is much heavier than caring for a child with an acute illness, who is more likely to recover quickly (Bouma & Schweitzer, 1990). Therefore, during analysis, we aimed to verify if such differences in the burden of care are reflected in the satisfaction and wellbeing of carers in the Saudi Arabian context.

A cross-sectional design was chosen because of its ability to provide a snapshot of this population at a certain time and draw conclusions on their caregiving burden, their unmet needs, and possible areas for improvement. To complement this snapshot, the qualitative phase of this study further explored in detail the experiences of carers and what contributed to their wellbeing when their child was hospitalised.

The study took place at King Fahad Hospital of the University (KFHU) in Al Khobar city in the Eastern Province of Saudi Arabia. KFHU is a teaching hospital that trains medical students. It has a 413-bed capacity with 25 beds for the paediatric ward, 20 beds for the paediatric surgical ward, 5 beds for paediatric intensive care unit and 18 beds for neonatal intensive care unit.
4.1.2 Sampling procedure

To recruit participants for Phase 1, the researcher visited the paediatric ward at KFUH from mid-September to mid-October 2016. Each day, the list of inpatients was reviewed, and new admissions were identified as possible participants who had not yet received the questionnaire. The nurses helped distribute the questionnaires in either English or Arabic depending on the language spoken by the carers. While handing out the questionnaires, the nurses explained to carers that participation was optional and that if the carers were interested in completing the questionnaires, a box would be provided in the nurses’ station where they were asked to return the completed questionnaires. The carers were also notified that the researcher was available for answering any questions or for any help needed in filling out the questionnaires. I was called upon several times to help some participants fill out the questionnaires, particularly in the case of those who were illiterate and therefore needed help in completing the survey questions. They asked me to read and explain the questions and to read out the list of possible answers to choose from. Some who could read and write were too busy to do it so they wanted someone to read the questions for them so they could complete the surveys faster. The questionnaires were administered to all carers of hospitalised children during the above-mentioned period.
4.1.3 The research tools

The surveys were comprised of a Satisfaction Questionnaire and a Wellbeing Questionnaire. These tools are further described in the sections below.

4.1.3.1 The satisfaction questionnaire

The Satisfaction Questionnaire was adapted from a mixed method study in Saudi Arabia by Zolaly (2012) that looked into the satisfaction of parents of paediatric patients with physicians’ communication skills. The author of that study developed the questionnaire based on the methods of another study conducted in North America (Hsiao, Evan, & Zeltzer, 2007; Zolaly, 2012), in which Zolaly (2012) translated the questions into Arabic and verified the translation by having it back-translated into English by another bilingual person who had not seen the original English version. The questionnaire was assessed by several family and community medicine consultants to estimate the reliability of the translation from English to Arabic, and it was estimated that 95% of the translation matched.

This Satisfaction Questionnaire asks for demographic information such as the age of the child, the disease the child is hospitalised for, the length of stay, the job of the carer and the carer’s level of education. The questionnaire measures satisfaction by including a total of 11 questions divided into four domains; relationship building (3 questions), information exchange (3 questions), degree of parental involvement (1 question), and demonstration of effort and competence of care for the hospitalised child (4 questions). Each satisfaction question was measured using a 5 point Likert scale and assigned a score accordingly: “strongly agree” and “agree” = 1, “strongly disagree” and “disagree” = -1 and “neither agree or disagree” = 0. If the participant answered strongly agree or agree on all 11 questions, then each question would be given a score of 1 and the total for that participant would be the maximum score of 11, representing the maximum possible satisfaction score. The mean score for all domains was calculated for each participant and an overall satisfaction score was calculated as well. However, there was no cut off point documented in the literature to indicate high, medium or low scores. Therefore, during analysis, the lowest score, neutral score and maximum score for each domain and for overall satisfaction were added as a point of reference to determine which was closer to the sample average score.
The diagnosis of the hospitalised children was categorised into either “acute” or “chronic”. Each day, the inpatient list was examined to verify the diagnosis given by the carer from the inpatient list. After that, the researcher worked with the head nurse to categorise each disease condition/diagnosis as either acute or chronic. Finally, before entering the questionnaire data, the accuracy of the categorisation was verified with the help of a paediatrician at KFHU. Almost two-thirds of children (60%) were hospitalised for a chronic disease.

4.1.3.1 Data Management

Every day, the completed survey questionnaires were checked and assigned an identification number. The identification numbers were written down on a separate piece of paper along with the room number and bed number of the participant’s hospitalised child. To maintain confidentiality, the researcher kept that paper in a locked drawer in the researcher’s locked room provided to her by the hospital. Because some patients were hospitalised for days or months, recording this information was necessary to keep track of who had already received the survey questionnaire. Also, the survey questionnaire asked if the respondent was interested in participating in a qualitative interview (as part of the qualitative study). While the questionnaire asked those interested in participating in the interview to write down their contact information (email and telephone number), some participants indicated that they wanted to participate in the study but did not write down their contact information. Therefore, having the identification number with the room number available for the researcher was important in identifying the participants that wished to continue through to the qualitative phase.

4.1.3.1.2 Statistical analysis

Statistical analysis was completed using the SPSS statistical software (version 22). Data were entered directly into SPSS. For data cleaning, frequency distribution of all variables was used to check for missing information. Three respondents had to be excluded as most of the questions were not answered.

Descriptive statistics were used to summarise the demographic information. Categorical data were represented by frequencies and percentages and the mean and the standard deviations were used for the continuous data.

The sample’s distribution was not normal; therefore non-parametric tests were used. The Mann-Whitney test (Mann & Whitney, 1947) was chosen to compare the two independent
samples (acute, chronic) because the satisfaction data were continuous and the assumption of normality (t-test) was not satisfied (McCrum-Gardner, 2008). Therefore, the test was used to determine the average satisfaction score of parents by disease status of the child (acute, chronic). The Kruskall-Wallis test (Kruskal & Wallis, 1952) is used when comparing more than two independent samples and the assumption of normality was not satisfied (McCrum-Gardner, 2008). Therefore, the test was appropriate to compare the average scores for overall satisfaction by education level and job type of the mothers. The level of significance was set at P≤ 0.05.

4.1.3.2 The wellbeing questionnaire

The sf12-v2 health questionnaire is a shorter alternative to sf-36v2 developed by McHorney, Ware, Lu, and Sherbourne (1994) and is a widely used tool for measuring of health and wellbeing (Fleishman, Selim, & Kazis, 2010). After using the sf-36 for 10 years, it was edited to make it less time-consuming and easier for participants to understand (Islam, Khan, Ferdous, & Rasker, 2017). The alternative sf12-v1 questionnaire draws 12 items out of the 8 subdomains in the sf-36 (Islam et al., 2017). More recently, the sf12-v2 was developed to be even easier than the sf12-v1 (Montazeri et al., 2011). A study conducted in Saudi Arabia translated sf12-v2 into Arabic with the help of an academic translator (Al-Shehri, Taha, Bahnassy, & Salah, 2008). To ensure content validity for that research, the survey was back-translated into English by three family and community medicine consultants. The survey was then tested in a pilot study of 20 participants and, as a result, some wording was changed to promote better understanding. The study also tested the reliability of the questionnaire using the test-retest method and concluded that it had good reliability (Al-Shehri et al., 2008). The sf-12v2 measures eight domains: general health, physical functioning, social functioning, bodily pain, vitality, role-emotional, role-physical and mental health (Kontodimopoulos, Pappa, Niakas, & Tountas, 2007; Quality Metric, 2011; Younisi, 2015). The Arabic translation of the second version of the sf-12 questionnaire was used in this PhD study to measure the health and wellbeing of the carers from their point of view.

As Table 4.2 demonstrates, the general health score reflects the participant’s perception of their health. The physical functioning score measures restrictions in everyday life due to health problems. The social functioning score measures the degree to which an individual’s health restricts social activities. Bodily pain relates to the degree and
frequency of pain and how it limits usual roles. The vitality score reflects the energy levels and the amount of fatigue. The role-emotional score measures the degree that emotional problems affect the usual roles. Role-physical measures the degree to which physical problems limit roles. Finally, mental health measures psychological distress (Busija et al., 2011). The score of each of the domains contributes to the Physical Component Summary (PCS) and Mental Component Summary (MCS). Steps for scoring each domain and summary measures are explained in Section 4.1.3.2.1.

Table 4.2: Description of summary measure and scale’s content domain (Quality Metric, 2011)

<table>
<thead>
<tr>
<th>Content Domain</th>
<th>Physical Component Summary (PCS)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>At lowest:</td>
</tr>
<tr>
<td></td>
<td>Substantial limitations in self-care, physical, social and role activities; severe bodily pain; frequent tiredness; health rated “poor”</td>
</tr>
<tr>
<td></td>
<td>At highest:</td>
</tr>
<tr>
<td></td>
<td>No physical limitations, disabilities, or decrements in wellbeing; high energy; health rated “excellent”</td>
</tr>
</tbody>
</table>

|                                | Mental Component Summary (MCS)                                                                 |
|                                | At lowest:                                                                                       |
|                                | Frequent psychological distress, substantial social and role disability due to emotional problems; health in general rated “poor” |
|                                | At highest:                                                                                      |
|                                | Frequent positive affect; absence of psychological distress and limitations in usual social/role activities due to emotional problems; health rated “excellent” |

<p>|                                | Physical Functioning (PF)                                                                       |
|                                | Performance of physical activities such as self-care, walking, and vigorous physical activities |</p>
<table>
<thead>
<tr>
<th>Role: Physical (RP)</th>
<th>The degree to which a person’s typical role activities (e.g., childcare, job) are limited by physical health</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bodily Pain (BP)</td>
<td>Intensity, duration, and frequency of bodily pain and limitations in usual activities due to pain</td>
</tr>
<tr>
<td>General Health (GH)</td>
<td>The beliefs and evaluations of a person’s overall health</td>
</tr>
<tr>
<td>Vitality (VT)</td>
<td>Feelings of energy, the absence of fatigue</td>
</tr>
<tr>
<td>Social Functioning (SF)</td>
<td>The degree to which a person develops and maintains social relationships (e.g., with family, friends, etc.)</td>
</tr>
<tr>
<td>Role-Emotional (RE)</td>
<td>The degree to which a person’s typical role activities (e.g., childcare, job) are limited by emotional problems</td>
</tr>
<tr>
<td>Mental Health (MH)</td>
<td>A person’s emotional, cognitive, and intellectual status</td>
</tr>
</tbody>
</table>

### 4.1.3.2.1 Data Management

Once the questionnaire was completed by a participant and returned, it was assigned the same unique identifier as the *Satisfaction Questionnaire* completed by the same participants. Measures explained earlier in Section 4.1.3.1.1 were followed to ensure confidentiality.

Data were entered directly into SPSS statistical software. Steps for scoring the *sf-12v2 questionnaire* outlined by Ware et al. (2009) were followed. These included “entering the data, recoding out-of-range item values as missing, reverse score or recalibrate scores for four items, compute raw scale scores and transform raw scale scores to 0-100 scale” (Ware et al., 2009, p. 29). The steps suggested by Ware et al. (2009) to score the data are explained below.

1. Data entry

While entering the data, as mentioned before, one respondent had to be excluded because she left all the questions unanswered. There were no out of range values so the second step outlined by Ware et al. (2009) was excluded.
2. Recalibrate scores

According to Ware et al. (2009), current research demonstrates that 11 out of 12 questions of *sf-12v2* show a linear relationship between the item scores and the underlying health concept that the domain represents. However, the general health (GH) score did not meet that criteria and therefore requires recalibration.

3. Compute raw scale score

This was performed by summing up the responses of all items under each scale. Then, the raw scores were transformed to a 0-100 score using the formula below (Ware et al., 2009):

\[
\text{Transformed scale} = \left( \frac{\text{Actual raw score} - \text{lowest possible raw score}}{\text{possible raw score range}} \right) \times 100
\]

Each domain is scored from 0-100 where the higher the score, the better health. Thus, individuals with a score approaching 100 indicate better health; 50 is considered the cut-off point, above which health is considered good. A participant with a score of below 50 is considered to have a low quality of life in the domain being measured (Lam & Lam, 2009; Molina & Munoz, 2012). In the bodily pain domain, a score close to 100 indicates an absence of pain (Molina & Munoz, 2012; Ware et al., 2009).

After the steps for scoring *sf-12v2* were completed, the physical and mental component summaries were calculated using the steps to score standard form scales and summary measures: “standardization of scales (Z-scores), aggregation of scale scores and transformation of summary scores” (Ware et al., 2009, p. 50).

1. Standardisation of scales

The standardisation of scales was accomplished by computing a z-score for each *sf-12v2 scale*. The z-score is computed by subtracting the US general population mean from the *sf-12v2* (0-100) score and dividing it by the SD from the US general population (Ware et al., 2009). The reason for using the US general population mean will be explained in Section 4.1.3.2.2. The formulas for each scale’s z-score transformation are as follows:

\[
\text{PF}_Z = (\text{PF} - 81.18122) / 29.10558
\]

\[
\text{RP}_Z = (\text{RP} - 80.52856) / 27.13526
\]

\[
\text{BP}_Z = (\text{BP} - 81.74015) / 24.53019
\]
2. Aggregation of scale scores

An aggregate physical component summary and mental component summary is computed by multiplying each scale’s z-score by the general population norm’s coefficient and summing up the eight products (Ware et al., 2009). Formulas for the aggregate PCS and MCS are as follows:

\[
AGG_{PHYS} = (PF_Z \times 0.42402) + (RP_Z \times 0.35119) + (BP_Z \times 0.31754) + (GH_Z \times 0.24954) + (VT_Z \times 0.02877) + (SF_Z \times -0.00753) + (RE_Z \times -0.19206) + (MH_Z \times -0.22069)
\]

\[
AGG_{MENT} = (PF_Z \times -0.22999) + (RP_Z \times -0.12329) + (BP_Z \times -0.09731) + (GH_Z \times -0.01571) + (VT_Z \times 0.23534) + (SF_Z \times 0.26876) + (RE_Z \times 0.43407) + (MH_Z \times 0.48581)
\]

3. Transformation of summary scores

The final step, according to Ware et al. (2009), is to transform the aggregate physical and mental score to the norm-based score by multiplying it by 10 and adding 50, as the formulas below indicate:

Transformed physical (PCS) = 50 + (AGG_{PHYS} \times 10)

Transformed Mental (MCS) = 50 + (AGG_{MENT} \times 10)

4.1.3.2.2 Statistical Analysis

Statistical analysis was performed using SPSS statistical software (version 22). The scores of the sample were compared to the US general population norm. Normative data are available for a few countries but not for Saudi Arabia. In addition, I found no comparative data for Saudi Arabia or any similar Arabic country. The literature suggests that there is little difference between standard US-derived scoring algorithms, which assume a mean of 50 and standard deviation of 10, and country-specific scoring.
algorithms. It recommends using the standard US scoring algorithm to enable cross-cultural comparisons (Busija et al., 2011; Kontodimopoulos et al., 2007; Younsi, 2015).

The analysis results are presented using bar charts. Continuous variables were expressed as means and categorical variables were expressed as percentages.

An independent sample t-test was chosen to test the significance of the difference in the continuous dependant variable (mean scale scores and summary measures) between the two independent categorical variables (acute and chronic).

A One-way ANOVA test was used to check the significance in the difference in the continuous dependant variable (average PCS and MCs) between more than two categorical variables (age categories).

4.1.4 Participants

The two surveys were used to provide descriptive statistics about the carers of hospitalised children at KFHU. Thus, participants for this quantitative phase included all carers of children hospitalised (acute and chronic) at KFHU during the study period. The term carer is used to refer to the adult accompanying the hospitalised child and taking care of him/her during the hospital stay – in most cases this was the mother.

4.2 Phase 2: The qualitative study

4.2.1 Methodology

As noted in Chapter 2, there is limited knowledge of the health and wellbeing of carers of chronically ill, hospitalised children in Saudi Arabia. Hence, a qualitative design was best suited to gain rich detailed data as it helped me advance my understanding of the hospitalisation and caring experience in Saudi Arabia from the eyes of the carer while examining the factors that enabled her health and wellbeing, as well as the barriers that came in her way. In addition, in the absence of previous studies and the limited knowledge of the health and wellbeing of carers and chronically ill children in Saudi Arabia, this study was exploratory in nature, and therefore required a qualitative approach, as it gave me the flexibility to go in a different direction as the study unfolded (Pope & Mays, 1995) and the opportunity to explore the perceptions of carers in depth – something that would not have been possible with a quantitative approach (Pope & Mays, 1995). Carers of chronically ill children have different roles and responsibilities and different experiences from each other. These differences are shaped by the level of involvement of each carer.
and by the actual chronic disease itself. It was therefore appropriate to adopt a qualitative design, as qualitative research employs methods that seek to bring out the unique experiences of the participants.

In this study, I was interested in exploring participant views within the hospital setting where carers spent most of their time with their hospitalised children. I was also interested in triangulating the data and gathering the perspectives of healthcare providers and managerial staff. The overall approach used in this study was qualitative descriptive research. I drew on ethnographic method of participant observation to complement the data gathered from interviews which I will explain in Section 4.2.3. Qualitative descriptive research gave me the opportunity to study the participants in their natural environment and capture their unique experiences (Lambert & Lambert, 2012), which would have been difficult to achieve using a standardised measure. With the use of qualitative descriptive methodology, I was able to acquire knowledge about the hospitalisation and experiences of care by the carer and get the meanings that carers associated with them (Sandelowski, 2000). In addition, the use of qualitative research in healthcare settings provides the optimal potential to identify opportunities for improving healthcare service provision, not just from the perspective of health service users but also from the service providers. As Pope, Van Royen, and Baker (2002) explain, the way that qualitative research gives emphasis to people’s experiences is of particular use when evaluating the quality of healthcare, as it identifies what really matters to patients and families, what obstacles are standing in the way, and opportunities for quality improvement.

4.2.2 Theoretical framework

As discussed in Chapter 2, this qualitative study was guided by the family-centred care model. This model was chosen because of the way it incorporates the patient and the family into the provision of care. It also is an appropriate framework that lends itself to a better understanding of the needs and concerns of carers of chronically ill hospitalised children, which is the focus of this research. The model puts the family and the chronically ill child at the centre of care provision and helps carers take responsibility and make informed decisions, thereby maximising the carer, their child’s wellbeing, and the quality of care provided. Therefore, to explore the experiences of carers of chronically ill children during the child’s hospitalisation, and to understand the facilitators and barriers of wellbeing to both children and carers, the family-centred care model was used to guide
this research – especially in developing the interview guide and in interpretation of the data analysis (the interview guide is included in appendices 5.1, 5.2, 5.3).

4.2.3 Research methods

In this research, ethnographic method of participant observation was used as a part of the data collection. Participant observation gave me the opportunity to get insights into what was going on between carers of chronically ill children and healthcare providers during the hospitalisation of the children. In addition, the use of participant observation and interviews provided the opportunity to offer a “nuanced understanding” of the healthcare setting and compare what participant said and did (Savage, 2000).

4.2.3.1 Qualitative interviews

Qualitative interviewing is a tool used to explore the opinions, views, experiences and motivations of individuals in relation to the area being researched. It is argued that qualitative interviews can yield in-depth understanding of a phenomenon that will not be revealed by relying on purely quantitative methods such as questionnaires (Gill, Stewart, Treasure, & Chadwick, 2008; Polkinghorne, 2005). The purpose of this research is to develop an in-depth understanding of the experience of the carers of chronically ill hospitalised children and the barriers and facilitators to health and wellbeing. Thus, qualitative interviews were the most appropriate method for me to discover carers’ perceptions of what it was like to be caring for their chronically ill hospitalised child.

This research was conducted using qualitative semi-structured interviews. As this method of interviewing comprises a set of predetermined open-ended questions, it provided me with the opportunity to explore ideas brought up by the participant and explore such ideas in more detail, as well as allowing for new questions to emerge from the dialogue between me and the carers. The flexibility of semi-structured interviews gave me the opportunity to explore certain things that I had not necessarily thought of at the beginning of the interview. For example, topics that were frequently mentioned by carers were language barriers and shortages of staff. In addition, when I got the opportunity to interview a healthcare provider in a managerial position, these same issues were raised. This gave me an opportunity to probe further into these matters and to explore what actions, plans or systems were being put forward to respond to these issues.
4.2.3.2 Participant Observations

In this research, participant observations, which I refer to as observations from hereon, were used in combination with interviews to clarify and supplement the data gathered during the interviews. It allowed me to see what was actually going on during the time that the children were hospitalised. Thus, observations gave me the opportunity to learn from the carers by informally interacting with them. These observations were used to try to better understand what was happening when the children were hospitalised, understand this from the perspective of everyone involved: carers, healthcare providers, family members, and others. At the same time, I could see how the carers and healthcare providers interacted with each other as well as how the healthcare providers interacted with the hospitalised children. This helped me to determine whether there were any differences between what actually happened and what the participants said was happening, as well as helping me to triangulate my findings.

During the time I was carrying out observations, I informed the participants of my researcher role and the goals of my research. When I undertook observations in the hallways of the paediatric wards, I often had informal chats with the nurses. In addition, on several occasions, I was recognised by some carers that had already participated in the interviews. The carers approached me, and we would start having informal chats. I usually listened and talked to them and, after I was done, I would go to the seating area and write down everything I remembered of that interaction. I also joined in on a morning round with a consultant, three resident doctors and five intern doctors. While on the round I was able to observe how the doctors introduced themselves, examined the patient, explained the progress to the mother, decided on the next course of treatment, explained the medications and procedures to take place and asked the carer about anything she may have noticed or if she had any questions. In order for me to be able to join this round, the consultant introduced me to the doctors and briefly mentioned why I was joining them.

The observations took place at the paediatric ward and lasted for a period of six months from mid-September 2016 to March 2017 with 53 observations covering a total of 72 hours. The observations periods extended for about 2 – 3 hours each time. I went at different times of the day: morning, afternoon, and during visiting hours at night. I also went on weekends as well as weekdays. When observing, I would look at what was happening and, as soon as I had a chance, I would write it down in my journal. The
observations focused on different aspects such as facial expressions, behaviours, body gestures, clothing and other non-verbal expressions. Observing these aspects helped me to understand more about their experiences with hospitalisations because these observations took place while the carer was undertaking her caregiving role at the hospital. After observations, I went through my observation notes and then compared what I have written down to what is relevant to my research and my research questions. I also noted down what I needed to focus on in subsequent observations.

4.2.3.3 Document analysis

Document analysis was conducted on relevant hospital policies and job descriptions of healthcare providers that included information on the roles, responsibilities and expectations from staff. Initially, when the study was designed, document analysis was not included. However, upon analysis of my interview data, I found that health care staff believed that they are not officially expected to offer care for the carer of the hospitalised child as it is not part of their job and the carer was not considered a patient. At this point it was decided that there is a need for reviewing and analysing relevant hospital documents that could triangulate these findings. Hence, hospital documents were reviewed to verify how the hospital supported the carers of hospitalised chronically ill children. Therefore, the findings from the document analysis was only relevant to section 6.10 and is presented in that section along with section 8.3.2. These documents included the Multidisciplinary Patient & Family Education Policy, job descriptions of the paediatric nurses, the Patient Assessment and Re-assessment Policy, the Delivery of Care Policy and the job description of the social workers.

4.2.4 Participant selection

To gain an in-depth understanding of the roles and responsibilities that carers of chronically ill children undertook at the hospital and the facilitators and barriers to their health and wellbeing, it was important to choose “information rich” participants for this study (Etikan, Musa, & Alkassim, 2016, p. 2). In this research, information-rich participants were carers of chronically ill children who had been hospitalised at least two times in the year prior to the time of data collection. Healthcare providers who were involved at any point in the delivery of services to the hospitalised children were also included in this study. These included doctors, nurses, allied health professionals and also managerial staff.
Recruitment of participants was based on sampling strategies that ensured maximum variation sampling (Patton, 2005). Maximum variation sampling is a purposive sampling strategy that involves selecting cases across a “broad spectrum” and ensures that different perspectives relevant to the topic of study are represented (Etikan et al., 2016, p. 3). With the use of maximum variation sampling (Patton, 2005), I was able to understand the experience of caring for chronically ill children amongst carers with different educational backgrounds (illiterate, primary school education, secondary school education, university and post-graduate degrees); different employment status, age groups, and nationalities (Saudis and non-Saudis); and differences in chronic diseases suffered by children. I tried to ensure that healthcare providers were also a diverse sample by including nurses, doctors, social workers and managerial staff, and that they included different nationalities (Saudis and non-Saudis).

4.2.5 Participant recruitment

4.2.5.1 Carers

The inclusion criteria for the carers was that the chronically ill child of the carer had been hospitalised in the past year at least twice and that the carer understood either English or Arabic. To recruit participants for the interviews, the satisfaction questionnaire mentioned earlier in this chapter (see Section 4.1.3.1) was used. As mentioned in that section, carers indicated their interest in participating in the qualitative interview when they completed the questionnaire. A time and date that was convenient for the carer was then agreed upon. As the carers were constantly at their child’s side and were unable to leave the room, all interviews with carers were conducted in the rooms with the child who had been admitted.

4.2.5.2 Healthcare providers and managerial staff

To recruit the healthcare providers, an invitation email was sent by the management of the hospital to all employees (see Appendices 3.1, 3.2). The email informed the employees of the research and its purpose and that participation was voluntary. The email included the criteria for participation explained earlier. Any interested staff were encouraged to contact the researcher. If I did not hear from the healthcare provider within two weeks, a reminder email was sent (please see Appendices 3.3, 3.4). The healthcare providers also had the option to email the researcher if they were no longer interested in the research and did not wish to be contacted further.
4.2.6 Conducting the interviews

The interviews lasted for about 45 minutes to an hour and were conducted in either Arabic or English depending on the participant’s preference.

During the interview, I took notes in addition to the audio recordings. On completion of the interview, I noted down my own thoughts about the interview and how it went plus notes on body language of the participant.

Throughout the interview, I tried to clarify what was said by the participants to ensure that I was understanding their perceptions and views accurately. For example, a participant was describing a day that her child got hospitalised and referred to it as “the hardest day of her life” and then she went on talking. Instead of taking her words at face value or making my own assumptions I probed to find out what made her feel like this – that is, what was it that made her feel it was “the hardest day of her life”. At the end of each interview session, I drew on my notes to summarise the key issues discussed during the interview and then asked the participant if she had anything else she would like to add. After each interview was completed, I developed an interview summary sheet. On the summary sheet, as part of reflexivity, I rated the quality of the interview and the strengths and weaknesses of my interviewing skills, how forthcoming the participant was, what could have affected the way the participant was responding, what could be improved in terms of interviewing skills and any other thoughts I had regarding the interview. I also sent a few transcripts to my supervisor who went through the transcripts and together we looked at areas where I might be influencing the data collection process and noted ways of minimising this such as not assuming things and probing for clarification. This checking in with my supervisor at the beginning was a way of engaging in reflexivity and minimising my influence in the data collection process.

Of the 20 interviews, 16 were conducted in Arabic and 4 were conducted in English. As a Saudi with Arabic as my first language and English as my second, I have studied in both languages throughout my whole education, I was able to translate the interviews as I was transcribing. When transcribing the Arabic interviews, I was aware that the construction of the meaning could be slightly different and the exact meaning might become lost in translation (Van Nes, Abma, Jonsson, & Deeg, 2010). Therefore, I initially transcribed two interviews in English before giving them to someone who was fluent in both English and Arabic. She back-translated them into Arabic. I then listened to the interviews again.
while reading her back-translation to verify the accuracy. This process helped ensure that the translation was reliable. The rest of the interviews were transcribed and immediately typed in English. Then I sat with the English translation and listened to the Arabic recording to ensure that the translation accurately reflected what the participants had said in the interview.

After each interview was transcribed, I referred back to the summary sheet of that interview and noted the main concepts and themes that were elicited as well as possible areas to explore in-depth in the next interview. Before each subsequent interview, I referred to the summary sheet to make sure that I included the areas I had noted down for further exploration.

4.2.7 Qualitative data analysis

In this PhD study, thematic analysis was chosen to be the most appropriate method to analyse the qualitative data. It provided an opportunity to gain insights about the individual experiences of carers and the meaning they attached to the hospitalisations and chronic diseases. As stated by Braun and Clarke (2006), thematic analysis involves “identifying, analysing and reporting patterns (themes) within data” (p. 79). I used inductive thematic analysis. The term inductive refers to the researcher not having a pre-existing coding frame or preconceptions that he/she tries to see the data through but, rather, the themes are grounded in the data or arise from the actual data itself – so it is “data-driven” (Braun and Clarke 2006). This approach to analysis involves immersion, coding, categorising and developing themes.

To immerse and thereby familiarise myself with the data collected (Braun & Clarke, 2006), I listened to each interview and read and reread the transcripts, after which I added to my interview summary sheet, as mentioned above. In coding the interview transcripts, I first manually coded about five interviews by reading through the interviews and underlining what was interesting in relation to my research questions and the interview questions I asked. When selecting the interviews to code manually, I chose from each participant category one or two interviews that I thought were most typical as well as the ones that were most different from all interviews. I also looked through my field notes for observations and examined the data to gain a sense of what was happening, and to look for points that were of interest. Then, I prepared a list of codes and made a coding structure, both of which were shared with my Primary Supervisor. We both reviewed the
codes and coding structure together and refined the coding structure in line with the methodology we were following in this research. All transcripts were then uploaded into Nvivo software version 11 (QRS International, 2015) and coded using the coding structure while keeping my eyes open for any new codes.

As outlined by Braun and Clarke (2006), the next step after the coding is complete is to develop categories that show the relationships between the different codes established to understand the data. To help develop these categories, I kept looking at the codes I had and the research questions and tried to see how these codes were related to each other and if there were broad themes that might connect the categories. The final step was looking through the dataset and the developed categories and comparing them with the literature on family-centred care – the framework used in this research – to help in the coding process and to develop themes. This was an ongoing process. The themes were constantly reviewed and refined, and the literature was re-visited to compare and contrast within the categories and across categories as well as within and across participant groups. The resulting themes are presented in findings Chapters 5 and 6.

4.3 Ethical considerations

Ethical approval was sought and obtained for the quantitative and qualitative phases from both the Human Research Ethics Committee (HREC) at UNSW (Approval #HC15830 – see Appendix 1.1) and from King Fahad Hospital of the University (Appendix 1.2).

4.3.1 Reimbursement for participation

Carers who participated in the interviews were offered reimbursement in appreciation for their time and cooperation in the form of a SR100 gift voucher (almost AUD$34) from a local children’s shop. The satisfaction questionnaire which was used to recruit carers included information about the reimbursement.

4.3.2 Informed consent

Both KFHU and UNSW had their own versions of the informed consent document. Because the study was conducted at KFHU, I was required to use their informed consent form and add elements that are required by the participant information sheet and consent form at UNSW. The resulting form was a combination of both forms and was written in both Arabic and English. Two variations of the form were developed for the different kind of participant, such as carer, medical staff or managerial staff (please refer to
Appendices 4.3 and 4.4). As mentioned earlier, at the beginning of each interview the participant was informed that participation was voluntary and that she/he was free to not respond to any questions he/she did not want to. Interview participants were told that they could stop the interview anytime they felt the need to and that they were free to discuss their participation with family members and ask any questions that they may have. Consent was also sought for recording the interview. All participants consented to the audio recording.

4.3.3 Maintaining confidentiality and anonymity

I used the following strategies to ensure confidentiality of the participants:

1) Pseudonyms were used for the participants throughout the research.

2) Each quantitative survey was given a unique identifier that did not include the name of the participants or link the participant’s identity in any way to the completed survey instrument.

3) The satisfaction questionnaire had a section for participants to note their contact information if they were interested in participating in the interviews. This part of the completed questionnaire form was removed from the questionnaire and kept separately in a secure location at UNSW.

4) All interview transcripts were identified using the same unique identifier assigned to that same participant in the satisfaction questionnaire.

5) Informed consent forms and any other documents with identifiable information were stored in a locked secure location at UNSW or KFHU with access only to the researchers.

4.4 Stance of the researcher

Qualitative research is dependent on the researcher as the instrument of data collection (Malterud, 2001). Hence qualitative scholars highlight the significance of acknowledging the researcher’s stance (Malterud, 2001; Råheim et al., 2016; Sutton & Austin, 2015). This involves providing a clear statement explaining the values that the researcher brings, the cultural background and the professional and personal experiences (Malterud, 2001; Shenton, 2004). As Malterud (2001) rightly argues, in qualitative research it is not a matter of whether the researcher affects the inquiry, it is how reflective the researcher is. Acknowledging the researcher’s stance in terms of their cultural and professional
background allows the readers to determine for themselves the extent to which the researcher may have coloured the research. Therefore, acknowledging the importance of reflexivity and how my own background may shape the research, I provide a brief description of my background.

I am a woman born in Dhahran in the Eastern Province in Saudi Arabia. Dhahran is a city that is well known for having the headquarters of Saudi Aramco, the national oil company of Saudi Arabia. Together with nearby cities of Dammam and Al Khobar, the three cities form what is known as the Dammam metropolitan area, covering a total area of 3,800 square kilometres with an estimated population of 1.8 million people (Aboukorin & Al-shihri, 2015). Both my parents worked and were successful in their jobs. My mother was an English teacher in a high school in Al Khobar. While working, my mother had six children – three girls (including me) and three boys. My parents did everything in their power to ensure that we had the best education. They were strong believers of the importance of the education in securing and ensuring our future. Their strong beliefs and their commitment to my siblings and I had a big influence on us; we all were passionate about pursuing knowledge and doing well in school.

After completing high school, I joined the University of Dammam where I completed my Bachelor’s Degree in Health Information Management and Technology. I then undertook a one-year internship, during which time I worked at three different top hospitals in Al Khobar and Dhahran areas. One of the hospitals I worked at was KFHU, where the current research was conducted. Thus, I was and am quite familiar with the KFHU setting. However, I worked in the IT department and did not have any direct relationship with the patients.

While doing my bachelor’s, I got married and had my first child. After completing my internship, my husband and I moved to the United States for two years while my husband pursued his master’s degree in petroleum engineering. I chose to be a stay-at-home mother during that period and to focus on my daughter. After coming back to Saudi, I had my second child. Soon after, I joined a company in Al Khobar and worked there in human resources.

My husband later got a scholarship to pursue his PhD in Australia and he encouraged me to seek sponsorship for myself. I took his suggestion and was awarded a scholarship and undertook a master’s degree in international public health from UNSW. For me, my
journey through my master’s degree was an eye-opening experience. I learned so much and enjoyed the classes and the different approaches to learning and teaching at UNSW, approaches that were very different from what I was used to in Saudi. My postgraduate coursework degree motivated me to pursue a PhD degree as well. Besides my educational background, the following aspects of my own health and my daughter’s health were key factors that prompted my interest in the broader area of chronically ill children.

**My own health:** I was first diagnosed with the chronic skin condition, psoriasis, ten years ago. For the first five years, my symptoms were very mild with hardly any limitations or added burden to my life. But my experiences with this disease became more severe in the last five years following my move to Australia. This is perhaps a result of a lot of changes in my life in general. I was pregnant, had moved to a new country and started my master’s degree and then my PhD studies. The psoriasis condition became more severe with my entire body being affected. My health deteriorated day by day and my disease affected my wellbeing so much that my family became worried and my father flew to Sydney to help. Unfortunately, every treatment I tried provided me with relief only for a short while. My last treatment was phototherapy, which involved exposing my body to ultra-violet light that would somehow suppress my skin conditions. It required a commitment of going three times a week to a dermatologist. This treatment was time-consuming for a mother with three young children who was also a PhD candidate.

My chronic condition affected me in numerous ways. I endured constant physical pain and itchiness from it. I also was and still am highly uncomfortable with other people seeing my skin or commenting on it. I feel ashamed of my skin and this has manifested in the way I dress. Being a Muslim, I always cover myself up and wear hijab. However, when in the company of females, you can show your hair, arms and legs. Having this disease, I didn’t feel comfortable doing so even in front of my female friends; I would wear long sleeves and long pants at almost all gatherings. On rare occasions that I didn’t, I followed my friends’ eyes when they were talking to me and tried to see if they were looking at my lesions. This has had a negative impact on my mental health as I get depressed very often – an experience common among sufferers of both eczema and psoriasis.

**My daughter’s health:** My eleven-year old daughter Deema was diagnosed with asthma when she was about eight years old. I was terribly worried when she started complaining
of chest pains and breathing problems three years ago. After many tests and doctor’s visits, she was diagnosed with asthma. Asthma can be very severe – in some cases affecting the capabilities of the diagnosed person and the quality of their lives. In her case, she had border-line asthma. Although not very severe, it does impact her especially the extent to which she engages in physical activity. After getting asthma, she asked me not to allow her to compete in her school marathon, something in which she is usually excited to participate. She did not want to participate as she believed it would make her tired and run out of breath. Also, we took her inhaler everywhere we went. On rare occasions, we would forget it and would panic and stop at a chemist to get it to avoid her getting breathing problems. My daughter’s diagnosis kept me worried about her constantly when she would run at a park or chase her sister when playing. Although her condition is not very serious, it helped me understand my participants’ experience in dealing with the chronic conditions with their children.

Although my study is about chronic diseases experienced by children rather than those of carers or adults, my own personal experience with having a chronic disease and that of my daughter, provided me with in-depth insights and understanding of what my participants were going through with their children. As I know firsthand how chronic diseases can impact the health and wellbeing of sufferers and their families, I was able to relate to my participants, empathise with them and understand what they were going through and how chronic conditions have affected them and their loved ones.

As a Saudi who lived, studied and worked most of my life in Saudi, I was able to understand the context from which these participants were coming, draw insights and better understand the experiences through which they were going. My own experiences as a Saudi woman and that of my own and my child’s health may influence and/or shape my research, and thus, by being aware of this, I engaged in reflexivity. For this, I kept a journal in which I constantly reflected on how my own background may have influenced the various stages of the research, I also engaged in ongoing discussions with my supervisors at various stages of the research process and I followed measures to ensure rigour within the research, as discussed in Section 4.5.

4.5 Quality of qualitative research

Sound and rigorous qualitative research involves a systematic approach to the research design, implementation, data collection and analysis, and interpreting and reporting
findings (Fossey, Harvey, McDermott, & Davidson, 2002; Pope & Mays, 1995). An essential way of enhancing the rigour of the research is to provide a clear and detailed description of the research process (Beck, Weis, Greisen, Andersen, & Zoffmann, 2009). Lincoln and Guba (1985) developed perhaps the most widely used criteria for ensuring the quality of qualitative research. The four criteria suggested by Lincoln and Guba (1985) include credibility, transferability, dependability and confirmability. Below, I will discuss how I have addressed each of these four criteria in my study.

**Credibility**, according to Lincoln and Guba (1985), reflects confidence in the truth of the research findings and how well and accurately the researcher explains and analyses the phenomenon of interest. They propose several techniques that can strengthen credibility. These include prolonged engagement, persistent observation, triangulation, peer debriefing, negative case analysis, and member checking. For the present study, prolonged engagement – usually recommended as six months or more (Anney, 2014) – was achieved through the persistent observations over a period of six months. Further details pertaining to the observations are provided in Section 4.2.3.2 (Page 77). In addressing triangulation, I chose to focus on methodological triangulation and data source triangulation. Methodological triangulation was achieved by using two different methods for data collection – data were collected using interviews and observations. Data source triangulation was achieved by conducting the interviews with three different data sources – that is, carers of hospitalised children, healthcare providers and managerial staff.

**Peer debriefing** refers to the process of asking a peer to review your work to test and verify the coding and themes generated. I was able to achieve this through constant consultations with both of my supervisors during data collection, coding and analysis of the data.

**Negative case** analysis is the constant search for instances that do not support the themes that are emerging from the data. For example, in most cases, both carers and healthcare providers spoke of negative impacts on the carer’s health. However, Nasra (one of the carers) reported that her child’s disease was “very easy” and did not affect her mental wellbeing. Hence, as Nasra’s account comprised a negative case, her transcript was further explored and analysed. Although her daughter had sickle cell disease and has required frequent hospitalisations since the age of one year, she seemed to have accepted
it and dealt with it as a normal thing. Nasra’s case is discussed in more detail in Chapter 6, Sections 6.2 and 6.5

**Transferability**, as described by Lincoln and Guba (1985), is addressed by providing thick description of the research and the context so that other researchers can judge for themselves if they can apply some or all of the research findings to a different context. In my research, I attempted to provide a thick description of the context in which the study took place, as discussed in Chapter 3. I also provided a detailed literature review that identified what is already known about the topic, a detailed description of the design and tools for data collection, a detailed description of the study participants, and detailed analysis of the findings.

**Dependability and confirmability**: Lincoln and Guba (1985) stress the close association between dependability and confirmability, arguing that, in research, they go hand in hand and research that demonstrates one will have some degree of the other (Lincoln & Guba, 1985; Shenton, 2004). Dependability of the research refers to what is known in quantitative research as reliability or the extent to which another person can easily duplicate the research or part of it elsewhere (Lincoln & Guba, 1985; Shenton, 2004). During the period of this PhD study, I kept an audit trail that I documented in my diary. This included details of every step taken during the research process. Such a detailed audit trail, described in Sections 4.2.3.2 and 4.4 (Pages 77, 83), is one important way to ensure the dependability of the research (Shenton, 2004). In addition to my diary, progress reports and minutes of meetings with my supervisors also can be counted as part of the audit trail.

**Confirmability**, the last criterion according to Lincoln and Guba (1985), addresses the degree to which the findings and results that were produced in the research are based on evidence. In this research, this was supported by having an audit trail, linking the findings of the research with the available literature, and by reducing any effects of “investigator bias” by admitting the researcher’s predispositions (Shenton, 2004), as discussed in Section 4.4.

### 4.6 Summary and conclusion

This chapter has presented a review of the approaches of inquiry used in this research. The methods used for collecting data, selecting participants and analysis have been
reported. Given how it is important to maintain reflexivity throughout the research process, I also outlined the methods used to ensure the rigour and quality of the research.

By being conscious of my role in the research and acknowledging how my actions, thoughts or background are an integral part of gathering the knowledge, I was able to develop an understanding of the experience of the carers of chronically ill children from their own point of view.
Chapter 5
Quantitative Study

The main objective of this chapter is to address research questions 1 & 3: how satisfied are the carers with the care provided by the hospital for their chronically ill child? How does caring for a hospitalised chronically ill child affect the wellbeing of carers?

As mentioned in Chapter 4, the aim of this quantitative phase was to describe the demographic characteristics of the carers and the hospitalised children and identify any unmet needs of carers and areas of concern as determined by the survey tools. To meet this aim, this cross-sectional study used two survey tools – the first was designed to measure the satisfaction of the carers with physician communication skills along with their overall satisfaction; and the second was intended to measure the level of wellbeing of the carers. As mentioned in Chapter 4 Section 4.1.1, the satisfaction with communication questionnaire was selected, as the literature provides evidence of the importance of physician’s communication with carers in promoting carer satisfaction (Espezel & Canam, 2003; MacKean et al., 2005; Nuutila & Salanterä, 2006; Swallow & Jacoby, 2001). Similarly, previous studies have shown that the hospitalisation of a sick child can have psychological impacts on the carer. Consequently, the wellbeing survey was selected to measure the effects that caring for a hospitalised child could have on the wellbeing of the carer. Therefore, measuring both satisfaction and wellbeing can provide us with a partial overview of the experiences of hospitalisation for the carers of hospitalised children. It also offers opportunities for improvements and priorities to address to enhance service delivery.

As mentioned in Chapter 2, the effects of having a child with a chronic disease are far more challenging than for a usually healthy child suffering from an acute disease. Although acute illness affects the family and disrupts usual life, it usually occurs for a relatively short period of time compared to chronic disease, which has prolonged effects that require the family to adjust and accommodate the sick family member (Marin et al., 2009). By using these two survey tools, this chapter can compare the experiences of carers of hospitalised children who have chronic illnesses with the experiences of carers of usually healthy children hospitalised for acute illnesses.
As one of the aims of this research was to describe the demographic profile of children who are hospitalised at King Fahad Hospital of the University and their carers, carers were asked to complete the survey tools that included questions on the demographic profile of the children and their families. The satisfaction questionnaire explored the carer’s satisfaction regarding relationship building, information exchange, level of parents’ involvement in the child’s care, physician’s demonstration of effort and competence in child’s care and overall satisfaction. The second questionnaire used was the sf12v2 health survey, which was administered to the carers to measure their self-reported wellbeing. This is a generic survey that measures the general health of an individual irrespective of age, treatment group or disease. The Arabic and English language versions of sf12-v2 were obtained from Qualitymetric (www.qualitymetric.com) with permission. A full description of the questionnaires and the materials and methods is available in Chapter 4, Section 4.1.3.

5.1 Results

The questionnaires were administered to all carers of hospitalised children between mid-September and mid-October 2016. There is a small difference in the sample size of the two questionnaires for two reasons. Firstly, some participants filled in just one of the distributed questionnaires and returned it to the provided box. Secondly, on one particular day, the nurse responsible for distributing the questionnaires mistakenly distributed only the satisfaction questionnaire.

A total of 88 satisfaction questionnaires were distributed and 78 of them were filled in and returned (88.6% response rate). However, when cleaning the data, three respondents had to be excluded due to missing information. For the wellbeing questionnaire, a total of 82 surveys were given out and 71 returned (86.5% response rate). However, one respondent was excluded because all the questions were left unanswered.

The level of significance was set at \( p \leq 0.05 \).

5.1.1 Results of the satisfaction questionnaire

The socio-demographic characteristics examined in the questionnaire included age of the carer and child, the diagnosis of the child, the number of children, job of carer and spouse, the carer’s level of education and other demographics.
The mean age of the carers was 33.63 years (SD = 7.4). All were female. Age range was 19-65 years. The mean age of the hospitalised children was 5.18 years (SD= 4.5). The children’s ages ranged from 9 months to 14 years. Of these, 58.7% were males and 41.3% were females.

The carers reported the child’s primary diagnoses as a free text response. To facilitate analysis, these responses were analysed by the PhD candidate and categorised as either acute or chronic and verified with the help of a health care provider (refer to Chapter 4 Section 4.1.3.1). As mentioned in Chapter 2, the working definition used to distinguish the chronic diseases was any long-term conditions with mild to severe symptoms that had some common features (AIHW, 2017). These common features are discussed in Chapter 2, Page 9. Almost two-thirds (60%) of the children were hospitalised for a chronic disease. Causes for paediatric hospitalizations were 41.3 % due to respiratory condition, 20% haematology and 12% due to infectious diseases.

More details about the demographic characteristics of the 75 respondents are presented in Table 5.1.
Table 5.1: Demographic characteristics of 75 carers of hospitalised children at KFHU participating in the study

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>No. (%)</th>
<th>Acute</th>
<th>Chronic</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N= 75</td>
<td>N= 30</td>
<td>N= 45</td>
</tr>
<tr>
<td><strong>Child’s sex</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>44 (58.7)</td>
<td>16 (53.3)</td>
<td>28 (62.2)</td>
</tr>
<tr>
<td>Female</td>
<td>31 (41.3)</td>
<td>14 (46.7)</td>
<td>17 (37.8)</td>
</tr>
<tr>
<td><strong>Carers’s job type</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>32 (42.7)</td>
<td>15 (50)</td>
<td>17 (37.8)</td>
</tr>
<tr>
<td>Unpaid domestic work</td>
<td>27 (36.0)</td>
<td>8 (26.7)</td>
<td>19 (42.2)</td>
</tr>
<tr>
<td>Skilled work</td>
<td>13 (17.3)</td>
<td>5 (16.7)</td>
<td>8 (17.8)</td>
</tr>
<tr>
<td>Professional</td>
<td>3 (4.0)</td>
<td>2 (6.7)</td>
<td>1 (2.2)</td>
</tr>
<tr>
<td><strong>Carer’s level of education</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cannot read</td>
<td>3 (4.0)</td>
<td>0 (0)</td>
<td>3 (6.7)</td>
</tr>
<tr>
<td>Primary school</td>
<td>18 (24.0)</td>
<td>4 (13.3)</td>
<td>14 (31.1)</td>
</tr>
<tr>
<td>High school</td>
<td>22 (29.3)</td>
<td>9 (30)</td>
<td>13 (28.9)</td>
</tr>
<tr>
<td>BS/ higher education</td>
<td>32 (42.7)</td>
<td>17 (56.7)</td>
<td>15 (33.3)</td>
</tr>
<tr>
<td><strong>Father’s job type</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>5 (6.8)</td>
<td>1 (3.4)</td>
<td>4 (9.1)</td>
</tr>
<tr>
<td>Unskilled work</td>
<td>2 (2.7)</td>
<td>0 (0)</td>
<td>2 (4.5)</td>
</tr>
<tr>
<td>Skilled work</td>
<td>52 (71.2)</td>
<td>20 (69)</td>
<td>32 (72.7)</td>
</tr>
<tr>
<td>Professional</td>
<td>14 (19.2)</td>
<td>8 (27.6)</td>
<td>6 (13.6)</td>
</tr>
<tr>
<td><strong>Father’s level of education</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cannot read</td>
<td>1 (1.3)</td>
<td>0 (0)</td>
<td>1 (2.2)</td>
</tr>
<tr>
<td>Primary school</td>
<td>17 (22.7)</td>
<td>4 (13.3)</td>
<td>13 (28.9)</td>
</tr>
<tr>
<td>High school</td>
<td>23 (30.7)</td>
<td>9 (30)</td>
<td>14 (31.1)</td>
</tr>
<tr>
<td>BS/ higher education</td>
<td>34 (45.3)</td>
<td>17 (56.7)</td>
<td>17 (37.7)</td>
</tr>
</tbody>
</table>

*Carers were either the mother or a female relative based on the rules of the hospital

*Fathers’ job type doesn’t add up to 100% because some were deceased
As mentioned in Chapter 4, Section 4.1.3.1, the questions on carer’s satisfaction were measured using a 5-point Likert scale and assigned a score accordingly: “strongly agree” and “agree” = 1, “strongly disagree” and “disagree”= -1 and “neither agree or disagree” = 0

Table 5.2 presents the average satisfaction score of carers by disease status of the child. The Mann-Whitney test was used to compare the average satisfaction score among carers of acutely ill and chronically ill children. No statistically significant difference was detected (P>0.05). The results suggest that carer’s satisfaction with physician communication skills does not vary according to the disease status of the child (acute vs. chronic).

In general, the satisfaction level in the sample ranged from satisfied to highly satisfied because the average scores in each domain were very close to the maximum attainable satisfaction score.

**Table 5.2:** Average carer satisfaction score with the care provided by the physicians by disease status of the child

<table>
<thead>
<tr>
<th>Domain</th>
<th>Maximum score</th>
<th>Lowest score</th>
<th>Neutral score</th>
<th>Acute</th>
<th>Chronic</th>
<th>U-value</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relationship building</td>
<td>3</td>
<td>-3</td>
<td>0</td>
<td>2.70 ± 0.70</td>
<td>2.47 ± 1.10</td>
<td>629.00</td>
<td>0.47</td>
</tr>
<tr>
<td>Information exchange</td>
<td>3</td>
<td>-3</td>
<td>0</td>
<td>2.50 ± 0.94</td>
<td>2.56 ± 0.92</td>
<td>643.00</td>
<td>0.66</td>
</tr>
<tr>
<td>Degree of parent involvement</td>
<td>1</td>
<td>-1</td>
<td>0</td>
<td>0.70 ± 0.65</td>
<td>0.87 ± 0.40</td>
<td>610.50</td>
<td>0.26</td>
</tr>
<tr>
<td>Demonstration of effort and competence</td>
<td>4</td>
<td>-4</td>
<td>0</td>
<td>2.93 ± 1.28</td>
<td>2.53 ± 1.77</td>
<td>615.00</td>
<td>0.49</td>
</tr>
<tr>
<td>Overall satisfaction</td>
<td>11</td>
<td>-11</td>
<td>0</td>
<td>8.83 ± 2.42</td>
<td>8.42 ± 3.33</td>
<td>671.50</td>
<td>0.97</td>
</tr>
</tbody>
</table>
Table 5.3 shows the overall satisfaction by educational level and job type of the carer of the child. Carer’s jobs were reclassified into job types: none, unpaid domestic work, skilled work and professional. Skilled work was used to refer to work that needs special training or a certain skill-set to be performed. Professional was used to distinguish very highly skilled work that requires specialised education, training and skill (e.g. doctors and lawyers).

The Kruskall-Wallis test was used to compare the average scores for overall satisfaction by education level and job type of the carers. The results show that there is no statistically significant difference between carers of different educational levels on overall satisfaction with the care provided by the physicians (P=.074). However the job type of carers approached statistical significance (P=0.056). Post-hoc testing was conducted to explore this further (Table 5.4).

Table 5.3: Average scores for overall satisfaction with the care provided by the physicians by education level and job type of the carers

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Satisfaction</th>
<th>K-W statistic</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level of education</td>
<td></td>
<td>6.935</td>
<td>0.074</td>
</tr>
<tr>
<td>Cannot read</td>
<td>6.67 ± 1.52</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary school</td>
<td>8.33 ± 3.12</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school</td>
<td>9.50 ± 2.92</td>
<td></td>
<td></td>
</tr>
<tr>
<td>BS/ higher education</td>
<td>8.28 ± 2.98</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Job type</td>
<td></td>
<td>7.569</td>
<td>0.056</td>
</tr>
<tr>
<td>None</td>
<td>7.91 ± 3.23</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unpaid domestic work</td>
<td>9.96 ± 1.34</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Skilled work</td>
<td>7.92 ± 3.66</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Professional</td>
<td>6.33 ± 4.50</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 5.4: *p*-values for *post hoc* comparisons between pairs of job types using the Mann-Whitney U test

<table>
<thead>
<tr>
<th>Pairs</th>
<th>Satisfaction</th>
<th>U-value</th>
<th><em>p</em>-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>None Vs. unpaid domestic work</td>
<td>7.91 ± 3.23</td>
<td>9.96 ± 1.34</td>
<td>275.00</td>
</tr>
<tr>
<td>Skilled work Vs. unpaid domestic work</td>
<td>7.92 ± 3.66</td>
<td>9.96 ± 1.34</td>
<td>201.00</td>
</tr>
<tr>
<td>Professional Vs. unpaid domestic work</td>
<td>6.33 ± 4.50</td>
<td>9.96 ± 1.34</td>
<td>37.00</td>
</tr>
<tr>
<td>None Vs. skilled work</td>
<td>7.91 ± 3.23</td>
<td>7.92 ± 3.66</td>
<td>123.00</td>
</tr>
<tr>
<td>None Vs. professional</td>
<td>7.91 ± 3.23</td>
<td>6.33 ± 4.50</td>
<td>19.50</td>
</tr>
<tr>
<td>Skilled Vs. professional</td>
<td>7.92 ± 3.66</td>
<td>6.33 ± 4.50</td>
<td>15.00</td>
</tr>
</tbody>
</table>

* *P*-values less than 0.008 with a Bonferroni-adjusted level of significance was considered significant.

Table 5.4 shows the results of a post-hoc test performed using the Mann-Whitney test to identify any statistically significant difference in the satisfaction scores between the different job type pairs. *P*-values less than 0.008 with a Bonferroni-adjusted level of significance were considered significant. The Bonferroni adjustment was used to reduce the chance of obtaining a false positive result due to testing multiple pairs in a single dataset (Armstrong, 2014). Results in Table 5.4 show that the difference between pairs was not significant with all *p*-values greater than 0.008.
5.1.2 Results of the wellbeing survey

A standard 4-week recall period of the sf12-v2 was used because the survey was administered only once. The carers in the sample had a mean age of 35 years and their ages ranged from 19–70 years old. Description of summary measure abbreviations and the scale’s content domain is provided in Table 4.2, Chapter 4.

As mentioned in Chapter 4, the scores of the sample were compared to the US general population norm for two reasons. First, normative data is available for a few countries but not for Saudi Arabia. Second, the literature suggests that there is little difference between standard US-derived scoring algorithms, which assumes a mean of 50 and a standard deviation of 10, and country-specific scoring algorithms. The use of a standard US scoring algorithm is recommended to enable cross-cultural comparisons (Busija et al., 2011; Kontodimopoulos et al., 2007; Younsi, 2015).
Figure 5.1: Average summary measures of carers of children admitted with chronic disease

*PF: physical functioning  
RP: role physical  
BP: bodily pain  
GH: general health  
SF: social functioning  
RE: role-emotional  
MH: mental health  
MCS: mental component summary

Figure 5.1 shows the average summary measures and scale scores for the carers in the chronically ill children sample. From left to right, the four physical health scales scores are presented: physical functioning (PF), role physical (RP), bodily pain (BP) and general health (GH), followed by the physical component summary score (PCS). On the right side of Figure 5.1 are the four mental health scale scores: vitality (VT), social functioning (SF), role-emotional (RE) and mental health (MH), and the mental component summary score (MCS).

As mentioned earlier, the sample’s scores are compared to the norm-based scoring from the U.S. general population, where each scale is scored to have the same mean (50) and a standard deviation of 10. The higher the scale score the better the physical health, mental health and wellbeing. A score of 50, i.e. the US population mean, is considered the cut-
off point; a participant with a score below 50 is considered to have a low quality of life in the domain being measured (Lam & Lam, 2009; Molina & Munoz, 2012). Individuals scoring higher than a 50 and closer to a 100 are considered to have better health. In the bodily pain domain, a score close to 100 indicates the absence of pain (Molina & Munoz, 2012; Ware et al., 2009).

As Figure 5.1 demonstrates, in general, the carers of chronically ill children in the sample had a lower health status in all domains compared to the US population norm.
Figure 5.2 presents the average summary measures and scale scores for carers in the sample with acutely ill children. The results were similar to that of carers of chronically ill children; the carers had lower scores in all domains compared to the US population norm.

*PF: physical functioning  
RP: role physical  
BP: bodily pain  
GH: general health  
SF: social functioning  
RE: role-emotional  
MH: mental health  
MCS: mental component summary
Figure 5.3: Comparison of average summary measures of carers of children admitted with acute disease and chronic disease

*PF: physical functioning  
BP: bodily pain  
SF: social functioning  
MH: mental health  
RP: role physical  
GH: general health  
RE: role-emotional  
MCS: mental component summary

Figure 5.3 compares the average summary measure and scale scores between carers of chronically ill and acutely ill children. An independent sample t-test was performed for each scale and summary measure to see if there were any statistically significant differences between the acute and chronic groups. No statistically significant difference were found.
Figure 5.4 displays the average physical component summary (PCS) score for the entire sample categorised into different age groups and compared to the US population age group norms. The graph takes into account the natural changes in PCS that occur with age. As shown in the graph, the average physical component summary scores in most age groups were lower than that of the general population. However, the mean PCS score of the 45-54 years age group was close to that of the norm. A one-way ANOVA test was performed to test for significance of the difference between PCS across different age groups; however, the results were not statistically significant ($p = 0.893$, df = 4).
Figure 5.5: Physical components scores by age group of carers of chronically ill hospitalised children

Figure 5.5 examines the PCS across different age groups amongst carers of chronically ill children. As shown in the graph, the average physical component summary scores of carers of chronically ill children in most age groups were lower than that of the general population. However, the mean PCS score of the 45-54 years age group was close to that of the norm. A one-way ANOVA test was performed to test for significance of the difference between PCS across different age groups of carers of chronically ill children; however, the results were not statistically significant ($p = 0.908$, df = 4).
Figure 5.6 examines the PCS across different age groups of carers of acutely ill children. As shown in the graph, the average physical component summary scores of carers of acutely ill children in all age groups was lower than that of the general population. A one-way ANOVA test was performed to test for significance of the difference between PCS across different age groups of carers of acutely ill children; however, the results were not statistically significant ($p = 0.968$, df= 2).
Figure 5.7 displays the average mental health component (MCS) summary score for the entire sample categorised into age groups compared to the general population age group norms. The graph takes into account the natural changes in MCS that occur with age. As the graph demonstrates, the carers across different age groups had a MCS which was lower than the norm. The carers in the 35-44 age range had the lowest MCS of (42.22). The MCS scores of the different age groups of the sample were compared to each other using a one-way ANOVA test and were found not to be statistically significant ($p = 0.885$, df= 4).
Figure 5.8 examines the MCS across different age groups amongst carers of chronically ill children. The results show that carers of chronically ill children had similar scores to those of the general sample in Figure 5.7. A one-way ANOVA test revealed that the difference in MCS across different age groups of carers of chronically ill children was not statistically significant ($p = 0.987$, df= 4).
Figure 5.9 displays the MCS across different age groups of carers of acutely ill hospitalised children. Carers in the age groups 18-24, 25-34 had similar MCS. Carers in the 35-44 age group had the lowest MCS with a score of (41.99). However, a one-way ANOVA revealed that differences in MCS in carers of acutely ill children in different age groups were insignificant ($p = 0.557$, df= 2).
Figure 5.10 compares the percentage of people from the sample at risk of screening positive for depression compared to the norm. A positive first-stage depression screening score is defined as a mental component score (MCS) less than or equal to 42. Previous research done by Ware and Kosinski (2001) has validated the use of MCS as a cut-off point for screening for depression. As the figure demonstrates, the percentage of carers at risk of screening positive for depression was more than double (44.3%) that of the percentage of people at risk in the general population (20%).

The difference between the percentage at risk from the general population and the percentage at risk from the sample of carers was tested with the Z-test for single proportion and was statistically significant $z = 5.083, p < 0.0001, 95\% \text{ CI } [32.42, 56.67]$. The results suggest that carers in the sample are at an increased risk of depression when compared to the norm.
Figure 5.11 compares the risk of screening positive for depression between carers of chronically ill children and carers of acutely ill children with the general population norm. The carers in the sample in both the acute (38.7%) and chronic groups (48.7%) had a higher risk of screening positive for depression than the general population norm (20%).

The difference between the percentage at risk in the general population and the percentage at risk among the carers of acutely ill children was tested with the Z-test for single proportion and was statistically significant $z= 2.603$, $P = 0.0092$, 95% CI [21.84, 57.80]. The results also show significant difference between the percentage at risk from the carers of chronically ill children and the general population $z= 4.481$, $p < 0.0001$, 95% CI [32.40, 65.20]. The difference between the percentage at risk among carers of chronically ill children and carers of children with acute diseases was tested with the Z-test for two patient population and was found to be not significant $z= 0.8$, $p= 0.4028$, 95% CI [-0.1343-0.3343].
Figure 5.12 displays the risk of depression across different age groups. The participants in the 35-44 years age group were the most at risk for screening positive for depression with a score of (48.3%). Next was the age group 25-34 and 45-54 with scores of (45.5% and 33.3%), respectively. The 18-24 age group had the lowest risk, with a score of 25%. However, a Fisher Exact test did not show statistically significant differences in the risk of screening positive for depression between the different age groups of carers ($p = 0.896$).
5.2 Summary of quantitative questionnaires results

This study tested carers’ satisfaction with physician communication skills. The average satisfaction scores across all four dimensions (relationship building, information exchange, level of parents’ involvement in the child’s care, physician’s demonstration of effort and competence in child’s care) were high and approached the maximum attainable scores.

The study compared the level of satisfaction amongst carers of chronically ill children and those of children with acute illnesses. The study found no statistically significant difference in the average level of satisfaction with physician communication between the overall participant sample, the carers of chronically ill children and carers of the acutely ill children. The results also showed no statistically significant difference in the overall satisfaction of carers with the care provided by the physicians with different job types and levels of education.

This study also measured the effects that caring for a hospitalised child could have on the carers’ wellbeing. The study compared the summary measure and scale scores for the overall sample and for two subgroups - the carers of acutely ill and chronically ill children.

The results indicated that the overall sample and the two subgroups (carers of acutely ill children and carers of chronically ill children) generally had lower physical and mental component summary measures compared to the population norm. There were no statistically significant differences in the PCS and MCS scores across the different age groups, in the overall sample and in the two subgroups.

However, the study found that the carers’ in the study had double the risk for depression compared to the population norm \((p < 0.0001)\). Carers of acutely ill children and chronically ill children were more at risk for screening positive for depression than the general population \((P = 0.0092, p < 0.0001\) respectively).

In conclusion, the key findings of this chapter were:

- The carers had a high level of satisfaction with the physician’s communications
- There was no statistically significant difference in the level of satisfaction of carers of acutely ill children and carers of chronically ill children.
• Carers in the study had double the risk of screening positive for depression compared to the population norm.

• There was a significant difference in depression screening between carers of chronically ill children and acutely ill children and the norm. Carers of chronically ill children had more than double the risk of screening positive for depression compared with the norm.

• There was no difference in the risk of depression between carers of chronically ill and acutely ill children.

The qualitative study (Chapter 6) provided good insights into the potential reasons for these findings. These will be discussed in Chapter 7 and in the general discussion in Chapter 8.
Chapter 6
Explaining The Concerns and Needs

In this chapter, I present the findings related to my research questions:

1) How satisfied are the carers with the care provided by the hospital for their chronically ill child?

2) What roles do carers play in caring for a chronically ill child in the hospital?

3) How does caring for a hospitalised chronically ill child affect the wellbeing of carers?

3.1) What factors facilitate the health and wellbeing of carers of chronically ill children?

3.2) What barriers do carers face in ensuring their own health and wellbeing?

In the qualitative phase of this study, I interacted with a total of 24 participants. These included 12 carers, seven healthcare providers, three administrative personnel and two management staff. The healthcare providers included doctors, nurses, social workers and diabetes educators. The diabetes educators were public health staff specially trained on diabetes. The managerial personnel included people from medical, nursing and administrative management.

The participants were aged from 18 to above 70 years. The carers I interviewed had children with a variety of chronic diseases, including sickle-cell anaemia, cancer, factor XIII deficiency, systemic lupus erythematosus, cerebral palsy, pancytopenia and asthma. The children included nine boys and three girls and their ages ranged from 1 to 13 years. Ten of them were school-aged children who were absent from school due to their hospitalisation. In terms of education, the carers ranged from illiterate to carers with a bachelor’s degree. The carers were also of different nationalities: seven were Saudis and
five were non-Saudis. The same was true for healthcare providers and managerial staff, with five Saudis and seven non-Saudis.

I have selected the cases of two carers and two healthcare providers to present in detail. These cases were deliberately selected because they give an idea of the typical experience of caring for a chronically ill child and the effects that the care had on the child, family and carer. They also reflect the mental health concerns and cultural restrictions on seeking professional help. Two cases of carers are highlighted to reflect women from different generations (one in her 40s and another in her 70s); both women were illiterate. Although both women had experienced poor health as a result of their caregiver duties, the psychological impacts of caring are experienced differently. One experienced what she referred to as extreme stress and agony and talked about hating her life, while the other did not speak much about psychological distress but talked about drawing on her faith in God to cope with her difficulties. The two healthcare providers were selected due to the different roles they perceived in caring for the carer (one saw it as a vital part of her role, and the other referred to it as “not part of (her) job”).

To maintain confidentiality, all names used in presenting the findings are pseudonyms.

Rihab

Adam’s mother, Rihab stood out for me. Of all carers who participated in this study, she seemed to show a high level of mental distress and appeared to be overwhelmed by her son’s illness. Her distress can be seen in the way she, throughout the interview, repeatedly spoke of how she hated her son’s condition and said that she frequently wished to die. This suggests she is experiencing a high level of mental distress because of her son’s chronic disease.

Rihab is a Yemeni woman residing in Saudi Arabia. She is in her mid-forties and has five children. She is one of two illiterate women I interviewed. Rihab is a stay-at-home mother who spends her day doing domestic chores. I found some degree of difficulty talking to Rihab, as she had a very different accent and I tried to verify the information she was sharing to ensure I was understanding her correctly.

Seven years ago, the youngest of her children (Adam) developed severe asthma. At that time, Rihab’s brother suddenly passed away – a brother who was everything to her in life. She referred to him as her brother, father, friend, everything. She was very distressed by
his death and cried day and night. Her son Adam became very distressed by her grief. Shortly after that, Adam got sick with severe asthma. Rihab believes that her son got sick because he observed her sadness over her brother’s death.

Amina

Amina, a grandmother in her 70s, was the first carer I interviewed. She was very friendly during and after the interview. She often saw me in the weeks following her interview and took the time to chat with me and thank me for doing this research. She seemed very friendly with everyone, and when walking in the hallway, she always greeted and spoke to every doctor or nurse that she saw.

Amina has six children and six grandchildren. One of her daughters, who was married when she was 17 years old, gave birth to Mohammed who had sickle cell disease. The mother was advised not to have any more children because they would have the same disease as Mohammed. Amina indicated it would have been hard to have another child that would “suffer” like Mohammed. The daughter eventually got a divorce, moved back with her parents and went back to studying at the university. Amina then assumed the role of carer for her grandson. Mohammed now calls Amina ‘mom’ and considered his biological mother as a sister.

Amina spoke of how hard it has been on her to take care of her grandson. It caused her to have poor sleep and taking care of him has affected her health. She is an elderly woman who seemed to be in a fragile state of health. However, Amina was reluctant to talk about her struggles as she believed God would reward her for her silence, and acceptance would pave the way for these rewards.

Nancy

Nancy is an experienced paediatric nurse, one of many paediatric expatriate nurses that I met daily during my data collection. She is over 30 years old and has worked at this hospital for more than 10 years. She was interested in being part of the study and sometimes helped me to distribute the questionnaires. Rapport developed quickly as we met every day and I usually greeted all the nurses and asked how they were.

Nancy first explained her roles as a paediatric nurse. She would orient the patient and the carer to the room when they were being admitted, explaining what the medications were
and how they were used, and what interventions were to take place. Nancy would also inform the carer of the roles that, as a carer, they would be expected to fulfil.

For Nancy, the most important thing in her job was to maintain a good relationship with the patient and carer and build a partnership with them based on trust, love, and the exchange of information.

Deema

Deema was a Saudi general practitioner and a friend I have known for many years. She works at KFHU and heard about my research and volunteered to participate. She is in her early thirties, married and has children of her own, with their ages ranging from 1-14 years.

Deema’s roles were to examine patients with acute or chronic problems and treat them in an outpatient clinic or refer them if necessary.

Deema valued the relationship with the family members and carers of the patient. Her relationships with the carers were particularly important to her. To her, the carers were a valuable source of information and knew the patients best. Deema considered keeping the carer informed about the disease that the patient has and how to manage the disease to be very important. Deema felt a connection to her patients. She offered them her direct telephone number so that they could call her anytime if they had questions.

Deema spoke about how the care of required by the carer for the hospitalised child could have negative impacts on the carer. One of the impacts Deema talked about was the challenge of dividing time and effort between the carer’s responsibilities at home and at the hospital. Moreover, the physical environment of the hospital affected the health of the carer.

In the following section, I present and discuss the main themes that were generated from the analysis of the interview transcripts which were: being burnt out, negative impacts on caregiver’s health, not being able to let go, shortage of staff, survival as a family, roles of the carer, expertise in providing care, drawing on faith in God, partnership between the carer and healthcare provider, and the care of the carer.
6.1 Being burnt out

The burnout of carers was a dominant theme and mostly related to experiences of poor mental health. Responses from all but two of the carers suggested that they experienced some form of mental distress. Research has documented that caring for a chronically ill child for a long time is linked to poor emotional and physical health for the carer (Brehaut et al., 2004; Murphy et al., 2007; Raina et al., 2005). When not dealt with, stress-related psychological exhaustion can lead to burnout (Bilgin & Gozum, 2009; Norberg, 2007). Burnout is “a constellation of symptoms including physical, emotional and cognitive exhaustion, [and] is a consequence of longstanding stress exposure” (Norberg, 2007, p. 131). It has been witnessed in parents with an excessive burden of caring for a chronically ill child (Bilgin & Gozum, 2009; Norberg, 2007; Weiss, 2002). In this study, burnout was mostly experienced in terms of emotional and cognitive exhaustion, although some experienced physical burnout too, as discussed in Section 6.2.

Burnout is most likely what Rihab was experiencing. Her words suggest that she was having difficulty coping with her son’s chronic disease and dealing with the stress it has caused her – to the extent that it was affecting her overall mental wellbeing. Rihab was “tired and exhausted” and “didn’t eat or sleep, all for [her son].” Throughout the 40-minute interview, Rihab repeatedly said she wished she could die. She referred to the psychological distress she was feeling as “killing [her]” which clearly suggests her mental health was seriously impacted every time her son had an episode. Rihab was constantly struggling to deal with her son’s disease. She mentioned that it was very hard for her to have a child who was constantly ill. It was clear that her son’s asthma was taking a toll on her, causing her extreme stress and possibly burnout.

*I swear I’m very tired because of his disease... every time he gets an episode, he is killing me. This asthma that he has made me hate my life. Every time he gets an episode I panic; after he gets discharged I keep reading Quran for him and I hope he will get better ... I pray to God.*

(Rihab, carer)

Rihab repeatedly mentioned that she hated her son’s condition. When asked how she felt about the first time her son was hospitalised, Rihab indicated this happened around the time her brother passed away. This loss and her son’s severe episode of asthma hit her so hard that she found the pain unbearable – so much so that she wished she would die.
he got hospitalised at the same time that my brother died... that was the hardest episode [my son] got in all of the 7 years he had the disease...
it was the hardest week ever because [my son] had shortness of breath that was very bad and didn’t go away. Very hard, like I was dying.
From one hand my brother’s death and from the other my son’s illness.
It all hit me very hard. I was wishing that I would die... from how much pain I was going through. I thought I want to die... I hated myself.
(Rihab, carer)

Rihab’s words above portray the impact of her child’s chronic condition on her own mental wellbeing. It is likely that her son’s illness coming on top of losing her brother affected her psychological wellbeing more than it would have otherwise. Rihab mentioned that her son almost died several times. When asked how she was feeling at that time, she said that it made her “hate” her life. The following words clearly portray that her son’s illness had even affected her will to live, suggesting that she was under extreme emotional distress:

I die 100 times every time he has an episode... I die a hundred times...
I panic. Because I get scared for him. (Rihab, carer)

Rihab’s words below signify how much her son’s illness has an impact on her own physical and mental health.

I felt like I hate my life because of my son... I don’t desire life anymore.
I keep crying because of what is happening with him. I become tired and exhausted... I don’t eat or sleep, all for him. (Rihab, carer)

Rihab was aware of the negative psychological effects on her. However, she did not seek any professional help; instead, she drew on her faith to cope. As I did not probe further into this, it is unclear whether she realised she needs professional care for her mental health issues. However, as a woman born to Saudi parents and having lived most of my life there, I am aware that it is quite normal in Saudi for women to just deal with this kind of everyday pressure alone or rely on their strong religious beliefs. As mentioned in Chapter 3 Section 3.6.6, in societies like Saudi Arabia, mental health is rarely discussed, and often mental illness is associated with stigma (Koenig et al., 2014). Therefore, identifying any psychological or mental health-related problems as something that needs
professional help and seeking such care is highly unlikely. Instead, the common practice is to take strength from their faith and religion as a means of coping with their psychological distress (Al-Krenawi, 2005).

Like Rihab, Salma seemed to be going through intense emotional distress. Her son was diagnosed with cancer a year ago in Egypt. He had a six-month course of chemotherapy and then they were told that his cancer was in remission. When they came back to Saudi for a follow-up, the doctors discovered that his cancer had returned. For Salma, her son’s relapse was immensely distressing, as portrayed by her words below.

I broke down... because he had it once and then it came back. I broke down more than the first time... it was harder than the first time... the second time was harder because, when it came back, I thought it might never go away. I lost hope. (Salma, carer)

Frequent hospitalisation for a chronic condition appeared to impact the mental wellbeing of not just the carer but also the hospitalised child. Salim’s mother Sarah spoke passionately about the impact of her son’s sickle cell disease on his mental wellbeing. Salim was 8 years old and, at the time of the interview, was hospitalised for the fifth time. He could not accept his condition and he was angry that he was sick and not others.

Last time, he told me “give me a knife I want to kill myself... why me? Oh God, why don’t other people have it but I do”... So sometimes he [son] says stuff that kills me and makes me feel bad for him. When he says that, I wish that I would die... Because I cannot do anything for him... it is very hard to see your son in pain and there is nothing you can do. (Sarah, carer)

The above words of Sarah clearly portray the implications for the mental health of both the carers and the hospitalised children. It also suggests the notion of being helpless in these situations, and this feeling of helplessness further impacts the mental health of the carers. Interestingly only Salim’s mother spoke of the impact of the child’s physical health on the child’s mental wellbeing. Although none of the other carers spoke directly of the mental wellbeing of their children, this may not necessarily be because it was not a concern for other carers. As I indicated earlier in Chapter 3, Section 3.6.6 Page 60, mental health issues are viewed in a negative light in Saudi culture (Koenig et al., 2014).
and this may be why no one else brought it up. Moreover, being ill may be considered as one’s fate and accepting God’s will is what a good Muslim is expected to do (Al-Krenawi, 2005; Koenig et al., 2014). Thus, this may be another reason that the carers did not speak about issues around the mental wellbeing of children. It is possible that further probing into this matter might have encouraged the carers to open up and share the effects that the chronic diseases were having on their mental health and that of their children.

6.2 Negative impacts on carer’s physical health

Almost all of the carers spoke of poor physical health and lack of sleep as a result of being caregivers for chronically ill children. Of the 12 women I interviewed, half of them spoke of serious physical health concerns such as high blood pressure, irritable bowel syndrome and heart problems. Carers seemed to believe that these were indirect effects of their carer role or of their presence at the hospital.

Understandably, carers pointed out that the hospital environment was a total shift from the comfort of their own houses. The participants attributed some of the physical health effects that they experienced such as the inability to sleep to the hospital’s physical environment.

All carers found sleeping or resting very difficult in the reclining chair provided for carers, as they did not actually recline much (please refer to Figure 6.1 below). Carers were also prohibited from bringing their own blankets or bedsheets due to infection control considerations. Instead, the hospital provided them with a thin bedsheet to cover themselves. Some carers mentioned that, because the chair was not comfortable, they sometimes had to ask for additional bedsheets to support their back. The concerns raised by the carers about the physical environment reflects some dissatisfaction with the physical facilities offered by the hospital.
For carers, such as Salim’s mother Sarah, sleeping was not possible at all. She did not feel comfortable sleeping next to her son who had sickle cell disease and would get cold easily. She also feared that he would experience pain in the morning if he slept on one side for a long time. Therefore, she would constantly turn him and give him massages during the night. This caused her a lot of worry and anxiety about him and, as a result, reduced the quality of her sleep.

At night, I cannot sleep with him... I need air-conditioning because I’m hot... but he doesn’t need it... or I have to let him wear a lot of layers and then he would sweat a lot... so I spend the nights uncovering him so he cools down and then covering him so that he doesn’t get cold... so I get anxious in my sleep... I also, don’t want him to sleep on his hand for a long time because if he does that, then he wakes up, his hand will hurt him... so all night I’m not sleeping... it is like I’m sleeping and awake at the same time... I’m very anxious... I’m afraid he would wake up and tell me [he] has pain... but I don’t know why I cannot sleep even when he is sleeping and everything is OK... I’m worried... (Sarah, carer)

During observations, I noticed that the chair (please refer to Figure 6.2 below) was much lower in height than the child’s bed. For someone like Sarah with a child with sickle cell
disease that requires constant massaging of the body to reduce pain, having the bed so high up meant that the carer has to stay on her feet for a long period of time throughout the night.

**Figure 6.2:** Height difference between carer's and child's bed

The concerns with sleep elicited in the carer’s interviews were also echoed by healthcare providers. For example, Deema – the family doctor – agreed that the hospital is not very comfortable for the carer, a factor that could impact on a carers’ sleep and health.

*Most of them, they don’t sleep... Because either they are sharing a room with another patient or because the nurses are coming in every four hours to take vitals. So, the caregiver doesn’t sleep well. They have to be awake for the patient... The patient is sick so he will wake a lot and be saying ouch and stuff. So who will take care of that? Not the nurses because they cannot be there all the time. The caregiver is the one who will tell the nurses... So there isn’t good sleep or good food... so they have to provide something comfortable for her to sleep in because the chair they have now is not comfortable. So, as I told you, we have to help them be comfortable so that they help us in treating the child.*

(Deema, healthcare provider)

Amal, the social worker, stated that the most frequent complaint she received from the carers was that the carer’s bed was uncomfortable and was causing them back pain. The
only advice she could offer them was to ask the nurse to provide them with more blankets to support their backs.

_They are complaining about the carer’s chair... Their back hurt from the chair... So they would tell us that it hurts... And here at the hospital, the policy states that it is prohibited for someone to bring a blanket or linen or a chair from the house... So you cannot do anything for the carer... Especially if she is pregnant or if she had back problems... So every time she would complain that the chair causes pain... The only solution we have is to tell them to ask the nurses for extra blankets to put on the chair._ (Amal, healthcare provider)

Additionally, nurses seemed to not be aware of how their actions impacted the carers. Some carers reported difficulty sleeping in the hospital when the nurses would come in every four hours and check on the vitals. Salim’s mother Sarah spoke of an altercation with a nurse that portrays her frustration and dissatisfaction with the nurse’s lack of understanding and compassion for the carer. When the nurse came to the room at night to take the vitals of the next patient, the nurse turned on all the lights in the room.

_Sometimes the nurse walks in and switches on the lights... One time I even fought with the nurse... I told her: you are going to the patient next to me, then switch on only the light that is in her section... you don’t need to switch on the lights for the whole room... and every time she walks in, she never closes the door behind her, I always have to go and close the door behind her... we need a little compassion... The machine in the room is very noisy... we don’t need any more noise..._ (Sarah, carer).

One of the carers noted that having a chronically ill son meant that she had to lift him regularly to shower or when he needed to go to the toilet. As a consequence, she had consistent back and shoulder pains, a problem that only got worse as the child grew and his bodyweight increased.

For the carers who already had a pre-existing health condition, their caring role exacerbated their condition. This was the case for Amina, Rihab and Ibtehal. All had their own physical health problems that they perceived to have worsened due to caregiving.
As portrayed above, caring for her grandson in the hospital meant that Amina’s own health condition worsened. Yet for these carers, their main focus seemed to be their child or grandchild’s health at the cost of neglecting their own health.

One of the carers that I interviewed spoke about how the hospital visitation policy was affecting her. As the hospital prohibits the visitation of admitted patients by children, Jana, the mother of Ziyad, would sometimes go up to 21 days without seeing her other children. Not being able to see her children would “exhaust her” and add to her worry and tiredness.

Some carers were not satisfied with the food served to them and had negative comments about it. Although the hospital provides food for the patient and the carer, sometimes the carer complained that they did not like the hospital food because it was tasteless and they went and purchased their own food from the cafeteria. Not all carers, however, complained about the food. Amina, for example, said that the hospital really cared and tried its best to accommodate her. She was on a special diet and requiring certain foods. The nutritionist at the hospital made sure to exclude what Amina could not eat and followed her dietary requests.

Many of the carers’ accounts presented thus far illustrate how lifelong caring for a chronically ill child is associated with decreased level of physical health, and this is supported by evidence from the literature (Dellve, Samuelsson, Tallborn, Fasth, & Hallberg, 2006; Murphy et al., 2007). However, although most of the carers seemed to have been affected negatively by the hospitalisations of their children, not all caregivers spontaneously spoke of the impact on their own physical health. For example, one of the carers (Nasra) said that the child’s disease was “very easy.” Although her daughter had sickle cell disease, and had required frequent hospitalisations since the age of one, she seemed to have accepted it and dealt with it as a normal thing.
Thank God... It [the chronic disease of her daughter] is not that hard.
Mostly I just sit here and monitor the machines. The doctors and nurses do everything. (Nasra, carer)

Normalisation of illness may explain Nasra’s limited involvement in her daughter’s care, which is a coping strategy used by chronically ill patients and their families to try to live normally in spite of their symptoms (Gjengedal, Rustøen, Wahl, & Hanestad, 2003; Joachim & Acorn, 2016; Knafl & Deatrick, 2002). Knafl and Deatrick (2002) argue that while parents of a chronically ill child are aware of the child’s impairments or special circumstances, they refer to their life as essentially normal and try to portray that normalcy to outsiders. This was perhaps what Nasra was doing. Her daughter’s sickle cell disease left her in the hospital for “too many to count” admissions for which Nasra had to leave her family in a city far away. Despite this, in her interview she said it was easy and normal for her. In addition, Nasra stated that her role when caring for her daughter at the hospital was simply to keep her company. When a carer assumes a more active role in the care of her/his child, it seems likely to me that this may lead to poor or reduced physical health of the carer. It is also possible that the frequent hospitalisations and the chronic illness were not easy on Nasra. However, in an attempt to normalise her experience with the daughter’s illness, she may have been acting like it was a normal thing as a coping mechanism to help her avoid being stigmatised for being different (Joachim & Acorn, 2016). This will be further discussed in Chapter 8.

6.3 Not being able to let go

One of the important findings of this study was that carers “could not leave [their children]” with others and felt that they “had to stay” with their child. This suggests a notion of not being able to let go of what they believed to be their responsibility of caring for their sick child. For these carers, being a parent meant “they had to be” at their children’s hospital bedside, even when another carer was present. The carers had different reasons for needing to stay with their children, some of which related to the child’s needs while others were to do with the carer’s sense of obligation or what they believed may happen if they were not with their child all the time.

Carers stayed to monitor their child constantly, as they viewed themselves as the ones who knew their children best and therefore would anticipate their children’s needs. In a qualitative study, conducted in four paediatric wards in Hong Kong, exploring the
parents’ experience with participation, Lam et al. (2006) argued that carers caring for their sick child had developed different knowledge to that of professionals. Knowledge of carers in the caring role came from the medical information associated with their child’s condition and the “experiential knowledge” they acquired from caring for their child. The experiential knowledge enabled the carers to detect any small changes in their child’s behaviour or appearance that could indicate that they were about to get sick. Carers in Lam et al.’s (2006) study believed that they acquired this knowledge as a result of close contact with their child; professionals might not have the time to develop such individualised care or may not even be interested in non-scientific knowledge. This might explain why the carers that I interviewed believed that their presence was vital to ensuring that their child got the individualised care and attention that they required, and that would otherwise be lacking.

Although the rules at the hospital dictated that there must be a carer present with the child, they allowed the carer to switch with another family member or a friend so that the carer could go home and unwind or attend to her other family members. However, having someone else present was not an option for any of the carers in this study; these carers stayed because they wanted to and they believed no one else could be as attentive to their child as they were.

Amina, for example, felt obligated to be constantly at her grandson’s side. She didn’t feel comfortable leaving him even when her daughter, the child’s mother, was present. Hence when Amina was rarely replaced as a carer by her daughter so that Amina could go home and relax, Amina would visit him constantly during that period of time as she believed that when she was not there her grandson would refuse to take his meals or medications:

*I even can’t let the housemaid stay with him… I have to be with him.*
*Even when his mom comes… it’s not the same as when I am with him.*
*If I went home and left him with someone else, I would come and visit him 3-4 times a day… He refuses to eat when I am not here… He becomes psychologically affected (Amina, carer)*

*I’m always here with Mohammed… he doesn’t want anyone but me…*
*He even refers to his mother as sister. (Amina, carer)*
The obligation to care for the hospitalised child was a recurring theme in all the interviews. Although alternative care was sometimes available, despite the negative effects on their own health, carers were simply not able to let go. This finding could be explained through the theoretical lens of social construction of motherhood. Typically, a “good mother” is a woman who dedicates herself and her time to her children, forfeiting anything that will distract her away from her children (Bosch, 2013; Tardy, 2000). Although the characteristics of a good mother are supposed to come naturally from a mother’s love for her children, Holmes (2006) argues that the concept is not natural by any means but is often dictated by society. In the Saudi culture, a good mother is typically viewed as a stay-at-home mother who is responsible for the nurture and development of the child, and who would prioritise the child’s need over her own (Tumulty, 2001). Thus, for the carers in this study, societal expectations dictate that, as good mothers, their job was to stay at their hospitalised child’s bedside. This will be further discussed in Chapter 8.

6.4 Shortage of staff

In all the interviews, carers and healthcare providers noted that there was a shortage of staff. This led to nurses sometimes not having the time they would ideally like to spend with each child. A senior member in the hospital indicated that they had a “chronic” problem of staff shortages. This led to the staff being overworked and impacted on the quality of service delivered.

*This is a chronic problem at this time because we have a shortage of staff. The patient-nurse ratio should be 1:4 but, due to the shortage, it is 1:6 and sometimes 1:7.* (Grace, management staff)

Grace was very appreciative of the help the nurses were receiving from the carers, which according to her lessened the burden of the nurse shortage.

*But really, the care will be jeopardised because of the shortage – they are sometimes handling 2 – 3 rooms! It’s good that there are mothers to help them and they just instruct the mothers that, if they need something, they can just call with the bell.* (Grace, management staff)

The shortage of staff was handled by prioritising the needs of the patients and giving more time to the more serious inpatients. Other means used to mitigate the problem include
keeping the patients in shared rooms to make it easier to monitor them and “the fallout system,” which is a hospital strategy to transfer nurses from one ward to another whenever there is a shortage in a ward.

_They have a lot of patients, so how can they keep an eye... the quality would be less... because when there is an increase in workload, they are just prioritising the needs ... patient’s needs... so I’m telling the head nurse that if there are [more critically ill] patients to give them priority, or at least to have them in the same room... because how will she see the other patients when she is in another room... so we keep them together as much as possible. (Grace, management staff)_

_This fall-out system: we have the staffing list and we see the number of patients and the number of staff on duty. So they will seek from other units who have extra, they will cover up. So if they have more nurses and there are fewer patients, they can pull them out so that they would help in other units. (Grace, management staff)_

The shortage of staff and the overload of work they were facing did not go unnoticed by the carers. Some wanted to help out as much as possible and took over more technical roles to lessen the burden on the nurses. That was the case for Jameela, who felt that the nurses were so busy that she had to take over Ahmad’s care and to be involved even when he was in the intensive care unit (ICU).

_I feel for them... I put myself in their shoes and see how they circle from one room to another... and I’m capable and can give him [the medications] myself and I feel it is better from my hands... (Jameela, carer)_

_They [nurses] are too busy with pressure and responsibilities... it is very clear... I have a table [of the medications] and I follow it to the letter... the nurses help... but I don’t need help. [I try] to lessen their burden. (Jameela, carer)_

Carers noted that the nurses were always too busy to be disturbed. Although some carers mentioned they were dissatisfied with the food and the physical facilities, carers agreed that they were satisfied with the nursing care they were receiving. However, they did
mention that they often had to take over care because they felt bad for the over-worked nurses. This was the case with Jameela, Eman and Amina, who did not want to “tire the nurses with [the child]” even though they believed that, in the ICU, it was the job of the nurses to take care of them.

Carers adjusted their duties because they felt that the nurses were too busy. Instead of asking the hospital to cooperate by increasing the number of nurses, the carers took over to provide individualised care for the child. Similar findings were reported by Lam et al. (2006), who investigated Chinese parents’ experiences with participation in their hospitalised child’s care using a qualitative exploratory design. Although carers in this PhD study were willing to help out by taking on further roles, their mental and physical exhaustion identified in these findings suggests the need to increase staffing levels to lift the burden off the carers.

6.5 Survival as a family

The interview data showed that the lifelong care necessary for a chronically ill child significantly impacted the lives of the whole family, and their ability to survive as a family in meeting the associated challenges. Surviving as a family required a balancing act, with the whole family sharing the burden, leading to the disruption of usual family life.

6.5.1 The balancing act

Being a carer of a chronically ill child meant many of the carers in the study were away from other family members for extended periods of time. Deema, a family doctor, spoke of the impact of caring for a hospitalised child on other members of the family. This included the challenges that carers face in dividing their time and efforts between home and the child in the hospital.

First of all, the carer has other responsibilities at home … So she assists with the hospitalised child and she is busy with other priorities at home.

So she tries to divide her time between the two (Deema, healthcare provider)

Most carers tried to keep things at home as smooth as possible in their absence. Some carers who did not have other social or family support to rely on would be on the phone all the time, giving instructions to family members at home, constantly monitoring what was happening at home. This became particularly clear to me during my observations.
On one particular day, as noted in my field notes, I noticed a carer calling her family at home at 6.00 am, to make sure everyone was awake to go to school.

Walking through the hallway of the paediatric ward at 6 in the morning, I noticed a carer on her cell phone walking back and forth in the corridor. She was talking to her children waking them up for school. Asking if the younger sibling has woken up. She was making sure that everyone had breakfast, performed their morning prayers. Finally, she said, please don’t forget to put your seatbelts on. Then she hung up. I asked her about it. She said that she had to make sure that her children are awake and dressed for school as her husband was basically “useless... He leaves all the responsibility to me” (field notes: 22 September 2016)

This family lived more than 800 kilometres away and she was handling a lot of the responsibilities from a distance. This might relate to the gender stereotypes in Saudi Arabia discussed in Chapter 3 Section 3.6.2 that define what is usually expected of each gender and the roles they are supposed to fulfil. Elamin and Omair (2010) conducted a study in Saudi Arabia on 301 male participants to explore male attitudes towards working females. The study used the Multidimensional Aversion to Women who Work Scale (MAWWWS) and found that the male sample held traditional views on women’s employment and believed that women belonged at home doing their domestic chores and child-rearing (Elamin & Omair, 2010). In this current study, the carer in this case was pre-occupied by her hospitalised son and was far away from her children. In the absence of family support and to fulfil what is accepted of her as a mother by society, she had to also manage those at home. The socially expected roles in Saudi mentioned previously in Chapter 3 Section 3.6.2 are further examined in Chapter 8.

6.5.2 Sharing the burden

Some carers were fortunate enough to have someone from their family to take over their household responsibilities during the time that they were with their child in the hospital. Salma had her husband’s support when her son was first diagnosed with cancer a year earlier while living in Egypt. He took on the role of the carer and stayed with their son at the hospital for 6 months while she attended to her other children at home. When they came to Saudi and her son’s cancer relapsed, she had to stay at the hospital as the carer
because of the hospital’s policy that requires the carer to be female. While no official explanation was given for the reasons behind such a regulation, as a Muslim from Saudi Arabia myself, I think the reason is that having only female carers only makes it easier for the ladies sharing the room and the toilet; they then do not have to be wearing their hijab all the time.

Salma’s case breaks the stereotypes of the gender roles expected in Saudi Arabia mentioned in Sections 3.6.2 and 6.5.1, Salma had the support of her husband, which helped her stay with her children while he was the carer for six months in Egypt. This makes me wonder whether more husbands would follow Salma’s husband’s example if the hospital regulations permitted carers to be male.

Salma also had support from her sister-in-law to take care of her two daughters while Salma was at the hospital with her son, who had cancer:

My sister in law... she takes very good care of my daughters and she treats me very very well. She takes care of my daughters as if they were her daughters. At first, when Mohammed got sick, I was sure they were in good hands… the only thing that made me anxious is that I left my children for a long time. But I knew she would take care of them.

(Salma, carer)

Salma’s words suggest the importance of having confidence in the social support available. The confidence she had in her sister-in-law was a crucial element in helping Salma cope with leaving her children at home. Knowing that her sister-in-law would take care of the children as if they were her own eased Salma’s worries. The importance of trust in the available social support was similarly reported by Murphy et al. (2007), who found that having trust in alternative care from family and friends helped to reduce negative emotions that the carer might have and strengthened the carer’s endurance and resolve.

More than one carer relied on help from their teenage children. With Rihab, her main source of support was her 17-year-old daughter. This teenage daughter took over her mother’s responsibilities in taking care of her other siblings and her father and doing domestic chores.
My 17-year old daughter... She helps her dad and siblings... she washes the clothes, irons, cooks, she cleans the house... everything is on her (Rihab, carer)

This was also the case for Hussa, whose teenage daughter was staying home from school to take care of her 10-month-old sister while her mother was at the hospital with her sick brother and sick sister.

For the carers, sometimes the necessity of staying with the chronically ill child was more important than taking care of their obligations in the home and their other children. Rihab mentioned that, as long as she was with Adam, she “didn’t care about anything else.” The most important thing to her was Adam. She didn’t care about whether her other children or husband: “did they eat or not; did they cook or eat from outside...? [she doesn’t] interfere with that when [she was] with Adam.” Perhaps the reason that Rihab was feeling this way was due to the fear that she might lose Adam. She mentioned that, every time he had an acute exacerbation of asthma, she felt “he would die.” This might have led her to be totally invested in Adam and his health to the point where she could not help but focus all of her attention on Adam and disregard the needs of her husband and other children.

6.5.3 Disruption of usual family life

Interview data with both the carers and healthcare providers indicate that having a chronically ill child in the family who requires frequent hospitalisations often results in disruption to day to day family life. Participants spoke of family separation, limited family outings, negative effects on other children’s education and reduced opportunity for carers to sustain paid employment. Similar effects had been reported in the literature (Barlow & Ellard, 2006; Brown et al., 2008; Hlopia et al., 2004; Lukemeyer et al., 2000). For example, in the overview of the literature on chronically ill children and the impact on single parents and families, Brown et al. (2008) reported that the families’ routines had to change to accommodate the illness. If the chronic disease was severe, family members had to be intensely involved in caring for the chronically ill child. In addition, family outings were affected and parents found little time to interact with the siblings.

As mentioned earlier, Hussa had a newborn baby at home whom she had to leave behind whenever her two children were admitted to the hospital. The 10-month-old baby was left with Hussa’s teenage daughter who took care of the baby. This meant that the teenager had to skip school in order to take care of her baby sister. Hussa referred to it as a
commitment. Her daughter had to be there to support and help her mother. Hussa felt that it was fine because it was only a few days each month.

*I now have a 10-month old daughter at home. I always think of her... but thank God it’s just a day or two and then we are out [of the hospital]. Her sister takes care of her when I’m at the hospital.* (Hussa, carer)

*I think of home... who will open the door for the children when they come back from school? Their sister is absent from school because she has to stay home and be absent from school to take care of her 10-month-old sister. She used to go to school previously... but after I gave birth to her sister she began to stay with her on days that I am in the hospital with Roa’a and Rakkan.* (Hussa, carer)

The absence of the mother from the family home not only resulted in disruption to the day-to-day activities within the home, in Hussa’s case it resulted in her daughter often skipping school. School absenteeism for siblings was quite common for some of the carers, as they relied on the help of their teenage daughters. While it is well documented in research studies that school-aged children with chronic disease are often regularly absent from school as a result of hospitalisations (Barlow & Ellard, 2006; Newacheck & Taylor, 1992), little has been written about how these hospitalisations may also affect the sibling’s education. This finding is further discussed in Chapter 8.

The reason carers in this study resort to leaving their school-aged children in charge at home and skipping school may be due to the common practice in Saudi, that children and infants, in particular, have to be taken care of by a family member – preferably the mother or a close relative.

As mentioned in chapter 2, caring for a chronically-ill child also leads to restricted or limited family activities or outings. Siblings of a chronically ill child may feel isolated and neglected trying to grab what is left of their parents’ attention and care (Barlow & Ellard, 2006; Brown et al., 2008). In Hussa’s case there were two children with factor XIII deficiency. Fearing that one of her children may bleed at any time, Hussa was very afraid to go out even on a brief and simple family outing. It also affected their celebrations, sometimes disrupting the celebrations because of unexpected
hospitalizations. Hussa spoke of how difficult it was when her son got hospitalised during Eid, which is a religious holiday for Muslims. It was very hard on her other children, not having their mom present at Eid time.

_Recently Rakkan got hospitalised at Eid because he bled.... We were visiting family at Hassa ... and he bled so we got hospitalised there so we didn’t get to celebrate Eid. It was hard on my other children... not being able to celebrate Eid (Hussa, carer)_

Sarah was the only carer in my study who had paid employment and she spoke about the effect her son’s illness had on her job. She was a school principal who loved her job very much but was thinking of early retirement. The sickle cell disease her son had was affecting her ability to perform her job. Sarah mentioned that her pension would be a fourth of what she now earns, but she thought that her son was worth the sacrifice. Her family, on the other hand, did not agree with her decision to retire. Her words below clearly demonstrate how hard this decision had been on her.

_His disease caused a lot of things for me ... I am a school principal. I love my work a lot. I love working in general ... but now I am thinking of retirement because he is getting hospitalised a lot and I feel like I am not preforming my job to the best of my ability. I am always absent. For example, now since the school has opened this is the third time he gets hospitalised. (Sarah, carer)_

_If I retire now I’m getting early retirement ... so I will lose ¾ of my salary ... but still I see that it’s worth it ... everybody is telling me not to do it ... They are against the idea that I retire (Sarah, carer)_

### 6.6 Roles of the carer

Most of the carers assumed an active role in caring for their children. These carers viewed the care of their sick child as part of their duty and, therefore, were actively involved in the medical management of their child’s condition. Similar to what has been reported in the literature (see Chapter 2), in this study, the degree of parental involvement in care differed from one carer to another. The carers had different roles that ranged from monitoring the delivery of care to choosing the right medications for the child.
The roles that are usually occupied by the carer of hospitalised children are well described in the literature. These roles include being a source of comfort and support for their children (Affram et al., 2008; Ames et al., 2011), the role of a learner and a teacher, provider of physical care (Affram et al., 2008; Gasquoine, 2005; Söderbäck & Christensson, 2008) and, in some instances, provider of technical care (Affram et al., 2008). In this current study, a number of different roles were apparent that were similar to what was found in the literature.

The carer as the monitor was a role that was occupied by all carers in this research. All carers mentioned that monitoring was their first responsibility towards their child. Monitoring involved looking after the child, observing the vitals, calling the nurses when the Intravenous drip had finished, and reporting any observations to the doctor in the morning rounds. This was also apparent in my observations in which I was able to view several carers monitoring the child. They would keep track of the results that the machines provide, like the heart rate, blood pressure, Electrocardiograph and blood sugar levels. However, while monitoring seemed to be the basic level of being a carer, they also usually occupied several roles in addition to monitoring. Nasra was the only carer who did not occupy other roles. She seemed to be the carer with the least responsibilities towards her hospitalised daughter. The responsibilities she had as a carer for her daughter were to just be with her and monitor her machines. She depended on the help of the healthcare team who were always there to provide care. As mentioned earlier, these were her words describing her role:

 Mostly I just sit here and monitor the machines. The doctors and nurses do everything. (Nasra, carer)

The carer as a comforter and provider of physical care was a step beyond monitoring. Carers were involved in keeping track of the medications and giving them, comforting the child whenever he/she became upset, and personal care related duties for the child. Rihab was more involved than Nasra in taking care of her son by providing physical care, monitoring his health, giving the medication and calming him. She was very satisfied with how she was contributing to her son’s care. She said:

 I just sit next to him holding his hand. I helped them give him the medication... I told him: come on Adam... take it for my sake. He would feel safe when I was with him and then they were able to give him the
medication and needles... I used to monitor everything ... all the machines... I called them when it was necessary... I also turned off the mask when it wasn’t needed... I learned everything... Because I stayed with him a lot, I learned everything. Now I know how to do everything (Rihab, carer).

Amina was very actively involved in Mohammed’s condition and understood the care he needed. She is an example of what I call the carer as the care manager. The carer as the manager refers to the carer who is keeping track of the medications, helps make medical decisions and advocates for her child. Amina knew which medication was best for Mohammed and helped the doctors decide on antibiotics. Despite her old age and illiteracy, because of her high level of involvement in care and understanding of her grandson’s illness, doctors would often involve Amina in decision making:

Oh, the poor child.... I honestly now know about everything related to Mohammed. I feel when he is in pain... I know what to do for him at the hospital... I know about the IV fluids... the needles, the medications... everything... now if we were at home... I can do anything he needs there as if he was in a hospital. (Amina, carer)

I know the medications ... What is good for him and what is not good for him, the names of the medications, all the antibiotics, what suits him and what doesn’t. (Amina, carer)

During my observations, I was able to witness the carers performing their different roles. One carer, whose son was on an artificial ventilator, was constantly suctioning out the mucus that was coming out from under the mask with a special suctioning machine. Another carried her 11-year-old son to the toilet as he was not able to walk. I saw carers of sickle cell disease patients giving a night-long massage to their children. One carer was questioning the antibiotic drip that the nurse brought in for her child. She was not sure if the doctor had prescribed it. She asked the nurse to call for an Arabic speaking nurse so that she could communicate her concerns more clearly. I felt that the carer was being an advocate for her son and ensuring he received the correct medication.

The above findings clearly show how each chronic disease is different, each patient is different, each family is different and each carer’s desired degree of involvement is also
different. However, healthcare providers in this research did not seem to pay attention to these differences. They considered the main role of the carer to be comforting the child, monitoring him/her, “facilitate taking the medication”, “reporting anything unusual to the [healthcare staff] and following discharge directions.” In addition, although the healthcare providers mentioned that the first thing they do when there is a new admission is to inform the carer of their expected roles and the nurse’s roles, the roles were not negotiated and the carer was not asked of her desired degree of involvement. Role negotiation is an important part of building an effective partnership between the two parties, and is one of the foundations of the family-centred-care model (Alabdulaziz et al., 2017; MacKean et al., 2005). This will be further discussed in Section 6.9 and Chapters 7 and 8.

6.7 Considering carers’ perspective of the child’s medical needs

A study by Balling and McCubbin (2001), revealed that carers of chronically ill children develop some kind of expertise in dealing with the care of the child as a result of providing care for an extended period of time. Therefore, one of the needs they have is to recognise the carer’s knowledge of the intricacies and specific aspects of managing his/her particular child’s care. This recognition means listening to the carer’s views about managing the child’s condition, recognising the carer’s knowledge about managing the child’s condition, taking their advice regarding the child’s care, and involving them in making care decisions. In this current study, the carers have been taking care of their children for years, and this involved even providing technical care (maintaining intravenous lines, administering medication, recording vital signs). Through their involvement, these carers knew what the child’s needs were and they have developed some expertise in managing the child’s condition. Therefore, the carer’s expertise needs to be recognised.

In my findings, the carers were very proud of the experience they have gained while taking care of their sick children. This was the case for Amina, Hussa, Rihab among others, and they were very keen to talk about how they knew the condition of the child now and “can figure out what [the child] wanted without even asking.” Hussa, for example, had so much experience that she thought she could detect if the child’s condition was worsening or not just by his physical appearance and the way the child sounds.
I have the experience... I am used to it. To the extent that I can tell by looking at my child if something is wrong. I can tell by seeing his skin and hearing the different sound of his cries. (Hussa, carer)

Rihab spoke of how the experience she had gained helped her take care of her son in the hospital. She was proud that she only called upon the nurses when it was necessary because she was experienced in everything including the machines.

I monitor everything... all the machines... I called them when it was necessary... I also turned off the mask when it wasn’t needed. ... I learned everything... I have the experience... Because I stayed with him a lot (smiles). (Rihab, carer)

Similar to Rihab, Amina gained her experience from her grandson’s hospitalisations and she also indicated that she knew how to operate the machines, and how to manage his medications and choose them.

The hospital is a necessity... But in terms of experience, I am now very experienced ... I know how to remove the IV lines, how to give needles and remove them, I know the medications... (Amina, carer)

As part of my observations, I attended a medical morning ward round with a consultant, some residents and interns. I noticed that the doctors did recognise the expertise of some of the carers. When the carer seemed competent and was perceived to be a reliable source of information, the doctors would ask her about the medications the child is taking and if the child is sticking to the dosage and schedule. When the carer did not appear to be very knowledgeable, the doctors tried their best to convey the information. The doctors sometimes also asked the carers of anything they had noticed, or what they thought of the medication that was prescribed and if they thought it was making the child better.

From my observations it was clear to me that the doctors relied on the carers as a valuable source of information and tried to involve them as much as possible. The expertise developed by the carer and the familiarity with the environment and illness empowered the carer – in this context, a woman – to take charge and be the family representative in talking to the healthcare provider, a role in Saudi Arabia that is usually occupied by a male member of the family. As a Saudi and therefore an insider, I found it fascinating.
how women such as Rihab were so proud that they can handle talking to the doctors and answering and asking questions in the presence of their husbands:

No... If I had anything I would tell them directly... I even talk to them in front of my husband. There is no need for my husband to talk to them... because I’m the one who is panicked more about Adam so I take the lead and ask all the questions. They even asked my husband a question and I’m the one who answered. (Rihab, carer)

6.8 Drawing on faith in God

To gain strength in facing the challenges that are associated with being a carer, the carers took comfort in praying to God and reading the Quran. Amina, Sameeha and Jude all talked about surrendering to God’s will and accepting the chronic disease as it was sent to them by God. Amina for example, spoke of how she took strength from her strong faith in God and from praying. Amina, Mohammed’s grandmother and his carer did not like to talk about how she was getting tired or was affected by what was happening. Like many other Muslims, she hoped to be rewarded by God for their good deeds:

It has affected me in a psychological way and my health also... but I don’t want to mention that. I want God to reward me. I don’t usually talk about this but you are asking me so I’m telling you that I want to be rewarded by God, so I don’t mention it. Everything I am doing I’m not doing for people to notice, no I swear... I keep it with God to reward me ... and with Him it is not wasted... I love Mohammed more than my own children and I have taken care of him more than my children, especially with his condition and with his health and wellbeing, so that has affected my health” (Amina, carer)

6.9 Partnership between the carer and the healthcare providers

I found from data in this study that there were a number of important actions necessary for an effective partnership to exist between the healthcare team and the carers. These were being performed to some extent by the healthcare providers and the carers, and included sharing of information, identifying roles and building trust.
Nancy in her interview, stated that the most important part of her job as a paediatric nurse was to establish a partnership between herself and the carers. She approached this in several ways. When a patient is first admitted, Nancy would orient the patient and the carer to their assigned room and explain the guidelines and the precautionary measures they have to take to keep the child safe from falls and harm. She also explained what medications the child would take and how they were used and what interventions were to take place. She made sure that the carer was clear about their roles and what was expected of them.

She then explained to the carer the details of what she considered to be their main role, which is to be the ‘watcher’ (carer) – that is, to monitor the child, administer the medications and follow the hospital discharge directions. She mentioned that the healthcare providers and the carers were partners and should work together to achieve their goals.

*Because we are here as a team, we cannot work alone... We are working here as a team – the doctor, the nurses, the patient and the watcher [carer]. Because if there is no coordination between us, the goal will not be met. We will not meet our goal of discharge in a good condition.* (Nancy, management staff)

Although Nancy perceived that the healthcare providers and the carers are partners who have a common goal, I did not feel that the relationships that she was describing were a true partnership. When asked to describe her relationship with the carers and the hospitalised children, Nancy described it as a relationship built on trust and love. However, what was noticeable is that her interactions with the carers were limited to giving them what she believed to be the required information and telling them about their expected roles. The carer was not involved in any kind of discussion or given a choice about her preferred level of participation in the child’s care. In this sense, to me, this did not feel like a true partnership.

Similar observations were made in the Abdulbaki et al. (2011) study, which explored family-centred care from the perspective of nurses in Egypt. They found that negotiations of care with the families were absent from the nurses’ practice. Although the nurses in their study knew of the importance of these discussions with carers, they had limited time and resources to fulfil these roles.
Research has demonstrated that sharing all relevant information with the carer is considered to be an essential component of an effective partnership between the carer and the healthcare providers (MacKean et al., 2005; Nuutila & Salanterä, 2006; Swallow & Jacoby, 2001). Providing sufficient information is important as it enables the carer and the child to participate in decision making (Smith, Swallow, & Coyne, 2015). In my interactions with Deema, a family doctor, it was clear that she considered sharing of relevant information as crucial. For her, the carer not only knew how to manage the disease but also had “all the relevant information that they needed.” This information reassured them about the illness and understanding the importance of treatment helped to improve their adherence to the recommended treatment.

Some doctors did try to share as much information as possible with the carers, as noted in some of my observations. For example, during a medical ward round, I observed that doctors made sure that the carer understood what was going on while they were examining the child, talking to the carer in Arabic to make sure there was no language barrier. The following excerpt from my field notes describes how the doctors behaved on morning rounds:

The consultant, residents and interns enter a patient’s room. They started by greeting the carer and the child in Arabic. They then asked the carer for permission to examine the child. The consultant then discussed the case with the other doctors in English. I wrote down all the information they said. Later, the doctors translated everything back to Arabic for the carer and the child to understand. They told the carer what they noticed while examining the child, the results of the lab work, the procedures and tests that are required next and that the child is expected to be discharged within a few days. Finally, she asked the carer if she had any questions or worries. The carer then asks a few questions and the doctor answers all of them. (Field notes 27 November 2016)

Role negotiation is another important aspect required for an effective partnership between the carers and healthcare providers. I found little evidence for this in my interviews and observations. It is vitally important for both sides to communicate and establish the roles that each of them will play. Each family is different and presents different circumstances
that influence their hospitalisation experience and their relationship with the healthcare providers.

6.10 Care of the carer

The findings of this PhD study showed that carers were mentally and physically exhausted as a result of their caring role and might be at risk of burnout. The carers were clearly in need of support from the healthcare providers. However, I found that the healthcare providers had conflicting opinions about their role in the wellbeing of the carer. They recognised when the carer was in need of emotional and psychological care, they also noticed when the physical health of the carer was being affected, but some did not see the involvement in the carer’s health as part of their job. This finding is best illustrated in my interactions with Nancy, a paediatric nurse.

Although Nancy spoke about the importance of building a relationship with the carer for effective healthcare delivery, surprisingly, that was where the relationship ended for her. She mentioned that she “[wouldn’t] dig anymore” because “you don’t want to know more” because it was not part of her job. To me, Nancy words “didn’t dig anymore” meant that if the carer did not want to share details of her health or how she was feeling, then Nancy did not want to probe further because, if she did not know about it, then it is not her problem and she is not expected to fix it. I was surprised by this as it indicated the passive role of the nurses in addressing the carers’ healthcare needs.

I tried to explore further and ask her how she would support the carer if they made it clear that they were not feeling well. She responded that she would send her to the emergency room to seek help or advise her to return home and organise an “alternative watcher.”

We usually tell them, if they are eligible, they could seek help from the ER if they need it. Otherwise, if she doesn’t want, she can let someone come instead of her to be the watcher [carer] for the patient. (Nancy, management staff)

Nancy then mentioned that the nurses do not have a role in helping the carer maintain good health and wellbeing. In her opinion, it should be the family’s responsibility – not the hospital – to help the carer maintain her health. Nancy believed that the hospital is only designed to take care of the sick who have been hospitalised there. Therefore, they can only help the carer if she becomes a patient herself.
Nancy believes that her role lies in “treating the sick only.” This is consistent with the disease-oriented model of care. This is a way of treatment that focuses medical care on the diagnosis and treatment of disease as the ultimate objective. However, Green, Carrillo, and Betancourt (2002) and Tinetti and Fried (2004) argue that it is ineffective to focus on the disease while blurring out the individual, his/her illness and the context. There is a need to foster “attitudes, values, and communication skills that focus on illness, not just disease” (Green et al., 2002, p. 143). It is therefore crucial that the focus on individual disease not be constrained but integrated into more holistic tailored care that encompasses disease treatment as one of the important goals but not as the goal itself (Reuben & Tinetti, 2012; Tinetti & Fried, 2004). The family-centred care model is an alternative approach to care that focuses on the patient and the family, their needs and individualised desired goals. This will be discussed further in the next two chapters.

Unlike Nancy, to Deema, the healthcare provider had a prominent role in the wellbeing of the carer. It began with taking care of the carer’s physical health by giving them medication if required and letting them seek care in the emergency room. However, it did not stop there. Deema thought that the emotional stability and wellbeing of the carer was very important. Deema saw that she herself and other healthcare providers had an important role in ensuring the wellbeing of the carer. This included sharing all the information with them to reduce their stress and anxiety, answering all of their questions, and being available for them.

We explain to them to ensure that they have emotional stability... We explain about the patient and see if they have any questions about them to reduce their anxiety. This really helps in de-stressing them... When they know what is happening to their son or daughter... we, the doctors, must take care of things like this and we give them the answers and even if they don’t have questions, we explain to them, which helps... the wellbeing of the child really relies on the wellbeing of the mother and the father... so when they are not stressed, and they understand.., They give emotional stability to the child. So we help ensure that happens by answering their questions and being available to them. (Deema, healthcare provider)
She further explained that it is not just the doctors or nurses that can play a role in the wellbeing of the carer but that all other workers at the hospital, like the social workers, security officers, janitors and nutritionists could be involved as well.

_The medical director, the attending physician... anybody... Even the janitors when they clean the room or not... The social workers... They always ask the carer if they need something and ask how the hospital is... So they have a big role... They always ask if the patient is comfortable or has any complaints... Also, the nutritionist and the dietician always comes and asks how the meals and the food are – are they liking it or needing something else... So these things help in them get comfortable and the patient becoming better... (Deema, healthcare provider)_

Deema’s descriptions reflect a way of delivering healthcare that is more aligned with the family-centred care model that puts the patient and family at the centre of care. She seemed to recognise the important part that the family members play in the wellbeing and health of the child, values supporting carers, and helps them to cope with the difficulties they are facing. However, as indicated earlier, Deema and I are old friends, and it is quite possible she was sharing with me what she thought I wanted to hear.

Nancy’s views about care of the carer not being part of the healthcare provider’s role were also echoed by Dr Moneer – a healthcare provider in a senior managerial position. Dr Moneer explained that carers have “no legal rights” and “did not exist in the system.” Healthcare staff had to take care of the patients registered in the hospital and “not anyone else.” By saying “didn’t exist in the system,” Dr Moneer meant that, since the carer was not actually an admitted patient in the hospital, they were not expected to care for her unless she had physical symptoms – then they would help her or refer her to the emergency room. Thus, addressing the health of the carers of hospitalised children would not be part of the expected roles of the healthcare providers.

_We only interfere when there is an emergency... For example, the carer fell or fainted (Dr Moneer, management staff)_

This is something that Nancy also noted. I also spoke to three administrative personnel responsible for document control, all policies and procedures, and strategic planning and
accreditation at the hospital. They were not sure about the exact obligations of the healthcare providers towards the carers. They asked me to review the hospital policies, procedures and job descriptions to learn about the hospital’s role in the health and wellbeing of the carer and family members.

My analysis of the hospital’s policies and documents relating to the roles of the healthcare providers and what was expected of them showed they were indeed only expected to care for the hospitalised patients. I found no mention of the carer or the family in any way in the hospital policy documents which as mentioned in Section 4.2.3.3 were the Multidisciplinary Patient & Family Education Policy, job descriptions of the paediatric nurses, the Patient Assessment and Re-assessment Policy, the Delivery of Care Policy and the job description of the social workers. The social workers were the only ones who were expected to provide counselling services to the patient, carer and family members. However, that counselling was only offered during grief or following bereavement. So, it appears unless there is death or tragedy, the social workers are not required to provide any support. The job description noted in one of reviewed documents stated the following:

Social workers shall provide social and psychological support to patients and their families during grief and bereavement (Socio medical services document).

6.11 Reflections and summary

The interviews and field observations I conducted with the carers and the healthcare providers provided a wealth of information about what is like to be a carer of a hospitalised, chronically ill child. Their accounts helped paint a picture of the roles they occupy as carers, the facilitators and barriers to wellbeing they face, and how this affected them.

Many of the carers in this study appeared to be experiencing psychological distress. They were aware of how the hospitalisations and chronic diseases were affecting their wellbeing. However, most of them were not aware of the need to seek professional help for their mental health issues. Societal and cultural norms in Saudi Arabia and other similar countries consider mental health needs as a taboo topic that was not normally discussed. Hence, the psychological distress they were feeling was normalised as part of the experience of being a carer of a hospitalised child. The carers also experienced some
degree of reduced physical health. Being a carer resulted in poor quality sleep, back problems and, in some cases, health complications.

The carers had difficulty letting go of their carer’s role even when they were not feeling well and when alternative care was arranged. They believed that they had the knowledge to understand the child’s needs and detect any change in his/her health. In addition, although carers were overwhelmed by their caregiving roles, they picked up nursing roles whenever the nurse seemed too busy, thus adding to their burden. This indicates the need to address the inadequate staffing levels.

The chronic disease did not come without challenges for the other family members – for instance, separation from the person who is caring for the child, and changes to their routine to accommodate the care and absenteeism of the sick child and other siblings.

The factors that facilitated the carers’ coping abilities were having the social support of the family, their involvement and expertise in providing care for the child, and their faith. They took strength from drawing on their faith and accepting whatever came from God. Acceptance was related to the Muslim belief that enduring the hardship that a person feels will get him/her rewards and benefits from God.

Partnership between the healthcare providers and the carers was viewed as very important to both parties. However, role negotiation – an important aspect of the partnership – was lacking. Perhaps there is a need to come to an understanding of each other’s roles through negotiations for an effective partnership to take place.

Healthcare providers had conflicting views of their roles and responsibilities in ensuring the carer’s wellbeing. One saw it as an added responsibility that was not part of her job. Another viewed ensuring the health and wellbeing of the carer as an integral part of her job, as this affects that of the child as well. Documentation analysis of the hospital policies revealed that the care of the carer and other family members was considered only to be part of the social workers’ roles and was only offered in times of grief which meant that they were not supported unless there was a death. In addition, care of the carer was not included in the job descriptions of other healthcare providers. Therefore, any support provided to the carer by other healthcare providers was provided on an ad hoc basis.

One of the most important needs highlighted from these findings is the need to address the mental health of not just the carer but the chronically ill child as well. There is also a
need to raise awareness of the available mental health services and the importance of addressing mental health issues. The study also indicated the need for additional staff to be employed to reduce the burden on carers who stepped in whenever they saw their help was needed, which resulted in them being further exhausted. The needs and implications briefly mentioned in this chapter will be discussed further in Chapters 7 and 8, through the family-centred care lens.
Chapter 7

Concerns and Needs Through The Family-Centred Care Model

In this chapter, I explore the findings through the lens of the family-centred care (FCC) model. As mentioned in Chapter 2, the FCC model was chosen to examine the findings of this research because it is an appropriate framework for understanding the needs and concerns of carers of chronically ill hospitalised children, which is the focus of this research. The model emphasises the collaboration between the families and the healthcare team. It also acknowledges that the hospitalisation experience is a stressful time for everyone involved, especially when the hospitalised person is a child. The model encourages care to be planned and delivered with the whole family in mind. Therefore, the findings of this research will be examined and studied against FCC and its principles. The core principles of FCC in paediatric care are presented below. They will be used as standards to examine how healthcare was delivered in practice in this research.

7.1 Definition and principles of FCC

Through the examination of FCC and its principles and the identification of family-centred policies and practices that could enhance service delivery, we can shed light on the advantages of adopting such a model and principles.

As stated in Chapter 2, although FCC was introduced more than 50 years ago, there still is some ambiguity surrounding it and no agreed-upon definition (Corlett & Twycross, 2006; Kuo et al., 2012; Shields, 2010). However, there seems to be some agreement on the defining attributes of the model (Mikkelsen & Frederiksen, 2011). FCC is defined by Shields, Pratt, and Hunter (2006, p. 1318) as “a way of caring for children and their families within health services which ensures that care is planned around the whole family, not just the individual child/person, and in which all the family members are recognised as care recipients.”

As diverse as FCC definitions may be, they all share main concepts and policies. MacKean et al. (2005, p. 75) condensed the main concepts most commonly referred to in the literature:
1. Recognising the family as the constant and centre of care

2. Acknowledging the uniqueness and individuality of each family

3. Recognising parental expertise

4. Recognising the potential of family-centred care in enhancing competency

5. Promoting the development of a collaborative partnership

6. Facilitating family-to-family support and networking (MacKean et al., 2005, p. 75)

These principles will be used to examine the service delivery in this study and identify possible areas for improvement and implications for practice, which will be discussed in Chapter 8.

7.2 Recognising the family as the constant and centre of care

FCC recognises the family as the constant and centre of care by having a system that recognises the needs of family members and that is aligned with those needs (MacKean et al., 2005). Griffin (2003) argues that one of the needs of carers and family members is to ensure that the visiting policy is responsive to their needs. The author adds that the visiting policies of the hospital may be problematic for the family members of the patients and for healthcare providers. The major issues include the visiting hours, who is allowed to visit, and the number of visitors allowed. Limited opportunities for visiting have been identified as a source of stress for carers and family members and recommendations for open visiting have been based on data demonstrating increased satisfaction and reduced stress amongst carers and family members when open visitation is implemented (Parsapour et al., 2011).

Visiting policies in hospitals often specify certain times for visiting and restrict who is allowed to visit. In the current study, the analysis of the existing hospital policies showed that only adults could visit and the visiting policy prohibited children from visiting their hospitalised sibling. As indicated in Chapter 6, Section 6.2, this had a clear effect on Jana, who was often at the hospital with her son Ziyad and would sometimes go 21 days without seeing her other children. Restricted visits were an added source of stress for Jana who noted that the separation from her other children was “exhausting her.”
While it may not be possible to have a visiting policy that is totally flexible due to a number of difficulties such as obstructing nursing care, increasing stress on the patients and causing physical and emotional exhaustion to carers (Khaleghparast et al., 2016), the FCC philosophy mandates that this policy should be responsive to the needs of family members and therefore less restrictive. As Griffin (2003) argues, while the healthcare providers may constantly change, the family – as acknowledged by the first element of FCC – is a constant in the patient’s life. It is therefore crucial that visiting policies acknowledge that the hospital is the temporary home for these families and, while family members are considered visitors to the hospital, they are not visitors to the patient and the carer (Griffin, 2003).

Moreover, as the hospital is a temporary home for the child and the carer, its physical environment could have an influence on their health. The findings from this study suggest that not only were carers dissatisfied with some of the aspects of the physical environment of the hospital, but their health was negatively affected by the hospital environment. Carers attributed their lack of sleep and their worsened health to the hospital environment. As mentioned in Chapter 6, Section 6.2, the carers identified the need for better sleeping arrangements, better quality meals, and the need for uninterrupted sleep. Some carers highlighted the need for separate rooms and cleaner facilities.

To promote the delivery of FCC, the hospital environment could be more carer and patient-friendly (Beck et al., 2009; Coyne, O’Neill, Murphy, Costello, & O’Shea, 2011). The needs of the patient as well the carer should therefore be assessed and emphasised. FCC provides opportunities to improve not only the services provided to the families and children, but also the environment in which they are provided. Knowledge and understanding of the carer’s experience with hospitalisation and perception of the physical environment provides an opportunity for improvement of the hospital environment and healthcare delivery. From these findings, one might conclude that potential opportunities for change would include providing a more comfortable sleeping arrangement for the carers and educating the nurses about the importance of respecting the carer’s sense of comfort, especially at night.

This PhD study found that the carer’s chair/bed was the most challenging aspect of the hospital’s physical environment for the carers. Beck et al. (2009) point out that the carer’s bed is the most important part of remodelling the hospital environment, as it signals the
welcoming of the carer into the care process and recognises the important part that the carer plays.

Previous research has indicated that changing or altering the physical environment while keeping the patient or carer in mind has had a positive influence on the patient and the family. In some instances, it has also resulted in reducing the length of stay at the hospital (Devlin & Arneill, 2003). Therefore, from a FCC perspective, there is a need for studies on improving the physical layout that acknowledges and responds to the health needs and concerns of the carers and families raised in this study. This will be discussed more in Chapter 8.

7.3 Acknowledging the uniqueness and individuality of each family and promoting the development of a true collaborative partnership

One of the practices of the FCC model is to provide individualised services that acknowledge that each child and family are different and unique and, therefore, their needs might be different (Espe-Sherwindt, 2008). For example, the degree to which each carer wants to be involved in the healthcare of the child can differ between families. Each family has to deal with different diseases and their desired involvement cannot be assumed. The findings of this study revealed that, although most of the carers were actively involved in caring for their child, there were some individual differences in the level of their involvement. As noted in Chapter 6 (see Section 6.6), carers took on roles such as being the monitor, a comforter and provider of physical care, and the care manager. The roles that carers occupied and the extent of their involvement were very different. The roles desired by each carer might also differ in the same family over time. The healthcare providers in this research viewed the carers’ role as that of monitoring how the child was doing and notifying the healthcare provider of any changes. Moreover, they had to follow the healthcare provider’s instructions. For some in this study, this kind of passive involvement was acceptable, as in the case of Nasra; others, however, really wanted to be actively involved in the care of their child.

Findings from the qualitative study suggest a general absence of role negotiation (see Chapter 6, Sections 6.6 & 6.9). As noted earlier, the essence of the collaborative partnership between the patient and family includes negotiating the different roles that each of these partners will play (Franck & Callery, 2004; MacKean et al., 2005). My findings indicate that, although some aspects of an effective partnership were achieved,
such as sharing of information, identifying roles and building trust, role negotiation between the staff and the families was clearly absent. In some instances, there was more of a passive one-way flow of information rather than carers being given the opportunity to actively participate in making decisions relating to managing the care of their hospitalised child. For example, as noted in Chapter 6, one nurse (Nancy) described her relationship with the carer as informing her of her expected roles as a carer and giving the carer what Nancy believed to be the relevant information. This clearly shows that the flow of information is more passive and one-way, rather than promoting active participation of the carer in decision making. However, as indicated in Chapter 6, Section 6.9, this was not always the case, as in some instances doctors were sharing as much information as they could about the child’s condition and asking the carer for her input as well.

The study findings clearly suggest the unique needs and preferences of each chronically ill child, his/her family and the carer. As noted earlier, this uniqueness should be acknowledged and their specific needs recognised and addressed rather than being assumed. Such an acknowledgement requires a collaborative process to determine what roles carers will play in managing their child’s medical care. The use of such a collaborative process to jointly determine the roles provides the foundation of the partnership between the healthcare staff and the families described in the literature as an important aspect of FCC (MacKean et al., 2005).

Results from other studies support the finding of this PhD study on the absence of role negotiation. In their review of studies around role negotiation, Corlett and Twycross (2006) found that role negotiation was not something that was actively pursued or planned. Another qualitative study that employed a multisite survey in Ireland to examine the nurses’ practice and perceptions around FCC found that role negotiation was also absent from practice (Coyne, Murphy, Costello, O’Neill, & Donnellan, 2013). In Saudi Arabia, a study exploring family-centred care practice found that the nurses knew the importance of discussing and negotiating roles with carers but could not fulfil these roles because of their limited time and resources. This has some implications for practice which will be discussed in Chapter 8.

Findings from this research also point to the shortage of staff. The staffing shortfall means that there is limited capacity to tailor the care to each family, something that has affected the quality of care provided and seems to have forced the carers to adopt more roles than
they would ideally like. The shortage of staff, extreme workload faced by nurses, and the increased carer responsibility for providing patient care has serious implications for the effective implementation of FCC. The model requires a higher staff-family ratio to cover all the requisites of education, negotiation and involvement that are essential for effective FCC (Coyne et al., 2011; Shields, 2010). Revised staffing levels will need to take into account the optimal responsibilities of the nurses within the FCC model, not just towards the patient but also the carer and family.

7.4 Recognising parental expertise

One of the key attributes of the family-centred care model is to recognise the carer’s, in most cases the parent’s expertise developed over time and to incorporate this expertise into healthcare delivery (Smith et al., 2015; Darbyshire, 1995). As strongly argued by Smith and colleagues (2015) and Balling and McCubbin (2001), carers undergo a transition from a novice to an expert over time by gaining knowledge and acquiring new skills, asking for information and learning how to respond to the demands of their caring role. The process by which the carers in this study developed this expertise involved blending their knowledge of the child with years of experience in dealing with the chronic disease he/she had and being aware and ready in case the child’s condition suddenly changed. Carers such as Hussa, Rihab and Amina started as novices at the beginning of their child’s chronic condition. However, as their children’s disease developed, so did their knowledge and expertise in managing their children’s conditions. For example, as noted in Chapter 6, Hussa’s years of experience have led her to recognize her child’s worsening condition just by observing the changes in the physical appearance and the sounds the child makes. Moreover, the carers recognized their own expertise in dealing with the chronic disease, the hospitalisation, the equipment, medications; they even made their own assessment of who the best healthcare providers were.

I now know who the good nurses are... who are the nurses that know how to find a vein and who don’t (Amina, carer)

This intimate and detailed knowledge and expertise of the carers was acknowledged by some of the doctors (see Chapter 6, Section 6.6) and these doctors relied on the carers as a valuable source of information.
It has been suggested that when carers recognize their own acquired knowledge and expertise, they will be more likely to trust their own judgement and therefore may be critical of the care delivered (Gibson, 1999). This was the case with Ghada, who as I observed questioned the nurse about the antibiotic being administered to her son (see Section 6.6). She was concerned that the physician may not have prescribed the antibiotic and therefore wanted to verify this by questioning the nurse rather than passively accepting what the nurse said.

The qualitative findings of this study clearly show that some carers had developed expertise in dealing with the chronic disease, and this was recognised and acknowledged by the healthcare providers. Recognition of the carers’ expertise – a crucial element of FCC – might have played a role in developing the ability of the carers to cope with the chronic disease and the hospitalisations.

7.5 Recognising the potential of family-centred care in enhancing self-management

Children growing with a chronic disease develop a need for self-esteem, social acceptance and autonomy (Rich, Goncalves, Guardiani, O'Donnell, & Strzelecki, 2014). Growing into adolescence, they develop their own identity and roles and feel the need for independence from their carers. Some might even envision a future that is not necessarily limited by their chronic diseases (Sawyer, Drew, Yeo, & Britto, 2008; Taylor, Gibson, & Franck, 2008).

However, carers of chronically ill children tend to over-protect their children, often taking over all caregiving responsibilities (Stam, Hartman, Deurloo, Groothoff, & Grootenhuis, 2006). This was the case for the carers in this current research. As indicated in Chapter 6, Section 6.3, carers in this study felt obligated to stay with their children, as these carers believed they were the ones who knew their children best and had the necessary experiential knowledge. Therefore, the carers were not able to let go of their caring role. Thus the carer was always present and as I observed, did everything for the child and did not involve the child in his/her own care. This over protective role of the carer is likely to create overdependence and reduce the likelihood of the child acquiring skills for self-managing his/her condition, and to overcome the challenges of the chronic illness.
In a family-centred approach to healthcare, healthcare providers are encouraged to recognise and build on the competence of families and children by empowering them with the skills and knowledge to be involved in the care and decision making (Committee on Hospital Care and Institute for Patient and Family-Centered Care, 2012). While the carers in this research were learning the skills and knowledge required to care for their chronically ill children, the children themselves seemed to lack these skills.

Therefore, healthcare providers and carers need to work together to encourage the carers to stimulate and empower their chronically ill children (Stam et al., 2006) depending on the child’s age. This will be further discussed in Chapter 8.

### 7.6 Facilitating family-to-family support and networking

Within FCC, healthcare is planned and delivered around the whole family. It involves assessing the health needs of the entire family, detecting factors that impact their wellbeing, listening to their concerns, empowering them, involving them in decision making and improving health service delivery to the whole family, especially the carer (Abdulbaki et al., 2011; Bourke, 1997; Smith & Conant, 2000). The findings of this study revealed that family support and networking was lacking in this hospital. Although the carer and other family members were being affected by the chronic disease and hospitalisations, there was insufficient support available to help them cope.

As mentioned in Chapter 6, in this study, with the carer always present at the hospital with the chronically ill child, the other family members were affected by the mother’s absence. For example, in some cases, teenage daughters looked after their younger siblings as was the case for Hussa and Rihab. Their young daughters, as a result, missed school. Other impacts on the family included missing out on family outings and celebrations. Hussa spoke about spending the month of Ramadan at the hospital without her family and not being able to celebrate Eid with her whole family because of the sudden hospitalisation of her chronically ill child.

“We were visiting family at another city at Eid... and he bled (the chronically ill child) so we got hospitalised there so we didn’t get to celebrate Eid... the thing is that it was at Eid time... so his siblings were left alone at home. When the mother is not with her children at Eid time... They feel incomplete. (Husaa, carer)
As noted in Chapter 2, (Section 2.8.1), previous research has acknowledged the negative impact on siblings and family members including other children feeling neglected by the mother (Barlow & Ellard, 2006; Hopia et al., 2004). This can lead to jealousy as the other children feel deprived of their mother’s attention (Barlow & Ellard, 2006; Brown et al., 2008; Vermaes et al., 2012). Alternatively, as Vermaes et al. (2012) argue, the children might in time learn that they cannot depend on their parents for support or turn to them for advice as the parents are pre-occupied with the sick sibling.

Therefore, siblings of chronically ill children in this research might become accustomed to the neglect of the parents and therefore suppress their negative feelings or learn to deal with any problems they have internally without asking for parental help or advice. What is quite worrisome is the apparent absence of any support or family networking service at the hospital that might buffer the effects of the chronic disease and its negative effects on other siblings. While this study has not looked at the needs of other family members in any detail, the carers in this study spoke of how their continued absence from the lives of their other children were affecting them.

One of the significant findings of this research was the mental distress experienced by most of the carers, putting them at risk of burnout. Results from the quantitative phase support the qualitative findings, with the carers of chronically ill children in the study having double the risk of screening positive for depression than the general population, with the difference being statistically significant. However, the mental health needs of these carers were not addressed by the healthcare providers as this was not a part of the healthcare providers’ job descriptions. Moreover, as mental health issues are rarely discussed and are often associated with stigma, the carers were most likely unable to reach out for psychological help. The wellbeing of the carer and/or family members was rarely addressed by the healthcare providers and when this was done it was on an ad hoc basis rather than as an integral part of their roles and responsibilities.

Another finding was the limited role played by social services towards the patient, carer and family members in the hospital. The interview with Amal, the social worker, provided an indication of what could be achieved if the social services in the hospital were actually effective. Closer examination of the job description of the social worker at the hospital revealed that they were indeed responsible for the provision of therapeutic social support to patients and families but only in times of grief. Therefore, the carer had no means of
actual social support unless the child’s condition had severely deteriorated or worse still their child died. If the social workers were not severely understaffed, as they were in this current study, they might be able to support the chronically ill children and their families, as well as others in times of need. In addition, carers had an obvious need to talk to somebody that understood what they were going through but had no support groups in the hospital. Therefore, they made their own groups and visited each other every night. This seemed to really help them cope with the long hospitalisations.

7.7 Reflections and summary

In this chapter, I have attempted to explain the findings through the FCC model. The needs and concerns of the carers and their children identified in Chapter 6 were examined against the main concepts of FCC. This presented an opportunity for determining the priorities for healthcare system change in Saudi Arabia to promote family-centeredness, which will be discussed in Chapter 8.

To acknowledge the family as central and constant in the patient’s life – the first element of the FCC model – the hospital needs to have a more lenient visitation policy that responds to the needs of the carers and the patient. The physical layout of the hospital also needs enhancement to be more patient and family-friendly.

While some elements of a successful partnership between the healthcare staff and the carers were present, role negotiation was clearly absent. It is important that the degree of parental involvement is negotiated and that carer’s individuality is recognised. Carers may have varying desires to be involved and some may be not capable of assuming certain roles. In addition, the shortage of staff was identified as an issue that will need to be addressed in order to respond to the demands of FCC.

Healthcare providers in this research seemed to have acknowledged the expertise gained by some of the carers and incorporated that expertise into healthcare delivery, which might have played a role in promoting coping.

Caregivers and healthcare staff seemed to lack knowledge about FCC. Some of the healthcare providers played a limited role in ensuring the carers’ health and wellbeing, with their role being acknowledged as related only to treating any physical symptoms that the carer may experience. Healthcare providers were convinced that the role they agreed to was that of addressing only the physical wellbeing of the carers. Their job descriptions
and the roles and responsibilities show this to be the case; wellbeing of the carer and family members was only part of the social worker’s role in times of bereavement or loss. Thus, these findings highlight areas for improvement with reference to the FCC model, and will be discussed in Chapter 8.
Chapter 8

General Discussion

This chapter ties together the findings from the quantitative and qualitative chapters. It begins with a discussion of these findings in relation to the research questions and within the context of the existing literature. Following this, the importance of the findings is examined and justified and the limitations acknowledged. Finally, I discuss the implications of the research for healthcare service provision in Saudi Arabia. I consider the priorities for change in healthcare delivery for care to be more family-centred in order to respond to the concerns and needs of the carers and families. The chapter concludes with a discussion of the implications of the study and recommendations for future research. The implications of this research go beyond Saudi Arabia, given that countries such as Australia, United States and United Kingdom have a significant number of migrants with an Arab background. The study findings, can therefore inform delivery of culturally competent and family-centred care in these countries. From a global perspective, this study adds to the existing body of literature on the needs and concerns of carers of chronically ill children.

8.1 Satisfaction of carers

One of the aims of this study was to examine the satisfaction levels of the carers with the care provided to them by the physicians at the hospital. This was done by carrying out a survey using the Satisfaction Questionnaire to measure how satisfied carers were with their communications with physicians. As communication is a very important element of care (DeVoe, Wallace, & Fryer Jr, 2009), it was used in this study as a surrogate measure of carers’ satisfaction with overall care delivered to their children by the physicians. Satisfaction was measured in the domains of relationship building, information exchange, degree of parental involvement, and demonstration of effort and competence in caring for the hospitalised child. Overall, the satisfaction score seemed to be very high in the sample, with an average of 8.42 for carers of the chronically ill children and 8.83 for carers of the acutely ill children. Similar results were found across all four domains (please refer to Chapter 5, Section 5.1.1).

This study shows that while the carers experienced considerable stress and were at risk of depression, overall they were highly satisfied with the care provided by the hospital...
physicians. A possible explanation for this is that carers interpreted the satisfaction with communication questions in the quantitative survey to be relating to the medical and nursing services provided for their hospitalised child. The qualitative findings highlighted dissatisfaction with the physical environment, food provided to carers, and the cleanliness of the facilities. These qualitative findings suggest that the carers were not completely satisfied with the overall services of the hospital. Hence, when the quantitative findings are interpreted together with the qualitative findings, it is likely that the real level of satisfaction may be somewhat lower than the quantitative study has revealed. In the light of the qualitative findings it is also likely there are other areas of dissatisfaction not picked up by satisfaction survey.

Previous research in Saudi Arabia has shown an inverse correlation between the level of satisfaction and the level of education of carers (Abadel & Hattab, 2014; Alnasser et al., 2017). A study by Cepuch, Citko, and Wojtas (2013) linked the increased level of educational attainment of parents with increased levels of stress (Cepuch et al., 2013; Parkes, Sweeting, & Wight, 2015). Higher levels of education might be associated with higher expectations of healthcare delivery and if the level of healthcare delivery is not meeting expectations, this might result in carers becoming stressed, which might in turn affect the levels of satisfaction. Surprisingly, in this current study, the satisfaction of carers did not differ according to the educational levels of the carers. One reason for this unexpected result may be that the sample size was not large enough to detect a statistical difference.

The literature suggests that a significant burden of care is associated with caring for a chronically ill child (Khanna, Prabhakaran, Patel, Ganjiwale, & Nimbalkar, 2015; Sav et al., 2015). Therefore, during the analysis, this research investigated if such a heavy burden was reflected in much lower satisfaction in carers with a chronically ill child compared to acutely ill children. The study did not find any statically significant difference in satisfaction between carers of acutely ill and chronically ill children in any particular domain or on overall satisfaction. This result is similar to previous research by Zolaly (2012) in Saudi Arabia, who found no statistically significant difference between the satisfaction of carers of acutely ill and chronically ill children. Thus the findings of this current study suggest that the satisfaction of carers with physician communication skills might not differ according to the disease status of the child. However, as mentioned
previously, this might be due to the small sample size, which could not detect any difference in satisfaction.

8.2 Roles of carers

Studies have shown that the carers’ presence, active participation in the care process, and establishment of roles as a carer can increase their satisfaction rate (Bastani, Abadi, & Haghani, 2015; Gooding et al., 2011). Most of the carers in the present study were actively involved in the areas of their child’s care that they were able to, and seemed to have established their roles as carers. This current study indicated a lack or absence of role negotiation between the carers of chronically ill hospitalised children and the nurses. The carers in the study appeared to be occupying different roles, which they took of their own volition; there was no negotiation of these roles with the healthcare providers. As discussed in Chapter 6, there were three different levels of participation, which were the carer as the monitor, the carer as a comforter and provider of physical care, and the carer as the manager. It is likely that the high workload of nurses noted in this research meant that the nurses did not have time to negotiate roles with carers. In addition, carers sensed that the nurses were too busy and therefore felt an obligation to help the nurses with their workload. The literature (Coyne, 2008, 2015; Power & Franck, 2008) has clearly documented that nurses unknowingly depend on carers as a critical resource in managing the nurse’s workload. Such dependence on carers suggests that they are being used as a resource instead of empowering carers and promoting their involvement (Coyne, 2008).

This was the case with Jameela and Amina, who felt bad for the nurses and wanted to help out as much as they could. However, it might be problematic that carers are taking on this additional role – as it has not been negotiated with them. Previous research has shown that, when roles are not negotiated, carers may feel isolated and not cared for by the nurses. As Coyne (2008) argue, the use of the carers as long-term unpaid help can negatively affect their family functioning, the child’s welfare, and the satisfaction of the carers. Therefore, the lack of negotiation and the overdependence on the help of the carers reflected in my research findings is likely to lead to these carers feeling overwhelmed by their caregiving, potentially contributing to their poor mental health, and the sense of wellbeing.
The qualitative findings clearly establish the carers’ “experiential knowledge” (Kirk, Glendinning, & Callery, 2005, p. 461) which came from years of experience in being always present with their child, vigilantly monitoring everything. Through their presence during the frequent hospitalisations of their child, these carers had developed their expertise to the point where they were able to detect the slightest change in their child’s condition. As one carer commented, “I know him and his every need... He doesn’t even have to speak to tell me what he needs.” Some carers were able to recognize when the child was unwell just by looking at the colour of the skin, how dry the tongue was and how black the areas under their eyes were. Such observation skills strongly suggests that these carers indeed had developed expertise in caring for their children’s condition.

The findings of this study suggest that the carer’s knowledge of the child or the “experiential knowledge” of the carer is of a different nature to that of the healthcare provider. These findings are similar to prior studies reporting that parental knowledge is different from scientific knowledge and is associated with the parents’ everyday care and the close contact with the hospitalised child (Caron-Flinterman, Broerse, & Bunders, 2005; Kirk & Glendinning, 2004; Kirk et al., 2005).

Perhaps, in an ideal healthcare setting, the carer and the healthcare provider would work together in an effective partnership to care for the child, and the different knowledge they have would help them to complement one another to provide the best possible care for the child. It is worth pointing out that the carers in this study needed this experience to be acknowledged, and as the findings indicate, the healthcare providers did recognize this experience, and when they did, the carers were proud of their accomplishment. Balling and McCubbin (2001) and Lam et al. (2006) note that carers might feel disappointed when their expertise is not acknowledged by healthcare providers. Therefore, recognition of this expertise in this current study may have contributed to the high levels of overall satisfaction with care that was measured by the satisfaction survey. However, as such a relationship was not specifically explored in this study, no such conclusions can be drawn. An investigation into the relationship between the recognition of carers’ expertise by healthcare providers and levels of carer satisfaction would be an area for future research.
8.3 Wellbeing of carers

This study investigated the extent to which caring for a chronically ill hospitalised child could affect the carer's wellbeing. This was carried out using the *sf12-v2 Health Questionnaire* (see Chapter 5). The *sf-12v2* measured health and wellbeing according to eight domains: general health, physical functioning, social functioning, bodily pain, vitality, role-emotional, role-physical and mental health (Kontodimopoulos et al., 2007; Quality Metric, 2011; Younsi, 2015). In general, the sample had a lower score compared to the norm in all of the wellbeing domains, which shows that their health and wellbeing was worse than what was expected. The difference in the physical and mental health component summary measures between the age groups of the sample and the norm was statistically significant. Similarly, when dividing the sample into acute and chronic, according to the disease status of the child and looking at the different age groups, the difference in the physical and mental health summary measures from the norm was not significant. While statistically not significant, there was a trend towards the carers of chronically ill children having a lower mental and physical component summary than the carers of the acutely ill children and the population norm. The lack of statistical significance was unexpected and might be due to the modest sample size and therefore the lack of power to detect small differences.

A key finding of this thesis is the presence of burnout among the carers of chronically ill hospitalised children. This is particularly important given that the results of the quantitative phase showed that the carers of chronically ill children had more than double the risk of the normal population of screening positive for depression. As discussed in Chapter 5, this difference was statistically significant. Yet from the qualitative findings, it was clear that no services were provided for addressing carers’ mental wellbeing (see Chapters 6 & 7). Moreover, healthcare providers were not expected to address carers’ wellbeing. This absence of mental health services for carers, combined with the high level of risk for anxiety and depression, clearly establishes carers’ mental health as an important concern and an unmet need that the health system should seek to address. Previous research has also suggested a link between the long-term care for a chronically ill child and mental distress and the poor wellbeing of the carer (Brehaut et al., 2004; Dellve et al., 2006; Murphy et al., 2007; Raina et al., 2005). Thus the findings of this current study add to the existing literature and provide strong evidence base for hospitals
to embed mental health services for carers as part of the service they provide for hospitalised chronically ill children.

The qualitative findings of this research showed that carers were experiencing caregiving burnout akin to what is documented in the literature as “compassion fatigue” (Perry, Dalton, & Edwards, 2010, p. 4). Previous research has suggested a link between prolonged family caring for a relative with depression and compassion fatigue (Perry et al., 2010; Showalter, 2010). In this thesis, the caregiving provided to chronically ill children by the carers creates stressful situations that, if undetected and unacknowledged according to Lynch and Lobo (2012), may lead to a greater risk of developing compassion fatigue. At the same time, the findings of the quantitative part of this study point to carers of chronically ill and acutely ill children having an elevated risk of depression. Given that the literature links depression to compassion fatigue, my study findings make a strong case for addressing the mental health needs of carers.

Physical health of carers was also an important concern highlighted in my study findings. The qualitative study demonstrated that the physical health of the carers of chronically ill children was also impacted by their caring role. The survey of the carers did show evidence of reduced physical health. In the SF-12-v2 Health Questionnaire (see Chapter 5), carers of chronically ill children had lower physical summary measures and scale scores, as well as lower scores across almost all the domains, compared to the general population norm. In fact, both chronic and acute groups had lower PCS scores; this probably reflects the acute physical burden in caring for children who are hospitalised regardless of whether they have a chronic illness or not.

As indicated in Chapters 6 and 7, the qualitative findings revealed that some carers had health conditions that became aggravated by assuming their caring role. As noted by one of the carers, her back pain problem got progressively worse as her child grew, as she was regularly lifting her child to help with his daily needs. This finding was echoed by several studies that found that caring for a chronically ill child and assisting the child with movement is associated with back and shoulder pain (Geere et al., 2013; Kaya et al., 2010; Murphy et al., 2007; Tong et al., 2003). These studies investigated the musculoskeletal pain associated with caring for chronically ill children that require help in moving and have found that the long-term effects of lifting are associated with decreased overall quality of life and increased risk of depression (Geere et al., 2013; Kaya et al., 2010; Tong
et al., 2003). Therefore, these carers need to be supported throughout their care process. Training on back health can also reduce the risk for the carers. Kaya et al. (2010) advised that carers who are suffering from lower back pain should receive appropriate care and rehabilitation before their back problems become chronic.

8.3.1 Facilitators for carers’ wellbeing

While most carers in this study seemed to struggle in dealing with the chronic disease of their children, one carer (Nasra) appeared to have normalised the illness of her daughter. Darling and Darling (1982) explained that normalising illness is the most common way for people to deal with chronic illness. Families dealing with chronic diseases learn to normalise the illness over time and come to view the situation as the new normal (Knafl & Deatrick, 2002). Accepting the chronic disease and its effects as normal enables the carer to manage the demands of the chronic disease in a way that preserves the family’s usual functioning (Knafl & Deatrick, 2002). However, normalisation can sometimes be an act that the carer uses as a façade in order to fit in with what society has labelled as normal and avoid being stigmatised for having the disease (Joachim & Acorn, 2016). In Nasra’s case, dealing with the chronic disease of her daughter – with her family members living in a different city and having no family and friends to help – must have been challenging. In addition, her daughter went through repeated hospitalisations that she described as “too many to count.” This poses the question of whether she has truly accepted her circumstances and learned to normalise her daughter’s illness or whether she has learned to maintain a public face to avoid being labelled as not normal by society. For other carers in this study, the chronic disease and the required hospitalisations might have made normalisation a goal to strive for. Therefore, healthcare providers should strive to help carers achieve normalisation. Healthcare providers could discuss with carers’ ways to achieve normalisation and pinpoint achievable goals, along with others that might need some extra work (Knafl & Deatrick, 2002).

Some carers in this study were more fortunate to have family support like a sister-in-law or a daughter who would help them out with their “homemaker” responsibilities whenever the carer was at the hospital with the chronically ill child. These expected gender roles also seemed to affect those closely related to the carer, like the sister-in-law or the daughter who might have felt obligated to help out. For example, when the daughter was occupying this role, she was missing school. Although, in some instances, the support of
daughters was considered an important facilitator for the wellbeing of the carer, it raises other concerns such as school absenteeism for female children.

The carers in the current study discussed school absenteeism as being quite common as they often relied on help from their teenage daughters. The literature acknowledges that school-aged children with chronic diseases are commonly absent from school as a result of hospitalisations (Barlow & Ellard, 2006; Geist, Grdisa, & Otley, 2003; Newacheck & Taylor, 1992). While a number of studies looked at the psychological impacts that children with chronic illness have on their siblings (Assa, Ish-Tov, Rinawi, & Shamir, 2015; Emerson et al., 2016; Geist et al., 2003; Sharpe & Rossiter, 2002), the impacts on the siblings’ education have not been adequately explored or described in the literature. The impact of chronically ill children on the education of their sisters, therefore, is a novel finding of this study and raises an important concern in a country where females already occupy a lower social position compared with males.

The carers in this study benefited from their strong faith, a source of strength and support used by all carers. Their faith in God and the belief in the power of prayer gave the carer the strength to carry on with their caring role. It also seemed to help them by giving them hope that the child could get better. For example, in the case of Jameela, when her daughter’s health was deteriorating and she was being transferred to intensive care, prayer and faith helped her cope. This finding is similar to what was reported in a study by Atkin and Ahmad (2000) on evaluating the service provision to carers of sickle cell disease and thalassemia children. The authors found that the Muslim participants in their study relied on their faith as a coping strategy. Similarly, Stewart, Sharpe, Kristoffersen, Nelson, and Stewart (2011) found that individuals who took comfort from their faith seemed to cope better with the disease and treatment. Therefore, the use of faith as a coping strategy noted in this study was an important facilitator for carers’ wellbeing. However, the faith of the carers and attributing everything to God might have also affected them negatively when carers used that as a coping mechanism for their mental distress instead of reaching out for professional mental healthcare. This will be further discussed in Section 8.3.2.

### 8.3.2 Barriers faced by carers

A significant finding from my research is that, without exception, all carers put their child’s health first – neglecting their own – even when the carers were unwell. Boling (2005) likewise found that one of the barriers that carers face is the difficulty in taking
care of themselves and always prioritising their children’s health. Other studies (Burton et al., 2008; Landsman, 2008) showed that carers of a chronically ill child – especially mothers – often felt guilty for not meeting the societal norms of what is expected of a “good mother,” which entails providing a normal life for their children. When faced with a chronic disease or a disability problem with their children, these carers might blame themselves for what is happening to their children. As a consequence, their identity as a “good mother” might be threatened (Gray, 2003). The idea of “engulfment” was introduced by researchers to describe situations where carers might be unable to separate themselves from their caregiving roles (Chou, 2000; Twigg & Atkin, 1994; Young, Dixon-Woods, Findlay, & Heney, 2002). Skaff and Pearlin (1992, p. 656) explained that the engulfed carer might suffer from “loss of self” in their caring role, which explains the cost of caring on the carer’s health. Some carers in my study could be described as “engulfed” in their caring role, which continues to shape and re-shape their identities as “good mothers.” Caring for their children seemed to dominate their lives and, hence, the carers might have lost themselves in their caring role and felt the need to prioritise the health demands of their chronically ill child, while often subverting their own needs and neglecting their health. As mentioned in Chapter 6 Section 6.5.3, Sarah was the only carer I talked to who had paid employment. She felt the obligation to prioritise her son’s need for care during hospitalisation over her work. Therefore, she opted to apply for early retirement in order to fulfil her role as a carer for her son. Young et al. (2002) pointed out that parenting a chronically ill child alters the mothering role significantly. The intensified sense of obligation and the way that the chronic illness shaped and dominated the carers’ concerns might lead carers to delegitimise their own healthcare needs. Burton et al. (2008) argue that when carers neglect their own needs, the healthcare effects of caring for the chronically ill will likely intensify. My findings strongly highlight the need for supporting carers in their caregiving role to help them avoid feeling engulfed and to improve their health and wellbeing. This is something that not only benefits the carer but also, according to Burton et al. (2008), benefits the health and wellbeing of the chronically ill child.

My research interestingly shows that even when the carers had others who could help take care of their child, the engulfed carers faced the barrier of not being able to let go of their caregiving role. The carers had different reasons for not letting go. Regardless of the reasons given, the constant presence of the carers in this study at the child’s bedside begs the question of whether this inability to let go has implications beyond the carers own
health. What stood out in this study was that the ill child was totally dependent on the medical care team and their carers for the management of their condition. Thus, there was no focus on empowering the ill child to become more involved in their own care even in the cases where the child was old enough to contribute to his/her illness management. Instead, the children were in some ways being forced into becoming helpless. The carer’s constant presence and overprotectiveness towards the child could have obstructed the child’s development and might even become a barrier to the child’s desire for self-care (Melnyk et al., 2001). My study did not look into this aspect in depth and, therefore, this should be an area of focus for further research.

This study clearly demonstrated that the mental health of carers was a significant need and concern. However, the qualitative findings showed that the healthcare providers had conflicting views about their role in ensuring the wellbeing of the carers. Although some saw that caring for the carers was an extension of their role, others saw that it exceeded their job description. This result is broadly consistent with results from other studies conducted in Britain and Finland, where researchers reported that caring for the patient’s family was a hidden area of the nursing job (Callery, 1997; Franck & Callery, 2004; Hopia et al., 2004). However, there is an important difference between previous research and the findings of this current study. In previous research, nurses agreed that caring for the carers was part of their job, but there was lack of clarity on the nature and extent of that part of their role (Callery, 1997). However, in this PhD study, healthcare providers did not agree that it was part of their job description. One nurse further explained that, even if she saw the carer upset, she would “tell them to go to the Emergency Room” or she would offer the carer some pain relief, but she would not ask or help further because “it was not part of her job.” The understanding that carer’s health was indeed not part of the nurse’s role was verified by an interview with a senior member of the managerial staff and through the analysis of hospital documents. Prior to commencing the research, I had not expected that the carer’s health would not be a part of the job responsibilities of the nurses. This suggest that there is a lack of focus on providing holistic and patient centred care.

It is important to note that most contemporary medical models of care, such as the family-centred care model (see Chapter 2) – especially in paediatrics – has moved on to include care of the carer as an important aspect to providing holistic care (Feudtner, Haney, & Dimmers, 2003; Pelchat & Lefebvre, 2004; Potts & Mandleco, 2012). The disagreement
amongst healthcare providers about their role in caring for the carer in this study meant that the carers could not be assured of receiving care or help when needed. This finding shows that carers might not have the means or access to mental health or psychological care, which is a barrier that carers faced in ensuring their health and wellbeing.

Seeking and receiving help is important for coping with mental distress (Al-Krenawi, 2005). In this study, as previously mentioned, carers drew on their religious beliefs to deal with the mental distress and possible burnout they were experiencing. The carers attributed everything to God and therefore were accepting of whatever was destined for them and believed that they need to face whatever came with strong faith. They followed the societal norm common in Saudi Arabia of not discussing mental health issues, as they are often associated with stigma. Therefore, even if the carers were aware of their need for mental healthcare, they were unlikely to reach out for professional help. Alternatively, they would take strength from their faith and family. This finding concurs with other studies that have generally reported that Arabs tend to underutilise mental services because mental illness is associated with stigma or because of a lack of awareness of the availability of mental health services (Al-Krenawi, 2005). A study by Basit and Hamid (2010) investigating mental health issues in Muslim communities in the United States found that, even when there were centres offering mental health services specifically tailored to the needs of this specific group, these services tended to be underutilised. Reason for this included the lack of understanding of available mental health services, language barriers, unfamiliarity with the concept of counselling, trust in traditional medicine and, finally, the stigma around mental health issues. So while one might think that Arab Muslims are more likely to seek medical help in Western contexts, where mental healthcare is more normalised, they were still hesitant to seek help and these services were still being underutilised.

Moreover, as mentioned in Chapter 3 Section 3.6.5, it is a common belief among some Muslim populations that physical or psychological illness has a supernatural cause, and therefore they may turn to traditional or spiritual healers for help (Koenig et al., 2014). This has serious implications for raising awareness about mental health services among this population. The findings from my study support this, as many carers spoke about the chronic disease of their child being a test from God and that they had to be patient and gain strength from reading The Quran and engaging in Dua’a (praying to God) to receive their reward. They believed that, by doing so, the reward from God might also include
healing the child. As a Muslim myself who believes that while illness is a test from God and that we should be patient and pray to God for things to get better, I also acknowledge that accepting help and getting necessary medical attention does not contradict the teachings of Islam. While Islam encourages us to be patient in times of hardship and to take strength from our faith, the following saying of the prophet Mohammed (peace be upon him) shows that Islam advocates for medical treatment for the sick:

A group of Arabs asked the prophet: “Messenger of Allah, should we make use of medical treatment?” He replied: “Make use of medical treatment, for Allah has not made a disease without appointing a remedy for it, with the exception of one disease, namely old age” (General Authority of Islamic Affairs and Endowment, 2017).

The traditional gender roles (explored in Chapter 3 Section 3.6.2) expected by Saudi society seemed to explain a lot of the findings of my study. Many families in Saudi Arabia still view the husband as the breadwinner (Katooa, 2014; Mobaraki & Söderfeldt, 2010) and women as the homemaker responsible for raising the children and taking care of them and their health. A study by Alyaemni, Theobald, Faragher, Jehan, and Tolhurst (2013) investigated Saudi women’s perspectives on how gender social structures affected their health. The authors found that women regarded themselves as disadvantaged when it came to how their reproductive roles and responsibilities affected their health. This was true to some of the carers in my study whose burden of having a chronically ill child had impacted them negatively. In the cases of Ibtehal and Sarah, both were fully responsible for the care of their ill child as, in their view, their spouses were “absolutely useless” when it comes to helping with the children or with the domestic chores around the house.

Interestingly the gendered role of mothers taking care of their ill child applies even to countries such as Sweden, where there is a high level of gender equality. For instance, a study exploring parents’ experiences of living with a child with juvenile chronic arthritis in Sweden found that the mothers in their study occupied the managing role while fathers had the waiting role (Sallfors & Hallberg, 2003). In their study, mothers seemed to want to occupy the role of managing and taking charge of care for the child. The fathers had no choice but to passively wait due to the minimal opportunities for engaging in the child’s care because of the dominant role of the mother. However, the fathers’ passive roles seemed to be essential for ensuring the wellbeing of the siblings and the rest of the family. Therefore, the study concluded that the traditional gender roles seemed to be
necessary for the family to cope with the chronic disease. In my study, some carers were negatively affected by traditional gender roles when their spouses did not step in to help with the siblings at home, as the husbands did not see this as their role. As a result, these carers were overstretched and seemed to be overwhelmed with the task of managing the child with the chronic disease, along with the other children and responsibilities neglected at home. When caring demands are this extensive, the carer might be at risk of psychological distress (Hatzmann, Maurice-Stam, Heymans, & Grootenhuis, 2009).

The physical environment was one of the barriers participants spoke about in this research and was also confirmed through observation. Being in a new, uncomfortable environment disrupted the carers’ sleep. One participant also spoke about the lack of compassion from nurses who would come in and switch on all the lights to check on the neighbouring patient. These results are similar to previous research (Dellve et al., 2006; Murphy et al., 2007; Uhl et al., 2013) that establishes the impacts of caring for a chronically ill child on the physical health of the carer.

8.4 Study strength and limitations

This study had the advantage of using methodological triangulation (Hussein, 2015). Incorporating both quantitative and qualitative research helped me gain an in-depth understanding of the experience of carers of hospitalised chronically ill children in Saudi Arabia. Using the qualitative approach in this research helped to explore in more depth the experience of carers of chronically ill patients and to identify the roles they play and the facilitators and barriers to their health and wellbeing. Additionally, prolonged engagement with the carers in the hospital (6 months) created possibilities for getting to know them and establishing rapport. This then helped carers to open up and share their experiences. The use of the quantitative study helped to assess and quantify the satisfaction and wellbeing of carers of hospitalised children – something that has not been done before in Saudi Arabia.

In the qualitative phase, the key strength was the way rigour was assured through the use of methodological triangulation (through interviews, observations and document analysis) and data source triangulation (carers, healthcare providers and managerial staff). See Chapter 4 Sections 4.2.1 and 4.5 for details.
In the quantitative phase, the study had several strengths which included: 1) a high response rate for the satisfaction and wellbeing surveys (88.6% and 86.5%, respectively); 2) the sampling of carers was consecutive; 3) the use of a validated tool to measure health-related quality of life (SF-12-v2); and 4) the use of a tool that was previously trialled in the Saudi population to measure the satisfaction of carers regarding their communication with healthcare professionals.

The study also had several limitations. The quantitative study used a small sample (75 participants for the satisfaction questionnaire and 70 participants for the wellbeing survey). The small sample size might have led to false negative results.

Since the aim of the quantitative phase was not hypothesis-testing but rather to describe the carers’ level of satisfaction and to measure the possible effects of caring on carers’ wellbeing, the appropriate study design was cross-sectional (Levin, 2006). However, using a cross-sectional design in this study had the disadvantage of measuring or assessing the satisfaction or wellbeing of the population at a single point in time, thus providing only a snapshot. It is possible that, if this aspect of the study were conducted at a different time, different results would be obtained (Levin, 2006). Therefore, it cannot be used to draw conclusions over a time period.

Additionally, the psychometric properties of the satisfaction questionnaire are not known since it has not been validated. However, the questionnaire has face validity because the questionnaire was developed from empirical findings, and the face validity was reviewed by at least two separate group of experts (i.e. the first paper that described the questionnaire (Hsiao, Evan, & Zeltzer, 2007) and also by this thesis). In addition, there is face validity in the suggested scoring system (e.g. 0 is neutral, -ve score is negative sentiment, +ve score is positive sentiment) which allows for making meaning out of the scores.

Another limitation was that the study focussed on the needs and concerns of carers in only one public hospital situated in Eastern Province, Saudi Arabia. It is possible that the experiences of carers of chronically ill hospitalised children differ in private hospitals and other hospitals situated in more rural parts of Saudi Arabia. In addition, the study was not able to explore the full picture of the situation of chronically ill children and their carers in Saudi Arabia, as it did not include the chronically ill children’s point of view. Another limitation in the qualitative phase was that one of the health care providers I interviewed-
Deema- was an old friend of mine and that might have affected the information she was giving me and might have led her to share with me what she thought I wanted to hear.

In addition, the qualitative study did not fully explore the researcher influence on data collection and analysis. Only some elements of reflexivity have been explored.

Moreover, the interview question did not specifically explore FCC in Saudi Arabia. Incorporating the health care providers’ perspective and understanding of FCC would have been beneficial in assessing healthcare providers’ knowledge and practice of FCC principles in Saudi Arabia.

8.5 Implications for integrating family-centred care into healthcare delivery in Saudi Arabia

The family-centred care model was the framework used to guide this research. The findings of this research were examined though the family-centred care lens in Chapter 7. The elements of FCC were used as points for discussing the findings of the research. In this section, I aim to examine FCC in the Saudi Arabian context and identify priorities for systematic change to promote family-centeredness in the Saudi context.

FCC is a model that has been developed as an ideal standard for healthcare delivery in Western contexts, but few studies have examined FCC in non-Western countries (Majdalani, Doumit, & Rahi, 2014; Shields & Nixon, 2004). A recent study by Alabdulaziz et al. (2017) explored the implementation of FCC in Saudi from the perspective of the paediatric nurses. In their study Alabdulaziz et al. (2017) found that the Western principles of FCC were generally accepted by the nurses in Saudi Arabia. However, the authors clearly point out that, while the nurses agree on FCC, its principles are not really implemented or even fully understood. The nurses had trouble practising the model due to hospital policies, communication issues, language barriers and cultural norms. They concluded that the Western concept of FCC cannot be implemented fully in Saudi Arabia and will have to be culturally modified to be successful or appropriate in the Saudi context.

Contrary to the Alabdulaziz et al. (2017) study, which revealed that the nurses had a basic understanding of FCC core principles, this PhD study has shown that knowledge of the FCC model among healthcare providers is very limited or even non-existent. In this PhD study, nurses were not specifically asked about their knowledge of FCC. However, when
explaining the extent of their roles towards the carer, patient and family, they seemed to portray limited or no knowledge about FCC. To investigate the extent of familiarity with the FCC model in this research, I interviewed three administrative personnel. None of the three had any idea about the family-centred care model. I then reviewed several hospital documents around the policies and procedures followed at the hospital and found no reference to family-centred care in any of these documents. As mentioned in Section 8.3.2, interviews with managerial staff verified that the healthcare providers in this hospital had a limited role towards the carer.

My study concurs with Alabdulaziz et al. (2017) that culture plays a dominant role in healthcare delivery in Saudi Arabia. The effect of cultural and societal norms is very evident in how the carers deal with their stressful caregiving role. For example, as mentioned in Chapter 6 Section 6.8, Amina, Sameeha and Jude’s way of dealing with mental distress was to take strength from their faith, read The Quran and not discuss the matter in the hope they will be rewarded for their good deeds from God. It is possible that societal and cultural norms that stigmatise mental health issues were the reason for not seeking help from professionals and relying on their faith in dealing with mental wellbeing. Hence, it is very important that these cultural constraints be front and centre when trying to incorporate FCC into the Saudi context.

Several other issues were found that could obstruct the implementation of FCC in Saudi Arabia. These include the absence of organisational commitment, the absence of supportive family services and the shortage of staff that would affect the time they have for building a trustworthy relationship with the carers and negotiating roles. Similar findings were reported by Alabdulaziz et al. (2017).

8.6 Applications of the findings in Saudi Arabia

In this section, the findings presented in my study and examined through the family-centred care lens in Chapter 7 will be used to recommend priorities for health system change. I use the main principles of family-centred care presented earlier in Section 7.1 as a framework to suggest system-level changes that can promote family-centeredness in response to the needs and concerns of carers of hospitalised children with chronic diseases. These changes may enable healthcare providers and the families to engage in a partnership that promotes shared decision making, information sharing and improved service delivery.
Figure 8.2: Schematic diagram of FCC adjusted to the Saudi context

Figure 8.1 represents a schematic diagram for incorporating FCC into healthcare delivery and represents opportunities for systematic changes that begins with familiarising FCC as a concept and supporting it through management. The perspectives of all the participants were taken into account when identifying opportunities for systematic changes. The potential outcomes of implementing the suggested changes are also detailed in the diagram. The two outer rings – culture and religion – are the overarching influences in the Saudi context that affect how people deal with disease, wellbeing and mental health.

8.7 Factors contributing to family-centred care: Priorities for systematic change and implications for practice

In this section, I attempt to identify the priorities for healthcare system change and the implications for practice in Saudi Arabia to promote family-centeredness. These implications were identified from the examination of the findings through the family-centred lens (please refer to Chapter 7).

8.7.1 Familiarity with family-centred care

The most important factor that drives the implementation of effective FCC is the commitment of management and senior leadership (Shaller, 2007). The sustained delivery of family-centred care requires the active engagement, involvement and commitment to
FCC’s standards through the different levels of policymakers, management and healthcare provider staff.

As mentioned earlier (in Section 8.5), in this research, it was evident that there was no recognition or implementation of FCC in the study setting. Coyne et al. (2011), in their study of seven different hospitals in Ireland, pointed to the need for hospital support in the successful implementation of FCC. This is also true for Saudi Arabia. The lack of managerial and organisational support for FCC could be a big challenge if FCC was to be implemented. Despite the limitations of the questions explored in this study, it is quite clear that the healthcare providers in this particular hospital setting in Saudi Arabia have limited knowledge of FCC. This has implications for practice, such as the importance of advocating for FCC and increasing the knowledge of all involved parties about it. Thus, providing continuous education about FCC for policy makers, funding agencies and legislators would help to raise the level of awareness about the expected short- and long-term benefits of operationalising FCC (Kuo et al., 2012). It is also crucial that healthcare providers are familiar with the FCC principles and seek to involve the families in healthcare delivery. Adopting FCC principles and incorporating them into the delivery of care would help clear the confusion about the exact extent of the staff responsibilities towards the carer and the family. The commitment to FCC and its implementation could also be promoted through the presence of healthcare providers and families on hospital committees and advisory councils (Kuo et al., 2012; MacKean et al., 2005).

It is important that hospital management communicates a strategic vision and plan to incorporate FCC into its operations. Such a plan needs to be specific, clear, and have attainable goals that can be targeted and monitored (Shaller, 2007).

8.7.2 Training needs of carers

As FCC had not really been implemented in this hospital, carers involved in this research (similar to healthcare providers) were not aware of FCC. Although there appeared to be some partnerships occurring between the healthcare providers and the carers, the partnerships lacked some of the core elements, such as defining each of the partner’s roles. The carers’ roles were also confined to the physical and technical care of the patient. Information about FCC and its application should be shared with families and patients. This could be accomplished by sharing this information when the child is admitted or on their first visit to the hospital. Families need to know the crucial roles they can play in the
care of the child. Health professionals should encourage the carers to become more actively involved in decision making and the right to choose their level of participation. For this to be realised, there needs to be familiarity with FCC among healthcare providers first for them to able to share such knowledge with the carers.

8.7.3 Supporting self-management and empowerment of the hospitalised child

The findings of the study suggest that there was some level of helplessness created among children as the carers took full responsibility for their care. This is an area that needs further research as the focus of this study was not on the children’s perspectives. Nevertheless, this section will discuss some of the more salient points as empowerment of the hospitalised children is an important element of FCC.

The FCC values the involvement of patients as well as families in care and decision making. It involves treating families and children with respect, listening to them and empowering them and involving them in care delivery (Zarubi et al., 2008). In addition, self-management is essential in chronic disease care as it demonstrates the autonomy and resilience developed by people living with chronic diseases (Franck & Callery, 2004; Tattersall, 2002; Wagner, Austin, & Von Korff, 1996).

However, there are significant challenges in applying concepts of FCC and self-management to the care of children with chronic disease in the Saudi context. The social expectations and cultural sensitivities will need to be carefully considered, including further research to identify families’ and children’s perspectives on individualising care delivery, and strategies that may be effective in empowering the children and their families.

This study provides important insights that help inform this potential future work. The findings show that the family presence is very important to the health and wellbeing of the child. Therefore, when implementing the FCC in Saudi Arabia, there needs to be careful consideration of the roles that the carers will retain and the roles that the child can take over. Studies show that parents can become very anxious about letting go and transferring some of their responsibilities to the children (Franck & Callery, 2004). Therefore, healthcare providers may be able to negotiate with the parents about the roles that they feel comfortable giving to the child, with the understanding that this will be different for each family.
Drawing from the findings of my study, there is value that could be added by creating family and child advisory councils to serve as vehicles to understand how to involve children effectively in care. It is through better self-management and empowerment of children that they can become active members of their own care. It is crucial to understand that chronically ill children and their carers each have unique perspectives of their objectives in care and involving them might lead to insights about what is working and what needs to change for the better. By involving the children in their care, these carers might actually grasp the option to let go when they observe how their children are more in control.

8.7.4 Building staff capacity to support family-centred care

The absence of staff training and knowledge about FCC was identified as an issue in this research. Healthcare providers seemed to lack the required education and skills to implement FCC effectively. There appears to be a need for educating the staff about FCC and developing their skills through workshops about conflict resolution, communication skills, assessing family needs, family-centred values and, most importantly, role negotiation.

8.7.4.1 Role negotiation

Role negotiations begin with a mutual understanding of carers’ and healthcare providers’ roles (Newton, 2000). Seeking and developing a partnership with carers can be awkward and different to what the healthcare providers were accustomed too. The carers can be viewed as the expert when it comes to the child’s wellbeing, and the nurse can be viewed as the expert in the medical knowledge and the family’s source for support (Newton, 2000). It is recommended that the nurses should be proactive and take the first step towards role negotiations as soon as a patient is admitted and do not wait for the carers’ negotiation skills to improve, which could take time (Corlett & Twycross, 2006).

To negotiate roles, it is necessary for the healthcare providers to be equipped with the required knowledge and relevant skills to communicate with carers and mediate roles successfully. While these skills are developed and strengthened by practice, they should also be fostered and incorporated into the nurses’ education (Corlett & Twycross, 2006). Additionally, the limited knowledge about FCC amongst healthcare providers (see Chapter 6 Section 6.10, Chapter 7 Section 7.7, and Chapter 8 Sections 8.5 and 8.7.1)
could be further addressed by the inclusion of the theoretical principles of FCC and its applications into the nursing schools’ curriculum at the universities as well as in the education of doctors and allied health professionals. In addition, there should be appropriate learning opportunities and professional development workshops on the application of FCC in practice.

8.7.5 Creating supportive environments

Family-centred care supports the provision of healthcare in the context of the family (Kuo et al., 2012). This involves having a supportive environment that is family-friendly, recognising the importance of family-to-family support, ensuring access to social services, and incorporating the patient and the family into the care process (Kuo et al., 2012; Maternal and Child Health Bureau, 2005). The findings of this research indicate that carers and families might need more supportive care, such as counselling, support groups and social care services. It is through the family-to-family-support that carers can learn to engage with families who are facing similar challenges and share meaningful and supportive experiences with each other. The following recommendations are offered on ways to provide a more supportive environment.

8.7.5.1 Strengthening the available social services

Family-centred care emphasises the importance of providing individualised services that take into consideration the fact that each patient and the family are different and therefore they have different needs that have to be assessed and addressed (Espe-Sherwindt, 2008; MacKean et al., 2005).

The findings of the current study strongly support the need for improved access to supportive social services for carers. Social services are positively linked to mental and physical health and longevity (Thoits, 2011). While there are social services provided at the hospital, and the need to care for the patient, carer and family listed as part of the social worker’s job description, the social worker was only expected to offer grief counselling. In addition, access to these services appeared to be limited. This was due to the shortage of social care workers, and the location of social services.

These problems may be overcome by strengthening the social services. This may include increasing the staff-to-patient ratio, bringing the physical location of services closer to
the patients, and raising awareness among the hospitalised patients and carers of available social care services.

8.7.5.2 Developing family-to-family support

The findings of this PhD study suggest a general absence of any support groups for the carer and family (Chapter 6 Section 6.10 and Chapter 7 Section 7.6). Previous research has suggested that support groups can help carers and families deal and cope with what they are going through (Tong et al., 2010). Families benefit from sharing their experiences as this reduces their feelings of isolation and promotes sharing of their medical management strategies (Tong et al., 2010). FCC recognises the importance of developing family-to-family support as one of its elements (MacKean et al., 2005). Therefore, to provide more patient centred care, there is a need to establish support groups to help the families cope with the hospitalisations and the chronic illnesses.

8.7.5.3 Incorporating the care of carer as part of the care plan

As discussed earlier, FCC ensures that healthcare is planned and delivered around the whole family. It involves assessing the health needs of the entire family, detecting factors that impact on their wellbeing, listening to their concerns and empowering them, involving them in decision making and improving health service delivery in response to the identified needs (Abdulbaki et al., 2011; Bourke, 1997; Smith & Conant, 2000).

A key finding of my study is the need to address the unmet mental health needs of the carers. As mentioned in Chapter 6, most of the carers in this study were showing signs of mental distress and, most probably, caregiving burnout (Chapter 6, Section 6.1). However, their health needs were not being addressed by the healthcare team, who did not consider the carer’s health as part of their job. Furthermore, healthcare providers’ perception of FCC seemed to be non-existent and might be the reason why they were not involved in the carers’ needs.

To implement FCC effectively, it is crucial that the healthcare providers play a more active role in helping the carer and the families in times of distress. One of the areas that should be addressed is the need for a systematic assessment of the carer’s and other family member’s unmet needs. Strategies to meet any identified unmet needs should be incorporated into the planning of care for the carer, as well as the patient and his/her siblings. Perhaps this will help to clarify the healthcare staff’s role towards the carer and
make it more transparent. Staffing levels would also need to be adjusted to be more aligned to what is needed. In addition, training needs and required skills for healthcare providers could be identified and incorporated into the healthcare staff’s education system (Callery, 1997). Newton (2000) argues that nursing education should foster strategies to incorporate empowering families. These strategies include talking with family members about what they are going through in an effort to normalise their experience, assisting the family to realise how people respond differently to the stress of chronic diseases and hospitalisations, alleviating any role stress experienced by family members by helping them to recognise their own strengths and develop different coping strategies and, lastly, putting them in touch with available support groups.

By addressing these issues, it might be possible to move past healthcare delivery that focuses on caring for the individual disease and move toward a more holistic care that encompasses disease treatment, not as the sole goal but as one of the important goals. The health and wellbeing of family members of the patient – especially the carer – are important aspects that should be integrated into the caring role of the healthcare providers if FCC is to be realised.

8.7.6 Enhancing the physical layout

To promote the delivery of family-centred health care, the hospital’s environment needs to be accommodating to the needs of carers and patients. FCC provides opportunities to improve service delivery as well as the environment where the care is taking place. As mentioned in Chapter 6 and 7, the carers in this study were negatively affected by the hospital’s environment. The carers identified several needs pertaining to the physical environment, such as the need for improved sleeping arrangements, uninterrupted sleep, better quality meals, and cleaner facilities.

It has been suggested that making the hospital environment patient and family-friendly has a positive influence on them and might also reduce their length of stay (Devlin & Arneill, 2003). Therefore from a family-centred care perspective, there is a need for an improved physical layout that acknowledges and responds to the health needs and concerns of the carers and families. Other opportunities for improvement include providing the carer with a more comfortable bed, enhancing the quality of the provided meals and restricting the use of the toilets in the room for the carers and patients.
8.8 Recommendations for future research

8.8.1 The use of longitudinal studies

This study used a cross-sectional design in the quantitative phase to measure the satisfaction and wellbeing of the carers at a single point in time. In addition, the sample size used was relatively small. Therefore, the results of the study cannot offer conclusive evidence about the satisfaction and wellbeing of the whole population nor can they be used to draw conclusions over a time period. Therefore, it would be useful for future research to use a longitudinal design which offers the opportunity to show patterns of the satisfaction and wellbeing of carers over time. Further research is also required to discover if the results can be generalised to the Saudi context and, hence, the study could be replicated using a larger sample across multiple sites.

8.8.2 Explore the knowledge of FCC amongst healthcare providers in the Saudi context

This study demonstrated limited knowledge or unfamiliarity of FCC concepts amongst healthcare providers. Although FCC is being debated in the Western countries, the evidence from low and middle income countries is limited if not non-existent. Apart from the current study, I found just one study conducted in Saudi Arabia that explored FCC from the perspective of nurses (Alabdulaziz et al., 2017). Hence, there is a need for future research to explore FCC in Saudi Arabia and discover whether similar or different issues exist with its application to that reported in Western contexts. This will also provide additional data to further refine the model developed through this study (Figure 8.1) so FCC can be successfully implemented in the Saudi and other Middle Eastern contexts.

8.8.3 Explore mental health needs

This study provided important evidence about the unmet mental health needs of carers of the hospitalised children. In the quantitative study, the results indicated that the sample in general (carers of children with an acute illnesses and carers of children with chronic diseases) had a lower mental health score (worse health) compared to the norm. They also were more likely to screen positive for depression. The qualitative phase demonstrated that the carers of hospitalised chronically ill children suffered from poor mental health and possibly burnout. However, there seemed to be a general absence of mental healthcare and a limited role for healthcare providers in providing it. The stigma that still surrounds mental health problems in Saudi Arabia and other Eastern contexts could exacerbate the
problem by discouraging sufferers from reaching out for help. Therefore, future research in Saudi Arabia should focus on mental health problems as a priority. There is a need to identify the populations that have a higher risk of mental distress, their demographics, factors that contribute to the risk of developing mental health problems, and to identify interventions and solutions that are appropriate in the Saudi context, given the social, religious and cultural background (Koenig et al., 2014).

8.9 Conclusion

This study explored the carers’ experiences with hospitalisations of their chronically ill children in Saudi Arabia and identified their level of satisfaction, the roles they play and the facilitators and barriers for health and wellbeing during the child’s hospital stay. The findings of this study adds to the global body of knowledge as they are not only relevant to Saudi Arabia but will be useful in tailoring medical and mental services to other Arabs with similar backgrounds. In a global world there are Saudis and people with Arab background living in Western countries. Therefore the needs and concerns of the participants of this study may help strengthen family-centered care in other countries.

The study highlighted some novel findings that have not been addressed in previous studies. First, the chronic disease of the children had an indirect effect on their sisters’ education. The hospitalisation of the chronically ill children and the absence of the carers affected the education of the sisters which should be highlighted as a serious concern. Second, this research identified the need for providing holistic family-centred care in Saudi Arabia that goes beyond the actual disease and its symptoms and considers and responds to the needs of the patient, carer and family. Third, it was clear from observations that the carers were constantly present, attending to their children’s needs. This suggests a level of overprotectiveness of the child and might have led to the children becoming passive in their own medical care and dependant on the help of the carer and the healthcare providers. However, in this study, this was not investigated further from the point of view of children or carers and therefore might be an area of focus for further research.

The findings of this study clearly establish that lifelong care for a chronically ill child places a significant burden on the carer’s physical and psychological health, adding further evidence to the existing literature. The quantitative and qualitative findings of this study highlight carers’ mental wellbeing as a major concern; I would argue that the
findings are strong enough to establish carers’ mental health as an important public health problem. Many of the carers were showing what is highly likely to be signs of burnout. All interview responses portrayed mental health issues that were being experienced by the carers and yet not all carers recognised the need to seek professional care. Those that did recognise a need for mental care were unlikely to receive the psychological help they required due to the stigma associated with reaching out for mental healthcare. The mental wellbeing of carers was a significant finding in the qualitative phase and also highlighted in the quantitative phase which showed high risk for carers screening positive for depression.

The poor mental health of carers was further exacerbated by the barriers they faced in trying to maintain their health and wellbeing and that of their children. These included the understaffing of nurses, the absence of role boundaries and negotiations, being engulfed in the caring role, not being able to let go and the stigma of seeking mental care. In addition, other than the roles that carers occupied in the care provision, they were aware of the nurses’ high workload so they tried to step in and help, which added to their own burden and stress.

Yet carers’ mental wellbeing was not addressed. For most healthcare providers, addressing the carer’s health was not part of the healthcare provider’s role. Moreover, as could be seen in the document analysis, carers’ wellbeing was not recognised as important in the hospital policies or by the hospital management. Therefore, the carers normalised their stress and took strength from their family support and their faith to accept what was happening to them. These were identified as important coping mechanisms that enabled carers to carry on with their caring burden and ensured their health and wellbeing. Faith in God and believing in predestination seemed to be a source of relief for participants when other sources of help with mental distress were not available or hard to reach.

The quantitative investigation reported that carers had a high level of overall satisfaction. However, there was no difference in satisfaction in different domains or on overall satisfaction between carers of acutely ill and chronically ill children. In addition, the satisfaction levels did not differ according to the education level or job type of carers.

The knowledge of the carers’ needs and concerns presented in this study provide a comprehensive basis for designing interventions, training programs and helping healthcare providers reflect on the services provided. This study used the family-centred
care model as a theoretical framework to guide the study as it was developing and to help determine appropriate interventions and system level changes. Despite the recognition of FCC and the evidence to support it, it is yet to be achieved. While Western countries are facing difficulties in achieving FCC, they are closer to achieving it than other Middle Eastern countries, such as Saudi Arabia, that still have a long way to go. Eventually, I hope that the results of this study will help with the introduction and integration of FCC principles within the Saudi context. My aim is that this will lead to the establishment of a mutually beneficial partnership between patients, healthcare providers and patients’ families – one that emphasises the integral part that the family of the patient plays in his/her health and wellbeing and leads to improved family-centred practices in Saudi Arabia.
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Appendices

Appendix 1: Ethics Approval

Removed from public copy for confidentiality

Appendix 2: the quantitative survey tools

2.1 The Satisfaction questionnaire

2.1.1 Satisfaction questionnaire Arabic version

2.1.2 Satisfaction questionnaire English version

2.2 The Sf12v2 wellbeing questionnaire

2.2.1 Wellbeing questionnaire Arabic version

2.2.2 Wellbeing questionnaire English version

Appendix 3: the invitation email

3.1 Invitation email Arabic version

3.2 Invitation email English version

3.3 reminder email Arabic version

3.4 reminder email English version

Appendix 4: consents

4.1 Implied consent for survey

4.1.1 Implied consent for survey Arabic version

4.1.2 Implied consent for survey English version

4.2 Consent for photographs
4.3 King Fahad Hospital Informed Consent Statement for primary carer

4.4 King Fahad Hospital Informed Consent Statement for staff

**Appendix 5: Interview guides**

5.1 Interview guides for primary carers

5.1.1 Interview guides for primary carers Arabic version

5.1.2 Interview guides for primary carers English version

5.2 Interview guides for Health care providers

5.2.1 Interview guides for Health care providers Arabic version

5.2.2 Interview guides for Health care providers English version

5.3 Interview guide for managerial staff

5.3.1 Interview guide for managerial staff Arabic version

5.3.2 Interview guide for managerial staff English version
Appendix 2: the quantitative survey tools

2.1 The Satisfaction questionnaire

2.1.1 Satisfaction questionnaire Arabic version

الموضوع البحثي والهدف:

كانت مهارة المشاركة في هذا البحث، إذ تم تقديم من خلال هذا البحث أن يدرس نظرية الأطراف الأساسي للمواقف في مستشفى الملك فهد الجامعي. سيتناول هذا البحث أن يدرس نظرية الأطراف الأساسي للمواقف في المستشفى. يهدف البحث أن يكشف المواقف والممارسات الصحية للمرضى، وذلك من خلال هذا البحث أن يتم التحكم في معلومات تفاعل الأطراف في قضايا الصحة في المستشفى، وتساعد المستشفي في تحقيق خدماتها الطبية للمواطنين في كل الأحوال، في المستقبل.

إن المعلومات تسهل علينا من خلال هذا البحث سرر كفاءة نجاحنا، وتم تكشف عن هذا بالنظر إلى مادة تفاعل البحث، إذا كنت يتوفر ذلك النص أو ما. تم الحصول على المعلومات من خلال هذا البحث من كل من مستشفى الملك فهد التعليمي و جامعة نيو ساوث ويلز أستراليا.

بيانات عالية:

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<th>معلومات المواقف الأساسية</th>
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<td>صناعة القراءة للمواقف</td>
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<td>اسم الباحث:</td>
<td>صناعة القراءة للمواقف</td>
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<td>اسم المشاركين:</td>
<td>صناعة القراءة للمواقف</td>
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<td>عدد ملتكا التمويل:</td>
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<td>عدد الأجزاء والأدوات:</td>
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إذا كان طفلك مصاباً بمرض مزمن و تعرض للتنويم مرتين أو أكثر هذه السنة، نود إجراء مقابلة معه لإجراء المزيد عن نجتته الشخصية. تنوي إجراء مقابلة في المستشفى، تستغرق المقابلة حوالي 45 دقيقة. سيتم إجراءها في الوقت المناسب لك، في مستشفى الملك فهد التعليمي.

في حال قررت المشاركة في المقابلة، سيتم تعويضك بقيمة شرائية بقيمة 100 ريال من متجر مميز.

إذا كان لديك طفلك مصاب مزمن و تعرض للتنويم مرتين أو أكثر هذه السنة، وأنت تريده بالمشاركة في الرجاء:

- تزويتنا بمعلوماتك.
- الرجاء الافتيام:
- أرغب/لا أرغب في المشاركة في المقابلة الشخصية

الإيميل:
الجوال:

أو الرجاء التواصل مع ميس يوسف على الإيميل أو الجوال التالي:

L_yousef@student.unsw.edu.au +96650333736

الرجاء إعادة الاستبيان المعبأ إلى الصندوق المنج في محلة الممرضات.

( ملاحظة للباحث: قد يفصل هذه الورقة و الاحتفاظ بها في مكان منفصل عن الاستبيان)
2.1.2 Satisfaction questionnaire English version

Concerns and Needs of Chronically-ill Hospitalized Children and Carers in a Saudi Public Hospital

What is the research study about?
You are invited to take part in this research study. You have been invited because you are a primary carer of a child that is hospitalized in King Fahad hospital. The research study will try to learn about your experience of caring for your children during his/her hospitalization. We are interested in understanding what helps you and your child’s health and wellbeing during this hospitalization and what are the difficulties that you face in caring for your child. We hope to use information we get from this research study to benefit others who get hospitalized in KFHU and help the hospital to improve their services to address your needs and the needs of others in similar situations.

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission, except as required by law. If you give us your permission to use your responses in our research by completing and submitting this document, we plan to discuss publish the results in peer reviewed journals. In any publication, information will be provided in such a way that you cannot be identified.

Ethical approval to conduct this research has been sought from both UNSW and KFHU.

1) General Information:

<table>
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<th>Date the survey was completed:</th>
<th>Child’s Information</th>
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<td>Child’s Age:</td>
<td></td>
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<tr>
<td>Child’s Gender:</td>
<td></td>
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<tr>
<td>Child’s diagnosis:</td>
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<td>Any other medical conditions:</td>
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<tr>
<td>Length of stay in the hospital:</td>
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<td>Number of previous hospitalizations for this child:</td>
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<tr>
<td>Reasons for previous hospitalizations:</td>
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<td>Number of children you have including the child that is hospitalised:</td>
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<th>Carer’s Information</th>
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<td>Relationship to the child:</td>
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<td>Carer’s age:</td>
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<tr>
<td>Carer’s job:</td>
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<tr>
<td>Carer's highest level of education:</td>
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<tr>
<td>Father's age:</td>
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<tr>
<td>Father's job:</td>
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<td>Father's highest level of education:</td>
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2) **Level of Satisfaction with service provided:** (Please rate your level of agreement with the following statements)

<table>
<thead>
<tr>
<th>The doctor introduces him/herself in a clear way (name, speciality)</th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Neither agree or disagree</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctor is capable and skilled in listening to concerns of the child and his/her family</td>
<td>Strongly disagree</td>
<td>Disagree</td>
<td>Neither agree or disagree</td>
<td>Agree</td>
<td>Strongly agree</td>
</tr>
<tr>
<td>The doctors clearly explain the child's medical condition, treatment and treatment plan</td>
<td>Strongly disagree</td>
<td>Disagree</td>
<td>Neither agree or disagree</td>
<td>Agree</td>
<td>Strongly agree</td>
</tr>
<tr>
<td>Doctor(s) capable of using simple language with no complicated medical terms</td>
<td>Strongly disagree</td>
<td>Disagree</td>
<td>Neither agree or disagree</td>
<td>Agree</td>
<td>Strongly agree</td>
</tr>
<tr>
<td>Doctor's gives enough time for explaining and answering questions</td>
<td>Strongly disagree</td>
<td>Disagree</td>
<td>Neither agree or disagree</td>
<td>Agree</td>
<td>Strongly agree</td>
</tr>
<tr>
<td>The doctor treats the patient in a sympathetic and moral manner</td>
<td>Strongly disagree</td>
<td>Disagree</td>
<td>Neither agree or disagree</td>
<td>Agree</td>
<td>Strongly agree</td>
</tr>
<tr>
<td>The doctor encourages the parents in getting involved in making the right decision for the child's medical treatment</td>
<td>Strongly disagree</td>
<td>Disagree</td>
<td>Neither agree or disagree</td>
<td>Agree</td>
<td>Strongly agree</td>
</tr>
<tr>
<td>Non-medicinal advice is offered for example, life style changes</td>
<td>Strongly disagree</td>
<td>Disagree</td>
<td>Neither agree or disagree</td>
<td>Agree</td>
<td>Strongly agree</td>
</tr>
<tr>
<td>The doctor(s) consults and suggests referrals to specialized social and psychological services for the child and family when necessary</td>
<td>Strongly disagree</td>
<td>Disagree</td>
<td>Neither agree or disagree</td>
<td>Agree</td>
<td>Strongly agree</td>
</tr>
<tr>
<td>The medical team is capable of delivering unpleasant</td>
<td>Strongly disagree</td>
<td>Disagree</td>
<td>Neither agree or disagree</td>
<td>Agree</td>
<td>Strongly agree</td>
</tr>
</tbody>
</table>
3) If your child has a chronic disease and has been hospitalized for two or more times this year, we would like to have a face to face interview with you to know more about your experience of being hospitalized. The interview will be about 45 minutes and will take place at KFHJ at a time that is convenient for you. If you decide in participating, you will be reimbursed for participating in the interview with a SR 100 gift voucher from a local kids shop.

If your child has a chronic disease and been hospitalized for two or more times, are you interested in participating?

- Yes/ No.
If yes, please provide your details below.

Email:
Mobile number:
You may also contact the researcher Lamees Yousef to inform her of your interest in participating: L.yousef@student.unsw.edu.au +966503833736

Please return completed surveys to the box provided at the nurse’s station.

(Note to researcher: Detach this sheet and keep separate from questionnaire)
2.2 The sf12 v2 wellbeing questionnaire

2.2.1 Wellbeing questionnaire Arabic version

**حالتك الصحية العامة**

يعتمد هذا الاستبيان على وجهة نظرك في صحتك. هذه المعلومات سوف تساعد على تتبع ما تشعر به و مدى قدرتك على أداء نشاطاتك المعتادة. نشكرك على الإجابة عن هذه الأسئلة!

للأسئلة المذكورة ماهي وضع عامة في المربع الخاص بالإجابة التي تصف بشكل أفضل ما تشعر به.

1. بشكل عام، هل تعتبر أن صحتك:

<table>
<thead>
<tr>
<th>شرطة</th>
<th>حادة تها ب حادة لا يشبرها</th>
<th>ضعيفة</th>
</tr>
</thead>
<tbody>
<tr>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>

1. الدراسات النتائج دور حول النشاطات التي قد تقوم بها أثناء يوم عادي. هل صحتك الآن نحًا من قدرتك على القيام بالنشاطات النشاط؟ إن كانت كذلك، فإن أي هدوء؟

<table>
<thead>
<tr>
<th>لا</th>
<th>نعم</th>
</tr>
</thead>
<tbody>
<tr>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>

1. نشطات المخاطرة مثل تدخين طائرة أو دفع مركبة كهربائية، أو نشاط

ب صعود الدرج لمسة طول

SF-12® Health Survey © 2005, 2009, 2014 Medical Outcomes Trust and OsmarMetric. Incorporated. All rights reserved.
SF-12® is a registered trademark of Medical Outcomes Trust.
(SF-12® Health Survey Standard, Saudi Arabia (Arabic))
3. خلال الأسبوع الأربعة الماضية، كم من الوقت حصلت معي أي من المشكلات التالية خلال تأدية عملك أو نشاطات اليومية العادية الأخرى كنتيجة لصحتك الصحية؟

<table>
<thead>
<tr>
<th>كل الوقت</th>
<th>معظم الوقت</th>
<th>بعض الوقت</th>
<th>كليل من الوقت</th>
</tr>
</thead>
<tbody>
<tr>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
</tr>
</tbody>
</table>

أ. أجريت كل مما كنت تريد

ب. كنت مسؤولاً في نوع العمل أو النشاطات الأخرى

4. خلال الأسبوع الأربعة الماضية، كم من الوقت حصلت معي أي من المشكلات التالية أثناء تأدية عملك أو نشاطات اليومية العادية الأخرى كنتيجة لمشكلات عاطفية (مثل شعور بالكآبة أو الطهور)?

<table>
<thead>
<tr>
<th>كل الوقت</th>
<th>معظم الوقت</th>
<th>بعض الوقت</th>
<th>كليل من الوقت</th>
</tr>
</thead>
<tbody>
<tr>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
</tr>
</tbody>
</table>

أ. أجريت كل مما كنت تريد

ب. أجريت العل أو النشاطات الأخرى

ب. أجريت كل من المحدد

5. خلال الأسبوع الأربعة الماضية، إلى أي مدى تعرضت للإدمام مع عملك العادي (بما في ذلك عملك خارج المنزل والعمل المنزلی)؟

<table>
<thead>
<tr>
<th>أم بتأثرت آنذاك</th>
<th>تأثرت بشكل كبير جداً</th>
<th>تأثرت بشكل كبير</th>
<th>تأثرت بشكل متوسط</th>
<th>تأثرت بشكل حلي</th>
</tr>
</thead>
<tbody>
<tr>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
</tr>
</tbody>
</table>

20 Jan 2014
6. هذه الأسئلة تدور حول ما تشعر به وكيف سارت الأمور مثلك خلال الأسابيع الأربعة الماضية. الرجاء إعطاء إجابة واحدة عن كل سؤال حيث تكون الأقرب لما كنت تشعر به. كم من الوقت خلال الأسابيع الأربعة الماضية:

<table>
<thead>
<tr>
<th>كل الوقت</th>
<th>معظم الوقت</th>
<th>بضع مرات</th>
<th>أحيانًا</th>
<th>نادرًا</th>
</tr>
</thead>
</table>

- ما أحسنت بالهدوء والطاقة؟
- هل كنت لديك طاقة كبيرة؟
- هل أحسنت بالظن والكلام؟

7. خلال الأسابيع الأربعة الماضية، هل من الوقت تعرضت صحتك الجسدية أو مشكلات عاطفية مع نشاطك الاجتماعي (مثل زيارة الأصدقاء والأقارب، إلخ.)؟

<table>
<thead>
<tr>
<th>كل الوقت</th>
<th>معظم الوقت</th>
<th>قبل من الوقت</th>
<th>أحيانًا</th>
</tr>
</thead>
</table>

شكرًا على الإجابة عن هذه الأسئلة!
Your Health and Well-Being

This questionnaire asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities. Thank you for completing this survey!

For each of the following questions, please mark an \( \square \) in the one box that best describes your answer.

1. In general, would you say your health is:

<table>
<thead>
<tr>
<th>Excellent</th>
<th>Very good</th>
<th>Good</th>
<th>Fair</th>
<th>Poor</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ 1</td>
<td>□ 2</td>
<td>□ 3</td>
<td>□ 4</td>
<td>□ 5</td>
</tr>
</tbody>
</table>

2. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

   a. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf ........................................... □ 1 ........ □ 2 ........ □ 3

   b. Climbing several flights of stairs ........................................... □ 1 ........ □ 2 ........ □ 3
3. **During the past 4 weeks**, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

<table>
<thead>
<tr>
<th>All of the time</th>
<th>Most of the time</th>
<th>Some of the time</th>
<th>A little of the time</th>
<th>None of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td><img src="symbol1" alt="Symbol" /></td>
<td><img src="symbol2" alt="Symbol" /></td>
<td><img src="symbol3" alt="Symbol" /></td>
<td><img src="symbol4" alt="Symbol" /></td>
<td><img src="symbol5" alt="Symbol" /></td>
</tr>
</tbody>
</table>

- Accomplished less than you would like ........................................... □ 1 □ 2 □ 3 □ 4 □ 5
- Were limited in the kind of work or other activities ........................................... □ 1 □ 2 □ 3 □ 4 □ 5

4. **During the past 4 weeks**, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

<table>
<thead>
<tr>
<th>All of the time</th>
<th>Most of the time</th>
<th>Some of the time</th>
<th>A little of the time</th>
<th>None of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td><img src="symbol1" alt="Symbol" /></td>
<td><img src="symbol2" alt="Symbol" /></td>
<td><img src="symbol3" alt="Symbol" /></td>
<td><img src="symbol4" alt="Symbol" /></td>
<td><img src="symbol5" alt="Symbol" /></td>
</tr>
</tbody>
</table>

- Accomplished less than you would like ........................................... □ 1 □ 2 □ 3 □ 4 □ 5
- Did work or other activities less carefully than usual ........................................... □ 1 □ 2 □ 3 □ 4 □ 5

5. **During the past 4 weeks**, how much did pain interfere with your normal work (including both work outside the home and housework)?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>A little bit</th>
<th>Moderately</th>
<th>Quite a bit</th>
<th>Extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td><img src="symbol1" alt="Symbol" /></td>
<td><img src="symbol2" alt="Symbol" /></td>
<td><img src="symbol3" alt="Symbol" /></td>
<td><img src="symbol4" alt="Symbol" /></td>
<td><img src="symbol5" alt="Symbol" /></td>
</tr>
<tr>
<td>□ 1 □ 2 □ 3 □ 4 □ 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

---

SF-12™ Health Survey © 1994, 2003 Health Assessment Lab, Medical Outcomes Trust and QualityMetric Incorporated. All rights reserved.
SF-12™ is a registered trademark of Medical Outcomes Trust.
(QOL- SF-12™ Standard, Australia (English))
6. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks...

<table>
<thead>
<tr>
<th>All of the time</th>
<th>Most of the time</th>
<th>Some of the time</th>
<th>A little of the time</th>
<th>None of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td><img src="image1" alt="All of the time icon" /></td>
<td><img src="image2" alt="Most of the time icon" /></td>
<td><img src="image3" alt="Some of the time icon" /></td>
<td><img src="image4" alt="A little of the time icon" /></td>
<td><img src="image5" alt="None of the time icon" /></td>
</tr>
</tbody>
</table>

1. Have you felt calm and peaceful?...........................................[ ] [ ] [ ] [ ] [ ]
2. Did you have a lot of energy? ..........................................[ ] [ ] [ ] [ ] [ ]
3. Have you felt downhearted and depressed?...........................[ ] [ ] [ ] [ ] [ ]

7. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

<table>
<thead>
<tr>
<th>All of the time</th>
<th>Most of the time</th>
<th>Some of the time</th>
<th>A little of the time</th>
<th>None of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td><img src="image1" alt="All of the time icon" /></td>
<td><img src="image2" alt="Most of the time icon" /></td>
<td><img src="image3" alt="Some of the time icon" /></td>
<td><img src="image4" alt="A little of the time icon" /></td>
<td><img src="image5" alt="None of the time icon" /></td>
</tr>
<tr>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
</tbody>
</table>

Thank you for completing these questions!
Appendix 3: The invitation emails

3.1 Invitation email Arabic version

إلى طاقم الرعاية الطبية:

لقد تم إعداد حلقات العمل لاستكمال البحوث المتعلقة بالمراض و مناطق دراسة المقترح في المستشفى فعليهم.

أنت مدعو للمشاركة في هذه البحوث التي ستجري في جامعة نيو ساوث ويلز أستراليا، والتعاون مع مستشفى الملك فهد التعليمي في الجامع.

الهدف من إجراء هذا البحث هو تفعيل واستغلال المعلومة عن استجابة الأطقم النموذجية للمراض مزمنة في مستشفى الملك فهد التعليمي، والعمل على التحول بطرق وآليات تطبيقية للبحث.

المشاركة في هذا البحث ستكون محدودة، بناءً على أن الأشخاص الذين يشاركون في تقديم الرعاية الطبية أو إدارية في المستشفى، سواء في السعودية أو بالخارج، كلهم من المستفيدين من المشاركة في هذا البحث.

إذا كنت بحاجة لملاحظات إضافية أو أردت المشاركة، الرجاء الاتصال بـ ميس يوسف

إليك الملاحظات:

إذا لم تتقدم الرغبة بالمشاركة، فأنت تقوم بتقديم الرغبة بالمشاركة.
إذا لم تتقدم الرغبة بالمشاركة، فأنت تقوم بتقديم الرغبة بالمشاركة.
إذا كانت لديك أي شكوك أو استفسارات عن هذا البحث، ثم برجاء التواصل مع تولى الرعاية الطبية.

للاستفسارات: LHunag@msw.edu.au

أو الاتصال على هاتف دافلا الرقم الثاني 593856222

 духراً لكم

ميس يوسف

طالبة الدكتوراة في جامعة نيو ساوث ويلز أستراليا
3.2 Invitation email English version

Dear healthcare provider,

**Research Project Title:** concerns and needs of chronically-ill hospitalized children and carers in a Saudi public hospital

I am writing to let you know about a research project that you have the option to take part in. The research is being conducted by the University of New South Wales Australia (UNSW) in collaboration with King Fahad Hospital of the University (KFHU). I am contacting you to invite you to participate in this study.

This research is being done to learn more about the needs and concerns for wellbeing of primary carers and chronically-ill children during hospitalization.

The reason we want to know more about the experience of hospitalization for chronically-ill children and carers is to explore the facilitators and barriers to health and wellbeing during hospitalization.

Taking part in research is always optional. We are looking for people who want to take part in this research and who are involved at any point in the delivery of services to hospitalised children at KFHU and who speak either English or Arabic fluently. That could include (but not be limited to):

- Doctors or nurses in the paediatric ward in KFHU
- Laboratory technicians
- Managerial staff

If you decide to take part in the research we would:

- Conduct a 45 minute to an hour face to face interview with you. We will ask you about your perceptions about the care that is provided to hospitalised children and carers.

If you would like more information or are interested in being part of the research please contact:

<table>
<thead>
<tr>
<th>Name</th>
<th>Lamees Yousef</th>
</tr>
</thead>
<tbody>
<tr>
<td>Email</td>
<td><a href="mailto:L.yousef@student.unsw.edu.au">L.yousef@student.unsw.edu.au</a></td>
</tr>
</tbody>
</table>
| Phone      | +61 65031833756  
+61 405155451 |

If we have not heard from you in 2 weeks, you will be sent a reminder. Should you not want the researcher to contact you and/or you are not interested in participating, please email us and let us know that you do not wish to be contacted further about this research study.

Taking part in research is voluntary. You may choose not to take part. If you decide not to take part in this research, your decision will have no effect on your relationship with the University of New South Wales or KFHU and will not have any impact on your employment at KFHU.

This research has been reviewed and approved by The University of New South Wales Human Research Ethics Committee and KFHU. If you have any complaints or concerns about the research project please email humanethics@unsw.edu.au or phone +61 2 9385 3323 quoting the following number HC 138209.

Yours sincerely,

Lamees Yousef  
PhD student
3.3 reminder email Arabic version

إيميل للتذكير

إلى: منظمة الرعاية الطبية.

تحت عنوان: ملاحظات ومعلومات الأطفال الذين يشاركون في هذه الأبحاث.

قد تعني هذه الرسالة شرحًا للجميع الذين يشاركون في هذه الأبحاث. يرجى مراجعة الرسالة المقدمة في ENV النموذج، الذي يشرح طريقة المشاركة في هذه الأبحاث. إذا لم تكن لديك أي نقصات، قد تكون رسالتك متماسكة.

المشاركة في هذا البحث هي تتبعية. تشمل الأشفاش الذين يشاركون في تقديم الرعاية الطبية أو إدارة في المستشفى.

للذين يتعرضون للرعاية الإنجابية تطلاعًا، قد يتضمن ذلك:

- الأماكن والمخصصات في قسم الأطفال في المستشفى.
- أخصائي الرعاية.
- الإداريين.

إذا قررت المشاركة في البحث سوف تنصح بإجراء مقدمة شخصية مع مدة 45 دقيقة في الوقت المناسب. ستقوم بإرسالك عن الرسمية المقدمة للأطفال. معلوماتك وأمانة رقمية ذات دلالة.

إذا كنت بحاجة للمعلومات إضافية أو أرادت المشاركة، الرجاء الإتصال بـ لوكس يوسف.

إذا تم تسجيلتك في مجزأة السيد، ستعيد لك عبر رابط المشاركة في الدراسة، فإن الرسالة أخرى.

المشاركة في هذا البحث تتبعية. يجري التسجيل في المشاركة في مكان محدد، والانضمام إلى المستشفى أو جامعة نيويورك وبيل أستراليا.

إذا كنت تريد أن تكواؤ أو تشارك عن هذا البحث، قد تبقي رسالتك التذكيرية على الرابط نفسه.

humanethics@unsw.edu.au

إذا تم إرسال على هاتفي رقم الثاني

0412442414

معي يوسف

طلبة الدخولقد جامعة نيويورك وبيل أستراليا
3.4 reminder email English version

Dear healthcare provider,

Research Project Title: concerns and needs of chronically-ill hospitalized children and carers in a Saudi public hospital

This is a friendly reminder of the research project that you have the option to take part in. The research is being conducted by the University of New South Wales Australia (UNSW) in collaboration with King Fahad Hospital of the University (KFHU). I am contacting you to because we have not heard back from you regarding this research.

This research is being done to learn more about the needs and concerns for wellbeig of primary carers and chronically-ill children during hospitalization.

The reason we want to know more about the experience of hospitalization for chronically-ill children and carers is to explore the facilitators and barriers to health and wellbeing during hospitalization.

Taking part in research is always optional. We are looking for people who want to take part in this research and who are involved at any point in the delivery of services to hospitalized children at KFHU and who speak either English or Arabic fluently. That could include (but not be limited to):

- Doctors or nurses in the paediatric ward in KFHU
- Laboratory technicians
- Managerial staff

If you decide to take part in the research we would:

- Conduct a 45 minute to 1-hour face to face interview with you. We will ask you about your perceptions about the care that is provided to hospitalized children and carers.

If you would like more information or are interested in being part of the research please contact:

<table>
<thead>
<tr>
<th>Name</th>
<th>Lanes Yousef</th>
</tr>
</thead>
<tbody>
<tr>
<td>Email</td>
<td><a href="mailto:L.yousef@student.unsw.edu.au">L.yousef@student.unsw.edu.au</a></td>
</tr>
</tbody>
</table>
| Phone   | +966503831736  
|         | +61465254351 |

If we have not heard from you in 2 weeks, we will assume that you are not interested in participating and you will not be contacted further about this research study.

Taking part in research is voluntary. You may choose not to take part. If you decide not to take part in this research, your decision will have no effect on your relationship with The University of New South Wales or KFHU and will not have any impact on your employment at KFHU.

This research has been reviewed and approved by The University of New South Wales Human Research Ethics Committee and KFHU. If you have any complaints or concerns about the research project please email humanethics@unsw.edu.au or phone +61 2 9385 6222 quoting the following number HC 15830.

Yours sincerely,

Lanes Yousef
PhD Student
Appendix 4: consents

4.1 Implied consent for survey

4.1.1 Implied consent Arabic version

<table>
<thead>
<tr>
<th>Arabic Implied Consent - PARTICIPANT INFORMATION STATEMENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>معلومات مفصلة عن الدراسة للمشاركين في الدراسة وشروط المشاركة.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Name of individual:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lamees Yousef</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>University</th>
<th>Role</th>
</tr>
</thead>
<tbody>
<tr>
<td>UNSW</td>
<td>Principal Investigator (PI)</td>
</tr>
<tr>
<td>KFHU</td>
<td>Co-Investigator (Co-I)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Consent</th>
<th>Arabic Version</th>
</tr>
</thead>
<tbody>
<tr>
<td>implied</td>
<td>موافقتهما على المشاركة في الدراسة</td>
</tr>
</tbody>
</table>

What is this study about?

This study is about understanding the experiences of patients receiving cancer treatment. The purpose of this study is to help improve the quality of care for these patients.

What is the purpose of this study?

The purpose of this study is to understand the experiences of patients receiving cancer treatment. The study aims to identify areas for improvement in the care provided to these patients.

Is participation in this study voluntary?

Yes, participation in this study is voluntary. Participants can withdraw from the study at any time without prejudice.

Confidentiality:

Confidentiality will be maintained throughout the study. Personal information will be stored securely and only accessible to authorized personnel.

Appendix 21

UNSW Australia
لا يเกوا مشاركين

ما الذي يعني علي طلبك إذا كنت المشارك؟

إذا كررت المشاركة في البحث، سيطلب منك اسمك الكامل، اسمك الكامل، آلة الحاسوب، إيماءة عن سبب تأمين طفلك في المنزل، إذا كررت المشاركة في البحث، إيرادات الأقمار، مرة أخرى، إيرادات الأقمار، مرة أخرى، إيرادات الأقمار، مرة أخرى.

إن رحّلنا بدلاً من الاستفسار على مدى 15 دقيقة.

في نهاية الاستفسار، سيكون هناك سؤال لمراجعة الراهنين في إجراء مناهضة شخصية لمدة 15 دقيقة تثبت أن يكون الطفل قد تكون مرتين أو أكثر هذه السنة والتي يتولى البلدية ببطاقة إيطالية السفينة، على التواصل مع الطلبة الأفقي أو إلغار معلوماتك للتنقلات المحمولة.

سيطلب الاستفسار من الأكاديمين الذين كادوا أن يقدموا أموالهم في السندور المتحرر في مكتب الممارسات.

هل سيفع في بعض مشاركين في البحث؟

بعد إكمال الاستفسار، إذا قمت بالمشاركة في القنابل، سيتم توضيحك عن وقتك بقيمة تراتبة يبلغ 30% من مبلغ مدركاً.

ما هو قواعد المشاركين؟

نأمل أن يكون هذا البحث هو تحصيل على معلومات تساعد الناس الذين يمتلكون في قسم الأطفال في المستقبل وكساعد المستقبلي في خمس خرائطها العامة أو الأخرين في وضع مشابه.

ما الذي سيحدث مع معلوماتي:

بجلبة الاستفسار، أنا توليد على استبدال رفق البحث المعلومات المجلة فيه، منحك هنا للإجابة أو المعلومات، في أي من المعلومات أو الدراسات، محترم، على استخدام المعلومات فيه الاستخدام فيبني ودليل الأمل عارض.

إذا ردت على المشاركة في هذا البحث، سيتم تذكر البيانات وتشمل رفع نسخة مع أن تكلم أن نقل إلى جزء أو إذا استناداً الطفول، بدلاً من نسيج المعلومات الشخصية على الاسم، إذا تم توثيقها.

كيف و مدى سطوع عن نتائج البحث؟

إذا أردت معلومات عن نتائج الدراسة، يمكنك التواصل مع السيد ليون الثالث، يوم في أي وقت على البريد الإلكتروني:

L_yousef@unsw.edu.au

و سوف توفر لك ملخص للنتائج الدراسة عند إتمامها.

ما إذا لم نرد الاستفسار عن الدراسة؟

تسجل الاستفسار على معلومات المشاركة في الدراسة، بإمكانك الاستفسار عن الدراسة في حال توفر رابط بحثي.

للمزيد بحث في

240
ماذا لو كنت لدي استفسارات أو طلب إيضاح لأي موضوع بإمكانك التواصل مع الشخص التالي:

<table>
<thead>
<tr>
<th>الاسم</th>
<th>عبير يوسف</th>
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<tbody>
<tr>
<td>المنصب</td>
<td>طالبة دكتوراه</td>
</tr>
<tr>
<td>الرقم</td>
<td>+966503833736</td>
</tr>
<tr>
<td>بريد إلكتروني</td>
<td><a href="mailto:L.yousef@uasw.edu.au">L.yousef@uasw.edu.au</a></td>
</tr>
</tbody>
</table>

ماذا لو كان لدي شكوى؟
إذا كانت لديك أي شكاوى بإمكانك التواصل مع لجنة الأخلاق:

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<thead>
<tr>
<th>المنصب</th>
<th>منصب لجنة الأخلاق</th>
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<tbody>
<tr>
<td>الرقم</td>
<td>+61 2 9385 6222</td>
</tr>
<tr>
<td>بريد إلكتروني</td>
<td><a href="mailto:humanethics@uasw.edu.au">humanethics@uasw.edu.au</a></td>
</tr>
<tr>
<td>الرقم المرجعي</td>
<td>HC 15830</td>
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</tbody>
</table>
4.1.2 Implied consent English version

The research study is being carried out by the following researchers:

<table>
<thead>
<tr>
<th>Role</th>
<th>Name</th>
<th>Organisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chief Investigator</td>
<td>Dr. Husna Razei</td>
<td>UNSW</td>
</tr>
<tr>
<td>Co-Investigator/s</td>
<td>Dr. Joel Rias</td>
<td>UNSW</td>
</tr>
<tr>
<td></td>
<td>Dr. Waleed Al-Baker</td>
<td>KFHU</td>
</tr>
<tr>
<td>Student Investigator/s</td>
<td>Lamessa Youssef is conducting this study as the basis for the degree of Doctorate of Philosophy at The University of New South Wales. This will take place under the supervision of Dr. Husna Razei, Dr. Joel Rias, Dr. Waleed Al-Baker.</td>
<td>UNSW</td>
</tr>
<tr>
<td>Research Funder</td>
<td>This research is being funded by the student</td>
<td></td>
</tr>
</tbody>
</table>

What is the research study about?
You are invited to take part in this research study about the concerns and needs of chronically-ill hospitalized children and carers.

To participate in this research study you need to meet the following inclusion criteria:
• You are the primary carer of a child that is hospitalized at KFHU
• You can read and write Arabic fluently
The research study aims to understand what being hospitalized was like for you, your child and your family.

Do I have to take part in this research study?
Participation in this research is voluntary. If you don’t wish to take part, you don’t have to. Your decision will not affect your relationship with The University of New South Wales or King Fahad Hospital of the University.

This Participant Information Statement tells you about the research study. It explains the research tasks involved. Knowing what is involved will help you decide if you want to take part in the research.

Please read this information carefully. Before deciding whether or not to take part, you might want to talk about it with a relative or friend.

What does participation in this research require, and are there any risks involved?
If you decide to take part in the research study, you will be asked to complete a written survey, which will ask you questions about the reasons for your child’s hospitalization, how frequently your child is hospitalized, age of child, the average length of stay, and the levels of your satisfaction. We expect this activity to take up to 15 minutes of your time.
At the end of the survey, there will be a question for primary carers who have had their chronically-ill child hospitalized two or more times this year and who speak Arabic fluently and would like to participate in a 45 minute interview to contact the student researcher or provide their contact information to be contacted.

The survey will ask participants who completed the survey to return their answers to the box provided for them at the nurses’ station.

Will I be paid to participate in this project?
After completing the survey, if you decide to participate in the interview you will be reimbursed for your time with a $30 gift voucher from a local Saudi shop.
What are the possible benefits to participation?
We hope to use information we get from this research study to benefit others who get hospitalized in KFHU and help the hospital to improve their services to address your needs and the needs of others in similar situations.

What will happen to information about me?
By completing the handed survey, you consent to the research team collecting and using information from the survey to complete the research study. We will keep your data for 7 years.

It is anticipated that the results of this research study will be published and/or presented in a variety of forums. In any publication or presentation, information will be published, in a way such that you will not be individually identifiable.

Any information obtained in connection with this research study that can identify you will remain confidential. If you agree to participate in this study, the responses you provide to the survey will be stored in a locked desk and will only be available for the research team or if required by law. No personal information will be collected in the questionnaire so none will be stored as data.

How and when will I find out what the results of the research study are?
If you have a right to receive feedback about the overall results of this study. After your participation, if you would like to have feedback, you may contact Lameen Yousef via email l.yousef@muw.edu.ae. This feedback will be in the form of a one-page lay summary and will be provided after the study is finished.

What if I want to withdraw from the research study?
Submitting your completed survey is an indication of your consent to participate in the study. You can withdraw your responses if you change your mind about having them included in the study, up to the point that we have analyzed and published the results. You can do this by contacting the student researcher Lameen Yousef via email l.yousef@muw.edu.ae and letting her know that you wish to withdraw.

What should I do if I have further questions about my involvement in the research study?
The person you may need to contact will depend on the nature of your query. If you have any problems which may be related to your involvement in the project, you can contact the following member(s) of the research team:

Research Team Contact
Name: Lameen Yousef
Position: PhD Student
Telephone: +966503335336
Email: l.yousef@muw.edu.ae

What if I have a complaint or any concerns about the research study?
If you have any complaints about any aspect of the project, the way it is being conducted, then you may contact:

Complaints Contact
Position: Human Research Ethics Coordinator
Telephone: 61 2 0585 6722

Consent Form – Participant providing own consent

Declaration by the participant
☐ I have read the Participant Information Sheet.
☐ I understand the purposes, study tasks and risks of the research described in the project.
☐ I have had an opportunity to ask questions and I am satisfied with the answers I have received.
☐ I freely agree to participate in this research study as described and understand that I am free to withdraw at any time during the project and withdrawal will not affect my relationship with any of the named organizations and/or research team members.
4.2 consent for photographs

**Concerns and Needs of Chronically-ill Hospitalized Children and Carers in a Saudi Public Hospital**

**CONSENT FORM for PHOTOGRAPHS**

**Background and purpose of study**

The research study will try to address the experience of the primary carers supporting chronically-ill children during their hospitalization. The study aims at Understanding the needs and concerns for wellbeing of primary carers and chronically-ill children during the child’s hospital stay.

You are invited to take part in this research study. You have been invited because you are a primary carer of a chronically-ill child that is hospitalized in King Fahad hospital and have indicated that you are interested in volunteering to participate.

**Subject selection**

If you decide to participate, we will ask if we can photograph you, your child or the space in which your child stays or uses while in the hospital. These photos will help us to supplement the information we collect during the in-depth interviews. We will take the photos in such a way that you won’t be identified and your face will be blurred before we use it. Photos will be taken on a digital camera. Once we take a photo we will also show it to you so that you can decide whether you are okay for us to use this or you wish for the photo to be deleted.

**Confidentiality and disclosure of information**

We acknowledge other people may recognize the buildings and environment in the photographs if it is published. However, we will present the photographs in such a way that you will not be identified. If there is even a remote possibility that you may be identified, then we will not use that photo.

**Benefits of participation**

There will be no immediate or direct benefit to you for participation.

**Questions and Complaints**

If you have any questions about your participation or the research now I will answer them, and if you have questions later you can contact Lomas Yousef 0503835736 or L.yousef@student.unsw.edu.au

**Your consent**

Your decision whether or not to participate will not harm your future relations with KFHU or UNSW. If you decide to participate, you are free to withdraw your consent and to discontinue participation at any time without any problems for you.

You will be given a copy of this form to keep.
Concerns and Needs of Chronically Ill Hospitalized Children and Carers in a Saudi Public Hospital
CONSENT FORM FOR PHOTOGRAPHY

You are making a decision whether or not you permit us to photograph you/your child/hospital room. Your signature indicates that having read the information provided above, you have decided to participate.

Agree to photographs of you/your child/hospital room

Signature of subject __________________ Signature of Witness __________________

Please PRINT subject name __________________ Please PRINT witness name __________________

Date __________________ Nature of Witness __________________

REVOCATION OF CONSENT

I hereby wish to WITHDRAW my consent to participate in the research proposal described above and understand that such withdrawal WILL NOT jeopardise any treatment or my relationship with UNSW or KFH

Signature of subject __________________ Date __________________

Please PRINT subject name __________________
4.3 King Fahad Hospital Informed consent for Primary carers

INFORMED CONSENT STATEMENT

For children/minors participating in this study, the term "You" addresses both the participant and the parents or legally authorized representative to consent.

PROJECT TITLE: Convergences and needs of chronically-ill hospitalized children and carers in a Saudi public hospital

Names of the Investigator: Lamsee Yousuf, Dr. Waleed Albakor

In collaboration with: Dr. Huma Razac, Dr. Joel Rhee

Affiliation: University of New South Wales Australia

1. You are being asked to participate in our study of convergences and needs of chronically-ill hospitalized children and carers in a Saudi public hospital for the period/duration of 45 minute interview. You were selected to participate in this study because you are the primary carer of a chronically-ill child currently hospitalized in KFHU, you speak Arabic fluently and your child has been hospitalized two or more times this year.

We are investigating this topic to learn about your experience when your child got hospitalized at KFHU. Your participation in this research study is voluntary. Before agreeing to be a part of this study please, read and or listen to the following information carefully.

Feel free to ask questions if you don’t understand anything.

2. To make sure we will not miss out anything you say and to accurately reflect what you share with us, we would like to have the interview audio recorded. This recording will be destroyed once we have written down the information in writing down the information we will remove all identifying information. If you feel uncomfortable with the audio recording I will just listen to you and take notes. No recording will be done.

3. Any and all information obtained from the interview will be confidential. Your privacy will be protected at all times. You will not be identified individually in any way as a result of your participation in this research. The data collected however, may be used as
part of publications and papers. In any publication and/or presentation, information will be provided in such a way that you cannot be individually identified in these publications.

4. “In case of any unexpected injury or illness during this study, the compensation or the necessary medical treatment will be given as per the rules and regulations of the hospital.”

Your participation in this study is entirely voluntary.

You have rights to discontinue or refuse to participate even after initiation of study at any time for any reason. Sack refusal will not have any negative consequences for you. If you do withdraw, you will be asked to complete and sign the ‘Withdrawal of Consent Form’. Alternatively, you can ring the research team and tell them you no longer want to participate.

5. Please feel free to talk to the researcher and ask questions. You may also want to talk to your family, friends, or your personal doctor or other health care provider about joining this study. If you decide that you would like to participate in the study, you will be asked to sign this form and you will be given a copy of the signed form to keep.

6. After your participation, in case you have any questions and/or concerns about research, want feedback, want clarification or report any matter related to your participation in the research you may contact Lamass Yousef any time on the number 0408337536 or via email L.yousef@unsw.edu.au

7. In addition, if any new information is learnt, at any time during the research, which might affect your participation in the study, you shall be informed.

8. Principal Investigator of the study will also sign the copy of Informed consent and the signed copy of the Informed Consent will be handed over to the Study Participant. Also, Signed copy of informed consent has to be kept in the PI file, SCR ELC file and patient’s medical record file. There will not be any personal information that you shared with us during the study linked to these informed consent forms kept on file.
I have read or listened to the above information and I have decided that I will participate in the project as described above. The researcher has explained me about the study, other beneficial treatments or procedures available and also clarified my doubts. I also understand what will be expected of me. I now understand that the purpose of the study is to further help the understanding of needs and concerns for the wellbeing of primary carers and children during the child's hospital stay. If I do not participate, there will be no penalty or loss of rights. I can stop participating at any time, even after I have started.

I agree to participate in the study on Concerns and Needs of frequently hospitalized children and carers in a Saudi public hospital.

My signature below also indicates that I have received a copy of this English consent form together with an official translation of this document in Arabic.

Participant's name

Participant's signature

Date

Principal Investigator name

Principal Investigator signature

Date
Form for Withdrawal of Participation

I wish to WITHDRAW my consent to participate in the research proposal described above and understand that such withdrawal WILL NOT affect my relationship with The University of New South Wales, or King Fahad Hospital of the University.

<table>
<thead>
<tr>
<th>Participant Signature</th>
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<tbody>
<tr>
<td>Name of Participant</td>
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<tr>
<td>(please print)</td>
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<tr>
<td>Signature of Research Participant</td>
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<td>Date</td>
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</table>

Form for Withdrawal of Participation

أود الانسحاب من المشاركة في هذه الدراسة وأفهم أن الانسحاب لا يؤثر على عاطفي بجامعة نيو ساوث ويلز أو مستشفى الملك فهد التعليمي.

<table>
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<tr>
<th>اسم المشارك</th>
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<tr>
<td>توقيع المشارك</td>
</tr>
</tbody>
</table>

التاريخ
INFORMED CONSENT STATEMENT

For children/minors participating in this study, the term “You” addresses both the participant and the parents or legally authorized representative to consent.

PROJECT TITLE: Concerns and needs of chronically-ill hospitalized children and carers in a Saudi public hospital
Name of the Investigator: Lamsaa Yousal, Dr. Waleed Al Baker
In collaboration with: Dr. Hanaa Rasee, Dr. Joel Blee (Affiliation - University of New South Wales Australia)

1. You are being asked to participate in our study of Concerns and needs of chronically-ill hospitalized children and carers in a Saudi public hospital for the period/duration of 45 minute interview. You were selected to participate in this study because you are healthcare provider at KFHU and you speak Arabic or English fluently.

We are investigating this topic to learn about the experience of chronically-ill children that get hospitalized at KFHU who are accompanied by their primary carers. Your participation in this research study is voluntary. Before agreeing to be a part of this study please, read and/or listen to the following information carefully.

Feel free to ask questions if you don’t understand anything.

2. To make sure we will not misquote anything you say and to accurately reflect what you share with us, we would like to have the interview audio recorded. This recording will be destroyed once we have written down the information. In writing down the information we will remove all identifying information. If you feel uncomfortable with the audio recording, I will just listen to you and take notes. No recording will be done.

3. Any and all information obtained from the interview will be confidential. Your privacy will be protected at all times. You will not be identified individually in any way as a result of your participation in this research. The data collected however, may be used as part of publications and papers. In any publication

4. If you are interested, you may be involved in a follow-up study after this research. More information about this follow-up study will be provided to you at the time of the interview.

5. If you have any questions or concerns about this research, please contact me at the email address provided in the consent form.

6. You have the right to withdraw from this research at any time without giving a reason and without any penalty.

7. If you have any concerns about the research, you can contact the institutional review board (IRB) at the University of New South Wales Australia.

8. If you have any questions about your rights as a participant in this research, you can contact the IRB at the University of New South Wales Australia.

9. If you have any concerns about the research, you can contact the institutional review board (IRB) at the University of New South Wales Australia.
and/or presentation, information will be provided in such a way that you cannot be individually identified in those publications.

4. "In case of any unexpected injury or illness during this study, the compensation or the necessary medical treatment will be given as per the rules and regulations of the hospital"

Your participation in this study is entirely voluntary. You have rights to discontinue or refuse to participate even after initiation of study at any time for any reason. Such refusal will not have any negative consequences for you. If you do withdraw, you will be asked to complete and sign the 'Withdrawal of Consent Form'. Alternatively you can ring the research team and tell them you no longer want to participate.

5. Please feel free to talk to the researcher and ask questions. You may also want to talk to your family, friends, or your personal doctor or other health care provider about joining this study. If you decide that you would like to participate in the study, you will be asked to sign this form and you will be given a copy of the signed form to keep.

6. After your participation, in case you have any questions and/or concerns about research, want feedback, want clarification or report any matter related to your participation in the research you may contact Lamees Yousef any time on the number 0501383736 or via email L.yousef@unsw.edu.au

7. In addition, if any new information is learnt, at any time during the research, which might affect your participation in the study, you shall be informed.

8. Principal Investigator of the study will also sign the copy of informed consent and the signed copy of the informed consent will be handed over to the Study Participant. Also, Signed copy of informed consent has to be kept in the PI file, SCRELIC file, and patient's medical record file. There will not be any personal information that you shared with us during the study linked to these informed consent forms kept on file.
I have read or listened to the above information and I have decided that I will participate in the project as described above. The researcher has explained me about the study, other beneficial treatments or procedures available and also clarified my doubts. I also understand what will be expected of me. I now understand that the purpose of the study is to further help the understanding of needs and concerns for wellbeing of primary carers and children during the child’s hospital stay. If I do not participate, there will be no penalty or loss of rights. I can stop participating at any time, even after I have started.

I agree to participate in the study on Concerns and Needs of frequently hospitalized children and carers in a Saudi public hospital.

My signature below also indicates that I have received a copy of this English consent form together with an official translation of this document in Arabic.

Participant’s name

Participant’s signature

Date

Principal Investigator signature

Date
Form for Withdrawal of Participation

I wish to **WITHDRAW** my consent to participate in the research proposal described above and understand that such withdrawal **WILL NOT** affect my relationship with The University of New South Wales, or King Fahad Hospital of the University.

**Participant Signature**

<table>
<thead>
<tr>
<th>Name of Participant (please print)</th>
<th></th>
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</thead>
<tbody>
<tr>
<td>Signature of Research Participant</td>
<td></td>
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<td>Date</td>
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</tbody>
</table>

أو، الاختيار من المشاركة في هذه الدراسة وأفهم أن الانسحاب لا يؤثر على علاقتي بجامعة نيو ساوث ويلز استراليا ولا بالتأكيد في الدفع التعويدي.

<table>
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<tr>
<th>اسم المشارك</th>
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<tr>
<td>التاريخ</td>
<td></td>
</tr>
</tbody>
</table>
Appendix 5: Interview guides

5.1 Interview guides for primary carers

5.1.1 Interview guides for primary carers Arabic version
ما الذي أمرني في الخدمة المقدمة من المستشفى؟
ما الذي أمرني في الخدمة المقدمة من المستشفى؟
كيف أثر على صحتك؟

 أهميتي عن موقف عمل خلال فترة التدريب، لم تكن:
كيف كانت مشاعرك في ذلك الوقت؟
ما الذي جعلك هذا الوقت لا ينسي؟
كيف كنت على سلامتك؟

أدرك أن تفكري بفترة التدريب هذه أو السابقة و تفكري ببوم شعرت فيه ذلك لست على ما يرام، ما الذي ساعد بإحساسي بك؟
كيف أسهمت المستشفى في إحساسي بهذا؟
كيف أسهمت خدمات المستشفى في هذا الإحساس؟
كيف ساهم أفراح سرتك في هذا الإحساس؟
ماذا فعلت تشجعي بحسن؟
ما الذي كان يمكن أن يساعدك تشجعي بحسن؟

للياقة والصحة: أسأل عن:
كيف أسهمت المستشفى في إحساسي بهذا؟
كيف أسهمت خدمات المستشفى في هذا الإحساس؟
كيف ساهم أفراح سرتك في هذا الإحساس؟
ما الذي قمت بفعله و ساهم لإحساسي بهذا؟

كيف كلنت من موارنة فترة التدريب مع احتياجات سرتك؟ أسأل عن:
كيف قمت إعداد الأسرة، مساعدتك، و ماذا استخدمت مختلفاً؟
ماذا ساعدك على التقلص؟
ماذا تناولتي بالإضافة إلى ذلك للتكفل بصحتي؟

صنفت نظاكاتك مع الطبق المفضل: أسأل عن:
من يكون الطعام الغني:
الوجبات والتغذية اليومية، كيف تهمست؟
المخلوطات التي شاركتها معك?
أي مساعد قدمها لك؟
ما أشي الجيد؟
ما سيлистوبات في المخاطر على علاقة جيدة مهما؟
kيف كان لهمسك على علاقة بالفرق الذي؟

(10) صغي لي كيف أصبحت صحك منذ تقشير فلكي بالمرض، ص، و تحويل. أسأل عن:
ما الذي سيعالج على دوام صحك الجيد؟
ما السحورات في الهدايا على صحك؟

(11) ما رأيك في بيئة المستشفى؟ أسأل عن:
ما شئ الجيد فيها؟
ما شئ الفجر جد فيها؟
كيف أثرت بيئة المستشفى على صحك؟

(12) صغي لي الخدمات المنتجة للح ولطفلك. أسأل عن:
ترتيبات اليوم للأطفال؟
دورات مياء عامة أو خاصة?
حجم المطبخة
المهارات أو الاختلافات المنجزة لكلا؟
هل تحملها أر؟ وكيف تذكر على كلا؟

تعتبر قبلان: شكر الله لإنستبة الوقت لكانك معي اليوم. شكرًا بالشكر من... (الحسي بالحسين بأسم الأفكار). هل هذه
شيء آخر تودون إضافته؟

مرة أخرى، أن أؤخذ الله بسرعة كل ماحدث فهذه اليوم. هذه المعلومات سوف تتوفر فقط للفرق البحث أو إذا أُقتِبَ القانون
ذلك وأنني سأرسل أي معلومة قد تساعد على التعرف عليك.

(دم)
5.1.2 Interview guides for primary carers English version

Introduction about the study: Thank you for your interest in participating in this research study. My name is Lamaee Yousef. As you know, this study is looking at the experience of primary carers supporting chronically-ill children during their hospital stay. I’m looking at this issue to understand what being hospitalized was like for you, your child and your family.

This interview will approximately take 45 minutes. I will be using an audio recorder so that I don’t miss out on any of your comments and to accurately transcribe your responses from Arabic to English. Once the interview has been transcribed, the recording will be destroyed. However, if you feel uncomfortable and prefer that the recorder is not used, please let me know. Is it okay with you if I record this interview?

[If the interviewer agrees for the recording to be used, switch on the recorder]

Thank you for agreeing to record this interview.

I will also take notes to help me remember all of our discussion today. All of the information you share with us today will be kept confidential and will only be available for the research team if required by law and any information that can identify you will be removed. Do you have any questions before we begin?

1) Tell me about your family. Probe for:
   a. Who are the family members
   b. Number of children

2) What was your experience with your child being sick? Probe for:
   a. How did that make you feel?
   b. How did that affect your own health

3) Describe to me how was the experience of your child’s first hospitalization. Probe for:
   a. Child’s medical condition
   b. Carer’s basic roles
   c. How were you feeling at that time?
   d. What was distressing and why?
   e. What was satisfying about the services provided by the hospital
   f. What do you wish was different?
   g. How did it affect your own health?
4) Describe to me how the experience of your child’s 2nd hospitalization. Probe for:
   a. Child’s medical condition
   b. Carer’s basic role
   c. How were you feeling at that time?
   d. What was distressing and why?
   e. What was satisfying?
   f. What do you wish was different?
   g. How did it affect your own health?

5) Tell me about an incident that happened while hospitalized that you won’t forget. Probe for:
   a. How did that make you feel?
   b. What made this incident unforgettable?
   c. How did this impact on your own health?

6) I would like you to think of this current hospitalisation or the last one and think of a day where you felt particularly unwell. What contributed to your feeling unwell that day? Probe for:
   a. How did the hospital staff contribute to your being unwell?
   b. How did the services provided by the hospital contribute to you being unwell?
   c. How did your family members contribute to you being unwell?
   d. What did you do to help you feel better?
   e. What could have helped you feel better?

7) I would like you to think of this current hospitalisation or the last one and think of a day when you felt healthy and happy. What contributed to your health and wellbeing that day? Probe for:
   a. How did the hospital staff contribute to your feeling healthy and happy?
   b. How did the services provided by the hospital contribute to your feeling healthy and happy?
   c. How did your family members contribute to your feeling healthy and happy?
   d. What did you do that may have contributed to your wellbeing?
8) How did you cope with being hospitalized with your child and attending to your family’s needs? Probe for:
   a. How did your family or friends support you?
   b. What helped you cope?
   c. What else would you require to ensure that your own health is maintained?

9) Describe to me your relationship with the healthcare team. Probe for:
   a. Who made up the health care team?
   b. Daily communications – how did this occur?
   c. Information they might have shared
   d. Any support they might have received
   e. What was good?
   f. What were the difficulties in maintaining a good relationship?
   g. What would have helped in maintaining a good relationship?
   h. How did you feel about these relationships?

10) Describe to me how your own health has been since your child was diagnosed with X and the resulting hospitalizations? Probe for:
   a. What has helped you to continue having good health?
   b. What were the difficulties in maintaining your own health?

11) How have you found the hospital environment? Probe for:
   a. What has been good about it?
   b. What is not good about it?
   c. How has the hospital environment affected your own health?

12) Describe to me the amenities available to you and your child in the hospital. Probe for:
   a. Sleeping arrangements for carer
   b. Personal or public toilet?
   c. The size of the space
   d. Activities or entertainment available for the child
   e. Do you like it, dislike it? How does that affect both of you?
Conclude by saying the following: thank you for taking the time to talk with me today. We have covered... (Provide a summary of main ideas). Is there anything else you would like to add?

Once again I would like to assure you that anything you shared with us today will be kept confidential and will only be available for the research team or if required by law and any information that can identify you will be removed.

Thank you
5.2 Interview guides for Health care providers

5.2.1 Interview guides for Health care providers Arabic version

مقدمة

 GetComponent identidad de la participación en este estudio. Se ha diseñado este estudio para documentar el programa y sus métodos. Se ha diseñado este estudio para documentar el programa y sus métodos. Se ha diseñado este estudio para documentar el programa y sus métodos. Se ha diseñado este estudio para documentar el programa y sus métodos.

"استثناء الغلافية حاليًا." 1)

لا تستخدم سؤال للسوغتة حتى لا تكوني أي من تحيطك. لا تكن أي من نزعة

شكراً على تجهيز الغلافية.

سؤال بكتابة بعض نقاط لتساعدك على تذكر محتلكاً اليوم جمع المعلومات التي تشاركك بها اليوم ستكون سوية، غير متاحة.

البحث إذا أبداً، أو إذا أبداً القانون وسرية أي من المعلومات التي تعدل على عدوك. هل لديك أي أسئلة قبل أن أبدأ؟

1) صفلي معلومات في تقديم الرعاية الدينية.

2) ما هي معلومات بمegree وعلاقته؟ أسئلة عن:

• الجوار والترابال (كاب، باب)
• نوعية المعلومات التي تشاركك بها القرارات الأساسية
• الاتصال المستدام
• مقدار الوقت الذي تعلته مع المريض/أهله

استقرار الرعاية. هن برهم بعد ذلك؟ مثلاً في العادة؟

3) كيف نرى دور المراقبة الأساسية في المشاركة في الرعاية الدينية الفئات الدموية؟ أسئلة عن:

• هذا ينطبق؟
• ما المطالب منهم قطع؟
• إذا لم يقلق الأشخاص المطالب منهم قطع؟
• ما الأمراض الجماعية في م Saddam رعاية طفلاً؟

ما الأمراض المحددة في مسامع رعاية الطفل؟

ما الذي قد يساعد المراقبة الأساسية في المشاركة في الرعاية الدينية الفئات؟

ما هي المهام المطلوبة للمرأة المراقبة الأساسية في رعاية الطفل الطبي؟

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في رأيك الشخصي، كيف تؤثر رعاية الطفل الموم في المستشفى على صحة المراقب الأصغر؟ أسل عن:

• ما الذي قد يساعد المراقب الأصغر في الحفاظ على صحته الجيدة؟
• ما هو السبب الذي أدى إلى نقص المراقبة الأصغر؟
• كيف يمكن أن يساعد الموم في الحفاظ على صحته وسلامته؟
• كيف يفيد تحميل الموم في المراقبة الأصغر في الحفاظ على صحته بشكل جيد؟
• كيف يمكن للذين المسؤولين في إدارة تقيم الطفل في المستشفى أن يساعدوا في الحفاظ على صحته بشكل جيد؟
• كيف يمكن للذين المسؤولين في إدارة تقيم الطفل في المستشفى أن يساعدوا في حفاظ الطفل الموم على صحته بشكل جيد؟ أسل عن:

• من هي تلك الأفراد المشتبه في رعاية الطفل؟
• ماذا فعل حماية الأولاد في تلك الأفراد المشتبه في رعاية الطفل؟

محمود. شكرا كك لإعادة فتح دوائي وأنت معي اليوم. قد بلغنا الحدود من حموم رحم الصغير. إن هناك...

شيء آخر تودين إضافته؟

مرة أخرى أود أن أشكرك لك سرية كل ما تحدثت عنه اليوم. هذه المعلومات سوف تتغير فقط بطرق البحث أو إذا استدعي القانون.

شكرا.
5.2.2 Interview guides for Health care providers English version

Introduction about the study: Thank you for your interest in participating in this research study. As you know, this study is looking at the experience of primary carers supporting chronically-ill children during their hospital stay. I’m looking at this issue to understand what contributes to the wellbeing of the hospitalized children and their carers. Your views as a healthcare provider will help me understand that much better.

This interview will approximately take 45 minutes. I will be using an audio recorder so that I don’t miss out on any of your comments. Once the interview has been transcribed, the recording will be destroyed. However, if you feel uncomfortable and prefer that the recorder is not used, please let me know and I will not record this interview. Is it okay with you if I record this interview?

[If the interviewer agrees for the recording to be used, switch on the recorder]

Thank you for agreeing to record this interview.

I will also take notes to help me remember all of our discussion today. All of the information you share today will be kept confidential and will only be available for the research team or if required by law and any information that can identify you will be removed. Do you have any questions before we begin?

1) Describe to me your roles as a healthcare provider.

2) What is your relationship with the carers and family members of patients? Probe for:
   a. Communication – what strategies and means are used
   b. Kind of information shared with the primary carers
   c. Support
   d. Amount of time spent with patient/family
   e. Continuity of care- do they see them or follow up after admission (e.g. in clinic)
3) How do you see the role of the primary carers in participating in the care of the hospitalized child? Probe for:
   a. What do they actually do?
   b. What is ideally required of them?
   c. What if they don’t do the things that are required of them?
   d. What is good about their participation?
   e. What is not so good about their participation?
   f. What would help primary carers to be more involved in the care of their hospitalized child?
   g. What are the barriers to primary carers’ involvement in caring for their hospitalised child?

4) In your opinion, how does taking care of a hospitalized child impact on the carer’s health?
   Probe for:
   a. What would help carer’s maintain good health?
   b. What are the barriers to carer’s maintaining good health?
   c. How can health care providers enable carer’s to maintain good health?
   d. What do you see as your role in the wellbeing of the carer?
   e. How can others involved in the management of the hospitalized child contribute to the wellbeing of the carer?
   f. How can others involved in the management of the hospitalized child contribute to the wellbeing of the child?
      i. Probe for:
         1. Who are the others involved in the care of the hospitalised child?
         2. What are the roles of others involved in the care of the hospitalised child?
Conclude by saying the following: thank you for taking the time to talk with me today. We have covered... (Provide a summary of main ideas), is there anything else you would like to add?

Once again I would like to assure you that anything you shared with us today will be kept confidential and will only be available for the research team or if required by law and any information that can identify you will be removed.

Thank you

2. What are the roles of others involved in the care of the hospitalised child?

Conclude by saying the following: thank you for taking the time to talk with me today. We have covered... (Provide a summary of main ideas), is there anything else you would like to add?

Once again I would like to assure you that anything you shared with us today will be kept confidential and will only be available for the research team or if required by law and any information that can identify you will be removed.

Thank you
5.3 Interview guides for Managerial staff

5.3.1 Interview guides for Managerial staff Arabic version

مقامه عن الحدث: شكراً للمشاركين بالمشاركة في هذا الحدث. إمام للمؤتمرات. كما قلتم، هذا الحدث يبرز حريصته المفرق
الأدبي للخادم. في السنوات الأولى لظهور الولايات المتحدة في المستشفيات والوادي. رائد Inspection سول
إيرى لما

مستشار المقدمة: سوف يتمكن، بفضل المشترون، من تشكيل أية من المشاركين وتقديره من درجة
كفاءة الفئة العربية إلى الإنجليزية. سيفعّل بشكل شرعيًا الفصل في حالة تصرفه لمصدر، في حالة إحساسه بعد
الراحة في تسجيل الصوت، الرجاء إعداد وساق بالاستثناء عن النسخة ومحوله لكتبة عامة. هل بإمكانك القيام بالتسجيل؟

[ في حال مواجهة المشتركون، الضغط المطهر]

شكرًا للمشاركين على تسجيل المقدمة.

سأقوم بكتابة بعض النافذة تستند على تذكر ملاحظاتك اليوم. جميع المعلومات التي تتشارك بها اليوم ستكون مرجعية، وعبر متاحة
إلى الفريق بعد أن إذا استدعي القانون، يمكن أن تقدم البيانات التي قد تقدم لموقع من هناك أن أستطيع أن أبدأ?

ما رأيك في الخادمة العامة للأطفال، في مستشفى الملك فيصل التعليمي في الخبر؟ نويهم؟ أسئلة عن:

1. ما الجيد في الخدمة العامة؟
2. ما الذين لديك في الخدمة العامة؟
3. ما الذي يحتاج إلى تغيير وكيف؟
4. ما المعلومة التي أقربك لخدمة طبية؟

ما هو مدى رضا الأطفال ونويهم في الخدمة العامة؟ أسئلة عن:

ما هو أكثر الحوادث التي تنظر في الخدمة العامة؟

ما هي أثر الشكوك التي تولد؟ أسئلة عن:

1. ما هو الشكل الذي تصرف؟
2. ما هو الطريقة الفائقة لاستدامة هذا الشكل؟

كيف سأهمني الأمثل للأطفال، في قيمة الرعاية الطبية لهما؟ أسئلة عن:

الأملاك التي تباكرين الأمثل؟
3. هل يشاركون في هذا قرار؟ عن الخدمة العامة?
4. لماذا يظهر الأمثل التي يظهرها من استخدام مريض من الرؤية؟

صف السماح في الخدمة العامة للأطفال، نويهم؟ أسئلة عن:

1. تربيت النمو لتمريض الأطفال
2. نمط الحياة، عامة أو خاصة
3. جمع المكان الشخص
4. الأخطار أو الإصلاح المتصلة للخادم اليوم

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في رأيي، كيف تؤثر بيئة المستشفى على صحة أطفالك؟ أسأل عن:
  • هل هي بيئة جيدة للاطفاء؟ ما السرطان فيها؟
  • في رأيي، هل هناك أي شيء يحتاج إلى تغيير؟ كيف؟

إذا تفضلن: شكرا لك لإعداد الوقت لكك، مع علينا، هذا البحث....
(تقديم مشخص بأكم الفكاهة). هنّاء
شراً أ鳍ر تزون إضافات؟
مرة أخرى، أطلب أن تكتب كسرية كل ما تشتهره عن اليوم. هذه المعلومات سوف تتوفر فقط لفريق البحث. إذا استدعى القانون
ذلك و كنت سأرسل أي معلومة قد تساعد على تحقيق تلك
شكراً
5.3.1 Interview guides for Managerial staff English version

Concerns and needs of chronically-ill hospitalized children and carers

Interview guide for managerial staff

Introduction about the study: Thank you for your interest in participating in this research study. As you know, this study is looking at the experience of primary carers supporting chronically-ill children during their hospital stay. I'm looking at this issue to understand what contributes to the wellbeing of the hospitalized children and their carers. Your views as part of the management and administration staff will help me understand that much better.

This interview will approximately take 45 minutes. I will be using an audio recorder so that I don't miss out on any of your comments. Once the interview have been transcribed, the recording will be destroyed. However, if you feel uncomfortable and prefer that the recorder is not used, please let me know. Is it okay with you if I record this interview?

[If the interviewer agrees for the recording to be used, switch on the recorder]

Thank you for agreeing to record this interview.

I will also take notes to help me remember all of our discussion today. All of the information you share with us today will be kept confidential and will only be available for the research team or if required by law and any information that can identify you will be removed. Do you have any questions before we begin?

1) What do you think of the services provided to children who are hospitalised at KFHU and their families? Probe for:
   a. What is good about the services provided?
   b. What is not so good?
   c. What needs to be changed and how?
   d. What are the barriers to providing optimal service?

2) How satisfied do you think the children and their carers with the services provided?
   Probe for
   a. What aspects are they most satisfied with?
3) What are the most frequent complaints you receive or hear? Probe for:
   a. Who complains?
   b. What processes are in place to respond to such complaints?

4) How are the family members of paediatric patients involved in their care? Probe for:
   a. Roles family members play
   b. Are they involved in making decisions about the care provided
   c. Why do they do the things they do? [Include specifics from answer to question 4a]
      (For e.g., do they have to?)

5) Describe to me the amenities available for the hospitalized children and the carers who
   accompany them. Probe for:
   a. Sleeping arrangements for carer
   b. Toilet facilities – both public and private?
   c. The size of the space
   d. Activities or entertainment available for the child

6) How do you think the hospital environment affects health of the child and carer? Probe for:
   a. Is it a good environment for them? What is good about it?
   b. Is there anything that you think needs to change? And how?

Conclude by saying the following: thank you for taking the time to talk with me today. We have
covered... (Provide a summary of main ideas), is there anything else you would like to add?

Once again I would like to assure you that anything you shared with us today will be kept
confidential and will only be available for the research team or if required by law and any
information that can identify you will be removed.

Thank you