



Faculty of Health and Social Care

**Experiences and Coping Strategies of Jordanian Parents of
Children with Beta-Thalassaemia Major**

A Thesis submitted for the Degree of PhD

By

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December 2014

The University of Hull

Faculty of Health and Social Care

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Abstract

Globally, thalassaemia is considered the most common inherited single-gene disorder. It is more prevalent in the Mediterranean Region (Tadmouri, et al., 2003). For instance, in Jordan there were about 1500 thalassaemia patients with a prevalence rate of about 4 to 6% of Beta Thalassemia Major (BTM) (Hamamy, et al., 2007). Jordan was chosen as the geographical location for this research because of a lack of studies of genetic haematological disorders in the country (Hamamy, et al., 2007). The study aimed to explore and understand parents' experiences of caring for their children diagnosed with BTM, as well as to identify their coping strategies.

In order to achieve this aim, grounded theory was adopted in this study. Data were collected through 'face-to-face' semi-structured interviews with forty Jordanian participants: 20 fathers and 20 mothers of children with BTM diagnosed for more than one year at three hospitals in Amman, Irbid and Al-Zarqa. Field notes and memos were also used in data collection.

Given the lack of qualitative research in this area the findings of this study provide new, profound insights and better understanding of parents' experiences and coping strategies caring for their child with BTM. The findings explored the positive and negative sides of parents' experiences, and how they coped in terms of their knowledge and feelings. They also showed that parents' experiences were negatively impacted by their lack of knowledge about BTM, and by restrictions from their social and cultural norms. Jordanian parents caring for children with BTM experienced an emotional burden and grief. However, parents were satisfied with the health care services that their children received, and with their role as carers. In addition, strategies such as faith and social support were also found to help parents to cope.

Exploring parents' experiences and coping strategies can assist nurses, health care professionals and stakeholders in recognising and identifying the gaps in parents' knowledge and needs. Furthermore, this study could assist health care professionals to have better understanding of parents' emotional and psychological status, to develop new perspectives towards parents of children with BTM and could therefore assist them to deliver quality care to the patients with BTM and their families. This study may also help to raise community awareness of BTM and other haematological genetic disorders by addressing the important role of socio-cultural norms and religion in identifying how parents experience and cope with their situation caring for children with BTM.

This thesis recommends that health care professionals need to support and empower parents and provide them with the appropriate and effective options to make their own decisions and adapt to their children with BTM condition.

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Dedication

To the spirit of my Mother and my Father. To my Brothers, my Sisters and my Friends.

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Introduction

This thesis is a qualitative study using grounded theory, designed to explore and understand the experiences and coping strategies of Jordanian parents of children with Beta-Thalassaemia Major (BTM). Ethical approval was obtained from the ethical research committees at the University of Hull, Faculty of Health and Social Care, Al al-Bayt University and the Jordanian Ministry of Health (JMoH). Data were collected through ‘face-to-face’ in-depth semi-structured interviews with Jordanian parents of children with BTM supported by field observation and memos. The interviews carried out in thalassaemia departments at three hospitals located in the major three cities in Jordan: Amman, Irbid and Al-Zarqa. Twenty fathers and twenty mothers of children diagnosed with BTM for more than one year were individually interviewed in this research. The interviews carried out by the researcher which was digitally recorded.

Participants requested to describe and narrated their experiences of having and caring for children with BTM and the strategies they used to cope to their situation. The empirical findings addressed the important role of socio-cultural norms and religion in identifying how parents' experience and cope. In addition, the findings explore the positive and negative sides of parents' experiences and coping in terms of their knowledge, feelings and attitudes. The findings of this research were summarised in four categories: ‘Knowledge Deficit’, ‘Sociocultural Perspectives’, ‘Personal Coping Strategies’ and ‘Grief’.

The findings of this study give new insights and better understanding of the parents' experiences and coping strategies while caring for children with BTM. On the one hand, the study found that participants lacked knowledge and they face some restrictions from social and cultural norms which impacted negatively on parents' experiences and coping. Furthermore, the study found that the participants experienced an emotional burden and

grief. On the other hand, parents satisfied with the health care services that their children with BTM received and with their role as caregivers. Moreover, the study found that parents used various coping strategies, focused on their faith and the social support they received from families and friends over a sustained period of time.

In conclusion, explored and understanding of the participants' experiences and coping strategies could assist the nurses, health care professionals (HCPs), and other stakeholders to support and empower parents of children with BTM and to provide them with appropriate and effective options to take their own decisions and adapt to their children's situation.

The thesis is structured in eight chapters. Chapter One, background to the study, provides an introduction to the study purposes, objectives and rationale, as well as a country profile of Jordan. In addition, the chapter presents an introduction about the thalassaemia as a global health issue, in the Arab region and in Jordan. At the end of the chapter, Jordan's social and health background discussed. Chapter Two, the literature review, this chapter discusses and introduces the process of the literature review which was used in this thesis; it then provides a review of the existing literature in the field. The chapter presents the literature review strategies, inclusion and exclusion criteria and discuss the outcome themes with particular focus on the Jordanian literature on thalassaemia, genetic and chronic illnesses. Chapter Three, discusses the historical background of thalassaemia, types, its complications and the available treatments and cured methods. Chapter Four, presents the selected research approach, explain and justify the research design, method and methodology. Chapter Five, discuss data collection and analysis techniques. The processes of gaining ethical approval and the recruitment of participants are also described. Data analysis strategies, measures taken to maintain the rigour and trustworthiness of the research are discussed in chapter five.

In Chapter Six, the research data from interviews, observations and memos discussed. In addition, the characteristics of participating parents and their children with BTM presented in chapter six. The responses to the interview questions are reported in categories presented participants' experiences and coping categories. Chapter Seven, discusses the research findings. The core-categories that emerged discussed in relation to relevant literature. The chapter is divided into three parts: the first discusses the theme of genetic screening, the second, social and cultural themes and the third discusses the religion, emotion and gender.

Finally, Chapter Eight, presents the conclusion of the study, highlights the answers to the research questions, presents the study limitations and offers some recommendations before drawing a general conclusion to the study.

Chapter One: Background to the Study

1.1 Introduction

This chapter provides an introduction and background to the study. It begins with an introduction to thalassaemia, followed by the research philosophy. The aim, objectives and the research rationale are also discussed. The chapter presents the research problem and the significance of the study. A profile of Jordan as the country hosting this study will also be presented.

1.2 Background to the Study

Having a child with a chronic illness can cause considerable stress to parents, as the care which needs to be provided can be highly demanding. Consequently, it can have emotional repercussions, as well as affecting parents' daily life. Parents exhibited a variety of patterns of stress responses, consistent with the nature of the illness and the care needed. Walker and Zeman (1990) found that parents' gender and the type of illness determine and have impact on their response.

Parents with chronically ill children experience a cycle of defining and managing adversity as they care for their children with life threatening and progressive disorders (Eiser, 1997). Furthermore, Eiser (Ibid) found that caring for the sick child in the family imposed extra burdens on the parent and increased the psychosocial challenges facing mothers and family members, as well as placing restrictions on their social lives (Gortmaker and Sappenfied, 1984; Eiser, 1997). Some literature describes the experiences of parents and families caring for chronically ill children, including children with BTM, as 'negative experiences' (Murphy, et al., 2007) because of the fact that parents need to provide continuous and lifelong demands care, including physical care,

administering medications, frequent hospital visits and the potential for increased demand on the family's financial resources (Barakat, et al., 2006), could all lead to increasing their stress levels. Parents could experience varied emotional burden; such as, shock, disbelief, anger, guilt and frustration (Melnyk, et al., 2001). It is essential to listen to families experiences caring for their chronically ill children, which can assist the HCPs to support and provide them with comprehensive care.

There are some commonalities in the experiences of caring for chronically ill children. For example, it is known that variables common to chronic illnesses and disorders, such as the child's age and gender, have been used successfully to predict both family functioning and child adjustment (Eiser, 1997; Lutz, et al., 2004). However, it would be incorrect to consider all chronic illness and disorders to be alike. For instance, in the case of children diagnosed with diabetes, cerebral palsy, BTM or sickle cell disease, there are differences in terms of the nature of the disorders, patients' characteristics, families' experiences, the stresses levels and the required adaptations. It is worth mentioning that chronic conditions affect patients and their families in various ways (Eiser, 1997; Lutz, et al., 2004).

Parents face a variety of challenges in pursuing their duty of care for chronically ill children. For instance, some parents demonstrate imbalance in their approach, fluctuating between being controlling of their chronically ill child and letting the child take responsibility (Leis-Newman, 2011). Newton and Lamarche (2012) argued that the mutual goal to the HCPs is to improve parental coping and the child outcomes. Arguably, parents' coping and adjustments could play a key factor to keep the unity of the family intact and to maintain a healthy lifestyle for its members. In order to contextualise this investigation of Jordanian parents' experiences and coping strategies in caring for children with BTM, the following sections present what is known about BTM, the global

view of thalassaemia, and the situation with regard to thalassaemia in the Arab region and in Jordan.

1.3 What is known about Thalassaemia

The word ‘thalassaemia’ derives from the Greek ‘thalassa’, meaning ‘the sea’, because the condition was first described in populations living near the Mediterranean Sea. Thalassaemia is a complex inherited abnormality of haemoglobin production which in the past took the lives of children before they reached their teenage years. BTM as a haematological disorder can cause profound anaemia, which can kill the patient before the age of three years if left untreated (Modell and Darlison, 2008). However, as a result of improved medical technology, community awareness, and advanced health services, the lifespan for children with BTM now extends into adulthood, through either regular blood transfusions and iron-chelating therapy or bone marrow transplantation (BMT) (Borgna-Pignatti, et al., 2004; Telfer, et al., 2005). The treatment of BTM requires regular lifelong blood transfusions from early infancy and treatment sessions at the rate of one session every three to four weeks in order to correct anaemia (Al-Qaddoumi, 2006). However, a possible side-effect of frequent blood transfusions is that the red blood cells are broken, causing iron to stay inside the body, accumulating in different body organs, thereby causing damage to the kidney, spleen and heart. The ineffective handling of iron overload can accelerate different complications such as cardiac and kidney disorders, which can result in early death to most patients in their early 20s (Dyson, 2005a).

Alpha and Beta-thalassaemia are the most common inherited single-gene blood disorders in the world. Worldwide there are around 240 million carriers (Cao, et al., 2002). In modern times it can be argued that the name ‘Mediterranean Anaemia’ is misleading because BTM and its associated haematological disorders can be found in many parts of the world, although different types of thalassaemia are more endemic in certain

geographical regions (Hassan, 2013). The highest prevalence occurs in areas where malaria was or is still endemic, in regions such as the Mediterranean, Australasia, America, South East Asia and North Africa (Weatherall and Glegg, 2001a; Dyson, 2005a). It was believed that different types of haemoglobinopathies include thalassaemia give protection against malaria, and it was thought that in malaria regions of the world, natural selection has been responsible to maintaining their gene frequencies. However, there are unequivocal evidence for protection according to the population and molecular genetic analysis of thalassaemia variants (Clegg and Weatherall, 1999).

Modell and Darlison (2008, p.6) argue that “*most children diagnosed with thalassaemia are born in low income countries*”. Possibly, this could be due to the unavailability of appropriate therapy, the failure of preventative and screening programmes, and the high rate of consanguineous¹ marriage in most of those low income countries. According to the Centre for Arab Genomic Studies (CAGS), both types of thalassaemia, Alpha and Beta, still represent a major public health concern in many parts of the world (CAGS, 2010).

Thalassaemia major follows an autosomal recessive pattern. If both biological parents are carriers of the thalassaemia gene then, in each pregnancy, there is a probability of one in four that the child will have BTM (Olivieri, 1999; Dyson, 2005b). If one partner is a carrier of the defective gene and the other has the normal gene to produce haemoglobin, there is a 50% chance of producing a carrier in each pregnancy; however, there is no chance that the child will be affected with BTM.

Thalassaemia is a chronic haematological disorder that can be diagnosed at an early stage of the child’s life, and which results in frequent hospitalisations (Ward, et al., 2002).

¹Consanguineous marriages: are marriages contracted between blood relatives. In clinical genetics, a consanguineous marriage is most commonly defined as a union between a couples related as second cousins or closer (Alwan and Modell, 1997, cited in Hamamy, 2005, p. 511).

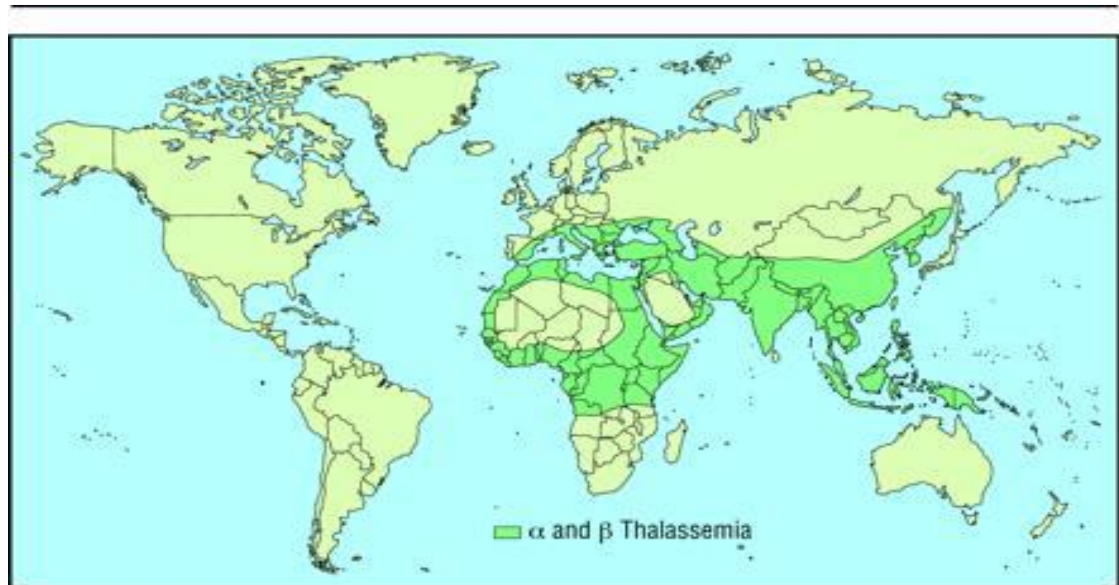
According to the Thalassaemia International Federation (TIF) (TIF, 2012) and the World Health Organization (WHO) (Modell and Darlison, 2008), the lifelong conservative therapy and management of BTM may include, but not be limited to, regular blood transfusions and iron chelating therapy with BMT as a curative procedure. Social and psychological therapy to support patients and their families to adjust and cope with their condition is also needed.

More details and discussion about BTM therapy, available treatments as well as the three types of thalassaemia - BTM, Thalassaemia Intermedia (TI) and Alpha-Thalassaemia (AT) - can be seen in Chapter Three.

1.3.1 Global view of Thalassaemia

The number of people affected by thalassaemia does not appear to be well established due to its high prevalence in developing countries where screening programmes and diagnostic resources are limited. It is estimated that around 15 million people worldwide have a confirmed diagnosis of thalassaemia (Hassan, 2013). Thalassaemia can be said to be a widespread disorder affecting around 5% of the world's population (Clegg and Weatherall, 1999; Rahim, et al., 2011). Worldwide, the disorders are found in more than 60 countries, with varying prevalence reported in each country. The global distribution of both Alpha and Beta thalassaemia is shown in figure 1. The highest prevalence is in Greece, Italy and most Asian countries where genetic carriers are reported (Mazzone, et al., 2009). For example, according to Hassan (2009), approximately 30 million carriers are reported in India. Dyson (2005b, p.8) estimates that *“every year worldwide, about one hundred thousand children are born with Beta thalassaemia major”*. This indicates that the number of children born with thalassaemia worldwide has steadily increased.

Figure 1 The Global Distributions of Alpha and Beta Thalassaemia.



Source: WHO (2001) ²

Most literature indicates that the two main types of thalassaemia, Alpha and Beta, are present among all ethnic groups and in almost every country around the world. However, certain types of thalassaemia are more prevalent in specific parts of the world. For example, BTM is much more common in Mediterranean countries, North Africa and East Europe, whereas AT is more common in India, Southeast Asia, the Middle East and Africa (TIF, 2013). Moreover, thalassaemia prevalence rates differ between specific populations. For instance, among Cypriots, it is estimated to be 1 in 7; among Greeks, it is 1 in 12; for South Indians 1 in 20; and 1 in 25 among Pakistanis. Thalassaemia has also become increasingly common in Northern and Western Europe due to population movement. For example, the prevalence of carriers in the United Kingdom (UK) is about 1 in 1,000 of the general population; Modell, et al. (2000) found that in the UK, 750 people were diagnosed with BTM, most of them from immigrant communities. In the

² Bulletin of the World Health Organization (2001) (Weatherall and Clegg, 2001 p: 707)

United States of America, there were about 1,000 cases diagnosed with BTM; most cases were among those with a Mediterranean background (Rahim, et al, 2011). It is clearly noted that the actual prevalence rates are influenced by local ethnic populations (Hogg and Modell, 1998; TIF, 2002). Rahim, et al. (2011) showed that in Iran there are around two million carriers of beta-thalassaemia, arguably because the Iranian population is considered to be a combination of different ethnic groups. Increasing mobility and migration to the many Western countries have increased the prevalence of the thalassaemia gene in these countries (Atkin and Anionwu, 2010). Recently, the number of children diagnosed at birth with BTM has increased; it is estimated to be around 56,100 yearly (Modell and Darlison, 2008), with more than 3,000 dying each year worldwide because of the complications of BTM. According to Trent (1997), Olivieri (1999), Thein (2000), Dyson (2005b) and CAGS (2010), there are more than 200 mutations that affect diverse levels of beta-globin genes, and these mutations also tend to vary from one ethnic group to another.

1.3.2 Thalassaemia in the Arab Region

The Arab region comprises 21 countries stretching from the Persian Gulf to the Atlantic Ocean (Zahed, 2001). Most of the Arab world shares language, religion, culture and a common history. Thalassaemia is endemic in most Arab countries (Zahed, 2001; CAGS, 2010). A study by Zahed (2001) found that a total of 52 types of beta-thalassaemia mutations specific to Mediterranean and Arab regions have been reported. The number of mutations reflects the heterogeneity of these populations and can be detected in each country depending on the geographical area. For example, in Jordan, more mutations have been detected in the North region than any other region in the country (Zahed, 2001). The different types of mutation give an indication of the severity of the condition by identifying the affected beta globin gene. The genetic defect in BTM cases is usually by

deletion of the beta globin gene and the surrounding regions, and it comes in two forms: Beta-Zero and Beta-Plus. In Beta-Zero, mutations prevent any formation of the beta chains, whilst Beta-Plus allows all or some beta chain formation to occur.

The CAGS (2010) has detected different mutations in most Arab countries, with regard to the different types of beta thalassaemia and the severity of the impact on beta chain formation. For instance, in Jordan, about 13 thalassaemia mutations were identified, a number of mutations similar to the total found in Israeli-Arab regions. In comparative terms, the number of mutations found in the Arab region suggests that Jordan has the fourth lowest number of mutations. Kuwait, which has about 9 mutations, has the lowest number in the region. The study also found that the Gaza Strip has about 10 mutations, there are 12 in Bahrain, 14 are found in Saudi Arabia, 15 in Oman, 16 each in Syria, Tunisia, and Algeria, as many as 18 in Lebanon, and Egypt has 19 different documented mutations (CAGS, 2010; TIF, 2012). The highest number of mutations was found in the United Arab Emirates, with a total of 21 reported mutations (TIF, 2002; CAGS, 2010). CAGS (2010) in Dubai reported more evidence that both Alpha and Beta-thalassaemia were endemic in most Arab countries, and defines BTM by utilisation of different ‘alternative’ names based on the mutation in the gene. These definitions are found in the ‘Catalogue for Transmission Genetics in Arabs Data-Base’. See table 1 for some of the suggested names:

Table 1 Thalassaemia Names

Suggested Name for Thalassaemia in CAGS, 2010
1. Beta-Thalassaemia
2. Beta-Thalassamis
3. Methemoglobinemia
4. Erythraemia, Beta-Globin Type.
5. Cooley’s Anaemia

From the previous statistics about thalassaemia mutations in Jordan and the Arab region, it can be argued that thalassaemia is a significant health problem, which needs more in depth search to assist patients and their families to adapt effectively to their situation.

1.3.3 Thalassaemia in Jordan

Jordan's population is estimated at 6.2 million; more than 42% are under the age of 15 years (WHO, 2013). The life expectancy at birth is 72 and 74 years for males and females respectively (WHO, 2013). Among the overall population, genetic inherited disorders are relatively common. For example, recent statistics show that the carrier rates for thalassaemia and sickle cell anaemia were in the order of 2 to 4% and 3.2 to 12% respectively (Hamamy, et al., 2007b).

Based on these statistics, Hamamy, et al. (2007a) raised major concerns about the equity and quality of genetic health care services in Jordan, as well as in most Arab countries. In another study Harteveld, et al. (2003) raised the issue of the limited knowledge on the exact distribution and frequency of thalassaemic disorders in developing countries. They argued that although there could be some treatment for patients diagnosed with thalassaemia in these countries, there was still a need to place emphasise on the education and prevention programmes as well as to increase the community awareness about thalassaemia, and utilise the screening programmes.

Jordan, like other countries in the region, has significant numbers of patients with BTM at different ages and stages. Despite national awareness campaigns on the risks associated with consanguineous marriages and purported improvements in national healthcare services and screening policies regarding genetic counselling in Jordan, the number of cases with BTM remains significantly high, at around 1500 patients. This figure is seemingly increasing by 50 to 80 patients per annum, and the number of the individuals

who are carriers of genetic disorders are increasing, reaching 4 to 6% of the total population (Eleftheriou and Immonen-Charalambous, 2009; Gharaibeh and Gharaibeh, 2011). This reflects a substantial increase from the figure of thalassaemia carriers to about 3.3 to 3.5% reported by Babiker, et al. (1999), and of 3 to 4.5% of the Jordanian population previously reported by Mrayyan, et al. (2004). In another study, Sadiq, et al. (2001) found that in 2000, Jordan registered about 900 patients with BTM in a single year. However, it is possible that the number of registered cases and carriers does not reflect the actual number of cases in the Jordanian community, because of the limitations in genetic screening programmes in the health care service. Having presented a statistical account of the prevalence of the disorder in Jordan, Mrayyan, and et al. (2004) claim that those thalassaemia patients could have a life expectancy of about thirty years. Currently, most thalassaemia patients receive treatment in four government health settings located in Amman, Irbid, and Al-Zarqa and there is small units located in the south of Jordan in a city called Al-Karak. Such services are not available in the private sector.

Jordanian patients with thalassaemia have free medical insurance and are entitled to free conservative treatments, which include regular blood transfusions and iron chelating therapy. BMT is the only available curative method in Jordan for patients with BTM. It is worth mentioning that in Jordan, the available genetic health services focused on health prevention programmes, through mandatory premarital screening tests for any proposed couples before their marriage contract is certified, and on treatment of the diagnosed cases. Genetic counselling is also available when needed for carrier. A study for El-Shanti (2001) found that although most genetic diseases in Jordan were incurable, there were some satisfactory treatments to the patients diagnosed with genetic disorders.

1.3.4 Genetic Services and Counselling

Globalisation and the availability of new medical technologies made it easier for parents to identify their own genetic status through screening programmes, and to allow this information to influence their decisions before embarking upon married life. In the JMoH the available genetic screening programmes were:

1. Mandatory premarital screening for Beta-thalassaemia carriers (Hamamy, et al., 2007b; JMoH, 2009).
2. Antenatal screening for chromosome abnormalities to detect congenital malformation and some genetic disorders carried out in some hospitals (Gharaibeh, et al., 2010).
3. Neonatal screening programmes, which were available in some hospitals to screen for Phenylketonuria (PKU) and congenital hypothyroidism (Alwan and Modell, 1997).

The genetic services available in Jordan are still being developed (Hamamy, 2012) and their effectiveness can be questioned. The screening programmes faced many social, ethical, political and practical challenges, such as termination of pregnancy, the screening tests cost, and social stigma. Such challenges will need to be addressed so as not to conflict with the community's culture, religions and social norms (Alwan and Modell, 2003). The JMoH announced the initiation of a mandatory premarital programme in 2004 (Hamamy, et al., 2007a; Halasa, 2008) after a period of political and religious debate. The programme consisted of free tests, mandatory by law for all couples before they got married, to be followed by a genetic counselling session. The premarital programme has increased awareness of BTM disorders and opened the gate to public and private health sectors to provide the recommended tests (Oseroff, 2011). Although the services were available in private laboratories, they are costly.

In both public and private sectors, the laboratories performed a Complete Blood Count (CBC) of a venous blood sample. If the result showed that the Mean Corpuscular Volume (MCV) was less than 80%, haemoglobin electrophoresis would be recommended, along with other tests to identify the type of the anaemia the couple might have (Al-Hait, 2009). The couples were advised to keep a copy of their blood tests results, which will be used in the form of a test certificate be presented in the civil court during certification of the marriage, as evidence.

It was noted that if the engaged couple were not thalassaemia carriers, they usually continued with their plan to marry. The official statistics showed that more than 40% of carrier couples decide not to go ahead with their proposed marriage after they had the premarital screening tests (Al-Hait, 2009), which left the acceptable numbers, could be more than half of the carriers couples who still go ahead with their marriage plan. This was similar to Iranian statistics, which revealed that half of the Iranian carrier couples decided also to get married (Alwan and Modell, 2003). However, in cases where it was confirmed that the couple were carriers, they were referred to the genetic counselling services to decide if they should pursue or cancel their marriage plans, by identify the risk of having children with thalassaemia in future.

The premarital programme in Jordan, has its own characteristics that observe socio-cultural and religious principles. However, the programme shares similar features with those in Arab countries such as Qatar, Bahrain, the United Arab Emirates and Tunisia, as well as the screening programmes in Italy, Iran, Sardinia and Cyprus (Hamamy, et al., 2007a). It can be said that the number of new registered patients with BTM has slightly declined since the premarital screening programme was launched.

1.4 The Research Problem

Worldwide, thalassaemia is considered one of the most common inherited single-gene disorder. It is more prevalent in the Mediterranean region (Tadmouri and Gulen, 2003).

Thalassaemia situation in Jordan could be summarised as follows:

1. Currently, the number of thalassaemia patients remains significantly high, at about 1500;
2. It is estimated that there are more than 200,000 people who carry the defective gene (Al-Hait, 2009) without knowing they are carriers;
3. There is a steady increase in the number of newly registered patients with BTM. In 2004 it was estimated that there were around 50 to 80 new cases yearly (Mrayyan, et al., 2004);
4. Jordan has an approximate BTM prevalence rate of between 4 and 6 per cent (Hamamy, et al., 2007a; Gharaibeh and Gharaibeh, 2011);
5. In Jordan, BTM is one of many inherited genetic disorders that have a variety of health and economic burdens (Hamamy, et al., 2007b);
6. The literature shows that there is a lack of studies of genetic haematological disorders in Jordan (Hamamy, et al., 2007b).

Health delivery services in Jordan have improved in recent years, due to political stability, effective governmental plans and positive social development strategies. However, health services for genetic disorders are still scarce and are not able to provide cover in all areas where they are needed, due to the major impediments of a paucity of financial resources and a shortage of trained HCPs in this field (Hamamy and Al-Hait, 2007). A preliminary review of the literature showed that to date, there is ambiguity in this area because there have been few studies conducted in Jordan that can be compared with the global literature.

It can be argued that in Jordan, genetic health disorders are associated with:

1. The high prevalence (30-39%) of consanguineous marriage in Jordanian society (Hamamy, 2012);
2. The high fertility rate of 3.5 births per Jordanian woman according to the Department of Statistics (DoS) (DoS, 2012);
3. The low incidence of the pre-marital medical check-up (18% of married couples);
4. The limitations of and challenges to professional genetic health counselling.

For the aforementioned situation about Jordan, this study conducted, aims to contribute to and enhance HCPs' knowledge to provide a mechanism whereby the quality care to patients with BTM and their families living with a chronic disorders can becomes reality. This study will explore, describe and give better understanding of Jordanian parents' experiences and coping strategies, in order to generate new knowledge for HCPs, especially nurses, so that they can provide the appropriate and effective health education and counselling that parents need. This in turn will impact on the quality of children with BTM life. Nuutila and Salanterä (2006, p.153) stated that *"to be able to help a child and his or her family, health care professional must have an understanding of the experiences that the child's long-term illness brings into the lives of the family"*. In addition, Lewis (2007) argued that it is essential to listen to their experiences in the parents' own words in order to be able to provide quality and comprehensive care to the families and their chronically ill children. In another study, Meleski (2002) argued that it's the clinicians' responsibility to build form of trusting relationships with the parents, thereby, enhancing ability to manage their children's illness.

The inadequate Jordanian literature in this area and the limited of nursing research on the topic motivated me to conduct this study and attempt to fill the gap in the knowledge. In

addition, I was inspired to conduct such a study because the parents are the primary and possibly the only, carers for their children with BTM. It was therefore of interest to explore their experiences, coping strategies, and the impact of BTM on their role and the quality of life for themselves and their children.

Adaptation to parents' experiences and coping strategies could be a significant factor in enhancing nursing and other HCPs' knowledge and practices in the clinical field. Newton and Lamarche (2012) argued that it is important to assess parents' responses to the child's chronic illness and their ability to cope with it. In addition, it will give an opportunity for the parents themselves to be able to contextualise and understand their situation, which could help them in better management. Moreover, it is envisaged that by exploring the role of parenting, family function and coping strategies, this study could assist nurses and other HCPs in delivering quality care services to the patients and their families and developing new perspectives toward parents of children with BTM. This study could also produce background information which could assist in the modification of health care policy and positively influence decision-makers in the clinical setting.

1.5 Significance of the Study

Jordan was chosen as the geographical location for this research because of the lack of studies of genetic haematological disorders in the country (Hamamy, et al., 2007b). A review of the Jordanian literature revealed that there have been few qualitative studies carried out on patients with thalassaemia and their families (see Appendix 1 and 1a). It is clear from reviewing Jordanian qualitative studies that they have focused on assessing knowledge, attitudes and economic impacts of BTM on Jordanian families. However, there is a gap in knowledge of Jordanian parents' experiences and coping strategies, in terms of fathers' and mothers' roles in the care of children with BTM. Previous Jordanian studies have not shown the impact of lifelong caring for children with BTM on families'

social lives and daily activities, or the coping strategies the families used. The relevant literature will be discussed in Chapter Two. A review of the Jordanian literature (see Appendix 1 and 1a) showed that the studies conducted on children with BTM and their families show only half of the picture in terms of the parents' situation, mainly focusing on parents' knowledge about the disorder, the benefit of counselling or education, and attitudes toward prevention screening programmes. The condition has not been studied from the point of view of the participants' experiences of coping and caring for children with BTM, nor the impact of their religion and culture on their experiences and coping strategies. Hence, one of aims in conducting this study is to fill this gap by exploring and understanding parents' experiences and coping strategies in the care of children with BTM, and by giving an analytical description of the influence of culture, religion and social norms on parents' experiences.

It is expected that the outcomes and recommendations of this study will assist in raising community awareness of parents' experiences and how they cope in dealing with their children. For high risk families, new parents and carrier couples of the BTM gene, this will draw a clear picture of the role played by parents of children with BTM, and of their experiences. Nevertheless, this study was not conducted with the aim of generalising, but rather of introducing thoughtful ideas about parents' experiences and coping in caring for their children with BTM. Moreover, since there are no studies carried out to date that exclusively explore Jordanian parents' experiences and coping strategies caring for children with BTM, it is expected that this study will help to increase nurses', HCPs' and community members' awareness towards not only BTM but also other genetic disorders. The findings and recommendations provided by this study could contribute to an appreciation of genetic health disorders within the health care system in Jordan. The findings of this thesis will be shared with the public and with worldwide health professional bodies, through published sources, in order to create more awareness, add

significant knowledge, and share Jordanian parents' experiences and coping strategies with the international community.

1.6 Research Aim

The aim of this study is to explore and gain better understanding of Jordanian parents' experiences of children with BTM, the impact of BTM on their life and their coping strategies as described by the Jordanian parents themselves.

1.7 Research Objectives

My aim in this study is to obtain and explore comprehensive views from the Jordanian parents of children with BTM in the three hospitals located in the main cities of Jordan: Amman, Irbid, and Al-Zarqa (DoS, 2010). These are the major cities in which patients with BTM from both rural and urban settings are concentrated. In order to support, educate and empower them to handle this responsibility, I intended to:

1. Explore and understand parents' experiences in dealing with children diagnosed with BTM;
2. Evaluate the impact of having children with BTM on parents' lives;
3. Identify and explain parents' coping strategies.

In order to set the study in its regional and social context, background about the Jordanian social and health care system will be presented.

1.8 Jordan Country Profile

Jordan is said to be one of the most developed countries in the Middle East. Jordan gained independence and was declared a Kingdom in 1946. Geographically, Jordan is almost landlocked except for one port at Aqaba, the only outlet to the sea. Figure 2 shows the

map of Jordan. Jordan's neighbours are Saudi Arabia to the South and East, Iraq to the Northeast, Israel and the West Bank to the West and Syria to the North.

Figure 2 Map of Jordan



Source: World Atlas³

Jordan has an area of about 91,880 square kilometres. The country is geographically varied, with heights ranging from 2 km above sea level in the mountainous areas to 500m below sea level around the Dead Sea and the extensive Eastern Desert. The Jordan Valley, a great north-south geological rift, and the Dead Sea are the dominant topographical features.

Administratively, the country is divided into 12 governorates. Jordan's population was estimated to be around 6.2 million in 2011 according to the World Bank Report (WBR) (2013). Around 37% of the population is under the age of 14 years (WHO, 2012), and 39% are between 15 and 64 years (WBR, 2013). More than 92% of Jordanians are Sunni Muslims, and about 10% are Christians. Arabic is the official language (Hamamy, et al.,

³ <http://www.worldatlas.com/webimage/countrys/asia/jo.htm>

2007a) and English is used as the second language. Jordanians, predominantly Arab, except for a few small communities of Circassians, Armenians, and Kurds, who have adapted to Arab culture. Social interactions in Jordan are shaped and controlled by Islamic law, called 'Sharia law'⁴, social norms and Arabic culture. Islamic 'Sharia' law was designed to regulate people's way of living, including the area of health related issues.

The family is the basic unit in Jordanian society. The typical Jordanian household usually consists of a married couple, their unmarried children, boys and girls whatever their age, father or mother in law, and unmarried or widowed sisters. It is argued that this arrangement helps social interaction and stability in the community (Dhami and Sheikh, 2000). Economically, Jordan relies on overseas assistance due to its limited natural resources, including water, natural gas and oil, compared to the other countries in the region (Dasouki and El-Shanti, 2010).

1.8.1 Jordanian Families

The family is the centre of social life and identity in Jordan. It is composed of people related to each other by kinship through marriage, and with time, most family ties extended into different structures of clans (Metz, 1991). In the Jordanian community, the gender and age are important features in determining social status. For instance, individuals who are advanced in age tend to command more respect than younger persons. In addition, social identity and loyalty continue to be oriented largely towards extended kin, as the extended family remains a strong feature in the Jordanian community (Khalaf, et al., 2008). Jordanians tend to rely on the extended family for a variety of reasons,

⁴ Sharia law is Islam's legal system. It is derived from both the Holy Qur'an, as the word of God, the example of the life of the prophet Muhammad, and from fatwas, the rulings of Islamic scholars (Casciani, 2008).

including economic support, social protection, marital partners, child care, domestic services and emotional support.

Culturally, the Jordanian family is based upon 'blood ties' between men and women; family structure can be modified over time, and various forms of families can be found. For example, families can change with a new birth, death or migration. In addition, it could be the scenario where permanent settlement to the family members in other countries can split the family unit. Such change can bring new family branches in different places over time. Traditionally, the adults in the family expected to get married, as well as remarry if they either divorced or become widowed. Furthermore, extended families and step-families tend to live together in the same house or locality. The rationale behind this cohesiveness is that most families prefer to raise their children among related family members, unless they have migrated for work or study. It is worth mentioning that men tend to have greater autonomy than women in the community, both inside and outside the family.

1.8.2 Marriage in Jordan

The marriage system in Jordan is mostly consanguineous. Although polygamy has not been widely practised in recent times, it is acceptable. It can also be acknowledged that for a variety of cultural reasons, arranged marriages are still common (Heaton, 1996; Hamamy, 2012). Most Jordanian marriages are traditionally arranged by parents. Usually, preference is given to cousins, and if there is no suitable spouse is found, the search is extended to either their kin or social contacts. Hamamy, et al. (2005) interviewed 1032 individuals in Amman, and found that the first-cousin marriage rate within a given population from the city was on the decline in marriages contracted after 1980, compared to marriages contracted before 1950 and between 1950 and 1979. Therefore, it appears that the proportion of paternal parallel first-cousins within first cousin marriage is

showing a steady decline from one generation to the other. The findings of Hamamy, et al. (2005) are in contrast with previous studies. For example, Khoury and Massad (1992) found that consanguineous marriages were customarily favoured, with the preferred marriage partner being the offspring of the father's brother. This study revealed that in Jordan between 1969 and 1979, 32% of two thousand marriages were between first cousins. Similar findings were reported in another study by Mahasneh (2001), which showed that out of 249 married women, 53.8% (n=134) were married to first or second cousins. However, statistics from the Higher Council for Youth (2005-2009) indicate that only 17% of young Jordanians believe that parents should plan marriages and identify spouses for young women without their participation. This seems to indicate that the majority of young Jordanians were not support traditional arranged and consanguineous marriages. Moreover, 49.5% of young male and only 25.8% of young females believe that women are not equal to men in social status (HCY and UNDP, 2009).

Although 'contractual marriage' is the basis of a family unit, there are other fundamental factors that contribute to the Jordanian marriage system, such as culture and religion. For instance, culturally, married couples are expected to have children in the first formative years of their marriage; otherwise, both partners may have to undertake a medical check-up in order to ascertain causes of infertility. The number of children per married couple (between 5 and 10) is considered high by international standards, but is still acceptable to most Jordanian families. Nevertheless, according to WHO (2013), Jordanian fertility rates declined to 3.7% in 2011. In addition, due to the high cost of living, there is currently a trend toward smaller families among average and below-average incomes family units. In addition, El-Shanti's (2001) study suggests that children born out of wedlock to single mothers are considered unacceptable and very unusual.

Another issue found in the Jordanian community concerns female virtue and virginity, which is important from a religious and cultural view. It defines a family's reputation not only in Jordan but also in most Arab countries. Nimry (2009) found that Jordanians particularly cherish 'virginity' among young adult females who have not yet been married, in order to keep a high 'family reputation'. These values tend to have a significant impact on the interactions and social relationships between the opposite sexes. Nimry (Ibid, p.7) states that *"the adult males in the families are the ones responsible for guardianship of the families' reputation and they have the right to punish females in the family who tarnish or damage this reputation"*. Punishment in such cases comes in the context of honour crime. According to Faqir (2001, p. 69), honour killings are *"the killings of women for deviation from sexual norms imposed by society"*: women killed because they are considered to have shamed and dishonoured their families if they are proved to have had a sexual relationship or become pregnant before getting married. There are no clear published data about the number of women killed due to the trend of committed suicide (Faqir, 2001); however, it is estimated that in 1999, out of a total 67 killings in Jordan, 17 (25%) were honour killings (Faqir, 2001).

1.8.3 Social Interaction Patterns in Jordan

An emphasis on culture and traditional values in Jordanian communities is probably a significant limiting factor in social interaction for women and men and that includes parents of children with BTM. Some parents could lack active participation in some social activities due to limited time and social restrictions on women's mobility. For instance, young girls and married women may be reluctant to visit a doctor unaccompanied with family members, because 'tradition' requires that women and girls be accompanied by their mother, sister or mother in-law, particularly when consulting a male practitioners on a chronic health issues, reproductive health or major health disorders. Consequently, their

ability to gain new information and knowledge could be limited. It should be further noted that in Jordan, freedom of mobility is primarily determined by age, gender and social status. Thus, women may experience considerably greater restrictions on their mobility than men. However, as observed by Ahmed (2002), that older women tend to command more respect for their 'hikmah' [wisdom] gained through life experiences.

It was also noted that most Jordanian women are expected to take the role of housewife or a mother, a factor that adds to their family and socio-economic challenges when they become widowed or divorced, or caring for chronically ill children like those with BTM. Women's well-being and their personal and social security are the responsibility of the male relatives such as, her brother, fathers, nephew, uncle or grandfathers as stated by Nimry (2009). Arguably, such traditions could directly or indirectly affect women's role in caring for their own health as well as that of their families.

1.8.4 Jordanian Health Care System

The health care system in Jordan has a variety of services available to all sections of society, controlled by the JMoH. It has the most available health network in the country, controlling the primary, secondary and tertiary services. The health care policy and strategies in various sectors are planned and guided by the JMoH in co-operation with the High Health Council (HHC), which is headed by the Prime Minister, the council is also responsible for easy access to and improvement of health services (Batieha, 2003).

The JMoH has numerous primary and secondary health care centres all over the country. In 2006, the Library of Congress (LoC) Federal Research Division estimated the number of centres to be around 1,245, in addition to the number of governmental hospitals distributed all over the country. Table 2 shows the three health sectors and their contribution to the total amount of beds in the country.

Table 2 Jordanian Health Sectors

Health Sectors	Health Services (JMoH, 2013)	Percentage of total country hospital beds
1. The National Health Services (Governmental Sector)	30 Hospitals	37%
2. The Jordanian Royal Medical Services (Military Sector)	11 Hospitals	24%
3. Private Services	60 Hospitals	36%
4. The United Nations Relief and Works Agency	23 Health Care Centres (UNRWA, 2002)	0%

Source: (LoC, 2006), (JMoH, 2013) and United Nations Relief and Works Agency (UNRWA) (2002).

These health centres and hospitals are supported by two public comprehensive health centres located in Amman, which provide services in the field of the major chronic diseases: the King Hussein Cancer Centre (KHCC) and The National Centre for Diabetes, Endocrinology and Genetics (NCDEG).

Military health services available for anyone associated with the military services. This sector has its own rules and regulations, quite different from the government sector. The private sector, which has become widespread in recent years, is also adequately equipped with new technology in its clinics and hospitals. This sector is principally accessed by the affluent community, because its services unaffordable to the general public. In addition, there are two large university hospitals that receive referrals from any sectors, or those who can manage to pay for the treatment, as well as for university employees who have health insurance as part of their employment contract. The majority of private clinics and hospitals are found in large towns and cities, and primary and comprehensive health centres are available all over the country.

Furthermore, the UNRWA health centres provide a variety of health care services around the country to refugees in Jordan from surrounding regions of conflict such as Palestine, Iraq, and recently Syria. The numbers of refugees have steadily increased due to the

political instability in the Middle East. For instance, Palestinian refugees are estimated at 1.4 million (UNRWA, 2010). The refugee sector has its own primary health care centres located within refugee camps. The JMoH is working to develop a new routes to community health services by introducing a ‘family health programme’, or its referred to as ‘family medicine programme’. This programme focuses on community health issues such as health promotion and illnesses prevention. The purpose of the programme is to identify the family as one unit and also to aim at achieving ‘family wellbeing’ (Batieha, 2003; Franco, et al., 2004).

Most thalassaemia and haematological disorder patients, except those with cancer, receive their treatment in thalassaemia departments located in the governmental hospitals. In term of HCPs there are around 24.5 physicians per 10,000 of the population, and around 40.3 nurses and midwives per 10,000 in Jordan (WHO, 2012). Reviewing the health statistics Jordan ranks tenth in the world in terms of infant mortality, with a rate of 22 deaths per 1000 and fifth in maternal mortality rate 41 per 100,000. Jordan’s birth rate is 3.7 per 1000 of the population; there are 3 infant deaths and 3 to 4 deaths under 5 years old per 1000 of population (WHO, 2013). The availability of the medical technology and HCPs in Jordan, along with the quality of the health care provided, have led to Jordan of being ranked number one as a health care provider and medical tourism destination in the region and number five in the world by the World Bank report (2009-2010) (WBR, 2013). It is also one of the top areas for medical tourism in the Middle East according to The Jordan Times newspaper (Malkawi, 2012).

1.8.5 Health Care Insurance

There are four health care sectors: the government, military, private and the UNRWA as discussed previously. The types of the health insurance which individuals own affects the quality of health services they received. However, some research studies report that there

is a direct correlation between the health insurance and the frequency of clients' visits to the health care providers (Ekman, 2007). In 2007, around 70% of all Jordanians have their medical insurance (LoC, 2006). The statistics showed that the population insured by the governmental sector comprises about 19.5%. The private sector, which includes private hospitals and centres, covers around 8.8%. The highest percentage of the population's health insurance is with the Military sector, at around 27%. The refugees receive their health services through UNRWA, and this comprises about 11%. The rest of the population, about 32%, is said to be uninsured (Brosk, et al., 2000).

The government health insurance system includes all chronically ill Jordanians, whether their family has its own insurance or not. This provision includes mental disorders, kidney failure, diabetes mellitus, thalassaemia disorders, sickle cell disease, cancer and cardiac disorders (JMoH, 2013). It is worth mentioning that in 2002, public health law number 54, regulation number 26, which covers health insurance, stated that all Jordanian children who are less than 6 years old are included under the JMoH insurance, unless they are covered by other health insurance (JMoH, 2004).

1.8.6 Jordanian Health Perceptions

HCPs in Jordanian communities are considered to be the decision makers on almost all aspects of the health issues for individuals. However, religion influence people's health status, as do cultural beliefs and social norms, which exert an impact and play an important role in health literacy and chronic illness, screening and health management plans. It should also be noted that Jordanians are generally very strong in their spiritual beliefs. Most of them may believe that the occurrence of illnesses and disorders are 'God's will'. Arguably, such beliefs and attitude could encourage tolerance of genetic disorders and alleviate the feeling of guilt (El-Shanti, 2001). However, it could be challenging to parents seek help and support from others. Religion, culture beliefs and

social values influence Jordanians' perception of health, as well as their ways of dealing with their health issues.

1.8.7 A Synopsis of the Current Political Situation in Jordan

Jordan considered the first place of asylum for many refugees from the Middle East due to the prevailing political stability (Mateen, et al., 2012). According to the United Nations High Commissioner for Refugees (UNHCR), Jordan has the highest number of refugees in the region (UNHCR, 2013). The Guardian News (Luck, 2013), stated that Jordan is host to more than 1.8 million Palestinian, 450 thousand Iraqi and 432 thousand Syrian refugees due to the prevailing political instability in the region. In addition, there are large numbers of illegal and non-registered refugees entering Jordan on a daily basis, including from Libya and Egypt.

It can be argued that this puts an enormous pressure on already limited national resources. It worth mentioning, that the main areas affected include health, social, education, political, economic and labour resources. Furthermore, the Syrian crisis has worsened the refugee situation in Jordan. According to the Guardian News (Luck, 2013), Syrian refugees now account for 10% of the population of Jordan. It was reported by UNHCR (2013) that the JMoH had a shortage in health resources and personnel, such as the number of hospital beds, HCPs and medications, especially for chronic illnesses. Arguably, these shortages in the provision of health resources have a great impact on public health promotion, illnesses prevention and health restoration. For instance, in their annual report, the UNHCR (2013) stated that the capacity of governmental hospitals in Jordan had increased by 250%, from 4,109 patients in January 2013 to 10,330 in March 2013. In addition, it was estimated that there were about 676 Syrian refugees in Jordan diagnosed with cancers, representing a 14% increase in the Jordanian disease burden. It is worth mentioning that with regard to the economy and employment, the Jordanian

Ministry of Labour (JMoL) states that, due to the Syrian political crisis, currently there are about 160,000 illegal Syrians working in unprofessional positions and in the private sectors (Luck, 2013). According to the JMoL, job displacement by refugees has increased the Jordanian citizen unemployment rate to 20% over the last few years. Recently, both the Jordanian public health and social care systems are overstretched and they faced a deficiency in their resources and HCPs, which puts health and social care services at risk. This is due to the steadily increasing numbers of refugees, coupled with limited resources in the country.

1.9 Conclusion

In this chapter, an introduction and background have been provided regarding thalassaemia as a haematological disorder globally, in the Arab region and in Jordan. The research aim, objectives, rationale were also presented and discussed. A profile of Jordan, where the study was carried out, was also presented in terms of social life, available health services and perception of health. In the next chapter, the literature will be reviewed and discussed.

Chapter Two: Literature Review

2.1 Introduction

This chapter aims to discuss the relevant literature on parents' experiences of having children with thalassaemia major, and their coping strategies. It will present the research idea, the review strategies, criteria and the process of reviewing the available literature. The review highlights the current knowledge about parents and caregivers in a variety of contexts, such as culture, religion and the impact of BTM on the patients and their families in multinational settings. The conclusions will be drawn at the end of this chapter.

2.2 Research Idea

The idea of exploring and gaining a better understanding of parents' experiences of caring for children with BTM arose from my clinical experiences as a nurse and university lecturer, during the time I spent in various clinical settings working with nursing students in providing care for patients and their families. During my clinical experience, I noted that most children with BTM were accompanied by their mothers, which inspired me to question the role of the father in the care of children. Also, as a researcher, I am keen to know how parents care for their children, what their personal experiences is and how they cope. My observations brought to mind many questions about how parents manage to provide care for children with a lifelong disorder. What do they do? How does time spent with their children impact on social life? What keeps them providing the required care, and how do they adjust to their situation? I noticed from health care plans that the responsibility for administering iron chelating therapy to children mainly fell on families. This encouraged me to find out more about fathers and mothers' experiences of caring for children with BTM at home. What this caring mean to them? What impact does a child's diagnosis with BTM have on the life of the mother and father? What is the role of the

father? In addition, I was interested in parents' perceptions of and attitudes towards caring for chronically ill children, as well as the impact of culture and religion on their experiences and coping strategies. All these questions demanded answers, which inspired me to carry out a comprehensive search of Jordanian literature on the experiences of parents of children with BTM. From a rigorous review, I found that the experiences and coping strategies of Jordanian parents caring for children with BTM was an ambiguous area that needed to be further explored and more thoroughly researched. Furthermore, I found that there is a gap in Jordanian and regional literature. Most existing Jordanian literature were focused on patients' experiences more than on their families. In addition, some scholars researched the prevalence of BTM, the clinical manifestations, and the side effects on affected children, as well as the complications of the disorder. Only a few studies investigated parents' knowledge about BTM and their attitudes towards genetic screening programmes.

The improved the understanding of the experiences of parents of children with BTM gained through an investigation of the above questions will assist and encourage nurses and HCPs in providing quality care to children with BTM and their families. In addition, this study could bring greater attention to the social and psychological status of the parents, help to improve the management care plans provided to families living with lifelong illnesses. Support and empower children with BTM and their families to achieve their life goals and fulfil their ambitions. Quality care in this context means fewer complications, a decrease in the burden of BTM on children and their families and improved their life style.

2.3 Literature Search Strategies

A comprehensive review to the relevant literature to the phenomena under study was undertaken to have appropriate background and to find studies which may help to answer the research questions. In the preparation stage, the review focused on the Jordanian studies and regional literature carried out in order to avoid replicating research already published. Although the literature review take place throughout the research project. However, the focused and the most of the review carried out at the stage of data analysis and the discussion in order to compare and challenged the findings with the existing literature.

The literature review strategy adopted in this study includes:

1. Background of the review,
2. Objectives of the review,
3. Inclusion and exclusion criteria,
4. Set and answer review questions.

In order to better organised and prioritise the searching time, I planned the literature review in advance by setting the aim, objectives and the review questions. A summary of the strategy plan used in this review on the experiences and coping strategies of parents of children with BTM is shown in table 3.

Table 3 Research Strategies Plan on the Experiences and Coping Strategies of Parents of Children with BTM

Problem statement:	Little is known about the experiences and coping strategies of Jordanian parents of children with BTM.
Review question:	Parents care for children with BTM: what are their experiences and coping strategies?
Aim:	The aim of this review is to explore and evaluate the experiences and coping strategies of parents caring for children with BTM.
Review objectives:	<ul style="list-style-type: none"> • Search for papers on the experiences and coping strategies of parents of children with BTM, families, caregivers and mothers. • Collect data on the experiences and coping strategies of parents of children with BTM, families, caregivers and mothers. • Compare the findings of this review with other reviews. • Provide recommendations and suggestions to support and empower parents who care for children with BTM.
Title	A literature review on parents caring for children with BTM: the experiences and coping strategies of parents of children with BTM.

Source: Author (2012) adopted from (Bettany-Saltikov, 2012)

To facilitate the search process the following research strategies was adopted which I found them easy and organised the searching process:

1. I wrote down the research title and the three research questions and identified the component parts to start the literature research;
2. I identified any synonyms, in order to have a more comprehensive search;
3. I identified combined words;
4. I identified my research literature sources.

After identifying the component parts of the research questions, I broke them down using the acronym PEO, which stands for patients (P), exposure (E), and outcome (O) which was adopted from (Bettany-Saltikov, 2012) as shown in table 4.

Table 4 The Qualitative Experiences Questions and PEO

Using PEO to ask clear qualitative questions		
Patients (P)	Exposure (E)	Outcome (O)
Parents of children with BTM	Having family member with BTM	Parents' experiences and coping strategies

Source: Author (2012) adopted from (Bettany-Saltikov, 2012)

Then I identified any synonymous words, to have more comprehensive search, to facilitate the search process and to confirm that different research concepts were covered in the literature review. I searched the database using keywords, component words and any synonyms. The search carried out by combining keywords and synonymous words using 'OR', and using related links and advanced search. The search strategy used helped me to expand the scope of literature review and to view a number of studies relevant to the study, among the keywords used in the search were:

1. Thalassaemia major,
2. Beta-thalassaemia,
3. Parents,
4. Children,
5. Jordan,
6. Experiences,
7. Coping Strategies.

During the search process, the keywords used either searched alone or in various combinations and arrangements. In addition, the search words were used either in the singular or plural forms, again combined in various ways using the keywords and synonyms. For example, 'thalassaemia in Jordan' gave different results in the database to 'Jordan and thalassaemia', and 'patient with thalassaemia' yielded different literature to 'children with thalassaemia'. This assisted me in getting access to a wide range of relevant

literature. In order to find global literature, both American and British spellings were used to facilitate inclusion of the relevant literature in the searching process. Furthermore, I used combining or link words such as 'AND' and 'OR'. These words used depending on the requirements of each online databases. In order to identify the words variation and give more alternative terms, truncations were used, such as the dollar sign (\$) or asterix (*) after the keyword. Truncations used with the root of the search term and replace the ending with an (*) or (\$) for example, when I type Jord* the search will give me Jordanian and Jordan. Table 5 shows the key words, synonyms and phrases used in the search process.

Table 5 The Key Words, Synonyms and Phrases used in the Literature Search

Combined with	Words, Phrases, and Synonyms
	<u>Patients</u>
OR	1. Parents (\$)
OR	2. Care giver
OR	3. Mother
OR	4. Father
OR	5. Family/Families
OR	6. Jordanian Parents
OR	7. Jordanian children/child
OR	8. Children (*)
	9. Combined 1- 8 using 'OR'
	<u>Exposure</u>
OR	10. Thalassaemia (\$)
OR	11. Thalassaemia Major
OR	12. Beta-Thalassaemia Major
OR	13. Alpha-Thalassaemia
OR	14. Beta-Thalassaemia
OR	15. Thalassemia
OR	16. BTM
OR	17. Haematological Disorders
OR	18. Chronic Disease
	19. Combined 10-18 using 'OR'
	<u>Outcome</u>
OR	20. Experience(*)
OR	21. Adaptation
OR	22. Adjustment
OR	23. Coping
OR	24. Social life
OR	25. Interaction
OR	26. Psychological status
OR	27. Quality of life
	28. Combined 23-26 using 'OR'
Combined 9, 19 and 28 together using 'AND'	

Source: Author (2012) adopted from (Bettany-Saltikov, 2012)

I used both general and advanced search engines, published and unpublished data and various available sources and databases. To ensure a comprehensive search, the sources of information varied. For instance, I used the online general and special databases, journal articles, books, theses, conference papers and e-books. In addition, I contacted some experts in the field from both academic and professional backgrounds.

The databases used in the search process included EBSCO, PsycINFO (APA), CINAHL, MEDLINE, PUBMED, and the Index to United Kingdom Theses. The online databases were accessed frequently, using a systematic searching process, storing and arranging the relevant literature. This allowed me to expand the search process by using the 'related articles' and 'similar findings' tools in the database website. A snowball sampling approach used, which helped me to expand and organise the applicable literature. Greenhalgh and Peacock (2005, p. 83) argued that the snowball approach is the most effective technique to search for relevant literature. One of the advantages of using electronic database resources in the literature search process is that it enabled me to create an 'Online Personal Accounts' that could be used to save and retrieve relevant literature at any time.

Specialized databases were also used, such as Evidence-Based Nursing (EBN), the Royal College of Nursing (RCN) and TIF. These databases helped me to expand the search and gave me access to the researchers, and in some cases to the full text of the literature. In addition, articles from journal and non-journal literature were reviewed, including published abstracts, theses and research papers. To have a full access to the literature, in some occasion, I contacted some researchers and experts through e-mails, telephones calls and personal meetings. Furthermore, I gained access to some experts in the field of haematological disorders, nursing, social and health care during workshops and national and international conferences which I attended (see Appendix 8). General search engines

such as Google, Google Scholar and The National Library for Health through the National Health System (NHS) were also used to have access to reliable and up to date web sources. They were also used as a gateway to access other database resources. The results of the search process were saved either in the database personal account, in computer files or as a hard copy in my office.

2.4 Literature Review Criteria

I adopted the inclusion and exclusion criteria shown in table 6 for reviewing the literature to increase the relevance of the results which also helped me to organise the work and save searching time. Aveyard (2010) found that inclusion and exclusion criteria give vital information about the scope and relevance of the review, it's improve the quality of the literature review which should be *“rigorously and transparently reported a priori (before you start the review)”* (Torgerson, 2003, p.26 cited in Bettany-Saltikov, 2012, p.55).

Table 6 Inclusion and Exclusion Criteria in the Literature Review

Inclusion criteria in reviewing the Literature	Exclusion criteria in reviewing the Literature
1. Literature on parents of children with BTM, caregivers, mothers, patients with BTM and family experiences, adaptation and coping strategies.	1. Literature published in languages other than English
2. Literature related to the parents of children diagnosed with other thalassaemia types, with haematological disorders or with chronic illnesses.	2. Primary research and studies that were totally focused on biochemistry and genetic detection and physiological and path-physiological of beta-thalassaemia disorders.
3. Published and unpublished literature on the phenomena under study, including the full text and abstract.	---
4. Literature written in English.	---
5. Published and unpublished data from various websites, the WHO, TIF and theses in the area of study.	---

Source: Author (2011) adopted from (Bettany-Saltikov, 2012)

Furthermore, to give a comprehensive, high-quality review of the literature, different types of studies were included in the review process on the experiences and coping strategies of parents of children with BTM; see table number 7 for literature inclusion and exclusion criteria.

Table 7 Literature Review on the Experiences and Coping Strategies of Parents of Children with BTM

Types of study	Inclusion Criteria	Exclusion Criteria
Qualitative	Phenomenological, grounded theory, case studies and ethnography	Letters and commentaries
	Descriptive articles	
	Qualitative theses	
Quantitative	Descriptive quantitative	
	Case control or clinical control studies	None
Mixed Methods	Qualitative, quantitative and mixed designs used	None
Study methods	Observation, focus group, surveys, questionnaire and interviews	None
Field of the Study	Nursing, social sciences and medical literature.	Pathological and gene detection, thalassaemia mutation types.

Source: Author (2011) adopted from (Bettany-Saltikov, 2012)

To give a systematic and organised approach in selecting the literature, population criteria were set, this approach adopted from Bettany-Saltikov (2012). For this study the criteria set to the parents and their children with BTM, which are summarised in table 8.

Table 8 Population Criteria for the Literature Review

	Inclusion Criteria	Exclusion Criteria
Clinical population	<ul style="list-style-type: none">- Mothers, fathers, couples, caregivers, parents and families of one or more patients with BTM.- Patients with BTM.	Nurses and HCPs.
Diagnosis	<ul style="list-style-type: none">- Parents of patients with BTM, haematological disorders, and other chronic illnesses.	None
Participants' age	<ul style="list-style-type: none">- Participants at any age who care for patients with BTM.- Male and female patients with BTM in any age group.	None
Stage or severity of disorder	<ul style="list-style-type: none">- Participants with different experiences and various coping strategies.- Patients diagnosed with different types of thalassaemia, including Beta, Alpha and Intermedia, at different stages of the disorders.- Patients with BTM who received both the oral or infusion types of iron chelating therapy.	None

Source: Author (2011) adopted from (Bettany-Saltikov, 2012)

2.5 Literature Review Process

Once the literature which are met the criteria had been identified, it was organised and reviewed in two phases: first, based on the titles and the abstracts, second by reading the full text. The reviewed literature was arranged and organised under the following headings and sub-headings relating to different stages of the research and chapters of this thesis:

- Experiences, coping strategies and quality of life of children with thalassaemia;
- Families' experiences of patients with BTM;
- Mothers' experiences, role, and involvement in caring for their chronically ill children;

- BTM genetic disorders; prevalence, complications and therapy;
- Thalassaemia types;
 - Treatment for children with Beta-Thalassaemia;
 - Psychological Therapy;
 - BTM Complications;
- The experiences and coping strategies of families ‘or’ parents ‘or’ caregivers ‘or’ mothers ‘or’ couples having or caring for children with BTM ‘or’ patients with BTM ‘or’ chronic disorders ‘or’ haematological disorders;
- Coping strategies used to deal with chronic disorders ‘or’ with thalassaemia ‘or’ with haematological disorders.

It is worth mentioning, that the relevant literature was reviewed before and after data collection as a matter of principle, according to the grounded theory approach advocated by Strauss and Corbin (1990; 1998). Strauss and Corbin claim that a preliminary review of the literature before starting the data collection can enhance the researcher’s theoretical sensitivity. Charmaz and Bryant (2007, p. 611) define theoretical sensitivity as “*the ability to see ‘relevant data’ and to reflect upon empirical data*”. They argued that some researchers reported their findings as a new ideas without knowing that their claims had already been developed by other researchers. Reviewing the literature before conducting the research avoids this problem. I carried out a focused and intense literature review of relevant Jordanian literature before conducting this research, to avoid replication of previous studies. This enhanced and enriched my background knowledge about the contributions of Jordanian literature in the field of thalassaemia and helped me to identify the role of the nurses and HCPs in conducting such studies. In their study, Chenitz and Swanson (1986) argued that reviewing literature could enhances the researchers’ awareness of the participants’ contributions in their studies. I agree with their findings that reviewing literature is important at any stage of the study, as long as the researcher

understands the objectives and the purpose of his/her own study and the review process, this view is also supported by Charamz (2008).

I believed that reviewing the literature before collecting the research data would also give an idea about the researchers' and the participants' inputs and the scope of their concerns. In this study, the literature review increased my ability to deal effectively with the key research issues, such as data collection and analysis. Arguably, this is important for new researchers and postgraduate research students. Reviewing the literature assisted me in gaining better understanding and gaining new insights from the professionals' knowledge and their experiences in conducting interviews and handling the research data appropriately. For instance, reviewing some literature before collecting the data enhanced my ability to deal with interviews' issues, coding and categorising the data in grounded theory. Chenitz and Swanson (1986) stated that in grounded theory research, reviewing the literature is an ongoing process throughout the different research stages. I followed this advice. However, I was aware that the purpose and the intensity of the review kept changing over the research process. In summary, I found that keeping up to date with the literature through the different research stages:

1. Gave me an opportunity to gain better understanding about the process of doing qualitative research using a grounded theory design;
2. Enhanced my ability to analysis the data through coding, categorising, comparing and contrasting the findings with existing literature;
3. Helped me to keep a reflective account, which enhanced my objectivity;
4. Assisted me in 'in-depth identification' of the significance of the research findings and the phenomena under study;
5. Helped me to identify the scope and range of the research related to the subject under study.

Charmaz and Bryant (2007) found that the researchers' confidence in reviewing literature increased over time. The reviewing process provided a framework for the research, as well as helping them to conduct the research study. My aim in the literature review was to acquire an acceptable understanding of the subject matter, through gaining knowledge of what had previously been researched. Identified the searching aim helped me to avoid becoming totally engaged in preconceived notions. However, it is worth mentioning that although my clinical experiences and academic background had already exposed me to certain aspects of the experiences and coping strategies of parents of children with thalassaemia. However, it did not draw the full and complete picture, which urged me to carry out this study. It can be argued that the previous experiences I had in the field effectively prepared me to conduct such study.

There is an ideological debate about whether literature should be reviewed before or after data collection in the grounded theory researches, Glaser (1992) disagreed with Strauss and Corbin (1998) about reviewing literature prior to data collection, arguing that this could taint the researcher's view about the findings and constrains the generation process of the categories (McCann and Clark, 2003). Glaser argues that the literature should only be reviewed after the data collection, during the data analysis phase, as the main themes and categories of the research begin to emerge. However, Glaser also argued that researchers should not categorise findings in isolation from the existing literature, in order to have chance to compare them. In addition, Glaser asserts that researchers should be cautious when reviewing literature and comparing the findings with the existing literature, to avoid unconsciously misleading or cross-contaminating the findings.

Glaser argues that researchers should try to focus on identifying new findings and new themes, with no or minimum impact from the existing literature. This argument could be connected with the researcher's objectivity which is an important issue in conducting a

qualitative studies, as it helps to maintain and increase the researcher's detachment from the findings and improve the rigour of the research. In this study, I focused on using memos and a reflective account at all stages of the research and to clearly identify the aim and objectives of the literature review which I conducted before the data collection and after. The comprehensive and in-depth review took place at the stage of data analysis, as I aimed to update, challenge and connected the research findings with the literature in the field.

Moreover, performing qualitative research is an ongoing learning experience that adds to the researcher's knowledge and skills. Each time the researcher engages in new types of research, he/she gains more advanced knowledge and experience. In practicality, the researcher cannot enter the work field with totally empty minded from knowledge about the research subject but with the minimal background which could help him or her to enhance their ability to carry out the study. The argument is any individual cannot isolate the knowledge and experiences he/she gained in school from what he/she is learning in a university degree. However, students' build on their background information and gain new knowledge over time, preparing them for a new stages in life. Arguably, by reviewing the relevant literature, researchers can gain better understanding to help them carry out their research and identify the phenomena under study. More details about the researcher theoretical sensitivity in Chapter Four section 4.6.4.

2.6 Relevant Literature on Beta-Thalassaemia and Chronic Illnesses

This section presents the relevant literature to highlight experiences and coping strategies adopted by parents of children with BTM. The review introduced and discussed the available literature under the following categories: mothers, families and patients with BTM experiences, coping strategies, and what is known about BTM in Jordan. I adopted the 'PRISMA' diagram (Moher, et al., 2009) (see Appendix 2) to identify and screen the

eligibility of the literature which was reviewed in this study (see Appendix 1 and 1a). However, it is worth mentioning that during the literature review I noted that most of the existing literature about parents', mothers', families' or caregivers' experiences and methods of coping originated in developed countries where genetic health services and screening programmes more advanced than the available in Jordan, or from countries with different social, cultural and religious backgrounds to Jordan. This inspired me to do an in-depth search of the Jordanian literature to identify gaps and to explore what is known about BTM in Jordan.

2.6.1 Quality of Life of Patients with BTM

In order to explore the experiences and coping strategies of parents of children with BTM, a review needed about the quality of patients' lives, their needs, experiences and the impact of the disorder on them. Furthermore, it was important to understand how caring for children with BTM could be differs from the care of healthy children.

Reviewing the literature showed that thalassaemia may lead to a variety of physical, psychological and social burdens in patients and their caregivers. According to Harteveld, et al. (2003), the incidence of psychological disorders such as depression and anxiety is higher in children with BTM than in children with other chronic disorders. The argument is that, as a haematological disorder, BTM has physical impacts including life-long blood transfusions and chelating therapy, which are needed for patients to survive. Many studies that measured the impact of BTM on patients' lives adopted the World Health Organisation Quality of Life (WHOQoL) (1995) questionnaires. It was developed in 1991 by international and multicultural centres worldwide (WHO, 2013) to measure quality and perceptions of individual life, taking account of variations in cultural and social background. For instance, a study by Shaligram, et al. (2007) investigated the psychological problems and the Quality of Life (QoL) of thirty-nine Indian children aged

between eight and sixteen years of age with transfusion dependent thalassaemia (TDT), those children attending day care blood transfusion in Bangalore. They found that around 44% of children with BTM had psychological problems. 74% had poor quality of life due to pain and discomfort and 67% had anxiety related symptoms. In addition, Shaligram, et al. (Ibid) identified depression as one of the emotional problems and various behaviour-related disorders. Similar findings were reported by Ismail, et al. (2006) in Malaysian children with BTM aged between twelve and eighteen years. They measured the quality of life of Malaysian children with BTM in Kuala Lumpur hospital using the QoL measure. They found that, Malaysian children with BTM scored lower QoL scores than healthy children of the same age group.

In Jordan, Gharaibeh and Gharaibeh (2011) measured the QoL of 128 Jordanian children with BTM aged between eight and eighteen years of age. They found that Jordanian children with BTM scored low in all domains of the QoL, and significantly lower than healthy children in academic and physical functioning domains. In addition, the poor quality of life was also documented among Pakistani children with BTM and their parents in Ammad, et al. (2011) study where they found that the children experiencing pain, sleep disorders and having limited leisure activities. Gharaibeh, et al. (2009) investigated and identified the psychosocial burden variable in the children diagnosed with BTM in Syria, they found that the psychosocial burden affected many aspects of the life of Syrian children such as education, sporting capabilities, and time off school, anxiety and stigmatization. Gharaibeh (Ibid) also found there is significant associated between the psychosocial burden variables and the children age, gender and family income.

In India, Khurana, et al. (2006) undertook a study aimed at measuring the psychosocial life aspects of adolescent children with BTM suffering from blood transfusion. The study found that most children not satisfied with their body image, and they experienced various

psychosocial burdens. In addition, the study found that BTM has a negative impact on education in 70% of the study sample, and on sports in 72%.

From the above review it is clear that children diagnosed with thalassaemia are likely to experience impairment in many areas of life, including physical, education, recreation and vocational pursuits. Furthermore, parents are also affected in terms of their social, economic and personal endeavours. To support children and families, and to minimise the negative impact of BTM, a great deal of literature suggested that there is a need to an education programme to assist and facilitate patients with BTM and their families management with the disorder, and to decrease the negative impact of the disorder on their lives (Sadiq, et al., 2000; Atkin and Ahmad, 2000a; Prasomsuk, et al., 2007). However, such interventions require HCPs to understand parents' experiences and coping strategies in caring for children with BTM.

2.6.2 Families' Experiences

Having daily responsibility for a child with a chronic illness is a great challenge. Therefore, it is important to investigate the families who care for children diagnosed with thalassaemia in order to find out how they manage to maintain their family unity, healthy lifestyle and wellbeing. Families of children with chronic disorders like thalassaemia tend to be caught up in a vicious cycle of psychosocial adversities as they endeavour to take care of their children, and tremendous burden when caring for them at home (Newton and Lamarche, 2012).

For instance, Gravelle (1997) found that parents of children with chronic disorders tend to develop deeper sorrow and stress as their child's disorder progresses over time. Moreover, there could be a significant shift in family social and daily life activities in order to dedicate more time to taking care of their chronically ill child, depending on the

child's age as well as the type of disorder. Another emotional burden was addressed in a study by Prasomsuk, et al. (2007) about parents caring for children with BTM. Major (2003) argued that it also could put other family members at risk for physical and mental health problems. Increased the stress and disequilibria the family unit (Meleski, 2002). In their study Pruthi and Singh, (2010) found that the psychosocial burden was greater in thalassaemic group participants followed by Cerebral Palsy (C.P) group and the quality of life and health was found to be very poor and dissatisfied in thalassaemic and C.P caregiver as compared to the control group participants. Pruth and Singh (Ibid) also found that due to the complex treatments and regular hospital visits, the psychosocial burden was most affected in the thalassaemic caregivers than the C. P group. To assist children with BTM and their families Eiser (1997) suggested that therapeutic interventions for chronically ill children and their parents should aims at offering positive coping strategies and decrease the negative impact of the disorder.

Social, religious and cultural issues are considered to be among the main factors in determining family attitudes, roles, and understanding of the consequences of chronic illnesses. Furthermore, they can be major determinants in shaping family coping and adaptation strategies. Atkin and Ahmad (2000a) found that religion and social support are the main factors help for mothers caring for children with sickle cell disease or thalassaemia. However, chronically ill children who are in single parent homes, or who are adopted or fostered, seem to register a higher rate of emotional and psychological problems than children with their biological parents. Therefore, there could be a need for extra support alongside the recommended treatment and counselling. In addition, Aydinok, et al. (2005) found that most parents of children with BTM tend to worry about their future health.

Olsson and Hwang (2001) found that parents of children with intellectual disabilities or autism had higher scores for depression than the control group in their study. Furthermore, another study by Sharghi, et al. (2006) found that there was an independent relationship between mothers' depression scores and the lifelong blood disorders of their children.

Arguably, the varied experiences of families and caregivers of the chronically ill depend on individuals' experiences, perceptions, attitudes and the support they received while caring for their chronically ill children, which could be either positive or negative. Another point worth mentioning is that variations in social environment, culture and religion have great impact on people's lives and their experiences. Barakat, et al. (2006, p.417) counter argue and present the positive impact of caring for chronically ill child on the families. In their study Barakat, et al. (Ibid) found that parents struggling with their child's illness for many years could positively impact on other family members and make them stronger in their lives. The results of their study indicated that about 86% of mothers of adolescent cancer survivors said the experience had *"a positive impact on how they think about their lives"*.

From the aforementioned research, it is clear that caring for chronically ill children and children with BTM has a negative impact on families and caregivers. Although there are some commonalities in the experiences of caregivers of children with chronic illnesses, it would be wrong to consider all chronic disorders alike. Lutz, et al. (2004) argued that chronic disorders varied in the manner in which they affect children and family members. For example, there might be a wide range of differences in the type and nature of stress, within the various types of chronic illnesses such as diabetes, cerebral palsy, and sickle cell anaemia. Cohen (1999) found that there is negative impact that illness demands can have on the family of children with chronic illnesses and the positive impact that family system resources can have on illness management.

Consequently, methods of adapting to each situation may also be quite different. Variables such as the child's age and gender has been successfully used to predict family functioning and child's adjustment (Lutz, et al., 2004). For instance, Cowan (2002) found that families with lifetime care of children with cerebral palsy tend to face unique types of stress and demands over the period of their child's life. Furthermore, some families of children with leukaemia rated themselves as less cohesive and more prone to family conflicts than did families of healthy children (Morris, et al., 1997). However, the result for children's adjustment may be different, according to Morris, et al. (1997), who found that there were no differences in adjustment between children with leukaemia and healthy children, but that both groups scored well within the normal range in measurements of adjustment. It is important to note that chronic illnesses can be challenging and have a greater impact on the adaptation and adjustments of families more than on the affected children.

The effects of some chronic illnesses on affected children and their families could be much greater than those of physical disabilities (Martin and Nisa, 1996). It is worth mentioning that family function can effectively shape the family's ability to recognise the child's need for independence. Chen and Clark (2007) stated that the function of families with disabled children displayed a significant correlation with the age of their children, and not with their level of disability. In addition, parents were able to support children through the process of attaining a complete 'own responsibility' of care at some stage in their life (Eiser, 1997).

The challenges and stresses the family face as a result of caring for their child with thalassaemia can also cause a family to become dysfunctional in respect of its position as a 'primary social unit'. Heydarnejad, et al. (2011) recommended that increasing the level of parents' knowledge could assisted them to decrease the emotional and social

burdens of the disorder. Of concern is the impact that progressive family dysfunction could also have on unaffected family members in the form of unintended neglect. Ray (2002) argued that the parents may not give the same attention to the healthy children in the family. According to Eiser (1997), healthy siblings can also become vulnerable. The magnitude of their vulnerability may depend on their age and the nature of the disorders of the affected child. For example, a toddler trying to become independent may conflict with his/her parents' perceptions. The latter may doubt the quality of their autonomy, which can negatively impact on the affected sibling (Eiser, 1993). Ahmad and Atkin (1996) found that siblings and partners could have the feeling of being neglected because of the focused care on the chronically ill family members. Similar experiences are reported by Beresford (1994), who highlighted the idea of disturbance in the social lives of the caregivers and siblings of children with BTM. For instance, siblings of children with BTM could experience social isolation and challenges to maintain their friendship over time which is also address in the Baldwin and Carlisle (1994) study. Meyer, et al. (1994) argued that siblings' coping strategies could be improved if they encouraged to share their concerns with their families.

2.6.3 Mothers' Experiences

Mothers tend to take an active role in caring for children with chronic disorders such as BTM. In many cases, mothers are considered the primary carers for their chronically ill children, more than other family members. If they employed, this may eventually lead them to relinquish paid work in order to concentrate on child care (Olsson and Hwang, 2001).

In the literature, I found that a great deal of studies such as (Goldbeck, et al., 2000; Atkin and Ahmad 2000b; Zahed, et al., 2002; Caro, et al., 2002; Prasomsuk, et al., 2007) reported that BTM has a negative impact on the mother's quality of life caring for a child

with BTM. For instance, Sapountzi-Krepia, et al. (2006) used a semi-structured questionnaire to interview nineteen mothers of children with thalassaemia about their experiences. The study found that there was a failure to provide adequate information regarding care, pre-marriage tests and genetic screening for thalassaemia carriers, both before and during pregnancy. In addition, emotional distress, fear of death, and difficulties in dealing with feelings were some of the mothers' concerns. Although approximately half of the participants wished that support had been offered on a more regular basis, most of them stressed that the support was affected by shortage of nursing staff.

It can be argued that mothers of children with thalassaemia may be at higher risk of suffering from psychological distress and depression, because they tend to bear a much bigger responsibility as caregivers than other family members. This argument is supported by a study conducted by Sharghi, et al. (2006), which compared the depression scores of mothers of children with either thalassaemia or blood malignancies to those of a control group. The results showed that the only variable bearing a statistically significant relationship with the mother's depression score was the child's disorder. Gazmararian, et al. (1995) and Altshuler, et al. (2001) reported that the incidence of depression in women was twice as much as in men, because of biological, socio-economic, and psychological circumstances. Furthermore, it is argued that mothers tended to tolerate more stress than fathers and were thus at a higher risk of depression (Olsson and Hwang, 2001). Prasomsuk, et al. (2007) found that fifteen mothers caring for children with BTM in Thailand experienced psychological problems such as fear and worries about their children's future.

A quantitative study carried out by Van den Tweel, et al. (2008) evaluated the quality of life of female caregivers of children with sickle cell disease. The researchers compared

two groups that were similar in socio-economic status. The findings showed that the quality of life of caregivers of children diagnosed with sickle cell disease was significantly lower on the subscales of depressive moods, daily activities, and vitality than the control group. In another study, Mazzone, et al. (2009) found that mothers of children with BTM had impaired perception about the quality of their life, especially in the physical and psychological domains. This also supported by Baker, et al. (2002) findings which indicated that mothers of children with thalassaemia seemed to have an increased risk of a lower level of well-being. From the previous review, it can be argued that mothers of children with BTM and other chronically ill children required ongoing support in order to be able to conduct their caregiver role and motherhood effectively.

2.7 Coping with Thalassaemia

The literature suggested that providing parents with appropriate health education and social support could be key factors in coping successfully (Baldwin and Carlisle, 1994; Midence and Elander, 1994; Ahmad and Atkin, 1996). Some studies such as (Hoch, et al., 2000; Angastiniotis, 2002; Louthrenoo, et al., 2002) suggest that families were the main sources of patients' support and coping, because in most cases, they are considered the primary caregivers for their chronically ill children at home and hospital. For instance, parents usually responsible for attending frequent hospital visits with their children for blood transfusions, and giving iron chelating medications at home. They also have to demonstrate adequate knowledge about BTM complications and its management to take the appropriate decision in case of emergency. According to Politis (1998) and Louthrenoo, et al. (2002) families of patients with thalassaemia must learn how to deal with frequent and demanding hospital visits, which in some cases may result in a psychosocial burden. It has been argued that there are many factors related to the coping strategies and adjustment processes of children with chronic illnesses and their families,

such as family type, the progress of the health disorder, and the availability of medical and social support (Wallander and Varni, 1992). Compas, et al. (2001) assumed that the family unit provides a primary context in which children grow and develop, as well as adopting ways of coping with stress. Findings from Betman (2006) seem to indicate that family coping is related to illness outcomes, and that coping strategies vary depending on the source and intensity of the stress. For example, the incidence of life stresses, marital satisfaction and family socio-economic status have a significant impact on families' coping. Coping strategies used by families were found to be significant predictor of their ability to cope positively, in order to maintain family functionality.

Chapple, et al. (2004) found that some families of children diagnosed with cancer believed that suffering through side-effects was 'necessary' for their children to overcome the disorder. They tended to believe that this would teach them to adapt more positively to their cancer experience. However, it was further observed that parents felt that all symptoms 'stuck' and that they were never completely eliminated with time.

It is therefore assumed in this study that exploring and understanding the coping strategies described by the parents themselves could give parents and HCPs an opportunity to review the impact of BTM on parents' lives. In addition, it will help to evaluate the effectiveness of those strategies in order to improve the quality of parents and children's life, as well as to maintain an acceptable level of wellbeing.

2.8 What is known about Thalassaemia in Jordan

Based on the literature review and background about thalassaemia in Jordan, it has become clear that thalassaemia is a relatively common haematological disorder in Jordan. Yet, its impact and its consequences for the family unit, function and society have not been studied in detail. The review of Jordanian literature showed that there were a round forty-five studies of patients with thalassaemia and their families, addressing and

exploring various areas (see Appendices 1 and 1a). After reviewing the studies, they were organised and classified into the following themes: The physiological impact of BTM; the side effects and complications of BTM; knowledge and attitudes of parents of children with BTM; and BTM mutations.

Based on the review, there were about four studies which explored and addressed how BTM impacts on the patients' bodies and physiological functions: for instance, some studies addressed thyroid function in patients with thalassaemia (Al-Hader, et al., 1993; Irshaid and Mansi, 2011) which indicated that patients with thalassaemia demonstrate thyroid dysfunction and significantly high level of serum ferritin, zinc and copper, the main possible cause is iron overload. Another study by (Al-Rimawi, et al., 2005) addressed the impairments of the hypothalamic-pituitary-gonadal function in adolescent females with BTM. Furthermore, Jordanian patients with BTM showed significantly lower in total cholesterol, high-density and low-density lipoprotein cholesterol study by (Mansi and Aburjai, 2008), and significant iron overload when compared with control group according to Abdallah, et al. (2011). There are studies measured the copper, zinc such as (Bashir, 1995; Mansi, et al., 2009) and cortisol (Bashir, et al., 1993) levels in the Jordanian children with BTM. The aforementioned studies highlighted the impairments level and how it negatively impacted on children's physical activity and wellbeing.

The second theme, comprised seven studies which evaluated and addressed the impacts of BTM on the process of growth and development. For instance, Abu-Alhaija, et al. (2002) investigated facial deformities in patients with BTM, they found that most of patients showed reduced posterior facial height and increased anterior facial proportion. In addition, there were many studies explored dental disorders such as (Al-Wahadni, et al., 2002; Al-Wahadni, et al., 2005; Hazza'a and Al-Jamal, 2006a; 2006b; Hazza'a, et al., 2010) which mostly found that dental caries was a significantly higher in patients with

thalassaemia compared to the healthy controls. Pubertal and hypothalamic-pituitary-gonadal function in adolescents with BTM were also explored by (Al-Rimawi, et al., 2006a), they found that despite recent therapeutic advances in the management of BTM, the risk of secondary endocrine dysfunction remains high. They address that the hypogonadism is one of the most frequent endocrine complications with the children. In another study Abu-Ekteish, et al. (2007) evaluate the pulmonary function in Jordanian patients with thalassaemia, they found that most patients have a predominantly restrictive lung dysfunction pattern.

The review also indicated that there is a relationship between thalassaemia genes and other genetic disorders, such as sickle cell disease has been researched to identify the genetic background and the progress of such disease in the Jordanian community studies conducted by (Barkawi, et al., 1991; Bashir, et al., 1992a). In addition, there were ten studies (Bashir, et al., 1992b; 1991; Sunna, et al., 1996; Gharaibeh, et al., 1998; Babiker, et al., 1999; Sadiq, et al., 2001; Al-Qaddoumi, 2006; Al-Sweedan, et al., 2009; El-Akawi, et al., 2009; Nusair, et al., 2011) carried out to identify BTM mutations and the prevalence of the disorder in the Jordanian community. Furthermore, there are some studies assessed the genotoxicity in patients with thalassaemia such as (Al-Sweedan, et al., 2012) as well as the subtype, molecular spectrum and characteristics of alpha- thalassaemia by (Abu-Ghoush, 2008; Al-Qaddoumi, et al., 2008) and beta-thalassaemia by (Sadiq and Huisman, 1994). For more details (see Appendix 1 and 1a).

The review showed that there were some qualitative studies which addressed the knowledge and attitudes of families, parents and caregivers of children with thalassaemia. Barkawi, et al. (1991) were probably the first researchers to show that there is a significant difference between sickle cell thalassaemia and sickle cell disease in relation to the nature of the disorders and the variety of clinical presentations of each disorder in a Jordanian

family. They also detected the severity in the progress of the sickle cell thalassaemia syndrome.

Sadiq, et al. (2000) conducted a qualitative study in the northern region in Jordan. They interviewed 77 families of children with BTM. The study found that around 75% of the families had not heard about BTM before having the first affected child. Although, most of the families were properly informed about BTM, the study highlighted two further issues: the psychosocial burden on the children and their families, as well as the enormous national costs of BTM treatment.

Mrayyan, et al. (2004) published a study which revealed that Jordanian families were aware that intermarriage was an important aetiological factor in thalassaemia. They assessed Jordanian families' knowledge and their attitudes toward genetic counselling by collecting data from 100 families of children with BTM using structured questionnaires. They found that around 70% of the affected families of children's with BTM discovered the disorders through its signs and symptoms and by chance. Their findings were similar to those of Sadiq, et al. (2000) about the parent's knowledge about the disorders and the nature of BTM. Another interesting finding from the study is that although most of the respondents were aware of the genetic origins of thalassaemia, preventative measures to avoid having other affected children were not taken. In another study Gharaibeh (2001) found a significant relationship between parents' knowledge and their perceptions about susceptibility and the benefits of counselling and testing. Furthermore, Gharaibeh (2001) found that parents' attitudes towards termination of affected pregnancies and limitations on having more children were barriers to the control and prevention of thalassaemia.

Gharaibah, Mrayyan and Sadiq's studies focused on researching parents' knowledge and their attitudes toward family planning, the disorders complications and preventative methods. The literature recommended that counselling and education programmes were

needed for the families of children with BTM. From these studies, it can be concluded that families of children with thalassaemia had limited options in having a healthy child and in termination of affected pregnancy. It is also clear that there is a need to assist Jordanian families in caring for their children, to evaluate the social and psychological burden, to highlight the impact of BTM on their daily lives, and to identify the available resources and the quality of care they receive as parents. According to Caro, et al. (2002), the affected children and their caregivers' mental, physical, and social well-being can be at risk of degradation in terms of outcome. El-Shanti (2001) and Hamamy, et al. (2007a) discussed the premarital screening programme and the strategies for thalassaemia prevention in Jordan. Both studies identify ethnicity, immigration, consanguineous marriage and the high birth rate as the major contributors towards controlling genetic disorders in Jordan. In another study, Hamamy and Al-Hait (2007) suggested that there is a need to implement community-based thalassaemia control programmes, such as the one already adopted in many Arab countries including Saudi Arabia, Bahrain, and Tunisia. Arguably, such a programme could be effective because Jordan shares a common language and culture with these countries. According to Hamamy and Al-Hait (2007), a community-based thalassaemia control programme was held in Amman in 2005 in collaboration between the WHO and JMoH.

El-Shanti (2001) and Hammay, et al. (2007a) give an indication of how the process of the genetic health care services may have improved in Jordan within the last few years. These advances in counselling, strategies and community education programmes could also be a response to annual increments in BTM figures of about 80 new cases (Hamamy and Al-Hait, 2007). This yearly increase in patient numbers was also highlighted in a 2004 study by Mrayyan, et al., which indicated that most Jordanian thalassaemia carriers did not take appropriate preventive measures to avoid having children with thalassaemia were not

taken. The authors stated that most families knew about the thalassaemia by evidence of its signs and symptoms within their children.

It is worth mentioning that the previous studies, which were conducted in Jordan, recommended that there is a need for more research on families of children with BTM to explore their experience and coping strategies used to adapt to the lifelong condition. Furthermore, the review showed that there are some theses have been conducted in the Jordanian community in the field of thalassaemia studies. For instance, Oseroff (2011) conducted a thesis evaluating the ethics of the Jordanian thalassaemia prevention programme and discussing counselling, consanguinity and premarital testing; Qubbaj (2003) conducted a thesis exploring the different approaches toward the prevention of thalassaemia in Jordan; and finally Gharaibeh (2001) assessed the Jordanian parents' knowledge and attitudes towards thalassaemia in Jordan in her thesis.

In this literature review, I noted that there are around six studies out of forty four focused on Jordanian families or parents of children with BTM, compared to around thirty two focusing on patients themselves. In addition, the majority of the published studies - around 28 out of the 44 (59%) - were conducted in north Jordan. This is probably because of the high prevalence of thalassaemia mutations occurring in that region (Zahed, 2001). Interestingly, the majority of the studies were quantitative in nature; there were around five qualitative studies out of forty four carried out in Jordan relating to patients with thalassaemia and their families (see Appendix 1 and 1a). Based on the previous reviews, there is a gap in the Jordanian literature regarding understanding of Jordanian parents' experiences and coping strategies in caring for children with BTM. The review to the Jordanian literature did not completely answer the questions I raised from my observations. It can be said that this review increased my research sensitivity, reshaped and developed my approach to thalassaemia in Jordan, and increased my awareness of

exactly what I need to explore about the phenomena under study. In addition, the review guided me to reinforce the previous questions about Jordanian parents' experiences and coping strategies which are not answered in the existing literature. I questioned Jordanian parents' lived experiences. In what way does caring for children diagnosed with BTM impact on parents' social lives? In which areas do parents need to be more educated? What they know, and what do they need to know more about? What are their coping strategies? Do culture and religion affect their experiences, adaptation and coping strategies in caring for their children? What effect do culture and religion have? How do fathers and mothers perceive their roles as parents of a child diagnosed with BTM? What do parents feel? Who cares in the family? How does this experience impact on their roles as mother and father? Is there any effect on family functioning? What keeps them going? How do they manage? What helps them cope? All these questions needing answers occurred to me while reviewing the Jordanian literature, which motivated me to carry out this study and start to organise and formulate the research questions. It inspired me to give the Jordanian parents the chance to talk about their experiences and coping strategies they used. I managed to abstract the previous questions into three main research questions.

2.9 Research Questions

After reviewing the literature about thalassaemia in Jordan, the following research questions were addressed in order to meet the research aim and objectives. The research questions helped me to identify and recognise my interest in this area, as well as kept me focused on the area of study.

Question one: What are the key experiences of Jordanian parents of children with BTM?

Question two: In what ways does caring for a child with BTM impact on the parent's life?

Question three: What are the coping strategies of Jordanian parents of children with BTM as described by the parents themselves?

2.10 Conclusion

This chapter reviewed some of the published literature on experiences and coping strategies of caregivers, with more focus on Jordanian literature that directed and assisted me to identify and formulated the research questions. The reviews started by identifying the aim and explaining the review strategies as well as set the criteria for including and excluding literature. The experiences of children with BTM, caregivers, families and mothers were reviewed, as well as the impact of having children with thalassaemia on parents' and family members' lives. Furthermore, the chapter reviewed the variables that help in caregiver coping and adaptation. In the next chapter I offer some details about thalassaemia. This background about BTM have been given before to enable us understand parents' experiences, we need to know how exactly the disorder presents and what parents are dealing with.

Chapter Three: Thalassaemia

3.1 Introduction

This chapter presents the historical background of thalassaemia. Its genetic origin, pathophysiology, types and complications. In addition, it addresses the available treatments and required therapy for patients diagnosed with BTM.

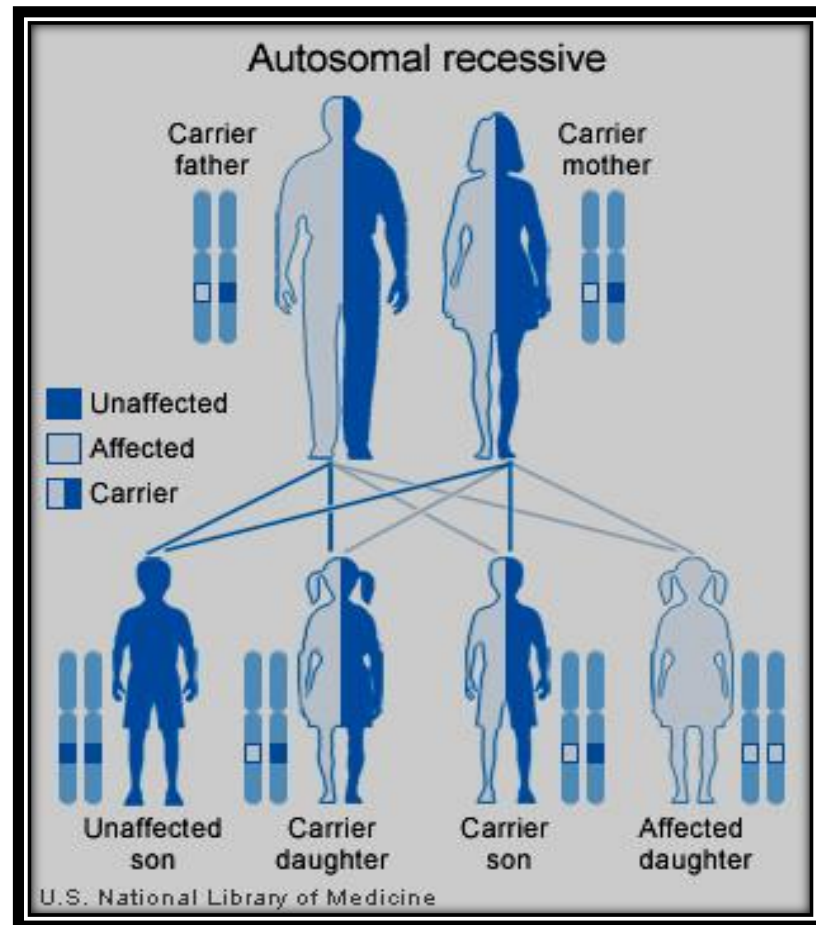
3.2 Genetic Background

Thalassaemia is an inherited genetic disorder entailing high treatment costs in order to allow a longer life expectancy (Dehkordi and Heydarnejad, 2008). The disorder was discovered in 1925, when Cooley and Lee (1925) were working with children in Detroit from different backgrounds, such as Greek, Italian and Syrian. They described it as a severe form of hypochromic, microcytic and haemolytic anaemia, reported in Cooley, et al. (1927) and Surapon (2011). However, the literature seems to suggest that there were some Italian investigations about the disorder before 1925, as observed by Chernoff (1959).

Haemoglobin disorders formerly endemic in around 60% of the world's countries. They were estimated to affect around 75% of the births in the whole world population (Modell and Darlison, 2008). Of the world's population, it is estimated that around 5% have a globin variation; however, around 1.5% have alpha and beta thalassaemia disorders (Rund and Rachmilewitz, 2005; Herbert, et al., 2009). Thalassaemia is transmitted from parents to their children in an autosomal recessive pattern. An 'autosomal recessive' means that if both parents are carriers of the defective gene, one in four children, on average, would be born with the disorder. If only one parent passes the defective gene to their child, the child will only have the thalassaemia trait and will not have the disorder.

Figure 3 gives the details of the autosomal recessive disorder and genetic transition in every pregnancy.

Figure 3 Autosomal Recessive Pattern for Thalassaemia Disorders



Source: (U.S National Library of Medicine)

3.3 BTM History

Although, historically thalassaemia was frequently reported in the Mediterranean area, it also reported in other parts of the world. The background indicates that the disorder was detected in Egypt as early as the 20th century B.C. (Atkin and Ahmad, 1997). It has been argued that the first documented reports of thalassaemia and other haematological disorders as 'Genetic Disorders among Arab Populations' come from Egypt (Diwani, 1944; Abbasy, 1951; cited in El-Hazmi, et al., 2011, p.599).

3.4 Pathophysiology

Thalassaemia is caused by mutation in a gene that has the instructions to formulate part of the beta-or-alpha globin chain. Some mutations prevent the manufacture of normal globin, while others just cause variation. The variation in gene mutations may cause different thalassaemia conditions. Dyson (2005a) and Olivieri (1999) suggest that BTM can be caused by 200 different genetic mutations. For example, the haemoglobin 'E-gene' can interact with b-thalassaemia alleles and cause a clinical severity ranging from B-Thalassaemia Intermediate (BTI) to BTM (Olivieri, 1999; Weatherall and Clegg, 2001b).

The classifications of thalassaemia are based on the chain of the globin molecule affected, either alpha or beta. The severity of the disorder depends on the defects, with either one or both adult globin chains affected (Cao, et al., 1998; Weatherall and Clegg, 2001a; Weatherall, 2010). Al-Sweedan, et al. (2009) stated that adult haemoglobin (HgbA) has four protein chains: two alpha-globin and two beta-globin. There are other types of adult haemoglobin composed of two alpha and two delta, known as haemoglobin A2 (HgbA2) (Herbert, et al., 2009). Moreover, foetal haemoglobin, known as (HgbF), is composed of two alpha chains (Alpha-chain) and two gamma chains (Y-chain) (Chernoff, 1959; Herbert, et al., 2009). According to Herbert, et al. (2009), the process of transition from HgbF to HgbA in a healthy baby normally takes place within the first six months of age. Defects can occur in one or both alpha or beta genes which determine the types of thalassaemia. In either case, the patient will not develop the full-blown disease; it usually produces few or no symptoms. This is known as AT, or thalassaemia minor, which manifests in mild anaemia (Al-Sweedan, et al., 2009). Generally, patients diagnosed with thalassaemia minor required no treatments. However, there could be a need to follow a special precautionary process in their diet and with medications. Around 3.4% of the Jordanian population were believed to be living with thalassaemia minor, according to

Sunna, et al. (1996). According to the WHO publications, around 20% of the world's population are known to be carriers of AT (Modell and Darlison, 2008).

The heterozygous forms trait called BTM is known to be caused by a b-gene mutation, otherwise known as either Mediterranean Anaemia or Cooley's Anaemia (Hazza'a, et al., 2010). Patients with BTM have symptoms of severe chronic anaemia that require frequent and regular blood transfusions. However, it has been found that the blood transfusion treatments lead to increased serum iron levels in the patient's body, which cause damage to some vital body organs. As a result, regular administration of chelating medication is also needed. Current statistics seemed to suggest that on a global scale there are about 80-90 million people carrying the BTM gene (Vichinsky, 2005; Al-Sweedan, et al., 2009). It is also suggested that patients are more likely to be found with other chromosomal anomalies (Al-Sweedan, et al., 2009).

3.5 Thalassaemia Types

Thalassaemia, is represented as a group of common recessively inherited haemoglobin disorders with a diversity of prevalence (Herbert, et al., 2009). It is classified into two main types, known as alpha and beta thalassaemia. There are also many different classifications within the two types, based on gene deletion. The classification depends on which pairs of globin chains is insufficiently synthesised. For example, AT is said to be due to insufficiency in alpha globin chain production, while beta thalassaemia denotes insufficiency in b-globin chain production (Weatherall, 2000). The insufficiency in the synthesis of the chains could be due to either a reduced or an absent globin chain (Herbert, et al., 2009). This imbalance in the globin chains can cause haemolysis, which is responsible for the production of the red blood cells, resulting in different levels of anaemia (Herbert, et al., 2009).

BTM occurs because the red blood cells are deficient in haemoglobin. Additionally, the bone marrow cannot produce enough red blood cells. The bone marrow attempts to compensate, which can lead to modifications in bone structure if not properly treated (Dyson, 2005a). There are many types of thalassaemia. However, the most common in prevalence are BTM, TI, and AT. BTM is a homozygote⁵ type that is a result of a change in the production of the beta (B) chain that makes up adult haemoglobin (Dyson, 2005b). BTM results mainly from gene mutations, although deletion types have also been reported in some patients (Weatherall and Clegg, 2001a).

In cases of beta-thalassaemia, the production of the beta globin gene can range from nearly normal to a completely absent. This range can produce a variety of alpha chains (Herbert, et al., 2009). The severity of the clinical symptoms which patients suffer is based on the extent of imbalance between the globin alpha and non-globin alpha chain (Herbert, et al., 2009; CAGS, 2010). Most symptoms start in the early stages of childhood, between the ages of three and eighteen months. CAGS (2010) stated that symptoms of BTM may include and not limited to childhood anaemia, weight loss, feeding problems, sleep disturbances, stunted growth, irritability, and pale skin colour. It is important to recognised that worldwide there are around 150 million carriers with BTM, translating to around 3% of the world population (Dehkordi and Heydarnejad, 2008; Modell and Darlison, 2008). There are also about 56,000 conceptions and births affected annually by thalassaemia major (Modell and Darlison, 2008). Moreover, in severe untreated cases of iron overload, patients with BTM could develop hepatosplenomegaly, or dysfunction and injuries in the heart, liver, pancreas and joints. For instance, patients could have bone deformities, cardiac failure and exercise intolerance (Barton, 2007).

⁵ Homozygote: an individual having two identical alleles of a particular gene or genes and so breeding true for the corresponding characteristics. Compare to heterozygote (Oxford English Dictionary, 2004).

Patients are diagnosed with asymptomatic BTM at birth because of the presence of ‘infant haemoglobin’ (HbF). In many cases, symptoms start showing at the age of six months (Herbert, et al., 2009). However, patients can be at risk of complications at early stages of their lives. For example, teenagers may develop cardiac and liver complications as a result of iron overload (Herbert, et al., 2009; CAGS, 2010). Moreover, Modell and Darlison (2008) estimated that there are about 100,000 patients with BTM currently living with regular blood transfusions. About 3000 of that number die annually before their 20th birthday due to complications related to uncontrolled iron overload.

The intermediate type is known as ‘Thalassaemia Intermedia’ (TI). TI is known to be less severe in its symptoms than BTM (Herbert, et al., 2009). TI may result in two forms, the first being an inherited form of a mild beta-thalassaemia mutation. The second TI form is the co-inheritance of AT with homozygous beta-thalassaemia (Al-Qaddoumi, 2006). Some children diagnosed with beta-thalassaemia intermedia have clinical features that can include jaundice, paler skin and hepatic-spleen disorders. In addition, patients with TI have a high tendency towards skeletal structure changes, leg ulcers, and a propensity to develop osteoporosis (CAGS, 2010).

Alpha-thalassaemia (AT) is known as the second most prevalent type, which is mainly caused by gene deletion. However, the literature suggests that there are also non-deletion types (Weatherall, et al., 1981; Nienhuis, et al., 1985). This condition is known as ‘a mild anaemia’ or ‘minor anaemia’ and is characterized by low counts of red blood cells, giving a borderline reading for haemoglobin. This usually reports as reduced in MCV and Mean Corpuscular Haemoglobin (MCH) (Galanello and Origa, 2010; Galanello, et al., 1979). In most AT patients, the disorder is discovered accidentally, with no indicating symptoms, suggesting that ‘silent carriers’ of this type of thalassaemia are common. The carriers’ individuals usually clinically asymptomatic. However, mild anaemia can occur in some

cases (Galanello and Origa, 2010). In such scenarios, the patients might have the situation, which one of the alpha genes is absent as opposed to two, leaving three out of four available. Dyson (2005b) stated that precautionary treatments may be effective in minimising the symptoms; consequently, patients rarely experience physical abnormalities. AT patients are usually advised to modify their lifestyle, as well as to continue precautionary management in their diet and medications. However, in some cases AT can cause some obstetric complications and foetal abnormalities (Weatherall, 2001).

Anaemia or what is identified as childhood anaemia is known as one of the clinical manifestations of thalassaemia. Arguably, the scenario in Jordan can be more challenging, as in some cases childhood anaemia and thalassaemia cases can be misdiagnosed. Childhood anaemia is known to be one of the most common childhood haematological disorders, especially Iron Deficiency Anaemia (IDA). IDA habitually associated with nutritional problems among most of the Jordanian population (Faqih, et al., 2006). In addition, the unavailability of regular tests for infant haemoglobin can lead to delays in diagnosis. In most maternity and child health centres in Jordan, the routine blood testing of children usually starts around the age of twelve months old or more. However, the tests can be done before and repeated only if requested by either family members or HCPs based on the child's health status, but not as regular follow-up tests. Arguably, there could be misleading the diagnosis of some cases of children with thalassaemia, with childhood anaemia particularly in families with unknown history of such disorders.

3.6 BTM Complications

Patients with thalassaemia major have many complications that vary in frequency and severity. These complications present at different stages of the patient's life (Weatherall, 1997; Ward, et al., 2002). In the majority of cases complications are correlated with

childhood treatment programmes, which include the effectiveness of chelating therapy and maintenance of blood haemoglobin levels within the normal range according to the patient's age (Cappellini, et al., 2011). According to Galanello and Origa (2010) and Barton (2007), the following are some complications related to BTM:

1. Iron overload, which is the most common cause of the disorder's morbidity;
2. Bleeding tendency and systematic reaction to the blood transfusions or chelating therapy, and high susceptibility of infection;
3. Endocrine dysfunction, such as diabetes mellitus;
4. Blood-borne disease such as hepatitis-B;
5. Osteoporosis;
6. Cardiac dysfunction;
7. Growth deficiency, such as delayed puberty.
8. Liver and hormone disorders, such as splenectomy and hypothyroidism.

The variations of thalassaemia types can have a direct impact on the patient's health status. For example, the severity of the anaemia is variable from one patient to another. Some children tend to exhibit different signs and symptoms ranging from minor, intermediate, to severe anaemia (Anie and Massaglia, 2001). These variations in children's health conditions and the occurrence of the complications are based on a number of factors, such as multiple blood transfusions and the effectiveness of the chelating therapy in case of BTM. Patients with thalassaemia also exhibit 'splenomegaly' and skeletal deformities due to bone marrow expansion. In both aforementioned complications, iron deposition also affects the cardiac, hepatic and endocrine systems (Toumba, et al., 2008). However, some complications can be more severe, exerting a greater impact on patients' social lives. In such cases, patients tend to develop severe forms of bone deformation, enlarged spleen, diabetes mellitus, organ failure, or abnormality of the endocrine system (Shamshirsaz, et al., 2003). Such complications could impacted directly on patients' life and their families.

Soliman, et al. (1998) stated that osteoporosis is one of the complications commonly found even in well-treated patients with BTM. In addition, hormonal disorders are known to be the second most common complication, after osteoporosis. Taher, et al. (2010) argued that osteoporosis could be the most common disease-related complication in patients diagnosed with TI, not only patients with BTM.

In Jordan, several literature such as (Al-Hader, et al., 1993; Al-Rimawi, et al., 2005; Irshaid and Mansi, 2011) stated that thyroid dysfunction was reported in most teenage with BTM which lead to various complications. In a 2007 study by Khan, et al., it was found that around 95.5% of 123 patients with BTM from Pakistan experienced a variety of hormone disorder complications. They stated that one of the common complications was growth failure, in which some patients experienced delays in their physical growth and development characteristics. Khan, et al. (2007) observed that 52.8% had growth failure related to short stature and delay in sexual maturity; liver problems were presented in 21.1% of cases, heart disease in 13.8% and endocrinopathies in 4.2%. Shamshirsaz, et al. (2003) observed that some patients exhibit endocrine disorders such as primary hypothyroidism, hypo-parathyroidism and electrolyte imbalances. Other two studies (Bashir, 1995; Mansi, et al., 2009) addressed impairments in copper and zinc levels in Jordanian children with BTM compared to the ordinary children and (Bashir, et al., 1993) found that patients with BTM in Jordan experienced alteration in cortisol level that impacted negatively on their physical activity. Al-Rimawi, et al. (2006a) argued that iron overload could be the main cause of pituitary and ovarian dysfunction in most of Jordanian children with BTM. The study found that out of thirty one females, there are thirteen (41.9%) had delayed puberty, fifteen (48.4%) had hypothalamic-pituitary-ovarian axis dysfunction and five (16.1%) had ovarian failure. Musallam, et al. (2011) argued that elevated liver iron concentration in patients is an indicator of increased

vascular, endocrine and bone diseases. In addition, alteration in pulmonary function was reported in most patients with BTM (Abu-Ekteish, et al., 2007).

The aforementioned thalassaemia complications not only affect the patient's major body systems but also cause a variety of oral infections such as 'Oral Candida Flora', which was found to be significantly higher in patients with BTM than in healthy subjects (Hazza'a, et al., 2010). It is also worth mentioning that as part of their life-long treatment, regular and frequent blood transfusions placed patients with BTM at serious risk of acquiring blood-borne diseases such as hepatitis and human immunodeficiency virus.

3.7 BTM Treatments

The TIF collaborates with the WHO to facilitate the adoption of thalassaemia treatment protocols in many countries. This assists in improving the quality of patients' life and increasing their life expectancy to nearly normal (TIF, 2011). Children with BTM may have severe anaemia; if untreated, this may cause death before the age of 3 years (Modell and Darlison, 2008). Fleming, et al. (1979) stated that untreated children with thalassaemia can die from infection in the early stages of their lives. Recently, BTM is known worldwide to be one of the most common causes of young adult mortality and premature death (Lawson, et al., 2003). Due to new technologies, the life expectancy of a patient with thalassaemia in the developed world is between 25 and 55 years. However, in the developing world, life expectancy could be as low as 20 years on average (Modell, et al., 2000). This is probably due to non-compliance with treatment, lack of availability of effective medical treatments as well as shortage of HCPs and financial support.

Conservative treatments, which includes blood transfusion and iron chelating therapy, is an essential treatment that every patient with thalassaemia should receive in order to survive. Conservative treatment has been made available in recent years in most countries where thalassaemia is common. Modell and Darlison (2008, p. 11) stated that "*patients*

with beta thalassaemia disorder can reach their full life expectancy if they are treated with regular blood transfusion and iron chelating therapy". However, it can be argued that conservative treatment, though necessary as a lifesaving and effective therapy, can be expensive, as it is needed on a life-long basis (Nadarajan, 2011). According to Nadarajan (2011), the objectives of conservative treatment can be summarised as follows:

1. To correct the patient's anaemia through maintaining the haemoglobin level within the acceptable average, usually above 9 -10.5 g/dl (Cappellini, et al., 2011), by giving the patient regular blood transfusions;
2. To decrease iron overload in the patient's body, which is accumulated as a result of frequent blood transfusions, and to avoid impairment of vital body organs such as the heart, liver and spleen, which could cause organ failure.

3.7.1 Conservative Treatment

The length and quality of a patient's with thalassaemia life depends on the availability and the effectiveness of the conservative treatment; in many cases the complications of BTM are mostly correlated with the patient's age, frequency of blood transfusion and compliance with iron therapy.

A. Blood Transfusion

Blood transfusion is the main treatment required for patients with thalassaemia to treat anaemia. Its aim is to compensate for the ineffectiveness of the bone marrow production of the red blood cell (Cappellini, et al., 2011). Patients with BTM need regular blood transfusions to decrease the chances of developing anaemia's complications, such as bone deformities and cardiac failure. Statistics indicate that about 12% of children who were born with BTM were on blood transfusion (Modell and Darlison, 2008); this health

condition is known as transfusion-dependant thalassaemia (TDT). This group of patients received regular blood transfusion and iron chelating therapy. Other types of patients with thalassaemia disorders are known as non-transfusion-dependent thalassaemia (NTDT) patients.

Worldwide there are three quarters of a million diagnosed with NTDT (Vichinsky, 2007). The frequency of blood transfusions varies from one patient to another, ranging from two to five weeks. Globally, there could be about 100,000 patients with thalassaemia dependent on blood transfusions (Vichinsky, 2007). Blood transfusion, as an invasive procedure, is usually carried out either at the hospital or health care centre under a health care professional's supervision. Recently, there have been some requests by some families in the United Kingdom to be given appropriate training to enable them to administer blood transfusions to their affected children at home (NHS, 2012). Arguably this could lead to complications and various impacts on the patients themselves and family members. Lack of availability of treatments is not the only challenge in some countries; compliance with life-long treatments among teenagers and young adults is also reported as an issue (Brittenham, et al., 1994; Atkin and Ahmad, 2000b). Atkin and Ahmad (2000b) found that compliance with treatment plans in children with chronic disorders is a major problem. In addition, the effectiveness of the provided treatments was highlighted by Cappellini, et al. (2011), who found that many patients with BTM require a splenectomy due to their steady increase in annual blood consumption and ineffectiveness and non-compliance with the iron chelating therapy, which causes spleen enlargement.

B. Chelating Therapy

TDT patients, received daily iron chelating therapy, which is commonly started after the patient receives between ten to twenty blood transfusion units, to remove excessive iron

from the body. Parents or caregivers can also be responsible for administering chelating medication at home (NHS, 2012). Iron overload is an inevitable side effect of frequent blood transfusion and can cause serious complications in long term transfusions (Cappellini, et al., 2011). The chelating agents currently available are of three types, used in different age's groups: 'Desferrioxamine', 'Deferiprone' and 'Deferasirox' (TIF, 2011). Each type has its own advantages and disadvantages in terms of use and administration route.

Desferrioxamine (DFO) is known as the first iron chelating medication available. In most cases patients receive DFO by infusion for about 10 to 12 hours daily. To administer this medication, caregivers have to insert a special sub-cutaneous needle in either the abdominal area or forearm, which also connected to an infusion machine. Many caregivers prefer to administer this infusion medication at night while children are in bed, in order not to limit their mobility during the day.

The second type is known as 'Deferiprone' (DFP). This chelating medication is available in either tablet or liquid form, which makes it easier and more convenient to be taken orally by children. Parents administer DFP on a daily basis, preferably in the morning. In Jordan the oral iron chelating form only available for the patients with BTM up to fifteen years of age, due to its cost.

The third type is known as 'Deferasirox' (DFX). This is a new oral form of iron chelating medication which has recently been introduced into most countries. For instance, it was first licensed in the United Kingdom in 2006 (NHS, 2012).

These three types of medication are used to remove excessive iron from the patient's body in order to prevent complications and early deaths among patients with BTM. However, a survey by Ward, et al. (2002) found that patients with iron chelating therapy experienced

a wide range of physical and social limitations recorded as iron-related complications. Despite the recorded complications of using iron chelating therapy, patient outcomes are improved where iron chelating agents are used (Cappellini, et al., 2011).

3.7.2 BTM Cure Methods

In 2012, TIF published the recent methods of possible cured for patients with BTM, including the following:

1. Stem cell transplantation;
2. Gene therapy;
3. Increasing foetal haemoglobin.

It is important to note that not all patients with thalassaemia worldwide can have access to these cure methods, since it can be expensive and inaccessible for most patients with thalassaemia in developing countries. Faulkner (2013) argued that there is a need for more structured and concentrated cooperation between high and low income countries, to produce more positive outcomes. The following discussions present the three available methods at the time this study was carried out.

1. Stem Cell Transplantation

Stem cell transplantation is known as the most available therapy for thalassaemia. It is referred to as 'Haemopoietic Stem Cell Transplantation' (HSCT). In this treatment, the red blood stem cells derive from the bone marrow. Hence, the procedure is known as Bone Marrow Transplantation (BMT) (TIF, 2012). The aim of this treatment is to transfer bone marrow cells from a thalassaemia negative donor to a patient with BTM. In some cases an umbilical cord blood cells or peripheral blood of the HSCT can be used (Lucarelli, et al., 1990; 1999; Issaragrisil, et al., 1995; Locatelli, et al., 2000; Angelucci and Lucarelli, 2001; Lawson, et al., 2003; NHS, 2012).

BMT was first adopted in 1981 as a cure method for thalassaemia. The first successful operation was performed in 1982 (Thomas, et al., 1982). It is estimated that more than 2000 BMT operations have been performed worldwide since then (Cappellini, et al., 2011). The treatment has an overall patient survival rate of 70% (Angelucci and Lucarelli, 2001; Lawson, et al., 2003). However, the survival rate of patients and the success of BMT operations are linked to a series of risk factors. These factors are also used as guidelines to classify patients' status based on the following characteristics:

1. The iron chelating therapy – the previous control of the level of the serum iron;
2. The presence of liver fibrosis – the degree of the damage to the patient's liver;
3. Hepatomegaly – the enlargement of the liver.

Lucarelli, et al. (2002) stated that these three characteristics, along with the patient's age, have a significant influence on post-transplantation outcomes. The outcomes of the BMT can include the improvement of the patient's health condition where the blood transfusion could stop and a significant decrease in the mortality rate. According to 'Pesaro class and iron overload pre-BTM' (Lucarelli, et al., 1990; Lawson, et al., 2003) patients are classified according to the three characteristics mentioned above. For instance, the patients can be classified as follows:

1. Patients in 'Class I' may have none of the three characteristics;
2. Patients in 'Class II' may have one or two of them;
3. Patients in 'Class III' may have all three.

It is worth mentioning that if the donor is an identical sibling, such as a twin, the success rate could be as high as 91%, if patient were in category Class I or Class II (Lucarelli, et al., 1999). However, the adult category Class III of patients is considered the highest risk category.

Umbilical cord blood is also used in BMT as one of the sources of the necessary stem cells to cure patients with BTM (Borgna-Pignatti, et al., 2004; Telfer, et al., 2006), especially in cases where there is no available matched donor. Arguably, BMT can be available and accessible in some health institutions world-wide. However, the availability of a donor, as well as the cost, can be a major blocking issue. BMT demands very specific criteria for donors. For instance, it is required that donors should be biologically related to the patient with BTM and have a matched in their 'Human Leukocyte Antigen (HLA). HLA is a special 'code' or 'mark' embedded in all human tissues (NHS, 2012). Most successful operations involve a patient and a donor with identical HLA, and in most cases the donor is a sibling from the same family (Cappellini, et al., 2011). It noticed that the major problem for the affected patients and their families has been the lack of compatible sibling donor (Gaziev, et al., 2008). Time could be also an important factor in the success rate of BMT. The statistics seem to suggest that the younger the children, the higher the success rate (TIF, 2011; NHS, 2012). Statistically, children under sixteen years of age tend to have a higher success rate of treatment through BMT.

A. BMT in Jordan

The stem cell transplantation has been performed in Jordan since the early 1990s in some health care facilities, such as the Jordan University Hospital, the Royal Medical Hospital and in some private hospitals. However, a comprehensive treatment programme was launched in 2003 in Amman at King Hussein Cancer Centre (KHCC) for most cases that need BMT, including patients with BTM (Abdel-Rahman, et al., 2008). Since 2003, more than 230 patients have undergone BMT, with a total survival rate of 65%. Based on these statistics, the survival rate for patients with thalassemia seems to be on the high side, including patients in Class II and III categories (Abdel-Rahman, et al., 2008). Most Jordanian patients, like any other patients in developing countries, are faced with financial

challenges in affording the BMT operation, which is considered as one of the most expensive procedures. For instance, at the time of this research, it was noticed that the operation and post-transplantation care may cost between 24,695 and 46,787 Jordanian Dinar (JD) (£21,692 and £41,097 GBP). For other types of BMT such as 'Haploidentical' transplantation, an operation on an adult may cost 141,577 JD (£124,358 GBP) (Abdel-Rahman, et al., 2008). However, as stated in chapter one (see section 1.8.5) most Jordanian patients with BTM have health insurance from the government and Royal Court to overcome the cost of such an operation. However, it should also be noted that due to the increasing number of cases with BTM, there are many patients on the waiting list with a readily available matched donors but who cannot be given the operation until the finances are made available, either in cash or from their health insurance or the Royal Court. Abdel-Rahman, et al. (2008) found that although government financial health support could be made available, it normally takes a longer time to get through the bureaucracy to the beneficiaries. Thus, the waiting time for the operation could be as much as three to five years. Such scenarios tend to increase the pressure and the stress of waiting on both the patients and their families.

B. Cord Blood Transfusion

Cord blood transfusion is an alternative resource to the haematopoietic stem cell procedure. In this procedure, blood is taken from the umbilical cord, which is considered a rich source of stem cells that can be transfused to a child with thalassaemia after an HLA test is performed on the foetus of a sibling. If the HLA is found to be matched, then the blood can be transfused to the affected older sister or brother. It is noted that these procedures have many advantages, including decreasing post-transfusion complications (Nadarajan, 2011). Although some studies reported a high success rate in cord blood transfusion procedures, there are still a limited number of cases performed in some

countries. For instance, around 79% of operations in the U.K are performed successfully with no deaths (NHS, 2012). In addition, some literature (Locatelli and De-Stefano, 2004; Cappellini, et al., 2011) reported that the use of the cord blood cells from a sibling is associated with no known reported deaths from post-transfer complications. In a retrospective data analysis study in Taiwan, Jaing, et al. (2011) stated that out of a total of thirty five operations using cord blood transfusion, thirty patients survived with occasional transfusion after thirty six months. In another study conducted in the United States of America, Ruggeri, et al. (2011) stated that retrospective data seemed to suggest that patients diagnosed with thalassaemia and sickle cell disease given unrelated cord blood cell survived for about two years. The study suggested that only certain types of cord blood cells, containing a certain dose of infusion cells, should be considered for transplantation to have a successful rate. The media in Jordan plays a crucial role in exerting pressure on authorities to expand BMT, as well as to assist patients who may not have available matched donors to use cord blood cells. Consequently, a 'Cord Blood Bank' [Baby Cord Jordan] was launched in June of 2005, against some opposition from some sections of the community. The access and use of the cord blood cells from non-biological relatives is not only costly but also considered unethical in some communities (Caocci, et al., 2011).

2. Gene Therapy

Gene therapy as a method to cure thalassaemia is still in its development stages and may need a few more years to be proven before being made available to most patients with thalassaemia (TIF, 2012), as there are many risks and limitations surrounding this procedure. This method takes place in cases where there are challenges related to finding a suitable matched donor. Gene therapy aims to modify a patient's own stem cells by modifying the gene inside them. In this procedure the patient's stem cells are cultured

outside the body and the missing gene introduced by means of a viral vector (TIF, 2012). Thereafter, the treated stem cells with the virus is administrated back to the same patient. This seemingly complex procedure is known as 'Autologous Transplantation'. There have been a few trials which indicated that there could be some challenges to overcome, as well as the possible adverse side effects. Recent statistics from the TIF showed that there is only one patient became free from regular blood transfusion after going through the gene therapy procedure (TIF, 2012).

3. Increasing Foetal Haemoglobin

This type of treatment was found to be effective in treating thalassaemia intermedia and not in BTM (TIF, 2012). Arguably, increased foetal haemoglobin is a new approach used in improving the clinical state of the patients as opposed to total cure (TIF, 2012). This procedure is made possible by increasing the production of foetal haemoglobin after birth, a component of gamma globin, not beta globin. Gamma globin has the ability to oxygenate the body tissues in the same way as beta globin. However; there are still many on-going tests to validate this procedure (TIF, 2012). In summary, the cured methods described above vary in availability and accessibility as well as in their success rates in improving the quality and life expectancy of patients with thalassaemia worldwide.

3.7.3 Psychological Therapies

Children with chronic disorders such as BTM, and their families could face many challenges, such as a life threatening disorders and long term treatments. El-Ghany, et al. (2010) argue that chronic illnesses can negatively impact on the livelihoods of the patients and their families. BTM has a significant impact on the patient's "*psychological status causing different emotional burdens, such as the feeling of hopelessness and stress*" (Mazzone, et al., 2009 p.5). The impact of BTM on patients is not only physical, but also

social, and influences their growth and development process. For instance, Monastero, et al. (2000) reported that some children with thalassaemia exhibit language, memory and attention deficit disorders, as well as impairments in constructional words and visual functions. In another study, Saini, et al. (2007) argue that a child's psychological wellbeing may be affected by their age and gender. For example, the study found that male children with BTM in particular tend to experience more negative thoughts, such as low self-esteem and anxiety, than female children. Furthermore, social and psychological support, which is important for patients with BTM and their families, is rarely available in most developing countries (Najmabadi, et al., 2001). The health related quality of life of Middle Eastern children with BTM was discussed in a study by Caocci, et al. (2012) through administrated Paediatric Quality of Life questionnaires (PedQoL4.0). Their study showed that the inappropriate start and administration of iron chelating therapy have negative impact on children's health, social and psychological status.

It is worth mentioning, that their results mainly reported lower emotional and psychological functioning. The study recommend that *"thalassaemia patients and their parents required lifelong psychological support for prevention of mental health issues"* (Caocci, et al., 2012 p.6). In another study Tsiantis, et al. (1996) compared the psychological problems and adjustments experienced by families of children diagnosed with thalassaemia in Greece, Italy, Cyprus and some participants in the United Kingdom. The findings of their study showed that in all the aforementioned countries; the disorders have a binding effect on the families. In addition, the family's knowledge of thalassaemia, and its complications, had a major impact on family adjustment. Anie and Massaglia (2001) argued that, in addition to the conservative treatments, psychological therapies can be appropriate to improved outcomes and encouraged adherence to the medical treatments.

Furthermore, the psychological therapies could help children with BTM adapt positively to their illness and reduce their psychological pain (Eccleston, et al., 2012). Anie and Massaglia (Ibid) found that psychological therapy allowed affected patients and their family members to cope effectively, alleviated their emotional stress, and encouraged a positive mood.

The study suggested the following psychological interventions:

1. Patient education;
2. Cognitive therapy;
3. Behavioural therapy;
4. Psychodynamic psychotherapy.

The main focus of psychological services in hospitals, health centres or the community is to support patients and their families, by conducting an assessment before applying the appropriate interventions. This is assumed to promote a positive and appropriate adaptation to their condition as well as to improve quality of their life. It is worth mentioning that the aforementioned therapies could be more effective if the social, religion and cultural background of the parents are addressed and evaluated when this type of therapy is provided (El-Ghany, et al., 2010). This is emphasised the important role of the religion, cultural and social norms on people coping. In their study, Tsiantis, et al. (1996) highlighted the role of cultural patterns and socio-economic developments in coping which vary between different countries and between families of children with thalassaemia in the same country. In another study to Ahmed, et al. (2006) they emphasise the importance of recognising diversity within different faith group and avoiding the stereotypical views based on people ethnicity or religion when the counselling or education offers to the families of children with BTM. Anie and Massaglia (2001) argued that psychological intervention could lead to effective coping strategies, alleviate patients'

symptoms, and reduce emotional difficulties for patients with thalassaemia and their caregivers. In addition, Telfer, et al. (2005) found that multidisciplinary psychological intervention, which involved parents actively in children with BTM therapy, enhanced ability to cope with thalassaemia. El-Ghany, et al. (2010) suggested that psychological support to children and adolescents with BTM should be focused on providing appropriate information to the children and their families. This is coupled with regular assessment, genetic counselling and social services in families, schools and communities. This support and counselling through multi-disciplinary reviews can cover both social and medical issues faced by patients and their families. In addition, the ongoing empowerment and support to the children with BTM and their families play a major role in adopting effective coping mechanisms and palliative care for the affected children and their caregivers. Cognitive Behavioural Family Therapy (CBFT) is one of the psychological interventions aims to improve the communication process, identify psychological factors, and minimise the emotional suffering of children with thalassaemia, as well as help to introduce positive coping strategies to the patients and their families. Mazzone, et al. (2009) argued that CBFT could increase children's compliance with treatments. Moreover, CBFT are also recommended by Caocci, et al. (2012) and Anie and Massaglia (2001). In their study about depression and thalassaemia, Koutelekos and Haliasos (2013) argued that regular screening is essential to the individuals at risk to promote emotional and physical health. The consequence of psychological support is an improvement in the quality of patients' life with BTM and their families. As mention earlier, in Jordan there are many hospitals and health centres offering free conservative treatments for all patients with thalassaemia. However, there were no professional social nor psychological support services available at the time this research was conducted.

3.8 Conclusion

In this chapter, the background information about thalassaemia as a haematological disorder, and its origin, different types, expected complications, and available therapy and curative methods were presented. The current situation of patients with thalassaemia in Jordan was also discussed. This chapter provides the necessary contexts to understand what Jordanian families of children with BTM are dealing with prior to investigating their experiences and coping strategies. The research approach, methods and methodology will be presented and discussed in the next chapter.

Chapter Four: Research Method and Methodology

4.1 Introduction

This chapter explains the research method and methodology used to explore the experiences and coping strategies of Jordanian parents of children with BTM. This chapter will present the research approach, the researcher's philosophical and theoretical background with appropriate justifications. In addition, this chapter will discuss the selection of the research design, method, settings, and the sample strategy and size.

4.2 Research Methodology

Hammell (2006, p.167) identified research methodology as *“a specific philosophical and ethical approach to developing knowledge; a theory of how research should, or ought to, proceed given the nature of the issues it seeks to be addressed”*. It can also be described as the researcher's procedural framework (Remenyi, et al., 1998) which indicates how the phenomena or area of interest will be researched. Qualitative approach with grounded theory were adopted according to the aim and objectives of this study.

4.3 Qualitative Approach

A qualitative approach has been selected for this study after reviewing and refining the research questions. Creswell (2003) identifies qualitative research as an umbrella which covers a variety of research methods. These multiple approaches could be organised under the five traditions of the qualitative research: biography, phenomenology, grounded theory, ethnography, and case study. A variety of qualitative approaches are available to answer different kinds of research questions, and each of these approaches uses different analytical tools. Burns and Grove (2010; 2003, p. 19) described qualitative research as *“a*

systematic subjective approach used to describe people's life experiences and situation to give them meaning". Polkinghorne (2005) argued that the type of research data, the setting and the participants, as well as the manner in which the data is collected, vary according to the research disciplines and the researcher's philosophical position. The qualitative approach, according to Noyes (1999, p. 428), is *"the best for understanding the meaning that human beings attached to their lives, the social structures that support such lives and the ways in which change in nursing practices can occur"*.

A qualitative approach was adopted in this research for several reasons. First, to allow the individuals to talk about their own personal experiences, which could enable the researcher to achieve a better understanding of the participants' point of view, experiences and coping strategies (Silverman, 2001; Bowling, 2002). Holloway and Wheeler (2002, p. 30) state that the main aim of qualitative research is to interpret and make sense of participants' lives through either exploring or explaining people's perspectives, experiences, feelings, attitudes and behaviour, which matches this study's aim and objectives.

Children with thalassaemia and their families are considered consumers of the health care services in Jordan. Using a qualitative method will give an opportunity for the parents' voices to be heard (Sim and Wright, 2000), as well as to understand parents' knowledge and actions as they encounter, engage and live through different life situations. Furthermore, it can assist in exploring the meanings and patterns of their lives, as well as inconsistencies and conflicts in the thoughts and behaviours of people who share similar experiences and live in the same conditions (Elliott, et al., 1999). This could help HCPs to understand what parents of children with BTM are going through. Giving the participants a chance to talk allows them to express themselves and to reflect on their experiences, rather than being confined to a questionnaire. Using a questionnaire would

be contrary to this study's aim of exploring and obtaining a better understanding of parents' experiences and coping strategies. It was important to give parents a chance to talk about their own experiences through interviews (Dalley, 2000; Nolan, 2000). A questionnaire with specific questions could limit their responses and potentially miss some important points.

A second reason for adopting a qualitative approach is the depth and richness of the data, as well as the direct responses from the participants (Sim and Wright, 2000). These have been noted as one of the advantages of face to face interviews as the main data collection method in qualitative approach. In addition, Silverman (2001) argued that using interviews could provide the opportunity to build a trust-based relationship, which can allow the participants to express their experiences openly and talk in detail about their various events in their lives.

A third reason is the nature of the participants; qualitative researches mainly focuses on an individual's, a family's or a group's experiences. Each individual has unique experiences, perceptions and perspectives that can be explored by giving each person involved sufficient time to converse and to present him or herself. In this study, qualitative research will give the participants a chance to talk about their personal experiences and to express their feelings, as the interviews will be carried out on a face to face basis, individually with a high degree of confidentiality.

Adopting a qualitative approach in this study also will give me an opportunity to directly observe, listen and gain access not only to the participants' verbal conversations, but also to their non-verbal language during the interviews and in the clinical setting. Such observations will give an opportunity to draw a full picture of the parents' experiences as they accompany their children to hospital in their capacity as support providers and caregivers.

4.4 Researcher's Philosophical Approach

A major reason why I was interested in carrying out this study was to provide an opportunity to those whose voices had not been heard before to fully express themselves in their own personal way, to narrate their story and to talk about their unique life events. I was encouraged by David, et al. (2002) on the importance of researching people's lives and encouraging them to talk about their diverse experiences of real life events, the activities they practise and their interactions on a daily basis.

My approach is not to treat the participants as passive subjects, but rather as active participants, by giving them the opportunity to talk about their experiences, express their feelings and identify their coping strategies. This will allow me to understand the impact of having and caring for children with BTM on family members' roles as parents, fathers, mothers, wives and husbands. Furthermore, it is envisaged that by taking part in this study, participants may share their experiences and knowledge with various stakeholders through publications. Thus, the research is undertaken on the basis of working "*with people and not on people*" (Heron and Reason, 2001, p. 179). It is important to listen to parents' experiences as described in their own words in order to provide holistic care (Lewis, 2007). People construct knowledge through interaction with others through their everyday lives. Interactions construct knowledge and constitutes it as a new version of 'truth', which varies historically and cross-culturally. In literature, researchers argue that there is nothing outside the text: when we talk about reality or realities, we can only be referring to the things that we know and construct through our language, and people use different registers and languages to present themselves (David, et al., 2002). For this reason, I am interested to know how the Jordanian parents of children with BTM construct their everyday experiences. What it means for them to care for children with BTM for the rest of their life, how that impacts on their lives, their perceptions and what helps them to

cope and adjust to their condition. Arguably, each partner or caregiver has his or her own reality and experiences, despite the fact that they live together and share the same events.

David, et al. (2002) state that when people talk about their realities, they may only be referring to the things that they construct through language. However, it could be argued that their knowledge of reality can be approached by giving them the chance to talk about it and to express what they think and feel, to describe their situation and to verbalise the information they have. Angen (2000) makes the valid point that, in epistemological terms, the researcher's position is inextricably linked to the whole research process, and cannot be separated from the process. Hence, I was optimistic when engaging in direct interaction with the parents and responding to their answers to clarify more details. At the same time, I was aware of my contribution to the structure of the meaning and knowledge obtained while conducting and recording the interviews (Nightingale and Cromby, 1999).

During this research, all interviews with eligible participants include 'face to face' interaction, because I want to explore part of the reality of the participants' lives, whilst encouraging them to talk openly and tell their stories of caring for children with BTM. This direct interaction will help me to capture their non-verbal messages and responses, which contribute to the narrative context.

I agree with Hesse and Leavey (2006) that in order to build a descriptive, exploratory and explanatory knowledge, the researcher should be active along with research subjects, rather seeking to be value-neutral and objective. I acknowledge that it would be hard for me to abandon my values, attitudes, experiences and skills while collecting the data. However, I will write memos and a personal reflective account as a technique to help me to visualise myself outside and inside the research process at the same time. I aim to be more reflective and sensitive in writing, bearing in my mind the following questions.

These questions need to be thoughtfully and carefully considered in the reflective account and the memos:

How will I represent myself in the research process? What are the different roles I have in the process of conducting this study? To what extent will I be aware of my own biases, values, and my points of view entered into my selection of the questions I asked? How much of my own voice is represented? (Hesse and Leavey, 2006, p. 367)

Ontology is regarded as the reality, and epistemology is “*the relationship between that reality and the researcher*” (Carson, et al., 2001, p.4). I adopted a ‘pragmatist’ ontology position, which “*is related to integrating different perspectives to help collecting and interpreting the data*” (Saunders, et al., 2007, p. 607). This allowed me to have dissimilar positions and perspectives as the research progressed. Sometimes my perspective is kept internal, for example, while conducting the interviews, and at other times it is external, such as when I interpret and analyse the collected data.

This is similar to a supportive investigation cycle: throughout different phases of reflection and performance, the research is considered from different angles (Heron and Reason, 2001). I concur with Creswell (2003, p.12) who talks about “*the researcher autonomy to choose the design, methods, data collection time and techniques, which help to meet different objectives*”. Arguably, these can also be modified as required. In addition, the inscription is a vital stage, because the researcher must go through numerous phases with the collected data. I had to be sure that the collected data was what I needed to collect, and that the information reflected what the participants wanted to say, addressed and answered the research questions.

Reflecting upon assumptions about knowledge, and thinking critically about the implications of these assumptions, is called epistemological reflexivity. One needs to consider the word 'positivism' as an epistemological position. Positivism proposes that there is a straightforward relationship between the world (objects, events and phenomena) and our perceptions and understanding of it (Willig, 2001). However, this relationship will develop a maturity and strengthen over time, and it could also vary even within a specific period of time. Qualitative research tends to be more interested in the meanings attributed to events by the participants themselves. Qualitative research aims to study and investigate people in their own context, within naturally occurring settings such as homes, schools, agencies or hospitals. Indeed, it could be in any place which tends to underline the facts and the truthfulness of the data gathered from real situations.

Willig (2001) states that ontology is concerned with asking, 'what is the nature of world?', while epistemology asks 'how can we know?' The question driving ontology is 'what is there to know?' These are difficult questions, as we may think that we know something, when it could be that we not know nothing. However, people construct their opinions and arguments to support their beliefs, and some of these constructions could contain errors. These constructions could be based on what, when and how they know. Our interpretation of that knowledge in our everyday life is the basic link between ontology and epistemology. Because of this dichotomy, I need to be aware and specific about what I wanted to know while conducting this research. This became clear when I transcribed the collected interviews and read them repeatedly, in addition to all other types of information collected, recorded and written, including memos and notes, verbal and non-verbal, such as comments, pauses and interpretations, using the same approach as the participants when they presented the data (Eder and Fingerson, 2003). Arguably, what parents know about themselves and how they know, as well as the way they present their knowledge in the interviews, could vary with time.

Philosophers search for the foundations of knowledge over time. They are sure it exists and they try to discover where knowledge comes from, what factors affect it, and how we acquire it, as well as the limits of our knowledge. There is ongoing debate between rationalism, the theory that knowledge is gained through human reason, and empiricism, which states that knowledge is obtained through human experiences. Arguably, both can be challenged because at different times, people can give different answers to the same question or describe the same picture differently. It is hard to state which view is right and which is wrong, because both can be justified by reasoning. It could be argued that those who can influence people are those who have access to and control over knowledge, therefore to possess knowledge is to possess power. According to Ryan (2005) the researcher himself/herself is part of the social system he/she studies, and his/her own behaviour may influence the social behaviour he/she wants to study. In sum, I believe that people construct and interpret the world and facts depending on where, when and how they live in this world. Our understanding spontaneously and continuously changes.

4.5 Research Theoretical Perspective

A grounded theory method was chosen for this study. The method is known as an inductive mode of analysis, or a process of moving from specific observations to a general theory. Glaser (1992) stated that the aim of using grounded theory is to discover the theory implicitly involved in the collected data. Furthermore, Glaser stresses that the researcher should be able to understand the distinction between forcing and merging the categories in order to be able to discover and build the theory, which for Glaser is fundamental to the use of grounded theory (Esteves, et al., 2002). Moreover, grounded theory is driven from or 'grounded' in everyday experiences. Glaser (1992) argues that the researcher's role is to make a sense of people's daily experiences in relation to specific phenomena. This argument matches the aim of this research, where using grounded theory was

intended to develop an understanding of parents' experiences and highlight their values, beliefs, meanings and their actions. This could be achieved by exploring and formulating people's actions in a specific context. Esteves, et al. (2002) stated that contextualisation would help people to question the reality of their lives, which is created by their actions and interactions in a specific time and place. This new way of questioning could help people to create and learn various ways of thinking, perceiving, coping and adapting to their conditions. In addition, it could help the nurses and HCPs to question, care, support and empower patients and their families by gaining better understanding of their life experiences. Furthermore, Strauss perceived human beings as active agents in their lives, not passively engaged in the social process, which is the fundamental basis of human existence (Charmaz, 2006).

People's actions and interactions can occur by a constructed language through the process of communication. This could contribute to the field of symbolic interactionism as stated by (Blumer, 1969 cited in Kendall, 1999, p.744). Furthermore, this fits with the idea of 'pragmatism informed interactionism', a theoretical perspective which presumes that people's reality, society and self are all constructed through their interactions reflected in their language and communication process (Charmaz, 2006). People can change with time and create their own new meanings and actions accordingly. Symbolic interactionism accepts that individuals "*can and do think about their actions rather than respond to stimuli*" (Charmaz, 2006, p.14).

Both Strauss' 'pragmatism informed interactionism' and the 'symbolic interactionism' followed by Glaser share an interest in the social psychological process (Charmaz, 2006). This was another reason why grounded theory fitted with this study. I was interested in exploring how parents perceived themselves, acted and interacted as carriers of the thalassaemia gene; how they expressed their feelings and explored the meaning of being

carriers and caring for children with BTM. In addition, one of the research objectives was to understand the impact of BTM on parents' lives as well as how they interpreted this in their own lives, families and communities. The research also aimed at identifying participants' coping strategies as constructed by parents themselves, which could help them to recognise their responses and their partner's to the current condition. Identifying their coping strategies could also give participants a chance to evaluate their old strategies and adopt new ones with time. Furthermore, this study could help parents of children with BTM to share their experiences and coping strategies indirectly through making recommendations, which could improve health care policy, especially in terms of long term health care plans.

Human beings derive and construct meanings, and adapt them to their own situations. However, those meanings can be modified with time and their interpretations can change with social and cultural context (Morris, 1967). For example, how parents understood the meaning of being thalassaemia carriers, or being a mother or father of a child with BTM, could have a different meaning and understanding with time, from one parent to another, or for parents in different cities or countries.

Furthermore, the meanings for men and women could have different contexts, and need to be interpreted based on their socio-cultural and religious background. Those meanings may be modified with social interactions and with time. The meanings can also be understood as negative or positive; thus, interpretations change with different circumstances. The other point worth mentioning is that the meaning of being a thalassaemia carrier or being a mother or father to a child with BTM could be change with time. For instance, being a thalassaemia carrier mother with a healthy child has a different meaning to being a carrier mother when a child with BTM is born; at that point, the role, responsibilities and identity of the mother could change, and the meaning of

motherhood may also be different. Arguably, being a carrier could be a barrier to achieving many things in life, because of the social and cultural barriers in the community. For instance, the social role many mothers are expected to fulfil is to deliver a healthy child. Mothers who carry the defective gene could face cultural pressure and social restrictions because they are in some cases seen to be unable to deliver a healthy child, and therefore unable to meet their expected social role.

Furthermore, in such scenarios, mothers may face social rejection, shame and stigma from their community if they fail to produce a healthy male child, because of gender preferences in their society. On the contrary, if the opposite were the case, it would raise a sense of security in the mother's parenting status. Arguably, this could impact positively on her and the meaning of being a carrier would automatically dwindle in importance.

4.6 Grounded Theory Design

Research design is the technique used by researchers to conduct their studies. Polit, et al. (2001, p. 167) identified research design as "*the researcher's overall plan for answering the research questions*". Burns and Grove (2003) stated that research design is a plan of what, when, how and where to conduct the study. For the purpose of this study it was agreed, after liaising with the researcher's supervisors and following revision of the research proposal, that 'Grounded Theory' is the appropriate design for this research.

4.6.1 Grounded Theory Historical Background

Grounded theory was first discussed in 1967 by Barney Glaser and Anselm Strauss in their book, 'The Discovery of the Grounded Theory'. They developed a systematic research method which aimed at building theories of human behaviour from grounded data and comprehensive explanations or exploration of a particular phenomenon. From the time of its inception, grounded theory has been used widely in the health field

(Urquhart, 2010). Over many years, a variety of publications have sought to develop and debate grounded theory as a research method (Glaser and Strauss, 1967; Glaser, 1978; Strauss, 1987; Strauss and Corbin, 1989; Strauss and Corbin, 1990; Glaser, 1992; Strauss and Corbin, 1994; Glaser, 1995; Glaser, 1998).

4.6.2 Grounded Theory Features

Grounded theory is an inductive research method (Glaser and Strauss, 1967), explanatory and descriptive approach (Corbin and Strauss, 1990) that aims to generate a new theory or to support an existing one. However, LaRossa (2005) argued that grounded theory in actuality could be both induction and deduction. In various research fields, grounded theory is used as an approach or systematic research method rather than to develop theory. In this study, my aim was not to construct a new theory but rather to generate a new and better understanding of the Jordanian parents' experiences and coping strategies. In this sense, I focused on drawing 'new lines' through existing literature. According to Haig (1995) a grounded theory is one that is:

1. Inductively derived from grounded data;
2. Subjected to theoretical elaboration and;
3. Judged adequate to its domain with respect to a number of evaluative criteria.

The above are the main key features of grounded theory as an approach and a research method (Charmaz, 2006). Glaser and Strauss constructed theoretical explanations of social processes. As such, they defined the components of grounded theory (Glaser and Strauss, 1967; Glaser, 1978; Strauss, 1987) to include the following:

1. Simultaneous involvement in data collection and analysis;
2. Constructing analytic codes and categories from data rather than preconceived logically deduced hypotheses;

3. Using the constant comparative method during each stage of data analysis;
4. Advancing theory development during each step of data collection and analysis;
5. Memo writing to elaborate and identify categories;
6. Sampling, which works toward theory construction;
7. Conducting the literature review after developing independent analysis.

The above features provide the researcher with a systematic and organised path through which to work, and give him/her an opportunity to control the research process as well as to increase the rigour of the research findings (Glaser, 1992; Strauss and Corbin, 1994; Charmaz, 2008). Many grounded theorists define grounded theory as a systematic, unified, inductive and comparative approach, rather than a formal research method (Charmaz, 2008; 2006). According to Charmaz (2006, p. 4) *“most qualitative research allows the researchers to follow up on the interesting data in whatever way they devised. Grounded theory methods have the additional advantage of containing explicit guidelines that show us how we may proceed”*.

4.6.3 Adopting Grounded Theory in this Research

Approaches to qualitative research have moved beyond descriptive studies into the realm of explanatory theoretical framework (Glaser and Strauss, 1967). Currently, grounded theory is widely used in many nursing studies as well as in other fields. This broad use could be because of grounded theory’s usefulness in either generating theories from grounded data, or modifying existing theories. In addition, grounded theory is known to be a complete research package that includes the following principles: simultaneous data collection, theoretical sampling, comparative analysis and memo writing (Elliott and Lazenbatt, 2004).

Grounded theory as an approach was adopted in this study for various reasons. The first is that grounded theory useful in relation to this enquiry which relates to phenomena that

are not well identified or sufficiently researched. Based on the literature review, the experiences and coping strategies of Jordanian parents' of children with BTM are poorly understood and not well researched. This study could therefore be the first in the literature to address this area. Stern (1980, p. 20) stated that the grounded theory method can be used "*to gain a fresh perspective in a familiar situation*", while Charmaz (1990) found that grounded theory as a research method can be used to explore and recognise how people manage their situation, such as having and caring for a family member with a chronic illness, which is what I aimed to achieve from this research.

The second reason for using grounded theory is to explore parents' social behaviour, actions and interactions during the time they cared for children with BTM. Grounded theory focuses on social behaviours, processes, phenomena and problems. LaRossa (2005, p.1) stated that grounded theory is the most popular among "*the different qualitative research approaches that may be relied upon in family theorising*". Glaser and Strauss (2009) argued that the job of grounded theory is to enable prediction and explanation of behaviours, it is also usable to give the practitioners better understanding. Furthermore, grounded theory is well-used in other studies focusing on groups of individuals experiencing a similar life event and exploring their social processes. There are many grounded theorists exploring the social process and experiences. For instance: the research on the process of 'Dying' by the pioneers of grounded theory (Glaser and Strauss, 1965); 'Alcoholism' by Bigus (1996), which explores the social process of becoming alcoholic; 'Cutting Back' after a heart attack by Mullen (1993); and 'Acquiring' by the expert nurse Bonner (2001), about nephrology nursing expertise.

The third reason is that grounded theory is known as "*a flexible and a stimulating research method*" (Charmaz, 2006, p. 15). It is also known as a systematic approach to data collection and analysis (Glaser and Strauss, 1967; Strauss and Corbin, 1994; 1998;

Charmaz, 2001). This approach encourages researchers to constantly interact with the participants and the data through theoretical samples and constant comparison during the stages of data collection and analysis. It also gives the researcher more flexibility in working with data collection and analysis. Constant interaction is also achieved through applying the concept of the constant comparative method, which could increase the research rigour.

Using constant comparison leads to identifying the categories through refinement and development of the data (Strauss, 1987). The process started by comparing the indicators in interview with the previous one during the stage of data analysis. The interviews were all coded in the same way, to allow the label concepts to be identified. The indicator is the result of the coding process. The same indicators build up together to create one concept. The new concepts are compared with each other in the same interview and with other interviews to find the links and the connections between them, to build the initial category. Each category and sub-category was identified through its properties and then compared within and between different interviews at the same hospital to see if similarities could be found. At this point they were grouped together and compared with interviews in another hospital to find again any different meanings, similarities or connections (Glaser, 1978; Strauss and Corbin, 1990). In addition, the constant comparison process confirmed that the research findings come from comparing the data between interviews, which validates the categories and forms part of the process of research rigour. These comparisons between the data confirmed that the information was repeatedly presented by and was relevant to the participants. Thus, it can be argued that using the constant comparison method gives an indication of an effective practice for incorporating the experiences and coping strategies described by all participants. Adopting grounded theory allowed me to discover and explore parents' experiences and

narratives of their nature, as well as the consequences of their experiences and coping strategies. In addition, I was able to identify and contextualise their interactions through constant comparison to their interviews with memos. However, like other qualitative research methods, grounded theory is dependent on how the researcher applies the research principles to achieve rigour. This could have a negative effect on the collection and interpretation of the research data, resulting in a lack of organisation and systematic approach.

The fourth reason for adopting grounded theory is the fact that it helps researchers to modify their own models and perceptions about the phenomena under study and to adapt new alternative perspectives based on the participants' beliefs and perceptions. This adaptation requires the researcher to be open minded and to use a flexible approach. Grounded theory gives the researcher control of the research process and enhances the analytical power of their work, according to Charmaz (2006).

Not only the researcher benefits from using grounded theory; participants are also able to share in and have a significant input into the research. Grounded theory is reconstructed as a problem-oriented endeavour in which theories are inductively generated from robust data patterns, elaborated through the construction of reasonable models and justified in terms of theories and perceptions (Haig, 1995). Finally, Charmaz (2003) argued that grounded theory designs are well suited to the identification of the basic social processes in health and illness.

Grounded theorists provide various guidelines on the process of data collection and analysis, as well as other applications (Strauss, 1987; Strauss and Corbin, 1990; Glaser, 1992; Corbin, 1998; Charmaz, 2008; Strauss and Corbin, 2008). Variations in the guidelines facilitated my research and gave me the opportunity to use grounded theory styles which suit and facilitate my study.

LaRossa (2005, p.4) argued that *“as long as [the researcher] kept the principle of the grounded theory, the details of the procedures can be modified to suit a researcher needs”*. Glaser and Strauss (1967) conveyed a similar message when they wanted other academics and researchers to modify their own methods for generating their own theory. In addition, Strauss (1987, p.8) recommended that, when it comes to guidelines, the researcher should *“study them, use them, but modify them in accordance with the requirements of [their] own research”*. In another argument, Strauss and Corbin (1998, p.295) advised research students that they should *“stay within the general guidelines outlined in Basics of the Qualitative Research and use the procedures and techniques flexibly according to their abilities and the realities of their studies”*. Eaves (2001) argued that Charmaz (1983) admitted that she developed her own style of using grounded theory, which was within the framework of the original methods created by Glaser and Strauss (1967). In addition, Eaves (2001, p. 662), in line with the Charmaz (1983) viewpoint, stated that *“every researcher using grounded theory will tend to develop his or her own variation of technique”*.

In this research I followed Strauss and Corbin (1990) in reviewing some literature before entering the field of data collection. This approach facilitated my work as a research student and improved my background understanding about the phenomena under study. In addition, I found that Glaser’s 1992 guidelines were more appropriate for the analysis of the research data. This does not imply any preference to any styles or schools, but is based on my ability, what I found more appropriate to the study and for me as a researcher. This issue is supported by Eaves (2001, p. 662) who argued that *“the issue is not who is right about grounded theory and whether you agree with Glaser and Strauss (1967), Strauss and Corbin (1990), or Glaser (1992). [The issue is] what you will take from them and do with it and how you will argue for, advocate, and defend your own position (M. Chesler, personal communication, August 19, 1996)”*.

In term of the researcher's theoretical sensitivity and reviewing the literature before beginning the field work, I agree with McCallin's (2003) argument that most postgraduate students these days are asked to search for gaps and limitations in the existing literature. The searching stage usually takes place either in the preparation phase, while writing their research proposal, or during a master's degree, which exposes the students an enormous level of knowledge in their field of study. It can be said that students' knowledge and background will directly or indirectly impact on their research, and the data they have in their mind could be integrated into their study. It was argued that using constant comparative analysis in grounded theory researches can modified any data the researcher had before and that include the literature review and usually will contribute into another perspective (Glaser, 1998 cited in McCallin, 2003, p.206). It could be argued that choosing a particular version or school of grounded theory for a study could not have modified the original version or the key feature of grounded theory as a research method.

I think the best summary of the current and ongoing debate over styles of grounded theory is that of Strauss and Corbin (1994, p. 283), who stated that *"no inventor has permanent possession of the invention... a child once launched is very much subject to a combination of its origins and the evolving contingencies of life... Can it be otherwise with a methodology?"*

4.6.4 Data in Grounded Theory

Data in grounded theory research can be collected by using different methods and techniques. According to Byrne (2001), data sources in grounded theory could be all the resources that produce information regarding the social interaction. In this research, semi-structured interviews will be used, supported by field observations, memos and a reflective account. This variety of data collection techniques could assist the researcher to collect in depth and comprehensive data.

I implemented Elliot and Lazenblatt's (2004) idea of viewing grounded theory as one package of research methods, including using 'theoretical sampling' at the stage of data collection, in which the participants were recruited from the three hospitals based on the research criteria and the saturation in the emerging categories. Draucker, et al. (2007, p.1138) argued that sampling in grounded theory is "sequential" starting with selective and moving into theoretical when the concepts are begin to emerge. Chiovitti and Piran (2003) stated that one of the eight methods of research practice used to enhance rigour in grounded theory research study is to let the participants guide the inquiry process. Secondly, memos, field notes, a personal diary and reflective accounts were used during the research process in order to maintain the researcher's objectivity and enhance the research rigour. In this research I used the following strategy in the data collection and analysis stages (Glaser, 1978):

1. Theoretical sensitivity;
2. Theoretical sampling;
3. Coding and categorization;
4. Constant comparison;
5. Use of the literature to compare with the collected data;
6. Use in combination with memos and field notes.

The main controversial issue in grounded theory data collection is theoretical sensitivity. Theoretical sensitivity is a concept developed by Glaser and Strauss (1967) who later developed two schools of thought which many other grounded theorists have debated. The main issues are how the researcher can achieve theoretical sensitivity, and the coding system. On the one hand, Glaser argued that the researcher was required to enter the research field with no preconceived ideas or extensive review of related literature (Charmaz and Bryant, 2007). In other words, it was the researcher's perception and thinking in different theoretical ways about the literature (Glaser and Strauss, 1967).

The main argument in Glaser's statement was that the researcher should maintain objectivity as much as possible. Glaser argued against reviewing related literature, because in so doing, the researcher's sensitivity to the collected data would increase. Glaser insisted that reviewing related literature should take place only at the stage of analysis, while the researcher interacts with the data through constant the comparative method (Glaser, 1978). Interestingly, Glaser (1998, p. 123) said that "*the researcher does not go blank or give up his knowledge. He goes sensitive with his learning that makes him alert to [the] possibility of emergence and how to formulate it conceptually*". This argument from Glaser indicated that the researcher can use their knowledge and review some literature which can assist them and increase their ability to conduct the research.

On the other hand, Strauss and Corbin (1990; 1998), who are advocates of the various grounded theory approaches that were adopted in this study, claim that a preliminary review of the literature before starting the data collection would enhance theoretical sensitivity. However, the two grounded theory schools (Glaser and Strauss, 1967; Strauss and Corbin, 1990; 1998) disagree on the timing of the literature review and how the researcher can gain theoretical sensitivity. However, they agreed that grounded theorists are "*theoretically sensitive*" (Glaser, 1978; Strauss and Corbin, 1990, p. 102). I concur with Glaser (2002) that each researcher who uses grounded theory brings different theoretical sensitivities to his or her own study.

I agree with LaRossa (2005) that in many cases, the way in which prior work and literature is reviewed is up to the individual researchers, and depends on why and what they need from it. I reviewed some relevant literature before the data analysis stage, mainly to avoid duplicating existing work by identifying the previous studies in the same field. This is also supported by many researchers, who stated that reviewing literature in the same field will allow researchers to not "*reinvent the wheel*" (LaRossa, 2005, p.850; Clarke, 2005;

Gilgun, 2005). Reviewing some literature increased the openness and sensitivity towards the data I collected, and gave me some experience in carrying out research. However, I did not complete an extensive and comprehensive literature review until the stage of data analysis, where the literature was used to challenge or support the findings. It is worth mentioning that, the purpose of reviewing literature change. For instance, at the stage of data analysis, the review of literature became more precise and connected to the research findings to compare and challenge them. Furthermore, I believe it is important to constantly update the literature during the progress of the research, in order to have an in-depth view of the field of the study, which will help to improve the quality of the work. Arguably, researchers can avoid being influenced by the existing work in the same field and be aware to what level they are conscious about what they read. They should be able to mine previous researches without stifling their own inventiveness (LaRossa, 2005). Eventually, "*prior conceptions need not become preconceptions*" as argued by several literatures such as (Strauss, 1987, pp. 306-311; Dey, 1999, p. 251; Strauss and Corbin, 1998, pp. 47-52 cited in LaRossa, 2005, p. 850).

The aim of this research is to gain better understanding of the parents' experiences and coping strategies, but not to build a theory. However, it is worth mentioning that Glaser and Strauss (1967) identified two types of grounded theory, known as the substantive and the formal theory. Some researchers tend to come out with one or both types and others conduct research to support and compare their findings with existing theory. Holloway and Wheeler (2002, p.108) argue that some researchers only link their findings with existing theories or related literature in the research areas.

4.7 Research Methods

The research method is the techniques and procedures used by the researcher to conduct research. These include collecting, analysing and interpreting data in order to answer the

research questions (Gelo, et al., 2008). Based on the objectives of this study, semi-structured interviews were used to investigate participants' perceptions, meanings, and views, to explore concepts, opinions and feelings about their experiences and to identify their coping strategies. Thus, I relied on face-to-face conversation to exemplify what participants said, supported with the field observations and memos. Using multiple resources was appropriate and gave the researcher an opportunity to collect comprehensive, in-depth data.

4.7.1 Semi-Structured Interviews

Semi-structured interviews were used to give participants a chance to express themselves by talking about their personal experiences and coping strategies. Morse (2002) found that the main difference between the three types of the interviews; un-structured, semi-structured and structured is the degree to which participants have control over the interviews and the content of the conversation. Corbin and Morse (2003) identify interviewing as a professional conversational skill, not as ordinary talking. The outcome of the interviews is the participants' responses as well as their own accounts and opinions (Byrne, 2001). Moreover, the information collected from the participants could not be obtained from elsewhere or from other individuals. Using semi-structured interviews enabled me to get close to the participants' viewpoint and at the same time develop my own conception (Horton, et al., 2004), since it enables both the interviewer and the participants to interact face to face. It also gives an opportunity to the interviewer to carefully listen to the interviewee and observe both verbal and non-verbal clues (Horton, et al., 2004). This interaction between the interviewer and the participants could enhance the flow of the conversation (Bowling, 2002) and encourage more in-depth information to explore. Holstein and Gubrium (2004) argued that the interview is a collaborative

production, in which both interviewer and interviewee use their skills and not just passive responses.

Using interviews in this research was thought to be useful based on the following assumptions:

1. The first is that the aim of this study is to explore and give better understanding of the parents' experiences and coping strategies. Thus, the best way was to give individuals a chance to express themselves through interviews. By talking to the participants, I will be able to gather details and deep insights about their experiences and how they cope with the lifelong caring for children with BTM, as well as an understanding of their perceptions and beliefs. However, interviews allow individuals to talk in their own way, not directed toward some ideal and wanted areas.
2. Interviews are considered a flexible method of collecting the research data, in terms of the order of questions that can be rephrased to suit each participant. The interviewer can arrange and rearrange the questions based on the interviewee's responses, which may not be the case in questionnaires. Moreover, the interviewer can explain his/her questions more in case of misunderstandings; they can also ask participants to make clarifications and use probing questions when needed, to collect in-depth information.
3. Using face to face interviews gives the interviewer some certainty because of the direct contact with the participants. In addition, it gives the interviewer the chance to explain, clarify and reach some reality with the conversation (Alvesson, 2003). It enables the interviewer to observe direct action and collect nonverbal communication, such as facial expressions and body language, which can be more expressive and give indications about people's feelings.

4. Using other methods to collect the research data, such as questionnaires or structured interviews, would produce pre-coded and limited responses committed only to the questions that have been asked. This may not allow participants to express their experiences and talk freely. Additionally, parents may not have the opportunity to openly respond in their own way and express what they felt. In this study, I was careful not to restrict the participants to the pre-defined limited coded questions. The main aim was to elicit as much information as possible, to explore and understand the experiences and coping strategies of the participants (Bowling, 2002). Horton, et al. (2004) found that using semi-structured interviews enables some unclear responses to be questioned in greater depth.

Semi-structured interviews were used rather than unstructured interviews, because the latter could allow the participants to raise issues and information not related to this study, which could be time consuming for both me and the participants (Silverman, 2001). Moreover, using unstructured interviews can give participants the opportunity to control the interview progress and divert the aim and the objectives of the interviews. In addition, it can restrict the interviewer's role in collecting the required data. Semi-structured interviews are situated between the structured and un-structured types. On the one hand, semi-structured interviews allow parents to feel free to talk about their experiences and present their coping strategies. On the other hand, it provided guidance to help me to maintain the interview as a formal conversation, allowing the discussion to flow within the area under study. In addition, semi-structured interviews gave me an opportunity to be closer to the participants' personal worlds, and to better understand their perceptions and attitudes. This, in turn, assisted me to use the appropriate probing questions. Glaser (1998) and Bowling (2002) found that using probing questions can allow more deep information to be generated. Probing questions give the participants a chance to explain

in detail what they think is important in their story and to express their feelings intensely. Participants can add more information, which makes them feel important as they are making a significant input into the interview. The aforementioned benefits of the semi-structured interviews could not be achieved with other research methods such as structured interviews or questionnaires in which the participants have to give limited answers to pre-prepared questions.

Although there are many advantages of using semi-structured interviews, there are some disadvantages that can directly impact upon the research process and findings. A few have been outlined in this study, as follows. The first is that the interviews mainly rely on the participant's cooperation with the interviewer, which is something the researcher cannot guarantee (Remenyi, et al., 1998). In this study, there were some participants who refused to be interviewed and asked me to use a questionnaire instead, based on their past experiences that research means filling in questionnaires, not talking with an interviewer.

The second is that using semi-structured interviews with some guidance could bring some challenges for the participants if the topics were considered sensitive in nature. This could affect some participants' responses, as well as the quality and the depth of the collected information. Lee and Renzetti (1990, p. 512) argued that "*it is possible for any topic, depending upon the context, to be sensitive*". Arguably, the sensitivity of any research topic is dependent on the research field and the environment. It is worth mentioning that parents in this research talked freely about their experiences and disclosed their coping strategies in the interviews. There was no incident where the interviewee refused to answer the interview questions or the probing. However, I have to admit that for this research the data collection and analysis were labour intensive and more time consuming than I expected.

The third disadvantage is that the interviewer's experiences and background can affect participants' responses (Bowling, 2002). For instance, a situation where there was mistrust resulting in a lack of rapport with the interviewee could lead to un-reliable answers. My background as a nurse and mentor to nursing students dealing with patients and their families in the clinical setting on a daily basis, and my preparations in the stage of data collection, assisted me successfully to collect rich and deep information.

I would like to address the issue that in some cases, over-identification in the interviews could lead to modifications of the outcomes. This issue is also reported by Silverman (2001). In some cases, the interviewer assumed responses from participants which were not always the case. To avoid this scenario, I was careful to give the participants enough time to respond with no previous assumption to their input in the interviews, taking into account any responses.

Using interviews in this study did not assume that the participants would be literate. According to United Nations International Children's Emergency Fund UNICEF (2013), the Jordanian adult literacy rate between young males and females aged 15 to 24 years was 99.2% in the years between 2008 and 2012. In addition, the demographic data showed that most of the participants' education backgrounds enabled them to read and write. Reviewing the research findings showed that around 38% of the participants had finished high school and around 27% had degree level qualifications.

4.7.2 Memos and the Reflective Account

Memos, field notes, diaries and reflective accounts were expected to record the missing points in the research process as well as to support the research findings. Using the aforementioned techniques could assist me to gain a multidimensional picture of what was happening in the research field with the participants. Memos will be used during,

before and after the interviews, and will be accompanied by the reflective account, as supported by Strauss and Corbin (1990, p.197). Moreover, using these data collection methods and techniques throughout the research process could focus the researcher's thinking and perception, and encourage him or her to look from outside at the research data, which can improve the neutrality of the researcher.

4.8 Sampling Strategy and Size

Burns and Grove (2003, p. 31) stated that sampling is "*a process to select a group of participants*". In this study, convenience, purposeful and theoretical samples were adopted, which the main sample types are recommended in grounded theory research (Charmaz and Bryant, 2007). The sample strategies in this study changed at different stages in the data collection process; these changes were guided by the purpose of the research and the research questions. Furthermore, recruitment of participants was carried out based on inclusion criteria, variation in their information, participants' characteristics and the level of data saturation at each hospital. In terms of the research sample, the aim is to have comprehensive and rich information from various participants.

Parahoo (1997, p. 232) suggested that the researcher is responsible for deciding and recruiting the research participants based on their ability to provide necessary information that will help to explore and answer the research questions. Morse (2007, p. 230) argued that the research skills is one of the principles of sampling in qualitative research, where the "*experiences could enable the researchers to know when to let the participants move forward in the narrative in to new areas, or when to move back in the interviews to obtain additional details*". Initially the interviews will be conducted with a convenience sample (Silverman, 2001; Mason, 2002) of parents of children with BTM. Sim and Wright (2000, p. 120) stated that convenience sampling is "*a process of drawing a research sample in term of the readiness and availability of the sample unite*". Convenience sampling is

recommended in grounded theory research by (Glaser and Strauss, 1967) and is used in many health care settings as supported by (Bowling, 2002, p. 187). Afterwards, the participants are selected purposefully to maximise the range of meanings and the scope of the phenomena under study (Charmaz and Bryant, 2007) which can be named as selected sample. Gelo, et al. (2008) argue that qualitative researchers mostly adopt purposeful sampling. Arguably, this could be connected with the nature of qualitative research. Participants continued to be recruited to enrich the initial information which was collected, as well as to saturate the initial formulated sub-categories. In this study participants were selected based on their comparable or dissimilar experiences or their condition with BTM, as well as whether parents agreed to participate or not (Charmaz and Bryant, 2007). For instance, I intended to recruit both parents who are relatives (related to each other before marriage) and non-relatives (not related to each other before marriage) and parents where the child with BTM is the first born in the family and those where the child is last or the middle. The recruitment will also include parents with male and female children at different age groups, to compare and understand parents' experiences caring for children with BTM in diverse contexts, as well as to be able to understand the impact of the child's gender and age on parents' experiences. I sought to recruit biological parents, excluding step-fathers or mothers, to identify the impact of being thalassaemia carriers as a mother or father and having child with BTM. Charmaz and Bryant (2007) suggested that in qualitative research, the participants should be interested in participating, and should be expert in the phenomena under study in order to reflect on their social experiences. In addition, Draucker, et al. (2007, p. 1138) argued that *"the researchers must decide when to shift from the selective to theoretical sampling"*.

Baker and Edwards (2012) stated that many qualitative research experts agree that the data saturation is the most indicator on how many interviews can be collect. This also supported by (Mason, 2010) who argued that the guiding principle for the sample size

should be the concept of saturation. However, some expert advice graduate students to recruitments sample between twelve and sixty. For instance, Bertaux (1981, p. 35) argued that fifteen is the smallest acceptable sample to all qualitative researches (Adapted from Guest, et al., 2006). Morse (1994, p. 225) suggested that for ethnography and ethno-science conducted the 30-50 interviews for both. Creswell (1998, p. 64) suggested 20-30 interviews and Morse (1994, p. 225) 30-50 interviews for grounded theory. Creswell (1998, p. 64) and Morse (1994, p. 225) suggested that 5-25 interviews for the phenomenological studies. Baker and Edwards (2012, p. 2) argued that the number of the qualitative research interviews controlled by “*the epistemological and methodological questions about the nature and purpose of the research*”. They also discuss some practical issues which also should take into account. For example, the time available, the institutional committee requirements and the level of degree.

There is no recommended sample size in qualitative research. However, Thomson (2004) suggested that conducting around 10-30 interviews could be enough to reach saturation. Some literature argues that the number of participants in a qualitative study should not be less than six. Ritchie and Lewis (2003) suggested that the sample in most qualitative studies is often less than fifty. Auerbach and Silverstein (2003) argued that it is important for the researcher to get an appropriate sample size that will generate enough data. Morse (2000) and Sobal (2001) stated that the sample size is dependent upon the scope of the research questions. For example, a broad research scope will need more data and resources, which means the researcher needs more interviews, time and effort. Grounded theory researchers do not seem to reach a decision regarding the sample size until they are engaged in the data collection and analysis stages (Glaser and Strauss, 1967; Corbin and Strauss, 1998). For this study, the sample size will guided by the data saturation, the aim and objectives of the study, which were to recruit adequate parents, including mothers, fathers and couples, in a comprehensive and representative sample from the three

thalassaemia departments located in the three Jordanian cities. Generally, in a qualitative study a small sample size is accepted and appropriate (Bowling, 2002) because the aim is to present the individuals' social experiences.

4.9 The Research Setting

It was decided to use Jordan as a focus for this research because of the limited research has been conducted in this area to date, based on the literature review which was carried out in Chapter Two. It is further considered that the culture in Jordan, dominated as it is by Islamic religion, was likely to influence people in many life domains, such as social, education and health. The data will be collected at three public hospitals in the three largest cities in Jordan; a summary of the research settings is provided in figure 4. The hospitals were the main health care foundations in Jordan dealing with BTM and other similar haematological disorders, such as sickle cell anaemia and haemophilia. The three regional areas were chosen in order to identify and capture the differences and similarities among the parents' experiences and coping strategies. The main three cities are: Irbid, Amman and Al-Zarqa.

A. Irbid:

Irbid is recognised as the second largest city in Jordan. It is widely regarded as a beautiful city, and being located in the northern region, it is fondly known as 'The Bride of the North'. Irbid has a population of around 1.2 million and a population density of around 692.3 per square mile. It is about 1572 square km in size and is surrounded by fertile agricultural lands to the north, east and south (DoS, 2010). Princess Rahma Teaching Hospital (PRTH) in Irbid is known as a 'Maternal and Child Teaching Hospital' which serves the entire northern region of Jordan. The hospital has approximately 100-150 registered patients with BTM receiving regular treatment, out of a total of around 350 patients with other haematological disorders.

B. Amman:

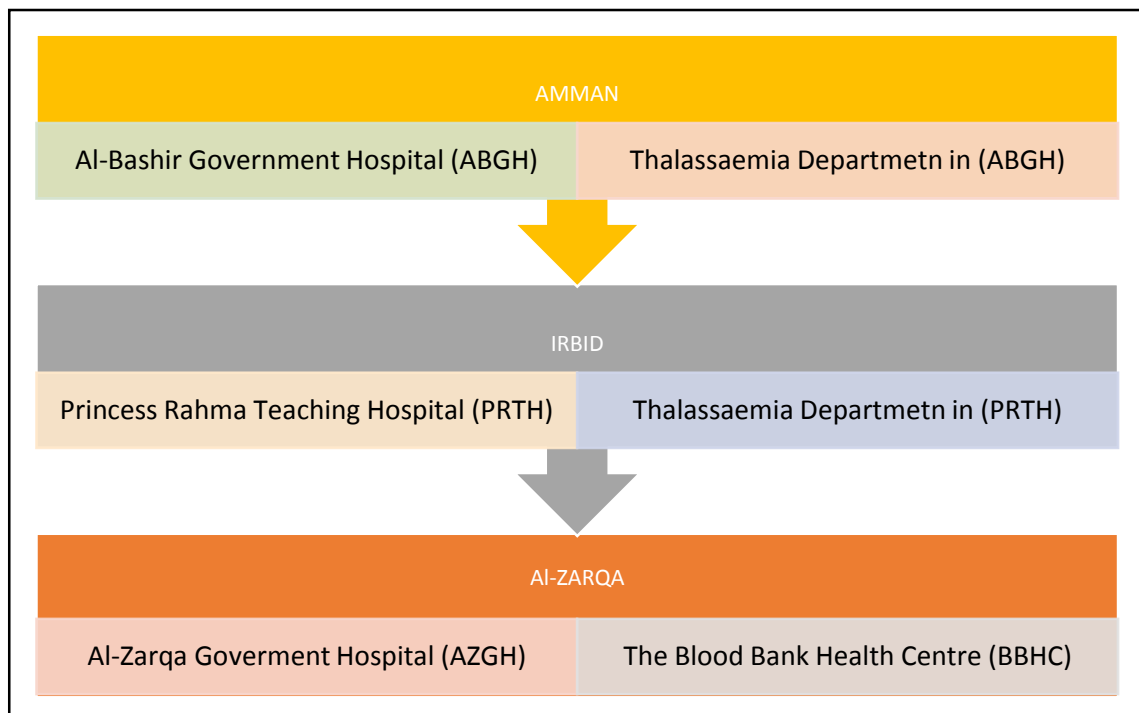
Amman is the capital of Jordan, and has a population of approximately 2.3 million. The city is known as 'The City of the Seven Mountains' because it was originally located on seven hills. Amman covers an area of about 7579 square km and is situated in the centre-north of Jordan. It has a population density of around 312.3 per square mile (DoS, 2010). During the data collection I noticed that Al-Bashir Government Hospital (ABGH) was the largest government hospital in Amman, with an estimated 350 to 400 patients with BTM out of a total of 675 patients registered in the thalassaemia department. In addition, I noticed that the departments had patients with various other haematological disorders, such as sickle cell anaemia, chronic anaemia and haemophilia.

C. Al-Zarqa:

The third city is Al-Zarqa, which is located in the mid north-west of Jordan and has a population size of around one million, with a population density of around 191.3 per square mile (DoS, 2010). Al-Zarqa covers an area of around 4761 square km. Geographically, Al-Zarqa is made up of a mixture of agricultural and industrial land together with wasteland. At the time of the data collection, Al-Zarqa's government hospital provided health care services to around 220 haematological patients, of whom an estimated 119 were diagnosed with BTM. These patients received their treatment from a special health care centre named 'The Blood Bank Health Centre' (BBHC), which was located outside the hospital area.

Essentially, the three hospitals provided the patients in the Kingdom of Jordan with the required therapy, including regular blood transfusion and iron chelating medications, through the three thalassaemia departments. Geographically, ABGH in Amman served patients in the middle and southern regions, BBHC in Al-Zarqa the mid northwest and PRTH in Irbid served patients with BTM in the northern part of Jordan.

Figure 4 The Research Settings.



Source: Author (2013)

4.10 Participants' Criteria

To meet the research aim and objectives as well as to answer the research questions, the following inclusion and exclusion criteria were set for the participants and their children with BTM (see tables 9, 10, 11 and 12).

Table 9 Participants' Inclusion Criteria

The participants' inclusion criteria identified for this research were that:	
1.	Participants had to have one or more children with BTM;
2.	Participants had to be the biological fathers and mothers of children with BTM;
3.	Participants had to be 18 years of age or older;
4.	Participants had to be able to communicate either in Arabic or English.

Source: Author (2013)

Table 10 Children's with BTM, Inclusion Criteria

For participants' children, inclusion criteria identified for this research were that:	
1.	The child had to be free from any other chronic and haematological disorder;
2.	The child had to be diagnosed as having BTM for at least one year;
3.	The child was currently being treated at one of the three selected hospitals.

Source: Author (2013)

Table 11 Participants Exclusion Criteria

The participants' exclusion criteria identified for this research were:	
1.	Non-Jordanian participants (the research aimed to explore Jordanian parents' experiences); both parents had to be Jordanian;
2.	Participants under the age of 18 years;
3.	Step-mothers or fathers (the research aimed to explore the experiences of the biological parents);
4.	Participants who had communication problems, for example, deafness or any verbal communication disorders.

Source: Author (2013)

Table 12 Children's with BTM, Exclusion Criteria

For participants' children, the exclusion criteria identified for this research were:	
1.	Children with BTM and in addition, any other chronic disorders, physical or mental (other than the complications of BTM), for example, children with BTM and cerebral palsy or diabetes mellitus;
2.	Children diagnosed with other types of thalassaemia that could including 'alpha' thalassaemia and thalassaemia 'intermedia' or/and any other haematological disorder.

Source: Author (2013)

4.11 Research Instrument

Literature presents the importance of the researcher's role in the qualitative approach where the researcher could play different roles during the research process. For example, he or she could be the research instrument, interpreter, translator and publisher of the research data. Priscillia (2003) highlights the idea that the researcher's role as a 'research

instrument' is a critical role. It places the researcher in an important position to appropriately share participants' interests, knowledge and different types of experiences, and to interpret and give meaning to their life. Speziale, et al. (2011) addressed the variation in the researcher's role according to the nature of the research data. These variations are significant and have a unique impact on the whole research process, especially at the stages of data collection and analysis. However, this variation in the researcher's role as well as its collaboration gives the researcher an opportunity to make informed judgements at every stage of the research.

Arguably, being a data collector, interpreter, translator and publisher, places the researcher at the centre of the research, which could also increase the degree of sensitivity to the research subjectivity. The main reason for these roles, according to Corbin and Strauss (2008), is the nature of the qualitative research data, which are mostly verbal and may only be accessible through personal interactions. In addition, qualitative data is distinct in its nature and requires more interpretative skills to be reflective and comprehensible. In order to ensure the credibility of data, the researcher's subjectivity plays a key role in the research process (Heron and Reason, 2001). This is because the researcher collects grounded information from people who are interconnected to one topic or who share the same experiences and life events. For example, the qualitative data could be participants' experiences, behaviours, attitudes, feelings and knowledge. The nature of such data requires the researcher to be comprehensive, synthesising, and theorising in order to give meaning and sense to the collected data (Mores and Field, 1996, p. 82). Furthermore, preparing data in new forms requires a high level of skill from the researcher, as well as reflectiveness to keep the researcher's objectivity, to bring the originality of the collected data and to be sensitive to his own background.

4.12 Conclusion

In this chapter, the research method and methodology were presented and discussed. This included the research approach and theoretical perspective. Justifications were presented for adopting a qualitative approach, choosing grounded theory and using semi-structured interviews in this research. This chapter also presented and discussed the research sampling strategies, settings, participants' criteria and my role as the research instrument. The discussion in next chapter will be about the process of data collection and analysis.

Chapter Five: Data Collection and Analysis

5.1 Introduction

This chapter discusses data collection and analysis process. The chapter presents the preparation stages for data collection, the recruitment process, interview issues and field observations. The ethical considerations and the challenges in the clinical field will also be addressed. This chapter also discusses how the data was analysed, what techniques were used, and the grounded theory coding system, with some examples from the research findings. In addition, the chapter presents how the researcher maintained rigour and trustworthiness in this study, the role of memos, and research reflexivity.

5.2 Preparation for Data Collection

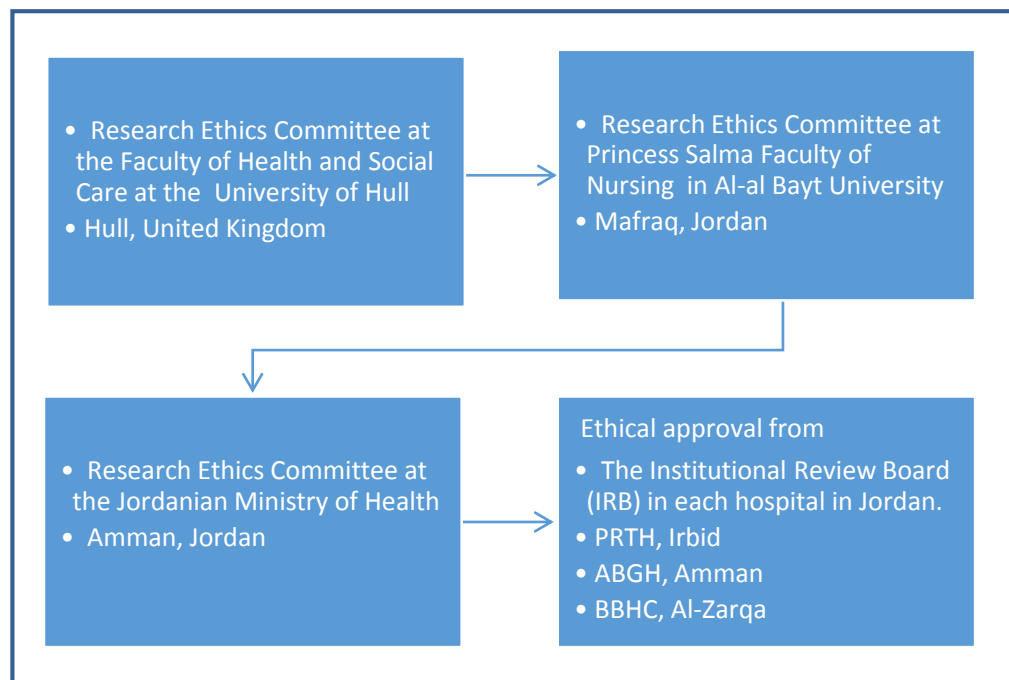
The preparations before entering the research field included obtaining ethical approval forms from all related institutions, preparing the research documents, and myself as an interviewer. A pilot study was carried out before conducting the main study, which assisted me in evaluating the interview guidelines and the participants' responses.

5.2.1 Ethical Approval

This study received ethical approval from the Faculty of Health and Social Care at the University of Hull in the United Kingdom, 'Princess Salma' Faculty of Nursing at Al-al Bayt University in Jordan, the ethical committee in the JMoH and the Institution Review Boards (IRB) at each hospital where the data were collected (see Appendix 3). Cooperation from the JMoH was followed by approval from the administrator in each of the three hospitals. A copy of the official letter from the 'Ethical Research Committee' in the JMoH was given to the manager in each hospital. The manager and the administration

office in each hospital also submitted an acceptance letter to the ethical committee or the relevant IRB (see Appendix 3). This process led to formal communication and access to the participants through the nursing department in each hospital, which secured their cooperation with the study. A summary of the ethical process is shown in figure 5. It took more than two months to obtain approval from all parties in Jordan; it had not been expected to take that long. However, ethical approval was obtained from the JMoH during the fasting month of Ramadan, during which working hours were reduced in all government institutions. However, I conducted the interviews after Ramadan. This was based on my experience with fasting, especially in summer time, when people would not be in the mood for participating in research interviews. While fasting, people may try to avoid sharing in lengthy dialogue because they could be at times tired, hungry and dehydrated, so those questions and demanding answers could be irritating to some of them.

Figure 5 Ethical Approval Process



Source: Author (2012)

5.2.2 The Research Documents

Prior to the data collection process, copies of the study documents were prepared in Arabic, including the invitation letter, consent form, research information sheet, and the participants' demographic information sheet (see Appendix 4). A verbal explanation was given where needed to the participants and the staff. After the introduction, each interview was given a specific code which was used for identification purposes and to ensure anonymity. In addition, documents providing an explanation of the study aim and objectives, and a copy of the ethical approval forms were provided to the nursing department when needed, in both Arabic and English versions (see Appendix 4 and 5). The nurses and staff, in the three health services, appeared to be positive about the research and expressed their support.

5.2.3 The Researcher's Language and Responses in the Interviews

As part of the preparations before starting data collection, I attended some university modules about research interviews and communication skills. In addition, I practiced performing interviews with two of my colleagues. This training was carried out for the purposes of testing my interview techniques and skills, estimating the time needed for covering the interview questions, and posing probing questions. The training enabled me to obtain feedback from interviewees, as opposed to the pilot study, where the interviewees were not in a position to give feedback.

I was constantly aware of the socio-cultural and traditional issues which are connected with the communication process, because they are considered important in the Jordanian community. For example, it is usual during formal communication or dialogue to keep providing reassurance and showing agreement to the respondents, in order to make sure that the other party is receiving the messages and following the conversation. For example,

at the end of a question, people would usually add; *“is that right? Isn’t it? Do you agree? It is always like that? Should this be? What do you think? Do you know what I mean? Is that clear?”* Such questions at the end of a conversation could lead to a long debate and sometimes change the direction of the conversation. I tried to be neutral in my answers and prepared some neutral answers. For instance, *“I understand, I see what you mean, and that could be the scenario”*, to keep the interaction in the interviews and avoid unwanted debate. In Jordanian culture, it is unacceptable to interrupt somebody when they are speaking, and this is more critical if the conversation is with a stranger or an elderly person. I kept in mind some statements designed to keep the conversation on the research topic and use the time available effectively, such as, *“Thank you... You really clarified the medication issues, but can I please ask you about...”*

Moreover, it was understood that interview questions about personal experiences were considered as a culturally sensitive issue to be discussed with a stranger. I planned to let the participants take their time in talking and presenting what they wanted to about their experiences and coping strategies without any obligations. The interviews ranged in duration from 30 to 100 minutes. In keeping with tradition, most Jordanian people did not speak directly about the required topics, but preferred to tackle the subject indirectly for a few minutes before opening up to the topic. This style of communication has been also noticed in most Arab conversations, where people avoid discussing direct issues, as observed by Deresky (1994). My background and experiences as qualified nurse added to my ability to perform the interviews with the participants, especially as I am from the same country, speak the same language and understanding of the socio-cultural, religion and traditional background.

5.2.4 Pilot Interview

A pilot study was carried after ethical approval was obtained and the preparations for the field work were completed. Conducting the pilot study enabled me to test and exclude potential problems that could rise during the main study. Polit, et al. (2001, p. 467) identify the pilot study as “*a small scale version, or trial run, done in preparation for the major study*”. In addition, pilot interviews assisted me in identifying the ineffective points in the interview questions, and any issues related to the questioning technique or the phrasing of the sentences (Cavana, et al., 2001; Yin, 2003). I performed two pilot interviews; the first was with a mother and the second with a father of children with BTM. For a representative sample from the pilot interview, (see Appendix 6). This was done to ensure the consistency of the interview questions and to assist me in detecting possible practical and technical problems during interviews.

The pilot interviews also assisted me in identifying how far and to what extent the participants were willing to go, and showed me their confidence to talk freely about their personal experiences and coping strategies. Furthermore, the pilot interviews supported me in estimating the time needed for each interview to cover all required areas of discussion. In addition, they gave me an initial idea of the information, events and issues that participants would probably bring up during the interview. After carrying out the pilot interviews, my interviews skills were enhanced and I acquired more confidence in my ability to collect the data from the parents of children with BTM. In addition, the interpersonal skills of communication and my responses were tested. Van Teijlingen and Hundley (2002) argued that performing a pilot study could provide an early warning of where the major study may be unsuccessful or where the planned techniques were unsuitable. Arguably, such warning could be important, because it would save the researcher's time and improve the quality of the research data. In addition, based on my

experiences, the pilot study is important so that the researcher will not face unpleasant surprises in the middle of their study, leaving them struggling with the data collected or with no data at all. It is worth mentioning that based on the pilot interviews, there were no modifications to the research questions and the plan, as the participants answered the questions without raising any concerns. However, some probing questions were added to the list to explore in depth areas which were raised by the participants.

5.3 The Recruitment Process

I started the recruitment process using a convenience sample by sending an invitation letter to the participants through the nursing department. The participants are those parents who accompanied children for blood transfusion. On average, parents spend around five to six hours in the department every three to four weeks. In addition, some parents visit the hospitals for other purposes, such as collecting their child's medication, prescriptions and other medical procedures. It is worth mentioning that parents who were recruited in this study were in the department for their child's blood transfusion.

In each department the nurses and staff recommended some parents they considered might be appropriate to participate. However, if I had relied on this mechanism, the participants would be only the parents recommended by staff, which probably would not have been representative of all parents who accompanied their children to hospital. I thanked the staff and showed my appreciation of their cooperation and suggestions. In order to avoid bias, I also checked the department's registry book with the staff to identify the eligible participants who met the research criteria, rather than recruiting only the participants suggested by the staff. Arguably, the nurses and staff in the departments might have chosen and suggested parents to participate in this study because they believed that they were an appropriate sample for the research topic, and they could have excluded others who they thought were not. This choice could be biased, because the selection

would be based on nurses' personal knowledge and experiences with the parents. However, selection based on judgement and pre-conceived ideas about the participants was not in my research strategies. I planned to give an equal opportunity to the parents of children with BTM in all thalassaemia departments, and I adhered to this strategy during the data collection stages in the three settings.

A list of potential participants in each hospital was prepared, to send them the invitation letters. The recruitment process started with ten potential participants. Depending on their responses, another ten would be approached, to avoid conflict among participants who would be interested in taking part in the study. The invitation letters were sent by the staff in the nursing departments. I then contacted the participants who had indicated that they were willing to be recruited in this study, in order to introduce myself and share the research documents with them. From the first few responses I quickly found out that most of the potential participants were not willing to have home interviews. This was noticed at all three thalassaemia departments. They preferred doing interviews at the hospital during the time they were accompanying their children for blood transfusion. Only one couple out of the forty participants agreed to have a home interview.

For each couple, fathers and mothers were invited individually by the nursing department to participate in the study. However, the majority of children with BTM in the departments were accompanied by their mothers. In most cases, the fathers would be at work during hospital visits. Therefore, some fathers' interviews were conducted during the weekend. Potential participating couples, both fathers and mothers, were given up to two weeks to respond to the invitation letter for participation. The potential participants were invited to choose their preferred location, either at their home or the hospital, as well as an appropriate date and time for the interview. It was noted that the majority replied to the invitation within days, many on the same day they received it. The time and date for

the interviews were agreed with participants once they appeared to understand the information and were interested in participating. At this point, the participant completed the demographic information sheet and signed the consent form.

The nursing department at PREH in Irbid was the only one that required submission of the numbers of those who were recruited in the study, and this information was supplied as required. The reason given by the nursing department was that the information was needed for administration issues, and to monitor the number of the research studies conducted in the department and the number of the participants who were involved in the research studies. The information would be recorded in their systems only. Staff mentioned that this data would also help them to avoid overloading the patients and their families with too many research activities, by identifying and monitoring how many research projects took place in the department, and at what time. However, they stated that this was not intended to prevent or impact on any participants' interest to share or take place in any research activities in the department at any time.

Participants were given two weeks to read a copy of the research documents, and to clarify and ask any questions. In some cases, participants needed help in reading and understanding some words or phrases in the documents. Either I or the nurses in the departments, based on the participant's preferences, read the invitation letter and other documents to them and explained the contents, to make sure that their participation was based on a full understanding. Thereafter, if they agreed to participate, they were asked to sign a consent form in Arabic (see Appendix 4 form 4.3). In practice most of the participants were able to read and write, but a few needed assistance in explaining the meaning of some texts in the research documents. In addition, the participants were advised to ask for assistance if they needed it, from their partners, staff or any third party, if that was appropriate for them. Participants were assured that any recordings or written

data would only be used for the purpose of this study and it was made clear that in the future, the study might be published or used at conferences. However, participants' identities would remain anonymous and protected at all research stages. The concept of 'ongoing' consent was also applied with the participants (Butler, 2002). I obtained verbal consent before I started the interviews and the recordings to confirm that the participant was participating voluntarily.

5.3.1 The Research Sample

For this study I recruited forty two participants from the three departments. However, two interviews were excluded from the analysis at the request of the participants, without any reason given. This left a total of forty interviews; seventeen participants from the first hospital, twelve in the second hospital and eleven from the third hospital (see table 13).

The variation in the number of participants from each hospital was because I did not aim to have the same number from each hospital, but rather to have a representative sample which was controlled and congruent with the level of the data saturation. The recruitment was stopped when the data revealed no new information (Douglas, 2005) and for some categories, when the saturation was reached. The objective was to maintain the quality of the collected data in order to saturate the emerging categories. During data collection it became apparent that many initial sub-categories were starting to emerge from the interviews conducted in the first two hospitals.

At a later stage of data collection, the sub-categories were compared, reviewed, examined and analysed through identifying indicators, dimensions and relationships, to create the core- categories. I adopted the techniques supported by Douglas (2003), who stated that the researcher has to continue expanding the number of interviews until the research data is saturated and the interviews reveal no new ideas. The cycle of collecting and analysing

the research data involves breaking the data down into sub-categories and linking them again in new dimensions to form new categories. The data reached the level of saturation for some categories at the first hospital. In each case, I worked to saturate data, and any new ideas coming from the interviews were cross-checked with another participant to establish if they had similar concerns. For example, some participants talked about their experiences administering the infused iron chelating therapy at home. I saturated this category by probing, asking another father and mother to talk about their experiences with medication at home, to identify their role in giving the medication and how they felt about being responsible for giving it to their children. In some cases, gender roles in the caring process were also discussed, including whether it was the father or mother who gave the medication to their either male or female child with BTM, at what time they usually gave it to their children, and the impact on them. In addition, to saturate this category, the parents of children of different age groups were asked about their experiences in administering the medication at home to capture whether there were any related issues connecting them together.

In most qualitative research, data saturation could be used as one of the indications of the sample size (Thomson, 2004). However, it can be argued that data saturation can be an indication that there is no need to conduct more interviews, because the information is already present in the previously collected data. I spent three months in the clinical setting, recruiting participants not only to expand the size of the sample but to saturate the categories, and to have a variety and a comprehensive representative sample from the participants in the three hospitals where the patients and their families were located.

Table 13 Recruitment Process

Recruitment Cities	Irbid (A)	Amman (B)	Al-Zarqa (C)
- Recruitment Hospitals	Princess Rahma Teaching Hospital (PRTH)	Al-Bashir Government Hospital (ABGH)	Al-Zarqa Government Hospital (AZGH)
- Recruitment areas	Thalassaemia Department in (PRTH)	Thalassaemia Department in (ABGH)	The Blood Bank Health Centre (BBHC)
- Number of Participants	17 Participants	12 Participants	11 Participants

Source: Author (2013) The data was utilised from the research data.

The aim of this study was to have a sample representing fathers, mothers and couples of the children with BTM, to meet the research aim and objectives. However, in cases where some fathers were unable to participate, I modified the hospital visiting schedule in order to be able to interview them, rather than replacing them with mothers who were more available and accepted to participate. It may be important to note that the quality of collected data matters more than the number of the participants. However, Holloway and Wheeler (2002, p.128) suggest that the sample size could change during the different stages of the data collection without affecting the quality of the study.

5.3.2 Interview Guide

The interview guide is the written questions and prompts to be used to focus the discussion and direct the interactions during the interview. The interview guide for this study consists of four pre-prepared open-ended questions (see Appendix 7). In addition, I used probing questions to gain more detail and to clarify what the participant had said. The interview questions were meant to be neutral, open ended and clear (Patton, 2005) to give the interviewees the opportunity to talk freely about their feelings, explain their personal experiences of caring for their children and to discuss their coping strategies.

Using open-ended questions in the interview guide allowed the participants to feel free to express themselves. Different probing questions were used in each interview. They took the following format: *“Can you tell more about the day you received your child’s blood results?”* and *“What about your work and the time to accompany him for blood transfusion? Please, can you explain this more?”* Such questions were designed to collect rich and in-depth data.

The probing questions were varied to reflect the different experiences discussed by each participant. The order of the questions and the format sometimes differed from one participant to another, depending on the participants’ narrative, the quality and the time of their input. For instance, I asked the participants about their experiences caring for children. Based on their responses, the next question could be asked or postponed. Some parents started to talk about their daily activities with children, or their social status, while others talked about their experiences with medication. Each parent had his/her own responses based on their interests and the way they wanted to talk about their experiences and ways of coping with their situation. Moreover, I noticed that this also gave the participants the sense of having some control in ordering and prioritising the conversation.

Another benefit of using the interview guide is to give me the ability to decide and use effectively the available allocated interview time to get as much information as I possibly can. In addition, using the interview guide helped me to show more flexibility and freedom to follow and respond to the interviewee accordingly. Moreover, not only were there benefits for both me and the participants from using the interview guide, but using the same guides with each participant also led to having more systematic and organised data, and gave the chance to understand, clarify and test the relationships and the connections between emerging categories.

5.3.3 Recording the Interviews

All interviews were voice recorded after participants had given consent. The reason for consent is to follow the research's ethical considerations and the participant's ethical and legal rights, which are explicit in the Jordanian Clinical Research Law of the 2001 (Ramahi and Silverman, 2009; JFDA, 2011). I found voice recording to be useful in this study for the following reasons:

1. Recording interviews assisted me to maintain the quality of the conversation (Burnard, 2005) by not missing any data. I could return to interviewees' actual words and statements, which kept the original form of the conversations. Voice recording helped me to maintain consistency without frequent interruptions or missing any verbal phrase, and to repeat them with no change.
2. Recording interviews ensured that the collected information was accurate and complete, which helped me in the transcription and analysis stages to capture the complete conversation (Silverman, 2001).
3. Moreover, recording enhanced the data reliability (Polit and Hungler, 1999) and reduced errors during translation, as I had an opportunity to listen to the recorded interviews more than once.
4. Recording gave me an opportunity to compare the interviews with the field observations, notes taken and the written memos. In addition, use of participants' words and phrases in the constant comparison method was facilitated by using the recorder (Strauss and Corbin, 1990; Glaser, 2001).
5. Recording helped me to maintain the appropriate eye-contact with participants and give full attention to their responses (Bowling, 2002)
6. Recording saved my time and reduced distractions during the interview, which could have been caused by taking notes during the conversation and asking

participant to wait until I finished writing. This could have disturbed their thoughts and the flow of their speech.

5.3.4 The Interview Process

Each interview commenced by welcoming the participants, thanking them for agreeing to take part in the research and introducing myself and my study. I followed the traditional welcome in Arab culture. For instance, I stood up to greet participants and initiated hand shaking with female participants, which is the Jordanian tradition in welcoming someone of the same sex. However, with male participants, I waited for them to initiate hand shaking, to avoid conflicts and embarrassments. These techniques were used based on my knowledge of and experience with Jordanian culture and the Islamic religion; not all men are willing to shake hands with the opposite sex. It is an individual preference, based on their religious and cultural background. After the welcome, I checked if the participants were comfortable with the interview environment. Then I introduced myself again, introduced the research documents and confirmed the verbal consent. Furthermore, I answered any questions raised by the participants and secured permission to record the interview before commencement.

At the beginning of the interview, the participants' demographic sheet was introduced to each participant as a tool to collect basic information on the recruited sample and as an initial topic to open and start the interview. More details about the participants' demographic data will be provided in Chapter Seven. Ritchie and Lewis (2003) recommend that background information such as age, household structure, education level and work status should be recorded at the beginning of the interview. This information allowed the interview to commence at a description-level discussion that was straightforward, allowing the participant to feel more comfortable and become more

familiar with me. The interviews were guided in an attempt to allow the participant to respond fully to each prompt and enabled the interview to be conducted within a reasonable amount of time.

I attempted to keep the conversation focused on the research area to ensure that the participants expressed information that served the objectives of the interview. At the end of each interview, I thanked the participants and assured them that their time was greatly appreciated. Participants were again assured that the data would be held confidentiality. Following each interview I checked the notes on the interview proceedings, including any interruptions. I checked the notes on non-verbal communications and participants' behaviour. In addition, I played back the voice recording to some participants, to confirm that what was said in the interviews was accurately what the participants had wanted to say. It is worth mentioning that none of the participants changed their recording. Some participants were excited to hear their voices recorded, stating that it was their first experience of participating in a voice recorded interview. I encouraged the participants to respond to the interview questions freely and to narrate their story. However, it was the participants who considered the best way to describe and illustrate their experience and coping strategies. To facilitate this, participants informed that there were no right or wrong answers, all answers were taken into account (Ritchie and Lewis, 2003), and that they were free to add any thoughts or information that they felt was part of their experiences and coping strategies. In addition, participants were encouraged to ask any questions they wished before, during and after the interviews (Ritchie and Lewis, 2003). This was to facilitate the establishment and maintenance of trust and mutual cooperation between me and the participants. It was considered that this approach would lead to a supportive, cooperative and trusting relationship between me and the participants.

I avoided presenting participants with several questions or probes at once without giving the interviewee sufficient opportunity and time to carefully accept the questions and make a considered response (Ritchie and Lewis, 2003). There were times when the participant was not clearly audible or fully coherent; this was often because they were thinking about matters that were emotionally challenging. At such times, I tried to show more sensitivity and would calmly ask the participant to repeat what had been said, such as, *“I’m sorry, could you repeat what you have just said, please?”*

I maintained a reflective diary, in which I recorded the experience of managing the interviews and dealing with any events that occurred during data collection process. This diary was also used to record any thoughts, feelings and evaluations related to the data collection and meeting appointments with participants and staff. The purpose of the reflective diary was to organise the work, facilitate the data analysis and assist me to make the study auditable. The working hours in thalassaemia departments and the practical constraints that these situations present effectively limited the number of interviews that could be carried out to about three per day. On some days only two interviews were conducted. This was usually related to constraints between the timing of the blood transfusion and other procedures required for treatment. Sometimes it depended on the availability of parents in the departments.

5.3.5 Probing Questions

Probing questions were used in an attempt to elicit material at a more than superficial level. For example, *“what do you mean by saying this?”* was used frequently in the interviews (see Appendix 7 and Appendix 5 form 5.5). I adopted Ritchie and Lewis’ (2003) suggestion that it was wise to give a signal when I was approaching the end of the interview, by using a phrase such as: *“the final question is ...”* or *“as we approach to the end of the conversation ...”* and *“this is the last thing I need you to clarify...”* this

approach allows the participants to gradually return back to the level and the daily rhythms of their life and the continuing demands of the rest of their day. Such signals are designed to permit participants' emotional feelings to return back to their normal state.

It was important to recognise the fact that the interview could cause the participants to dwell on emotionally sensitive matters and even to have discovered some feelings for the first time. To overcome this, I stayed for a few minutes with the participants at the end of the interview to make sure that the interviewee was comfortable and had returned to the normal mood of the day, talking about daily events and some time on the research subjects. In addition, a continuous conversation about the topics with the parents before, during and after the recorded interviews was used to confirm that certain information had been saturated (Strauss and Corbin, 1998). This allowed me to document some important information that may have been mentioned by the participants. According to Strauss and Corbin (1998) and Cutcliffe (2005), such evidence could increase the trustworthiness of the research. Rubinstein (2002) describes the timing and position of the interviewer's responses; whether the interviewer should respond directly, probe, or ask for more clarifications during the interviews or wait until the participants have concluded their stories before asking them for clarification. The second position is based on a belief that any intrusion into the interview process has the potential to alter its course (Schutz, 1992 cited in Corbin and Morse, 2003, p. 339). Arguably, both styles could be used during interviews and the choice of route is the researcher's decision, based on rapport, interview stage, communication skills and the interviewer's experience.

5.4 Interview Issues

During the interviews, I faced and managed some unexpected practical issues such as: (a) situational issues, (b) personal factors and (c) technical errors.

A. Situational Issues

I was aware of some situational issues that might have contributed to the collected data and influenced the participants' responses. This included managing some environmental factors, such as the lighting, external noise and room temperature. These precautions were taken to ensure that the participants were comfortable and relaxed, so that the interviews were not affected. Moreover, I also made a point of offering refreshments to the participants during interviews.

B. Personal Factors

Participants' temperament and mood may have an influence on their responses. I ensured that the interview schedule was flexible and took into consideration the interviewees' interest, and that the timing was convenient to avoid clashing with the participants' other commitments. Furthermore, some parents preferred to be interviewed while their children received blood transfusion, not before, as they were more comfortable spending time in the interview room while the nurse or their partner looked after the child. Others preferred when the children had completed the blood transfusion. In some cases, the interviews were rescheduled at the interviewee's request.

C. Technical Errors

Technical errors can be expected at any stage of the research. However, I used a digital audio recorder which is reachable from a computer, and I had extra batteries and another voice recorder to avoid any unexpected function failures in the devices. Additionally, I prepared a second copy of the research documents, and extra sheets and a notebook, in case they were needed. The room's reservation was checked before the interview to save the participant's and my time.

5.5 Translation and Transcription of the Interviews

Transcription and translation took more time than I expected. The interviews were conducted in Arabic, the first language of the participants and me. For a sample of the interviews conducted in Arabic (see Appendix 9). Since this study aimed at gaining better understanding of the participants' experiences and coping strategies, through giving the participants a chance to talk about their knowledge, feelings, ideas and attitudes, it was easier for the participants to speak in their own language.

Participants used colloquial, everyday language during the interviews. Therefore, I did transcribe them verbatim. The transcriptions and translation took place during and after the data collection. To maintain the quality of the collected data, two colleagues, who were fluent in both Arabic and English languages, checked the translation. Some participants in the interviews used some phrases that originated from their religious background. For example, some of them quoted statements from the Holy Noble Qur'an. In this case, I used the English version of the Holy Noble Qur'an as a reference, when it was necessary to use the same quotations. I used the literal translation for some words and phrases that originated from Arab culture, having agreed with colleagues to use contextualised translation which gave the same meaning. For example, *"it is too hard for me to accept"* and *"it's killing me from inside"*, meaning the individuals experienced a lot of stress, feeling hurt and broken-hearted.

In a few cases, where a term was difficult to translate, I consulted colleagues who were fluent in both languages to find the appropriate English meaning. For example: *"Inshallah"* means *"If God wills"*, *"Haram"* means that someone is *"doing something religiously wrong"* or *"it could be forbidden"* or in some cases it means it is *"religiously unacceptable to do it"*. I found translation and transcribing time consuming. For instance, on one occasion I spent more than eight hours transcribing and translating one paragraph.

5.5.1 Non-Verbal Communication

Not only participants' verbal information, but also their speech patterns, body language and other non-verbal communications were considered to be important and salient, and were therefore documented. Some participants became passionate about certain aspects of the discussion and topics, and they presented their experiences in detail. For instance, as some participants became more emotional, their tone of voice became low and they started to move their hands frequently when they spoke about their experiences and thought back to the time when they were first informed about their status as a thalassaemia carrier and their child's diagnosis with BTM was confirmed. I constantly observed the participants' body language and their non-verbal communication. For example, when I detected a hesitating tone or sad expression, I asked *"How do you feel?"* and probed, *"is this something that has just come to your mind that makes you feel like this? Do you want talk about it?"*

I tried to be responsive to the participants' facial expressions and body movements, because these are used in Jordanian culture to give the appropriate meaning to the spoken word, feelings and emotions. For instance, when the participant nodded their head or putting their hands to the side of their face, I typically responded by asking: *"you look unhappy with this. Can you tell me more about it? Are you ok to talk about it now? Why? What happened at that time? Can we talk about this in detail from the beginning? With whom were you in this situation? When did that happen to you?"* I used my advanced knowledge and skills to guide and perform effective interactive interviews, by giving more attention to eye contact, which helped to keep participants connected and interacting. Notes were taken before, during and after the interviews to record the participants' non-verbal communication and clues such as facial expressions and body language, which cannot be captured by the voice recorder (Silverman, 2001). Furthermore, I took notes

about the interview and my reflections immediately after each interview, so as not to forget any information. During the interviews I adopted the following strategies:

1. Maintaining eye contact as appropriate with the participants;
2. Changing my tone of voice when needed;
3. Using a wide range of probing questions;
4. Summarizing the participant's statements;
5. Maintaining flexibility with time;
6. Asking for more comments and examples;
7. Following the participant's manner;
8. Answering participants' questions and providing clarification when needed;
9. Giving breaks when needed.

5.5.2 Interview Atmosphere

It was my responsibility to ensure that participants were comfortable answering the interview questions and to control the environment. Efforts were made to keep the interview free of distractions. Interviews were carried out in a comfortable room while the interviewee's partner waited in a treatment room with their child or in the department reception. Every effort was made to ensure that the staff in the thalassaemia department understood the importance of keeping the interview environment free from disturbance and undue noise. However, the clinical settings were often busy and there were times when interruptions occurred. For example, when participants received unexpected phone calls during interviews, some participants asked to take a break to answer, while others postponed answering until the end of the interviews. However, I encouraged the participants to act normally; they could answer their phone call or take a break at any time they wanted to. I thought that otherwise participants might be distracted and worried about missing the calls they received.

5.6 Field Observations

Field observations were used in this study in order to support the collected data from the interviews. The observations were carried out in order to give a comprehensive idea of the parents' experiences in hospitals while they accompanied their children. Furthermore, hospital observations gave me an opportunity to compare the difference between what parents said in the interviews and the reality of what parents do. How they spend their time? What activities do they do? What is their role? In addition, the observations enabled me to have an account of the parents' relationships with the HCPs. Observations in this study were expected to assist me to identify and draw full pictures of parents' experiences at the clinical settings.

I spent three months in the research field, and this gave me the opportunity to explore how parents spent time at the hospital and how they were treated in the clinical setting. Admittedly, spending a month in each thalassaemia departments may not be enough time for me to observe parents' experiences and to have a complete picture of their hospital experiences and coping strategies, especially as I used part of that time for conducting interviews. However, the data collected from the field observations helped in giving me a fundamental and appropriate background about the time parents spent in hospitals with their children, which was also used to saturate the categories which emerged from the individual interviews. It also gave me some understanding of the parents' hospital experiences as they attended the hospital regularly. I was in the thalassaemia department on a daily basis. This made me more familiar with the staff, patients with BTM and their families. Field observations were carried out in the three hospitals in the thalassaemia department reception, the nursing station, waiting areas the children's play room, general practitioner clinics, and the patients' treatment rooms. The findings of the field observations will be presented in Chapter Six.

In conclusion, I managed to gather some information and ideas about the following issues: firstly, the time parents' spent with their child in each visit. Secondly, parents' communication, discussion and interaction with their children, HCPs and other children with BTM and their families. Thirdly, the parents' roles and activities during those visits which were recorded. Arguably, when observations are combined with the interviews, a closer understanding can be gained of the parents' experiences and coping strategies.

5.7 Challenges in Data Collection

During the data collection period there were some practical challenges and unpredicted issues which were addressed that necessitated modification to some features of the original design and some of them solved. These issues related to interviews settings, fathers' participation, individual interviews, obtaining permission, couples' participations and interview recording.

5.7.1 Interviews Settings

The original plan was to conducted home and hospital individual interviews with eligible participants. However, it was found that not all participants were willing to be interviewed at home. Most participants indicated that they preferred the interview to take place in hospital while they waited for their child's treatment to be given, for example while the child received their blood transfusion or other intervention. In practice, all interviews were carried out in a private room on the hospital premises. Not all participants given reasons for refusing home interviews. However, among those who did give reasons, some cited limited time, lack of an appropriate place for a private conversation, or the view that such issues had to be discussed at hospital and not at home. Some participants stated that hosting strangers in their house and talking about their personal life experiences is something unacceptable. This attitude was found with some parents according to their

socio-cultural background and traditional norms. For instance, some fathers stated that the home is a place designed only for social life, not for discussion of health issues. It was noticed that within the Jordanian culture, the hospital is one of the very few places where it is acceptable for men and women to be together and to communicate without social restriction. In this sense, talking with the researcher was not considered to be different from talking with a doctor or a nurse. In practice, only one couple accepted a home interview. In addition, I realised that conducting the interviews in hospitals facilitated fathers' interviews, which could be more difficult if the interviews were conducted only at parents' homes. These developments led me to conduct hospital interviews, as requested by participants. In conclusion, the sample was limited to the fathers, mothers and couples who attended the three hospitals during the time of the data collection.

5.7.2 Fathers' Participation

Many fathers who accompanied their children to hospital refused to participate in this study for many given reasons connected to a gender, cultural and religious issues. They might have felt unease at a female researcher attempting to interview a male participant in a private room. I was aware of this issue and recruited a male research assistant in case some fathers refused to allow me to conduct the interviews. However, with the engagement of male researcher's assistance some fathers still nor willing to be interviewed. In fact, as a result there are no interviews carried out by the research assistant. The limited number of fathers involved prompted me to adopt different strategies in data collection, which helped to maintain the gender balance. I scheduled some interviews to take place at the weekend, on Saturdays, where I expected some fathers might be accompanying their children to the blood transfusion session. In some cases I had to reschedule the interview time and date to suit fathers' availability, leading to a scenario where I spent the whole working day in thalassaemia department to conduct one interview.

The strategies I adopted were successful in recruiting 20 fathers out of 40 participants, which meet the research aim and objectives.

5.7.3 Individual Interviews

The interviews were designed to be conducted with just one participant at a time. Thus, if a couple were being interviewed, the wife and husband would be interviewed separately. It was commonplace and, for some, part of their culture, for a wife to ask permission from her husband before agreeing to be interviewed. On some occasions, the husband agreed to this but only on the condition that he was present during the interview. It followed that some potential participants could not be interviewed because the husband did not give the wife permission to be interviewed alone.

5.7.4 Obtaining Permission

The prevailing culture in Jordan has an impact on research, especially that which seeks to elicit from individuals experiences on issues considered private or which are construed as belonging to the whole family. For instance, there are social and cultural issues about gender mobility and freedom, where wives are not considered to be free to communicate personal matters to those outside the family about family issues, even where such information will be managed confidentially. On the whole, some wives expressed the need to ask for their husband's permission to be interviewed and submitted to their husband's authority on this matter, which limited the number of mothers to those who had permission, supported and empowered by their husbands to take part in the research process and have a role in the community. In some scenarios, mothers were motivated to share, but their husband's objection stopped them.

5.7.5 Couples' Participation

The number of couples who accompanied their children to blood transfusion was limited. It was noted that usually one partner accompanied the child to hospital, either the mother or father. In most cases, mothers were the main accompanier to children with BTM rather than fathers. I originally planned to individually interview couples of parents caring for their children. However, at the end of the data collection stage it was possible to recruit 8 couples out of 40 participants. In summary, I adopted a variety of strategies to avoid restricting the study to the mothers' experiences, and to keep the fathers', mothers' and couples' involvement in order to explore parents' experiences and coping strategies.

5.7.6 Using the Recorder

This study was the first time that most participants had been involved in a research interview. Some participants were anxious about being interviewed and the prospect of the interview being recorded seemed to increase their anxiety. Some participants questioned the need for the interview to be recorded, and some refused to permit the recording to take place. Other participants suggested that a questionnaire should have been used instead of the recording. The issue seems to be that audio recording would allow people to examine what they said during the interview. Some participants asked me only to take notes and not to record their voice. Unfamiliarity with interviews and recording was noted for some participants. I explained that writing notes during the interviews could be a distraction, and could be time consuming for both the participant and the interviewer. The audio recorder was a small device, similar in size to a computer memory stick. The small device was chosen because it was thought that it would not be distracting to participants. I tried to allay participants' concerns by assuring them that the recording would be anonymised and that their name would not be mentioned at any stage of the research.

Where the participant was willing, I recorded a few seconds of the participant's voice and then played it back to them to reassure them, perhaps by making it clear what the device did, which helped them to agree for the interview to be recorded. Based on their preferences, I excluded participants who refused the recording of the interviews.

5.8 Ethical Considerations

In this study I followed the appropriate ethical principles while conducting the data collection, including volunteer participation, beneficence, human dignity and justice as supported by (Strydom, 2002, p. 62).

5.8.1 Voluntary Participation

Participants who met the inclusion criteria were informed that their participation in the study was voluntary, and that even though they had signed the written consent form, they were committed to participate. It was stated clearly that they could withdraw from the research at any stage without any obligation or consequence and without providing a reason (Grout, 2004). I confirmed to them that their withdrawal from the study would not affect their children's care, rights or status in the hospitals. To confirm voluntary participation, oral consent was also collected at the beginning of each interview.

5.8.2 Beneficence and Non-Maleficence

In any type of research there is always some potential to expose the participants to some harm, whether emotional, social or physical (Strydom, 2002, p. 64). The principle of non-maleficence holds that it is incumbent on the researcher not to cause any harm and to keep risk to an acceptable minimum level. The participants were informed that their participation in the study could have many advantages. For example, it could help to reform or improve the health care services that they and their children received.

In addition, the research could be used as basic data for further research in the future, to fill the gaps in literature and health research. In addition, this study gave them a chance for their voice to be heard, which could play major role in raising community awareness toward their children's condition and other genetic disorders in Jordan.

In consideration of participants' well-being, where the participants appeared to be distressed or emotionally uncomfortable, the interview was paused to give the participant time to relax and collect his or her feelings. She/he was then asked if they were ready to continue again or not. Interestingly, I noticed that most of the participants felt relieved after talking about their stories and narrating their life experiences. In addition, some of them expressed gratitude to me, because they said that it was the first time for them to have an opportunity to talk about it. It was noticed that none of the participants withdrew or discontinued the interviews after a break was given.

5.8.3 Confidentiality and Anonymity

It was my responsibility to maintain confidentiality and anonymity as stated in the research information sheet and in the consent form. The Jordanian Clinical Research Act (2001) protects the confidentiality of participant information, and this applies equally to both manual and computerised data (Ramahi and Silverman, 2009). Participants' documents, recorded interviews and transcripts were stored securely. All research documents will be destroyed when they are no longer needed (Robson, 2011). To ensure confidentiality, codes were allocated to the hospital and to participants' names. In addition, I informed the participants that they were under no obligation to answer all interview questions. These approaches to data confidentiality followed the advice of Polit and Beck (2006, p. 150) who stated that *"a promise of confidentiality is a pledge that any information participants provide will not be publicly reported in a manner that identifies them and will not be made accessible to others"*.

Each participant was given a code which was attached to their recorded interviews, consent form, and demographic data sheet, and was connected to the transcriptions and the recorded interview memos. For example, in Irbid city, the interviews were conducted in PREH. This was given as a code the alphabetical letter (A). Each participant from this hospital, whether a mother (M) and father (F), was given a serial number beside their interview based on the order in which the interviews took place, such as M.3a and F.4a. This coding process was followed for the participants at the other hospitals. ABGH in Amman was given the alphabetical letter (B) and each participant was given a code number, for example M.2b and F.4b. The same was done for the BBCH in Al-Zarqa, which was represented by the letter (C) and where the participants were also given code numbers, for example M.5c and F.6c (see table 14).

Table 14 Interview Coding System

Character	Code	Explain the code
- Hospital Name	A, B and C	A = Princess Rahma Teaching Hospital B = Al-Bashir Government Hospital C = The Blood Bank Health Centre
- Interview order	1, 2, 3....	1 = first interview 2 = second interview 3 = third interview ... etc.
- Participant	F, M	F = Father M = Mother

Source: Author (2012)

Participants were given a copy of my personal contacts detail in Jordan and in the United Kingdom. In addition, contact details were left with the hospital and nursing administration (Polit, et al., 2001, p. 82). Participants were told that a summary of the final report would be made available to them if they needed it.

5.8.4 Principle of Human Dignity

The participants received full oral and written explanations before making a decision about whether to participate in the study. In addition, they were informed that they had

the right to withdraw from the study at any time without giving a reason, with the participants' right to self-determination and full disclosure (Polit, et al., 2001, p. 77).

5.8.5 Principle of Justice

The principle of justice suggests the participants' right to be treated fairly and to have equal opportunity without discrimination. In this regard, I was aware of showing respect to the participants' beliefs, culture, religious, social and traditional values. Moreover, the selection of the participants was based on the inclusion criteria and the potential participants who met the criteria were given the same opportunity and time to decide whether to participate or not. In addition, the participants had the opportunity to choose the interview place, date and time.

5.9 Data Analysis Strategies

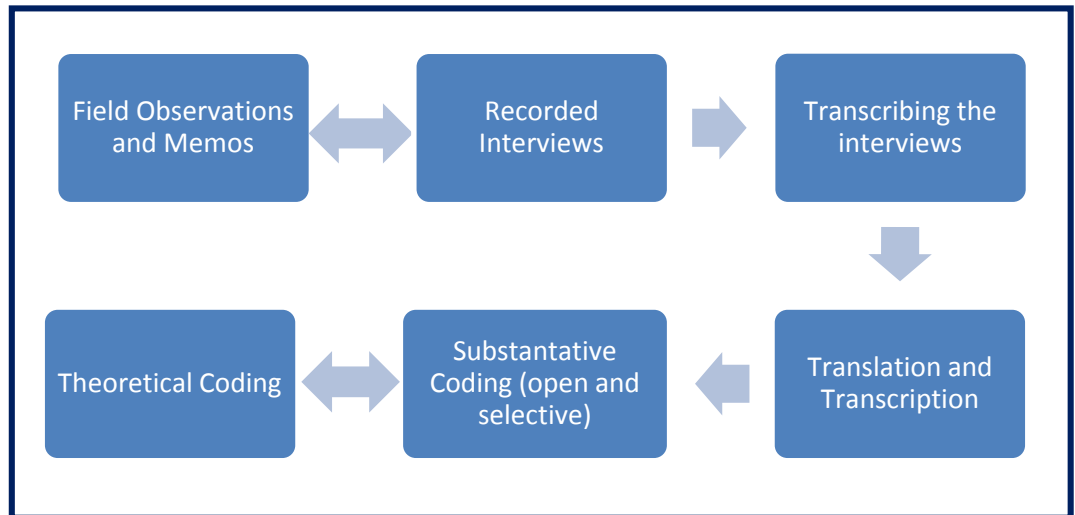
Data analysis is a process of active and interactive dialogue between the researcher, interviews, memos and related documents, such as field observations and the reflective account (Polit, et al., 2001, p. 383). It is an ongoing process that occurs concurrently with the stage of data collection (Holloway and Wheeler, 2002, p. 235). I focused on generating enough in-depth data to illuminate patterns, categories, properties and dimensions of the study phenomena (Strauss and Corbin, 1998). The data analysis strategies are presented in figure 6. Adopting grounded theory assisted me to organise the data and be more familiar with the transcripts. In addition, the constant comparative method was adopted to develop and refine theoretically relevant categories in order to conceptualise data into patterns or concepts through different groups and subgroups. Constant comparison was used at the different stages of data analysis, including the stage of coding and categorising. The data were compare with each other and with the existing literature to support or challenge them which assisted to improve the quality of the data.

Comparative analysis involves recording the similarities and differences between categories which were generated from interviews, field observations and memos, and comparing them within and between the hospitals to support the emerging categories, and find connections and links within the categories. The research categories were compared with the existing literature at the stage of discussion. The computerised software 'NVivo 9' was initially used in data analysis. However, based on my background and experience in using software analysis, a decision was made to perform manual analysis, which was what I preferred to do. I tried both software and manual analysis, but I felt closer, more confident and more familiar with the data by using manual analysis.

I adopted the following strategies to handle the research data:

1. Collecting and organizing the field observations, memos, and notes from the three hospitals;
2. Transcribing the recorded interviews;
3. Translating from Arabic to English and back translating;
4. Analysing inductively; starting by coding, categorizing transcripts and comparing emerging core and sub-categories between the interviews from the three hospitals, to reach the saturation level;
5. Adopting the classic grounded theory coding system which includes; (a) substantive coding which consists of open and selective coding. The code system helped to generate the sub-categories; (b) theoretical coding, generating the core categories supported with memos and my field notes and observations;
6. Identifying the relationships between the core categories to develop the theoretical framework.

Figure 6 Data Analysis Strategies



Source: Author (2012)

5.10 The Collected Data

The collected data revealed two main areas that addressed the research questions; the first addressed parents' experiences and the second addressed their coping strategies. In the two areas, data was also generated on the impact on parents' lives and daily activities. I reviewed the recorded and written data where the new categories were built by exploring specific text in the interviews. At the same time, other text in the same interview would be used to add new information to another category or to saturate the existing category. Some participants' narratives and text used as examples more than others, this is also supported by (Morse, 2003). This was because not all of the collected data was equal in quality or represented specific area in participants' experiences and coping strategies effectively; some data were used more than others in terms of representing meaning (Charmaz and Bryant, 2007).

The more I was engaged with the collected data, the more conceptualising, selecting, categorisation and prioritising I did. The connection between me and the research data was supported more by using the constant comparative method.

I kept listening to the recorded interviews and compared them one to another, and with the transcribed documents, interview notes, field observations, memos and the reflective account.

5.11 Coding and Categorisation

Coding in grounding theory research is the process in which “*the data is fractured, conceptualised and integrated*” (Strauss and Corbin, 1998, p. 3). I started coding, categorising and comparing the data findings using the constant comparative method from the early stages of data collection (Glaser and Strauss, 1967). Grounded theory has two types of coding system. The first is called the classic grounded theory coding system, created by Glaser and Strauss (1967) and Glaser (1992), which was adopted in this study. This classic coding system is composed of substantive and theoretical coding. Substantive coding consists of open and selective coding (Charmaz and Bryant, 2007). Theoretical coding is where the researcher conceptually integrates the core-categories and the relationships between them, which could result in forming a theory.

The second coding system, generated by Strauss and Corbin (1990), has more ‘Axial Coding’. This code system, which is generated by organising the middle stages and structuring the emerging core categories, was criticised by Glaser (1992). On the one hand, Glaser stated that this new coding system would force the data into categories and could affect the researcher’s creativity, which is needed to grasp the concepts. On the other hand, Charmaz and Bryant (2007, p. 268) argued that the goal of grounded theory and the coding system was to offer conceptual explanations of the participants’ underlying patterns of behaviour within social settings. They stated that coding was neither descriptive nor interpretive of the meaning as stated by the research participants. Charmaz and Bryant (Ibid) advocate that the coding is not forced, but is a process of conceptually abstract explanation of the pattern of participants’ behaviour, events or thoughts.

The coding system and categorisation used in this study will be discussed with some examples as follows:

5.11.1 Substantive Coding

Substantive coding is the process of conceptualisation of the empirical substance of the area under study. I started with open coding, followed by selecting codes in order to reach the data saturation categories.

A. Open coding

I started the open coding process by listening to the recorded interviews and reading the transcripts several times. The transcripts were coded line by line to cover all significant information (Glaser, 1978; 1998). Furthermore, manual 'colour coding' was used to underline participants' words, phrases, or statements, using the same colours for similar input in different interviews. My aim at this stage was to codes by conceptualising the information to give it meaning, which resulted in building many indicators which again compared to build the concepts. In between, I wrote notes on each interview transcript which summarised the main findings 'the indicators and concepts' from the interviews, and kept another sheet for comments. The initial result of the coding and categorising process was 57 initial concepts for parents' experiences and 25 initial concepts for parents' coping strategies. The previous concepts were constantly compared to identify similarities and differences and to identify and build on the categories. They were then arranged on a separate sheet, and grouped into one table to identify the emerging sub-categories (Glaser and Strauss, 1967; Strauss and Corbin, 1998). Glaser and Strauss (1967, p. 36) argued that a category "*stands by itself as a conceptual element of the theory*".

B. Selective Coding

The emerged concepts were compared to identify the sub-categories and core-categories. I looked at the selected categories and focused on saturating them by incorporating and elaborating on them (Charmaz and Bryant, 2007). It is worth mentioning that in the two schools of debate, Glaser (1992), in his rebuttal to Strauss and Corbin (1990, p. 38), said that a category is a “*type of concept*” that is “*usually used for a higher level of abstraction*”. The second advanced level of conceptualisation took place when I was able to identify the underlying meaning of categories and properties, which allowed sub-categories to be moved to the advanced level. In addition, I used the field observations and memos in order to support the emergence of the sub and core categories through identification of the relationships, frequencies and connections between them. Table (15) gives an example of the open and selective coding.

Table 15 Example of the Coding Process

Data texts	Open codes	Selective codes	Sub-categories
<i>“I usually don’t talk about it even with my friends... <u>Only my husband understands me...</u> You know how hard it is to see all the children play in the backyard and your son look at them from the window and he can’t join them... <u>Oh that is really killing me from inside...</u> It’s an awful feeling... And if I don’t allow him to watch he will keep crying... <u>But it’s hurting...</u> Only Allah knows it and I’m sure <u>Allah will help me go through that ...</u>”</i>	Partner understanding	Partner support	Social support
	Help from Allah	Allah Support	Religious belief
	Hurts, stressful	Feeling stress	Personal stress
<i>“My husband told me because <u>our last born has BTM the next pregnancy will be normal as the disorder comes every fourth pregnancy...</u> You know <u>I need more kids...</u> My family in law <u>keep saying I cannot have a healthy boy like my other sisters in law...</u> It is only me, in the big family, who has blood transfused children... This month if I’m not pregnant <u>I can imagine how angry they will be...</u>”</i>	Knowledge-genetic process of BTM.	Need to know more about BTM.	What is BTM?
	Need more kids	Being labelled and stigmatized	Social and cultural pressure
	Ability to have healthy kids		
	Fear, social pressure		

Source: Author (2013)

5.11.2 Theoretical Coding

Charmaz and Bryant (2007, p. 283) identified the theoretical code as the “*result of the conceptualisation of how the substantive codes are related to each other as hypotheses to be integrated into a theory*”. At this stage, I identified the relationships and properties, analysed similarities between the sub-categories and rearranged them in new connections, which helped to elicit the core categories, which among all the data are the ones which are theoretically and centrally relevant. LaRossa (2005, p. 851) stated that according to Strauss and Corbin (1998) the core category [variable] is a variable that has “*analytic power*” because of “*its ability to pull the other categories [variables] together to form an explanatory whole*”. See examples of the theoretical coding in table 16.

Table 16 Examples of Theoretical Coding

Parents’ Experiences and Coping Strategies	
Core categories	Sub-categories
Theoretical Codes: <u>‘Core Categories’</u>	Substantive Codes: <u>‘Sub-Categories’</u>
Knowledge Deficit	- Health history; need to know more about their own and their family’s history
	- What is BTM?
	- Health Services; genetic health care services, antenatal screening and family planning programmes
Sociocultural Perspectives	- Satisfied with the social support from their family and friends, with the health services and their role as caregivers.
	- Religious beliefs and practices
	- Cultural barriers; stigma, socially unaccepted, cultural pressure, gender preferences, insecure marital relationship, and work problems.
Personal strategies	- Avoid having more children with BTM, through avoiding pregnancy, abortion or changing marital status
	- Keep it secret, which led in some case to social isolation
	- Time; parents cope with time
Grief	- Fear
	- Hopelessness
	- Stress
	- Unprepared

Source: Author (2013)

The theory is the outcome of the researcher's work. Glaser and Strauss (1967) stated that there were two types of theory, known as the substantive and the formal theory, on which a researcher could build:

1. The substantive theory exists where the researcher studies one particular situation.
In this case, a theory would be limited to a particular context, time and people.
2. The formal theory is where the researcher's study is conducted in different situations, contexts and settings that share some commonalities.

As mentioned earlier, the main aim of this study was to explore and gain better understanding of the experiences and coping strategies of parents of children with BTM, not build a theory. Using grounded theory as a systematic organised research design, its features assisted me in exploring participants' social context and interaction through theoretical sampling and using constant comparative methods.

5.12 Rigour and Trustworthiness

Trustworthiness in qualitative research includes four criteria (Guba and Lincoln, 1989; Krefting, 1991; Cutcliffe, 2005) which were adopted in this study: (a) credibility; (b) transferability; (c) dependability; (d) confirmability.

5.12.1 Credibility

Credibility is a concept that refers to confidence in the data (Polit and Hungler, 1999). According to Thomas and Magilvy (2011, p. 152) credibility can be achieved by "*checking for the representativeness of the data as a whole*". In addition, Krefting (1991, p. 218), stated that "*a qualitative study is considered credible when it presents an accurate description or interpretation of human experiences that people who also share the same experiences would immediately recognize*". Guba and Lincoln (1989) suggested the following actions, which were adopted in this study to improve the research credibility:

(1) prolonged involvement; (2) persistent observation; (3) triangulation; (4) peer debriefing; (5) member checks.

1. Prolonged Involvement

Prolonged involvement with the participants assisted me in building a trusting relationship with the participants, in understanding research issues and in dealing with different field circumstances. I'm familiar with Jordanian culture and the language, and coming from the same country facilitated the communication and conducting the interviews with the participants. In addition, as a nurse I'm familiar with the clinical health care system and services.

2. Persistent Observation

During the interviews, most of the participants were granted sufficient time to talk about their personal experiences. The parents' actions and interactions were accurately recorded and documented. I paid special attention to the participants' everyday events and stories to assess the impact of having children with BTM on their lives. I was also keen to know the beginning of their story, from the moments they were informed about their children's status up to the current issues. My daily appearances in the departments, helped me to draw a picture about parents' experiences, made me more familiar with the staff, the participants and everyday work rhythm.

3. Triangulation

Triangulation is defined as *"the mixing of the data or methods so that diverse viewpoints or stand points last light upon a topic"* (Olsen, 2004, p.3). The idea is to use different approach and a variety of data collection methods and investigations. The main aim of triangulation is to obtain validation of the data by using more than one method (Flick, 1992). For this study, the data were collected by conducting face to face semi-structures

interviews with eligible participants supported by field observations, daily notes, memos and the personal reflective account. This variety of data collection methods assisted me in drawing a full picture of the work field. It is worth mentioning that using the constant comparative method between the interviews within and between the hospitals, as well as with the research memos, field observations and the existing literature, assisted to validate the categories.

4. Peer Debriefing

The translation and back translation of the interviews were validated by colleagues who are fluent in both languages. Furthermore, the supervisors reviewed and validated the research findings in regular meetings at every stage of the research process. This reviewing process facilitated me to develop, improve and organise the research findings.

5. Member Checks

To ensure the validity of the research data, I repeatedly returned to the participants, to check and give feedback on the interview outcomes and verify that what was recorded in the interviews was what they were wanted to talk about. Some participants listened to their recorded interviews many times; at the beginning, after the break and some at the end of the interview. Moreover, during the interviews I made sure to paraphrase and repeat participants' words and statements to confirm that the information given was accurate. Arguably, by adopting these strategies, I aimed at maximising the research credibility. The translated interviews were checked and reviewed by colleagues to confirm that the meaning given reflected exactly what the participants wanted to convey.

5.12.2 Transferability

Holloway and Wheeler (2002, p. 255) identified transferability as how the research findings can be generalised or transferred from the representative sample of the population to similar groups. However, generalisation was not the major aim of this study. The aim was to explore and gain a closer understanding of parents' experiences and coping strategies. I adopted Field and Morse's (1985) recommendation to enhance the research transferability by clearly explaining the participants' criteria, and describing the details of the research setting and the methods used in the process of data collection and analysis. Thomas and Magilvy (2011, p. 153) suggested that "*to establish transferability is to providing a dense description of the demographics and geographic boundaries of the study*". This clarity in the research process gives the readers a sound foundation for making judgements on whether or not the research conclusions can be transferred to other contexts.

5.12.3 Dependability

Establishing credibility at various stages of the research also assists in achieving dependability (Robson, 2002). Dependability refers to the data being stable, consistent and accurate over a period of time. For this research to reach dependability the work generated would need to be assessed by using the following approach:

1. Stepwise Replication

This approach involves comparing the findings and the conclusions with existing literature as well as the feedback from colleagues and supervisors. Comparing and contrasting the research findings took place at various stages of the research. In addition, the research findings were compared with existing literature and the new findings were

addressed (see the research findings in Chapter Seven). The continued feedback from the research supervisors and colleagues on the work supported me and validated the data.

2. Inquiry Audit

Inquiry Audit refers to the review of the data and relevant documents by external examiners. In addition to the supervisors' feedback, the research findings were presented and discussed in international conferences, academic meetings and workshops. I presented and discussed the research findings with various researchers and HCPs (see Appendix 8). The feedbacks and comments were much valued.

5.12.4 Confirmability

Confirmability refers to the link between research data and the original sources to start interpretation and conclude the results. According to Polit, et al. (2001, p. 315), confirmability refers to the objectivity of the data, focusing on the data characteristics and highlighting that the research findings were not the researcher's own assumptions. Therefore, the research components should all be examined by auditors. The researcher have *"to maintaining a sense of awareness and openness to the study and unfolding results"* (Thomas and Magilvy, 2011 p.154) and how his/her own preconceptions integrated and affect the study which requires a self-critical attitudes. A personal reflective account is one of the strategies used in this study. I used memos, diaries and field notes. In addition, comments which reflected my feelings, new ideas, personal thoughts and impressions were recorded throughout the data analysis stage and the whole research process. Moreover, I kept discussing them with colleagues and the research supervisors in regular meetings, emails, and personal tutorials when needed. Discussions with postgraduate students also had a positive impact on different areas that assisted me to identify and classify my own assumptions from the participants' inputs.

5.13 Memos in Data Analysis

I found that the various types of memos guided me to reflect away from the participants' data and the research findings. In other words, it assisted in keeping the originality of the collected data and increased my objectivity. Data in grounded theory could be collected from all resources; the research memos, field notes, interview transcripts and recordings were used at the data analysis stage (Strauss and Corbin, 1990; Holloway and Wheeler, 2002, p. 109). These documents allowed the research to be more auditable, which is one aspect of trustworthiness. Memos were used to support the existing categories, and to give another view about some issues and areas which were revealed and highlighted in the participants interviews.

5.14 Reflexivity

Reflexivity is considered an individual activity (Christine, et al., 1999). It is the examination of the researcher's subjectivity and its impact on the research process, especially at the stages of data analysis and interpretation of the data (Somekh and Lewin, 2005). I was aware of my contributions to the construction of meanings throughout the research process. However, I also acknowledge that remaining totally outside of one's subject matter while conducting research could be an impossibility. Nightingale and Cromby (1999, p. 228) stated that reflexivity urges an exploration of the ways in which a researcher's involvement with a particular study influences, acts upon and informs such research. The researcher's subjectivity is important in qualitative studies. In this study I worked in a cycle of collecting and analysing data using interviews, memos and reflective accounts in order to control the quality of the data and decrease the potential misrepresentation during data analysis. According to Elliott and Lazenbatt (2004) and Charmaz (2006), memos could be the best way to improve the quality of the data, maintain the researcher's subjectivity and increase the research rigour.

In addition, memos increase the researcher's sensitivity to their own personal biases (Elliott and Lazenbatt, 2004; Charmaz, 2006). I was mindful of my own position in the research and my background, as well as my prior knowledge and how my assumptions may have an impact upon all aspects of the research. All of this was reflected in diaries and a personal reflective account for a representative sample during the interview process (see Appendix 11). I kept writing my reflections on the interviews to make sure that my ideas, thoughts and my personal opinions were put aside and not part of the research data. In conducting the research, I adhere to Hesse and Leavey's (2006) advice that the researcher should be active along with the research subjects, rather than assuming a value force and objective stance, in order to build descriptive, exploratory and explanatory knowledge. I personally reflected continuously on my own actions, feelings and unexpected issues while conducting the interviews, not only in writing but also in discussing them with the academic supervisors in order to reduce researcher bias (Holloway and Wheeler, 2002, p. 263). During the interviews, I used notes sheets and account documents to download the events in each hospital. For a sample of the field notes sheet, (see Appendix 10).

5.15 Conclusion

This chapter has explained in detail the data collection and analysis procedures. The preparations stage, field observations and interviews issues were presented and discussed along with the ethical considerations. The steps in data analysis through the grounded theory coding system were described with some relevant examples. Research rigour and trustworthiness were valued and the way they were achieved was discussed. In addition, the strategies used to deal with data analysis were presented. In the next chapter, the research findings from the interviews, memos and field observations will be presented, with quoted extracts from interviews and memos.

Chapter Six: Research Findings

6.1 Introduction

This chapter will present the research findings. The findings will be presented in sections as follows:

- The process of data analysis;
- The participants' demographic characteristics;
- My observations and analysis of the field notes and memos;
- Participants' responses during the interviews;
- Summary of the participants' recommendations, and conclusion.

6.2 The Process of Data Analysis

This study adopted a grounded theory method, in which the data analysis took place concurrently with data collection. Theoretical sampling, constant comparison methods and memos were used to collect the grounded data from parents of children with BTM. Classic grounded theory (Glaser and Strauss, 1967; Glaser, 1992) was adopted in the analysis process to code and discover the meanings that the participants expressed in the narrative of their experiences and coping strategies while caring for children with BTM. I read the interview transcripts line by line, then coded the data through substantive and theoretical coding.

The coding process started by highlighting, grouping and identifying the participants' statements, phrases, words, ideas and thoughts. The constant comparative method was used to saturate and conceptualise the data, where similarities and differences were detected. The end result of the data coding and analysis process was four main core categories, with many sub-categories representing parents' experiences and coping

strategies. Computer software and manual analysis were used in data analysis. The process began by importing data into 'NVivo 9'. This qualitative software program was used as recommended by Morse and Richards (2002), Creswell (2003) and Richards (2009). However, the time taken to import the data in the 'NVivo 9' programme and arrange them was longer than I expected because of my limited experience and background in using such software analysis tools. This encouraged me to use a manual analysis. Charmaz and Bryant (2007, p. 287) argue that the computer software programmes organise and arrange the data but do not lend themselves to coding or analysing.

I found that using manual analysis was more productive, though it was time consuming. I realised that manual analysis gave me an opportunity to interact with the collected data more than would have been possible using the software. I found that using manual analysis facilitated my creativity in the generation and conceptualisation of categories, through writing, organising the data in tables and charts, and colouring and labelling the categories.

6.3 Participants' Characteristics

This study was designed to explore the initial, on-going experiences and coping strategies of parents caring for children with BTM. In this research the participants' children were the recipients of health care services in the three government hospitals. Forty Jordanian fathers, mothers, and couples were recruited, each having one or more child with BTM for more than one year. The participants' demographic data from the three hospitals were analysed; the data revealed various participant characteristics, as follows:

6.3.1 Participants' Age

The data showed that the youngest participant was 23 and the oldest was 60 years old. More details about children's characteristics are found in (section 6.3.6). This wide age range in the participants and their children assisted to represent different experiences and coping strategies.

6.3.2 Participants' Gender

In the first instance, the research samples were almost balanced with regard to gender, with eight fathers and nine mothers recruited from the PRTH in Irbid. In the second hospital, in Amman at ABGH, initially only two fathers and six mothers agreed to participate. Most males refused to participate for reasons alluded to in the previous chapters. In order to re-balance gender, I focused on recruiting seven fathers from the third hospital, BBCH in Al-Zarq. I also back again and recruited another two fathers from ABGH in Amman. I purposefully recruited gender-balanced samples because the aim of the study was to explore both mothers' and fathers' experiences in caring for children with BTM. At the end stage of data collection, a total of 20 men and 20 women were recruited from the three hospitals.

6.3.3 Participants' Relationship before Marriage

Many of the Jordanian parents in this study were related to each other prior to their marriage. For example, the parents could be first or second cousins. Table 17 illustrates that 28 (70%) participants⁶ were relatives, and that 12 (30%) participants were not related to their partners prior to marriage.

⁶ Participants and Couples: Note that all couples in this study were participants but not all participants' were couples.

Table 17 Participants' Pre-marriage Relationships

City	Irbid	Amman	Al-Zarqa	Total
- Participants <u>related</u> to their partner before marriage	10	10	2	22
- Participants <u>NOT</u> related to their partner before marriage	1	0	1	2
- Interviewed <u>couples</u> (husband and wife) who were <u>NOT</u> <u>related</u> to each other prior to marriage	6 (3 couples)	0	4 (2 couples)	10
- Interviewed <u>couples</u> (husband and wife) who were <u>related</u> to each other prior to marriage	0	2 (1 couple)	4 (2 couples)	6
- Total	17	12	11	40

Source: Author (2013) * the data in the table was generated from the research findings.

6.3.4 Participants' Employment

The study found that most of the mothers who took part in this study were not employed. However, the fathers valued having a secure job in order to support their family financially and maintain the cultural and religious norms in which it is their responsibility to provide for the family. Table 18 presents the employment status of the participants. The data showed that 20 (50%) of the participants (i.e., the mothers) were not employed. There is a different scenario for the fathers: the data indicates that 4 (10%) of fathers were retired and 16 (40%) were still in secure full or part time jobs.

Table 18 Participants' Employment Status

City	Participants	Full time	Part time	Retired	No Job	Total
Irbid	Fathers	6	0	2	0	8
	Mothers	0	0	0	9	9
Amman	Fathers	4	1	1	0	6
	Mothers	0	0	0	6	6
Al-Zarqa	Fathers	3	2	1	0	6
	Mothers	0	0	0	5	5
Total		13	3	4	20	40

Source: Author (2013) * the data in the table was generated from the research findings.

6.3.5 Participants' Education

The study found that most of the participants were able to read and write in Arabic. The findings showed that there are 29 (73%) participants had completed high school, 8 (20%) had diplomas and 3 (7%) had university degrees, as shown in table 19.

Table 19 Participants' Education Status

City	Participants	Primary School	Secondary School	High School	Diploma Degree	University Degree	Total
Irbid	Mothers	0	3	3	3	0	9
	Fathers	0	1	4	2	1	8
Amman	Mothers	0	3	3	1	1	8
	Fathers	0	2	2	0	0	4
Al-Zarqa	Mothers	1	2	1	1	0	5
	Fathers	0	2	2	1	1	6
Total		1	13	15	8	3	40

Source: Author (2013) * the data in the table was generated from the research findings.

6.3.6 Participants' Children's Characteristics

The following tables present the characteristics of the participants' children, including child age, gender and time of diagnosis. The findings in table 20 show that there were 31 (70%) female and 13 (30%) male children who were diagnosed before the age of one year.

Table 20 Children's Age at Diagnosis

Children's age at diagnosis				
Child Factors	City			
	Irbid	Amman	Al-Zarqa	Total
- Average child age at diagnosis	8 months	10 months	11 months	Average of 9.5 months
- Number of Female children	5	6	2	13 children
- Number of Male children	15	9	7	31 children

Source: Author (2013) * the data in the table was generated from the research findings.

Table 21 illustrates the children's with BTM age groups. The findings show that 29 (66%) children were in the school age group, 5 (11.3%) were in the toddler and preschool age groups and 5 (11.3%) patients were young adults.

Table 21 Children's Age Groups

Children's age groups	
Total patients with thalassaemia in three cities: Irbid, Amman, and Al-Zarqa	
- Toddler age (1-3 years old)	5 children
- Preschool age (3-6 years old)	5 children
- School age (6-16 years old)	29 children
- Young adult age (16-18 years old)	5 young adults
Total	44 children

Source: Author (2013) * the data in the table was generated from the research findings.

Table 22 presents the patients' with thalassaemia ages. The findings show that the average age was 13.2 years. The youngest patient with thalassaemia was 14 months old and the oldest was 18 years old. It is worth mentioning that some of the children with thalassaemia had siblings who had also been diagnosed with BTM. Their ages ranged between 24, 22 and 19 years old.

Table 22 Children's Age Range

Children's age range			
City	Youngest age	Oldest age	Average
- Irbid	2.5 years	15 years	6.7 years
- Amman	1.5 years	18 years	13.2 years
- Al-Zarqa	1.2 years	18 years	8.2 years

Source: Author (2013) * the data in the table was generated from the research findings.

6.4 Field Notes and Diaries

In order to respond to the research questions, the data collected from field notes, memos and diaries were used in the analysis along with the interviews. The data was filtered, arranged and organized based on the research setting. The observations and memos were recorded as below:

1. The notes, memos and field observations were recorded based on time, date and place. Separate sheets were used to write down memos before, during and after each interview, and a notebook was used for reflections and field observations.
2. For each interview, separate sheets were used to code the similarities and differences in the findings and to highlight negative responses from the participants.
3. New ideas, thoughts and comments were also documented separately in order to support the researcher's objectivity.
4. During the data collection there were some informal dialogues with the nurses, patients with BTM, visitors and HCPs. The ideas from those dialogues were reported and used to support some research findings.

The memos assisted in filling the gaps and highlighting special areas in the interviews. Field observations and notes were used to support interview findings and provide a picture of the real situation of parents in the clinical setting, as well as to address visual issues which are not mentioned in the recorded interviews.

6.5 Findings of the Observations

Field observations provide a background picture on the health care settings where data collection took place. The three settings were (a) PRTH in Irbid; (b) ABGH in Amman; (c) BBHC in Al-Zarqa.

A. Princess Rahma Teaching Hospital (PRTH) in Irbid

PRTH in Irbid is a government paediatric hospital with a total capacity of around 109 beds. I noted that the thalassaemia department had 15 beds distributed between two separate wards. The first ward area was for female patients and patients accompanied by a female relative. The second room was for male patients and for patients accompanied by a male relative.

The department had a nursing station located in the middle of the first room. The registration office was located in front, this office was used by physicians as a medical clinic and to register new cases. The health care personnel at PRTTH consisted of one haematologist, two registered nurses, and one vocational nurse, working for about eight hours per day, six days per week. They were providing health care services to about 400 patients per month with different haematological disorders. It is worth mentioning that the nurses in this department were all female.

In Irbid, at the time of data collection, there were around 100 to 150 blood transfusion-dependant patients. I noticed that some of the regular invasive and non-invasive interventions were carried out in the department. These included medical check-ups, counselling, growth and development monitoring, blood sampling, blood transfusion and medications. Patients ranged in age from infants to adults. There was a substantial number of young adult patients. It is worth mentioning that, of those patients, one adult female only and five male patients -none of them diagnosed with BTM- were planning to get married at the time of the data collection. Getting married for adult patients and having their own family was the main social challenge for many reasons, but particularly due to perceptions towards BTM. For example, being diagnosed with BTM would mean (a) that the individual would be perpetually sick, as it is a lifelong disorder and (b) the person's offspring would have a high probability of having the disorder.

Another important point to mention is education, since many patients in the three cities faced challenges in continuing with their formal education and securing a job. I noted that most children dropped out of school early, and few had a certificate. Consequently, none of them were in formal employment or had secured a government post. In addition, establishing a family was a complicated goal for patients with BTM and their families, not only because of the social challenges but also because of infertility, which is a

common problem for most of them. Endocrine disorders can be one of the complications of BTM, causing hormonal disorders resulting in delayed puberty and infertility. Jordanian adolescents with BTM have been found to experience a high risk of secondary endocrine dysfunction, leading to delayed puberty (Al-Rimawi, et al., 2006a). Irshaid and Mansi (2011) found that thyroid function and iron levels were significantly elevated in 36 Jordanian adolescents aged between 12 and 18 years old with BTM, compared to a control group which impact negatively on their growth and developments. The level of social support they could give to their children with BTM changed with time because the parents were getting older, especially for patients who were the only child in the family, or the last born. Hence, for some adult patients, establishing their own family is very demanding. I noticed that some patients managed to study for a degree from a community college. However, few had completed a university degree, and most left high school before they had completed their formal studies. Although most patients were unemployed, some managed to obtain temporary unprofessional work in the private sector, or were self-employed. This perhaps indicates the degree of difficulty faced by younger patients. These observations were also an indication that BTM itself cannot be fully understood without an understanding of Jordanian culture and of the social consequences of the disorder's prevalence in the population.

B. Al-Bashir Government Hospital (ABGH) in Amman

In Amman, the thalassaemia department was located at ABGH. The department had been expanded to deal with the steady increase in patients (see figure 7). It is worth mentioning that permission to take photographs inside the departments was obtained via an ethically approved letter from the JMoH, and from the head of the ABGH thalassaemia department. The department consisted of three large patient rooms and a long wide corridor, with a capacity of about 30 beds. The nursing reception and the treatment rooms were connected

and located at the front of the department together with two physicians' offices. Unusually, the department had a reasonably large children's play room with a variety of books and games for different age groups. At ABGH there were around 650 patients with thalassaemia. The team of HCPs in the department consisted of two paediatricians, two haematologists, one family medicine consultant, two registered female nurses, one practical female nurse and one practical male nurse. The staff worked from 08:00 to 15:00, six days per week. ABGH catered for a wide range of patients, from infants to adults. The oldest patient was 35 years of age. The variation in the patients' ages meant that patients exhibited a wide range of BTM phases and complications. Consequently, the department had to deal with heterogeneous groups of patients facing different life challenges. It was also noted that only five adult NTDT male patients diagnosed were married and three adult NTDT females were in the process of arranging a wedding at the time of data collection. Furthermore, it was observed during the study that most of the adult patients were experiencing financial difficulties and had experienced problems accessing education and work.

Figure 7 The Thalassaemia Department at ABGH.



Source: Author (2011)

C. The Blood Bank Health Centre (BBHC) in Al-Zarqa

Most patients with haematological disorders living in and around Al-Zarqa had recently been moved from Al-Zarqa Governmental Hospital to BBCH. It was noted that BBCH was located a long distance from the main hospital and the city centre. Therefore, it required visitors to use some form of transport, and travel from the city centre to BBHC was time consuming. Furthermore, not all medical procedures and interventions were performed at BBHC. However, if patients needed other tests or procedures, they would be referred to the Al-Zarqa Governmental Hospital.

The structure of the BBCH building gives indications of some of the challenges to the patients and their families. For example, the thalassaemia department was situated on the third floor with no public access to the elevators in the building. This meant that patients and their families, including those with physical disability, were using the stairs to get to the department. Patients with physical disabilities were carried to the third floor by family members. This scenario was not found in the previous two hospitals, where the thalassaemia departments were easily accessible. I noted that the department consisted of two treatment rooms. The smaller one was furnished with two standard hospital beds and the larger room with three beds. The latter room had an open connection to the nursing reception. On the right hand side of the entrance there was a small treatment room and registration office, used by the paediatricians as their clinic. On some days this room was used for the research interviews.

The team of HCPs consisted of three female nurses; one was a registered nurse, and the other two were practical nurses. There were no males nurse available to care for the patients with BTM and their families in the department. The staff worked from 08:00 to 15:00, six days per week. The paediatricians were present for two hours per day during the time of the data collection. Their attendance depended on the number of new

registered cases and on the number of patients requiring new prescriptions or consultation. One of the areas of concern raised during the study was the limited availability of physicians at the BBCH, especially in emergency cases. It is worth mentioning that the BBHC was the only thalassaemia centre working on Saturdays.

The total number of cases with BTM at the BBCH was about 300. At the time of data collection it was noted that most patients were school age children and younger, with a small number of young adult patients. As in other departments, there were few, if any, young adult patients who were either married or in employment. They faced challenges accessing higher education as well as raising their own families.

6.5.1 Memo 1: The Current Situation of Jordanian Patients with BTM

The treatments and complications of BTM were discussed in general terms in Chapter Three. In particular, it may be helpful to present the background information about the current condition of children with BTM in Jordan. The majority of children in the three departments were school going age, had TDT. These were diagnosed early in life and experienced various complications related to BTM. I noticed that the three thalassaemia departments preferred to transfer washed packed red blood cells rather than whole blood. The HCPs argued that this was because the aim of the transfusion is to correct patients' anaemia, and to decrease the possible side effects which could occur as a result of frequent transfusions. During data collection, the following issues were addressed in the three thalassaemia departments:

1. Iron chelating therapy available for patients with BTM at the three hospitals in two forms: the oral, which was available for patients under 15 years old, and the infusion, for older patients. The cost of medications was one of the factors underpinning this age classification, according to parents and HCPs.

2. BMT is the only curative method currently available for cases with BTM. The treatment was surrounded by restrictions and challenges, such as time, child age, donor availability and operation costs (see section 3.7.2).
3. Psychological therapies were not formally available and accessible in the three hospitals.
4. I noted that out of the three thalassaemia departments, there was only one male nurse, working at ABGH in Amman. The nursing staff in the other departments were all female.
5. The departments were considered a part of the paediatric ward in terms of policies, work schedules, and the staff circulation.
6. The availability of the treatment rooms and the distribution of patients in the departments were designed based on patients' gender and age.

6.5.2 Memo 2: Thalassaemia Departments in Three Hospitals

The field observations took place in the three hospitals, at different areas in each department. Some similarities and variations were noted during data collection. These notes and observations recorded some parents' actions and interactions during the time they accompanied their children for blood transfusion. In addition, I recorded events, challenges and general atmosphere, which reflected some parents' experience when attending the hospitals with their children. The following are the field observations and memos carried out in the three thalassaemia departments at the following areas:

1. Department reception;
2. Patients' admission rooms;
3. Waiting areas;
4. Children's play room;
5. General practitioner clinics;
6. Treatment rooms.

I noted that most participants preferred to arrange their schedule for hospital visits to achieve all the required interventions. The following are the findings of the field observations and memos.

1. Department reception

I noted that each reception had a register of each patient's name, age, transfusion date and time, medical diagnosis and contact address. The nurses checked the register on a daily basis to confirm that the scheduled patients received their blood units on time. In cases where patients failed to attend appointments, a reminder phone call was made to schedule a fresh appointment. Preparing patients for blood transfusion took about 15-30 minutes for each case.

2. Patients' admission rooms

In the department, there were separate treatment rooms for male and female patients. Separate areas for males and females are common in Jordanian health care settings. However, I managed to collect my observations in both rooms. In the admission rooms some mothers chatted and shared their home experiences with each other. They discussed issues related to administration of infusion medication, their children's academic and social achievements and everyday events. On the father's side, the conversations were mostly limited to and with their children, and some spent their breaks outside the hospital. In the three departments, it was noted that the transfusion time varied based on the number of blood units. However, on average, parents spent five to eight hours in the department on each visit.

3. Waiting areas

The waiting areas were the place where visitors spent most of their time in the department. I noted that most of the children were accompanied by their mothers, and only a few by

their fathers or both. Another observation was that some of the young adult males attended the hospital on their own. However, the same scenario was not observed for female patients; most young female adult patients were accompanied by their mothers. It was only in Irbid, at PRGH, that I noticed a few young adult females attending the hospital on their own. After the preparation for the blood transfusion, the children and their families had to wait for more than 60 minutes for the blood transfusion to start. In the waiting room some parents appeared to enjoy speaking with each other about their children and having social conversation about daily living activities and issues.

4. Children's play room

An activity room or play room was available only at ABGH in Amman. The room was filled with many games to suit various age groups (see Appendix 12). The children appeared to enjoy playing in the room while they waited for blood transfusion.

5. General practitioner clinics

During the time I spent in the departments, I had the opportunity to witness parents attending meetings for follow up results and feedback with the HCPs. In Amman and Irbid, the availability of the paediatricians and the haematologist made it possible for parents to approach and speak to them during their duty hours. However, in the third hospital, in Al-Zarqa, the physicians either attended the clinic for a few hours or when they were called to address urgent issues raised by patients.

6. Treatment Rooms

The participants usually spent between 15 and 20 minutes in the treatment room, while the staff prepared children for blood transfusion. I observed how some parents tried to talk with the staff, but this was difficult because of the short time available and the staff's workload. Some parents waited outside the room, as they seemed not to want to see their children crying while the transfusion needle was inserted (see Appendix 12, figure 16).

6.6 Findings from the Research Interviews

A total of forty face-to-face in-depth interviews were conducted for this study. Interviews were conducted in the hospitals, except for one couple who agreed to be interviewed at their home. Participants were asked if they wanted to listen to the interviews to confirm that what was recorded was what they wanted to say, in order to validate the recorded conversation. Ten participants listened to their recorded interviews.

The interviews totalled about 28 recorded hours. The shortest is about 30 minutes and the longest is about 95 minutes. The interviews were transcribed all into around 750 pages. As mentioned earlier, the interviews were conducted in Arabic and had to be translated into English before analysis. The transcribed interviews were arranged and managed in hard and soft copy folders. The classification was based on the code which was given to each interview. The interviews were arranged in three sections based on the three hospitals, each hospital being given a different colour. Furthermore, individual and couples' interviews were arranged and stored separately to facilitate constant comparison between interviews, and to find out the similarities and differences. Each group was colour coded. I started by analysing each hospital separately before doing a comparative analysis. Furthermore, interviews were validated by two knowledgeable colleagues in the field of nursing research. Field observation, notes and memos were also used as complementary means of data verification. The categories were reviewed and validated by another two colleagues and the research supervisors.

Participants responded to the interview questions by narrating and revealing their initial and ongoing personal experiences and coping strategies. The responses of each participant to each category are presented in (Appendix 13). The details of parents' experiences and coping strategies were categorised into four core categories and many sub-categories. The impact of having and caring for children with BTM on parents' lives,

their attitudes and perceptions were also presented. Table number 23 shows the research core categories and sub-categories representing parents' experiences and coping strategies.

It was noticed that during the interviews the participants talked about their social experiences and coping strategies over time; presented their personal, social, cultural and religious issues as well as psychological impact of caring for their children. In addition, parents talked about their future expectations as well as fears of the unexpected. Moreover, based on their experiences, parents offered some suggestions and recommendations to many stakeholders, and especially to the health care services.

Table 23 Interview Findings: Core Categories and Sub-categories

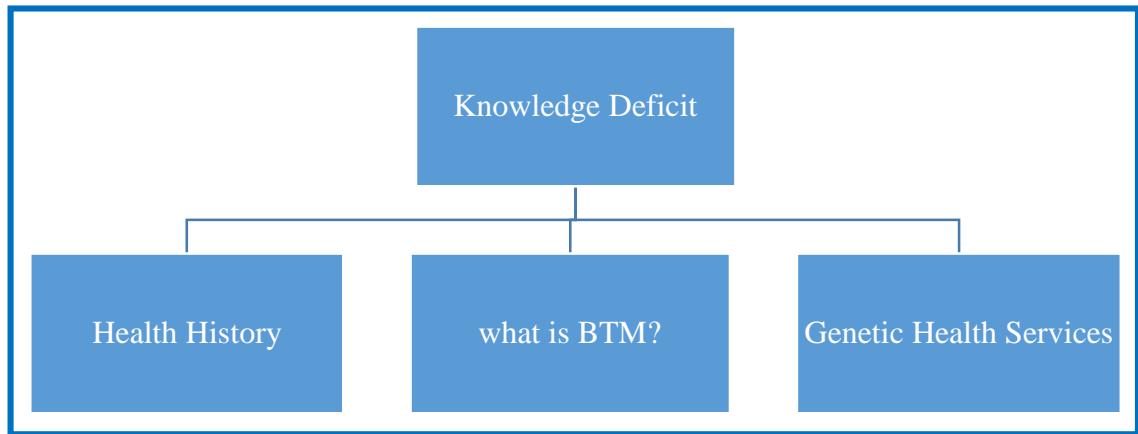
Core Categories	Sub-categories
Knowledge Deficit	- Health history
	- What is BTM?
	- Genetic Health Services
Sociocultural Perspectives	- Socio-cultural Barriers
	- Faith
	- Satisfaction with
Personal Coping Strategies	- Avoid having more children with BTM
	- Keep it secret
	- Time
Grief	- Fear
	- Hopelessness
	- Stress
	- Unprepared

Source: Author (2012)

6.6.1 Core category 1: Knowledge Deficit, 'Need to Know More'

This core category emerged from three sub-categories: health history, understanding what BTM is, and genetic health services (see figure 8). The three sub-categories reflected parents' knowledge and the level of their understanding in relation to having and caring for their children.

Figure 8 Core category 1. Knowledge Deficit



Source: Author (2013) *the data in the figure was generated from the research findings.

6.6.1.1 Sub-category 1.1: Health history - known and unknown.

Participants were categorised into two groups based on their knowledge of their own health history, and that of their family. ‘Known family history’ refers to mothers or fathers who knew that there were carriers of BTM gene in their family in the previous generation, or knew about patients with BTM in their family.

“We had negative results in the premarital tests because my husband insisted on going through the premarital tests, because he knows that there were many thalassaemia cases in their family but not in mine... It was really devastating news to all of us... even the paediatricians did not believed...it was a really big shock to all of us.” (M.11c)

“My sister in law has one girl with thalassaemia. I didn't know about it until after my daughter diagnosed; my husband did not tell me that they have it in their family.” (M.9b)

‘Unknown family history’ means that either mothers or fathers did not have diagnosed patients with the defective gene in their family, that they were not aware of carriers in either family, or both. In such cases, family members could be dormant carriers of the defective gene, only learning about their own genetic status when they had a first child with BTM, as was revealed during the interviews from the following participants:

“I never in my entire life heard about it [thalassaemia] until I had H. T. [Initial of her son]” (M.1c)

“I did not know that I was a carrier... no, it never crossed my mind even to check or do any blood tests.” (F.7c)

“I did not know that I and my husband were carriers of the disease...” (M.17a)

“Wallah [I swear to God] I don't know what is thalassaemia. They diagnosed her at the beginning with ‘iron deficiency anaemia’ after she started taking blood. One day my brother in law told me that she had thalassaemia, and that it is a genetic disorder and that my daughter didn't have just anaemia.” (M.7a)

“In our both families there are not any patients with thalassaemia known to us, or anybody who we know to have received regular blood transfusions. No... no... no... The first time we knew we were carriers was when my son diagnosed.” (F.2a)

Out of forty participants, only four participants had undergone carrier pre-marriage counselling. Unexpectedly, the couples' first born were diagnosed with BTM despite the negative results of their pre-marriage tests. The tests was proved to be incorrect, as one father claimed:

“Yes, we did the pre-marriage tests and I am still keeping the original copy of our results but when my daughter was diagnosed with thalassaemia, we were shocked, we didn't believe it... Even the paediatricians... It took us two months to confirm that she had BTM... We excluded all other diseases because of the negative pre-marital test we had... And of course after me and my wife repeated the test I swear to God it was more than three times to just confirm she had thalassaemia.” (F.12b)

Parents was devastated and shocked because of the inaccurate result they received in their premarital tests, as this mother said:

“After around a week the results come that we both carriers me and my husband, the premarital test we did was wrong and our daughter diagnosed with thalassaemia... That was a big shock to both of us, it was like a disaster.” (M.11c)

“It was really shocking for us to know that our daughter has thalassaemia... We did not believe it... Because we did the premarital tests in private lab and they told us our result is negative which is obviously wrong because they told us now that we both carriers.” (M.13b)

Another father claimed that:

“I have been married for ten years and I have four children. We carried out different premarital tests and one of them was the thalassaemia test... They told us we are not carriers, we are both healthy, and now I have two children with thalassaemia. Can you believed that? Because the tests were not accurate... When the first child with thalassaemia was diagnosed my wife was pregnant with our last born who also diagnosed to have thalassaemia... Yes, it was a private medical lab which is supposed to do quality work.” (F.10c)

Most of the participants were unaware of their parents' genetic status. However, having a child with BTM clearly enabled each participant to know his or her status as a carrier of the gene. It took a long time for some participants who were already known to have a negative family history of BTM to confirm the diagnosis, as well as to understand that they were carriers. Most parents repeated the diagnostic tests for their children many times, using different health services, and public or/and private laboratories, to confirm the results. Furthermore, neither fathers nor mothers knew about their family health history of having genetic disorders. As these two mothers claimed:

"I didn't know that, my husband and I were carriers... We didn't know even that it's inherited. We were not related to each other before we were married... None of his family members had any disease like that, or even me. That was really shocking... I had never heard about thalassaemia before." (M.1a)

"Oh my God... We were all surprised and shocked... We went through different tests many times. It took them three months to confirm to us the diagnosis because at first they said it was only blood anaemia." (M.17a)

Another father said:

"When we had a child diagnosed with the disease [thalassaemia] we started to know about it... Actually I knew nothing about thalassaemia before that time, and before knowing that my wife and I were carriers." (F.3a)

Another participant claimed:

"I never heard about thalassaemia until they diagnosed my child... When the physicians informed us I was thinking it was a type of blood cancer. My brother in law explained to us what the meaning of having thalassaemia. He is a student nurse. We did not believe that we were both carriers. None of our family member have such a disease. We did many blood tests in different labs to confirm that was thalassaemia." (M.8a)

Some participants questioned their genetic status and its connection to the fact that they were related before marriage, as the following two mothers claimed:

"It is not only me who married my first cousin... I have a sister who also married our first cousin but all her children are ok and they are looking well." (M.17a)

"My cousin from my father's side married another cousin. Nobody has this problem, they have healthy and normal children." (M.1a)

Another father claimed:

“No, we did not know that she and I are carriers... Can you imagine that it was only us [himself and his wife], the only carriers in both families. All my cousins were ok.” (F.7c)

Knowing about previously diagnosed cases in the family increased family members' awareness of the early detection of thalassaemia. Many dormant carrier couples were revealed and a variety of family planning methods were adopted, as the following participant claimed:

“...my sisters and brothers went through the blood tests after they knew about my son... They were afraid that they were also carriers... And that was right, we discovered that two of my sisters were also carriers...But Alhamdulillah [Thank God] their children are ok, and none of them have thalassaemia.” (F.6a)

“All my sisters and my brothers in law did the blood tests for themselves and to their children after they knew about our situation... They didn't tell us about the results.” (M.11c)

“All of my sisters and brothers carried out the blood tests. Three of them are also carriers but their children are ok, Alhamdulillah [Thank God].” (M.17a)

“After they told us that she has thalassaemia, I told him [her husband] that I need to take the [contraceptive] pills. I do not want more children but I felt that he did not.” (M.9a)

It is important to mention that if parents knew about their family history, it could help them to use suitable family planning methods to prevent having further pregnancies, thus reducing the likelihood of having other children affected with BTM. As the following mothers claimed:

“I was pregnant when my daughter was eight months old. It was unplanned but I was ok, we wanted to have a baby boy... Unfortunately she was diagnosed with the disease at the age of twelve months... It was shocking news [moved both hands up]. I did not know what to do at that time, it was the worst days I ever had in my life... We went through many tests from the first week in different labs... I was desperate to know if she was ok or had thalassaemia. However, the paediatrician said we need to wait at least six months... All this stress of waiting to know that she has thalassaemia... You know I swear to God, if I knew about it before, I would have done anything to not get pregnant.” (M.6b)

“Two of my children were lately diagnosed thalassaemia major. I started using contraceptive pills after that. However, if I knew about that before, I might not have had my last born daughter, but what should I do? Alhamdulillah [Thank God], everything comes in its right time.” (M.2b)

“I was also pregnant... Which made it worse for me, because they told me that my unborn baby could have thalassaemia as well... If I knew about it before I would not have had this pregnancy... No, no, things are different now I use contraceptive pills.” (M.2a)

6.6.1.2 Sub-category 1.2: What is BTM?

The parents’ understanding of what BTM was impacted on their social experiences, perception, decision-making and coping strategies in caring for their children. Participants had their own interpretations of BTM and other genetic recessive disorders. For example, some parents said that genetic disorders could occur for the carriers in just one pregnancy and the family would have only one affected child, as these mothers claimed:

“My oldest daughter has thalassaemia but all of my seven children were healthy [not affected or carriers]. We were all surprised that my youngest daughter was diagnosed

with the disease... They said it occurs only once in the family... Oh poor little girl... She is still too young.” (M.3b)

“...My husband wants me to get pregnant now and he says it will be an unaffected child because my last born - my daughter- has thalassaemia so my next born will be free. Thalassaemia does not come in each pregnancy, does it? It is only comes once in each carrier’s family.” (M.7a)

Parents’ misunderstanding about the process of transmission of BTM as a genetically inherited disorder resulted in having two or three affected children in some families, as this example shows:

“No, we didn’t know that was thalassaemia. My oldest son was diagnosed, then after one year my second son and after few months the third confirmed that he also has thalassaemia. Three of my sons now receive blood in this hospital.”(F.14a)

“The paediatrician said: your son has thalassaemia and I asked him: what do you mean? What is thalassaemia? He said: it is blood disease like anaemia. I didn’t know that I and my wife passed it to our children until my daughter was also diagnosed.” (F.3a)

“Two of my daughters have thalassaemia, R and H [Initials of her daughters]. I didn’t know it could come in each pregnancy.” (M.9b)

Surprisingly, some parents’ believed that if one had an affected child, then the second pregnancy should be unaffected or carriers, as these two participants stated:

“The disease comes in one after another; one child is affected and the following is not. My first born child was diagnosed with thalassaemia, then I had my son who they said is a carrier. After that I thought I would have another free son but instead I had a thalassaemia girl... I do not want to take the risk anymore and have more children with thalassaemia.” (M.1a)

“When you have a child with thalassaemia, the second usually comes free... They did not come one after another. I had B.A [Initial of her son] then my next born was free.” (M.8a)

Another scenario presented by the participants was that if a carrier mother has three pregnancies, then the fourth should be unaffected, as the following participant claimed:

“...We have a son diagnosed with thalassaemia, then twins’ girls who were not diagnosed with thalassaemia and my wife had one abortion... And now we plan for another pregnancy which is number four. ‘Inshallah’ [God willing] we expect a free child or at least a thalassaemia carrier...” (F.3c)

Another mother claimed that:

“Yes, this is my fourth child. Thalassaemia comes in every fourth pregnancy. Even the lady in the next bed said her first four children were healthy but her last born daughter was diagnosed with thalassaemia.” (M.7a)

Another participant said:

“They said you will have only one child with thalassaemia in every four pregnancies. My first born has thalassaemia, which mean the second and the third child will be unaffected or carriers, because thalassaemia comes in every fourth pregnancy.” (F.1b)

Some participants understand that thalassaemia affects certain families in a systematic pattern. For example, if you have an affected child then the next will come a carrier or unaffected. The third child will be affected with thalassaemia, and the fourth a carrier or unaffected, and so on. As the following participant claimed:

“I know that in each family the disease pattern occurs differently. For us, we have a thalassaemic child, then free, then again we have a child with thalassaemia, and the four pregnancy becomes a carrier. I will tell you more about my children: first of all we have

K.M [Initial of his son] diagnosed with thalassaemia at the age of one year. Then my R.M [initial of his daughter], her test was free, F.M [Initial of his son] is diagnosed to have thalassaemia and now we expect the next born to be a carrier.” (F.6c)

Another participant said:

“They told me that because I have my son with thalassaemia, the second pregnancy will come free. Thalassaemia comes only once in the family, so I said, let me try my luck. But unfortunately the luck gave me a girl and she has thalassaemia... Then I stopped having any more children.” (M.2b)

Moreover, some parents believed that BTM is a sex-linked genetic disorder in some families. They believed that if they had unaffected females, then a male child would be affected, and vice-versa. The following participants said:

“My son has thalassaemia, my two daughters are carriers and I have another girl who was free [unaffected and not carrier]. Because my husband and I are carriers, I can’t conceive a healthy boy. The disease comes in males... See the mother in the next bed... Her girls are healthy and the only two boys she had are diagnosed with thalassaemia.” (M.2c)

Another father said:

“It only affect the boys in our family... All my daughters were ok and my three sons have thalassaemia... Can you imagine? ‘Alhamdulillah’ [Thank God] at least all my daughters are healthy.” (F.14a)

A mother claimed that:

“The disease occurs in women more than men. My sister in law has one girl with thalassaemia. For me, I have two daughters with thalassaemia but ‘Alhamdulillah’ [Thank God] my son does not.” (M.9b)

“My two boys have thalassaemia and my daughter is a carrier... Even my sister in law, all her daughters are free, but recently her two boys were diagnosed with thalassaemia... In their family it comes to girls only.” (M.13a)

During the interviews most parents stated that they did not know the meaning of BTM when their children were diagnosed, because it was the first time they heard about it, as the following mother claimed:

“They told me that my son has thalassaemia and that was the first time for me to hear about it. I asked the nurse what thalassaemia is... I asked her outside in the corridor... I didn’t know what thalassaemia was. I never heard about it before.” (M.13a)

“After the doctors did the diagnostic tests to Y.M [initial of her sons] and confirmed to us that he has thalassaemia. That was my first time to hear and know about thalassaemia. Then they asked us to do the tests for all family members.” (M.2c)

“I know nothing about thalassaemia... Never heard about it in my entire life” (M.1a) and (F.6a)

“You know what? [Silent for minutes] They told me that ‘your son has thalassaemia’ but the problem was I knew nothing about it. I was with my friend to collect the results. I told him: I really don’t know what thalassaemia is. He said: me too.” (F.9a)

“I understood what thalassaemia meant only after many hospital visits. After my son started blood transfusions I met many patients and saw what they look like.” (M.2b)

Some parents blamed HCPs for not providing them with basic information about the original, the genetic process of thalassaemia and the expected complications their children could face in future, or about the appropriate way of caring for children with BTM. One participant explained:

“...Nurses and doctors only answered your questions... But I need them to tell me what I do not know or need to ask about. They told us that we will give him medications and blood, but I do not know what is next... Let me tell you this, I just saw some patients here talking about the spleen surgery and when I asked one patient why he did it... He told me that my son will also have it, and all children with thalassaemia will have it at some time of their life.” (F.5c)

Other participants preferred to talk to parents rather than health care professional, either because of the available time, or the communicative way of transferring. Information. These mothers claimed that:

“I prefer to talk to mothers more than the physicians and nurses. Mothers give me advice about medication because they used it for their children for a long time, and they told me stories about what is happening with their children with thalassaemia. I found that effective, and easier than talking to the physicians, because you stay for a long time in the waiting room to meet them for few minutes, and sometimes they use complicated terminology which I found hard to understand.” (M.3b)

“I spend the whole morning and afternoon in the departments but the nurses are always busy. They come and go... no, there is not enough time.” (M.12b)

“They talked to us only when she was diagnosed, but this is not enough. I need to know more details about her situation, what will happen to her in the future, but nothing. No lecture or discussion or anything.” (M.13b)

Other fathers stated that:

“Thalassaemia nurses are very good but they rarely talked to us about details and when we asked they said, ‘ask the doctor, he can tell you the details’.” (F.5c)

“Nobody talks to you. We came to the department to give him blood and go home again... Nothing... No discussion or any talk.” (F.8c)

Participants focused on the physicians more than nurses in terms of health education, counselling and interpreting the blood results, as the following example showed:

“When we were in the clinic to receive the test results the paediatrician talked to us about the thalassaemia... Yes, that was the only talk we had with him. Since that day we come here for blood transfusion.” (F.5b)

“His doctor didn’t say that much: it is blood disease, your son will be dependent on blood transfusion for the rest of his life... Nobody told me there is a risk that the next born could also have the same problem, because my wife was pregnant at that time.” (F.6a)

“In each visit to the clinic the physician tells us that life and death are in God's hands... ok we all know that and we don’t object to God’s work, but I think they should find different way to say that my son's health deteriorated... I know they try their best but their way of passing on the information could be much better, couldn’t it?” (F.4c)

“When we did the blood tests it was the doctor who explained to us and interpreted the results... No, there were no nurses in his clinic.” (M.8a)

Some participants revealed that reading about thalassaemia helped them to understand more about the disorder. They used a variety of resources such as the internet and books, as these fathers explained:

“I had never heard about thalassaemia before... I wanted to know more about why it happened and how I became a carrier. I asked the doctors in the department and they explained to me but I still was not happy with that, so I have been reading about it in the internet. I used to read for hours and hours. I wanted to understand what my sons are going through and why the three of them have this blood disease.” (F.15a)

“To be honest with you, I was shocked, it was really hard for me because I had never heard about thalassaemia in my entire life... What helped me to accept the situation and keep holding on with my family was that I read books about the disease.” (F.3a)

One mother stated that the booklet she read from the department helped her to recognise what ‘inherited disorder’ meant and understand the transmission methods. This, she added, helped her to know more about the recommended diet for her son:

“I was shocked, I cried a lot, I did not know what I should do. I thought it was cancer because the paediatrician said he has anaemia and blood disease and low his blood cells were low, and he needed to take blood at hospital. I felt like I need to do something to help him. One day I found a booklet in the department. I took it home and read everything about thalassaemia, which helped me to understand and calmed me a little bit.” (M.2b)

“I kept searching and reading on the internet about thalassaemia. It helps me to understand what my son and daughter are going through and what I should do.” (M.13a)

6.6.1.3 Sub-category 1.3: Genetic health services

Some participants stated that the available family planning programmes and genetic health services did not meet their need to have healthy children and help them to avoid having another child with BTM. Most participants stated that their preference would be to have healthy male child in the family, especially when so far they had only healthy females in their families. As this mother claimed:

“I wanted a healthy child. Everybody in the family accuses me of not being able to conceive a healthy baby. I don’t want to use the pills [contraceptive pills] but nothing else helping. I need to have healthy baby, not another child with thalassaemia...” (M.17a)

“I wanted to use contraceptive pills but because I’m 40 years old I’m afraid it would cause me complications... I don’t know what to do.” (M.6b)

“This is my first girl and I want another healthy child... But I don’t know what to do right now. My husband and I, we use traditional methods.” (M.13b)

Performing Chorionic Villus Sampling (CVS) was not well known as an antenatal diagnostic procedure for most of the participants. In the interviews, parents did not talk about performing the procedure, or about its availability in the Jordanian health care setting. Three mothers out of forty participants knew of or had heard about it. I sought to saturate this category by probing more about the diagnostic and screening genetic tests, parents claimed that they did not know if such tests were available and they had not heard about them before:

“What was that test? No, I have not heard about it before... Can you please tell me more?” (M.2c)

The following participants claimed:

“I did not know there was any test that the carrier mother can do... No, no, nobody explained to me... Listen to me: I was already pregnant four months of my first child was born... I gave birth at hospital... Is that test available in hospitals or in maternity clinics?” (M.5a)

“We were both stressed and upset because we agreed no more children, but we didn’t know what would be the appropriate contraceptive to use. She tried the pills but I was surprised that she got pregnant. Maybe something went wrong... No, I didn’t know that

there was a test to know if the pregnancy is thalassaemia-affected... I was very angry when she told me.” (F.9a)

“I don't want more children. I started taking oral contraceptives because it was the only thing I know. My husband advised me to do tubal ligation... but I refused. I told him I'm young, but I will use the pills and wait, we'll see how things work... No, I didn't know there was a test that can be performed during pregnancy to know if the unborn child has thalassaemia or not.” (M.9b)

“Nothing, no plan or any tests. I discovered my pregnancy by chance... No, we didn't do any tests during pregnancy... We just waited until I gave birth and we did the blood tests.” (M.1a)

Some parents indicated that such antenatal tests are either not available, or are ineffective because abortion is forbidden and knowing the genetic status for the unborn child will only increase their stress and anger. The following participants claimed:

“No we didn't do it... This antenatal test is rejected totally... Do the tests during pregnancy, then you have to decide where you want to do the abortion if the unborn child does have thalassaemia or not if he is free...? No, no, no, we can't go through all this. Whatever the scenario is, abortion is already forbidden so it is pointless to do it.” (F.2a)

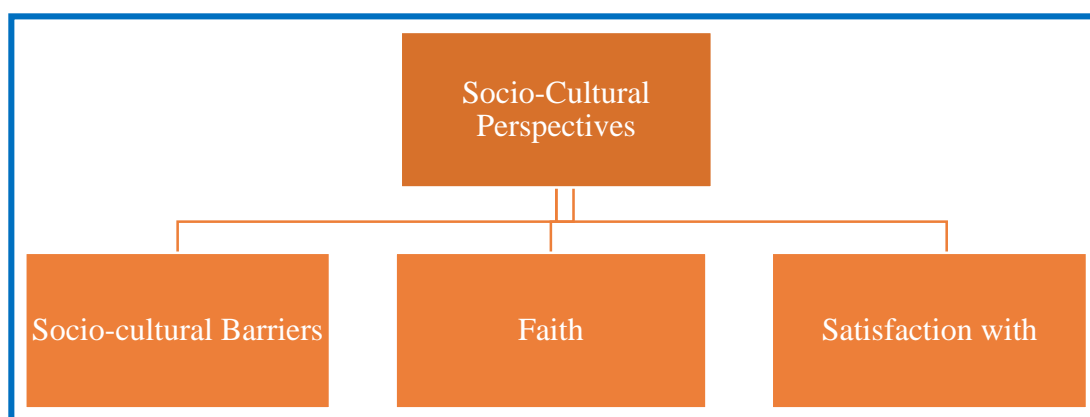
“I don't think I want to do such a test [meaning the CVS]... I can't have an abortion [silent for minutes]. I discussed this before with my husband and there is no way I can do it.” (M.17a)

“But if the abortion is religiously forbidden, why this test? How can it help me?” (M.3b)

6.6.2 Core category 2: Sociocultural Perspectives

This core category is composed of three sub-categories: 'Socio-cultural barriers', 'faith' and 'satisfaction with' (see figure 9). Participants in these sub-categories showed the impact of religion, social values and culture on their role as a father or mother caring for their children. Participants expressed the positive side of their experiences with the health care services and the social support they received, as well as the negative side caused by socio-cultural issues such as social pressure and stigma. Participants in this category revealed how their faith was a major coping strategy which helped them to positively adapt to their situation.

Figure 9 Core category 2. Socio-Cultural Perspective



Source: Author (2013) * the data in the figure was generated from the research findings.

6.6.2.1 Sub Category 2.1: Socio-cultural barriers

This sub-category presents the impact of cultural and social values on parents' experiences. Participants in this area highlighted the impact of having a child with BTM on their life and reported how their cultural and societal values impacted on them and shaped their experiences. Various socially issues were mentioned, such as socially unaccepted events, social isolation, employment issues, insecure marriage relationships and being carers to their children. These areas were interrelated and connected to each

other as well as to some cultural issues also revealed in the interviews. The cultural issues most connected to their experiences caring for children with BTM were stigma and the preference for a male child. In addition, the socio-cultural barriers impacted directly on parents' daily activities and decisions concerning their health and social status.

A. Socially unaccepted events

Participants disclosed how some social norms and behaviours which they commit to in their community directly shaped their life and impacted on their experiences caring for children with BTM. Parents in this study reported compliance with some issues in their society which were connected to their culture, religion and social norms which might be not their preferred choice. For example, parents stated that it was not socially acceptable in their society for the only male child in the family to be chronically ill. Some parents claimed that their closed community expected them to have at least one healthier male in their family:

"We have three girls. Only the youngest has thalassaemia but my husband argues with me that he needs a boy, because all his brothers have many male children...And he threatened me that if I did not remove the Intra Uterine Device he would leave me and my daughters." (M.17a)

"I need a boy. My husband was very angry when I delivered her, he wanted a boy, not a girl." (M.11b)

"He said it to me twice that if I do not have a healthy boy my husband will have a second wife. I warned him... If he had a second wife... I will ask for a divorce and leave him... This is not my fault. I'm caring for my children all these years and at the end of the road he would reward me by having second wife. No, no, no, I can't handle this... I know his family is putting more pressure on him to have a healthy boy." (M.13a)

Another mother stated that her close family insisted on the need for a male to secure her future. Culturally, having male children strengthens the women's social relationship and status with their in laws, their husband and in their community.

"My husband always listen to his dad. He doesn't care for me or for his children... He did not take any responsibility for us at all in or out of the home... My father in law, he is the leader for everything, he told me, 'if you have any more thalassaemia boys, go to your family home, we don't need you here.' This talk was in front of my husband but he did not say a word." (M.9a)

"Yes, I need healthy boys... Its only me and her [his wife] in the whole family who do not have healthy boys. All my three boys have thalassaemia and I'm the oldest between my brothers. I will takes over from my father... You know what I mean." (F.14a)

"My mother in law frankly said it to me, 'if you want stay in this family you have to have a healthy boy, we do not need thalassaemia one.' I swear to God she believes that I'm the only one who brings the disease to my kids, and since then she argues with me and is always threatening me." (M.13a)

Socio-cultural norms influenced the way individuals behaved and expressed their feelings. For example, most participants stated that crying in private or public was socially accepted for women but not for men. Culturally, men should behave in public in more a masculine manner, showing some degree of control, power and support. This clearly excluded showing their emotional reactions:

"She is very sad. It is the first time I have seen my wife upset like this, she keeps crying each month when we bring our son for blood transfusion. I asked her at least to not cry in front of her [his daughter] ... Me, no, no, I do not cry." (F.8c)

"I can't hold myself I just cry... You know, you see your child at home hypoactive and his face pale and you can't do much for him. What you can do?" (M.13a)

"I was walking going home and my eyes were full of tears, people in the street looked at me... I was walking like a crazy woman... I was totally shocked, I didn't expect his result." (M.9c)

There was one father only who stated that he expressed his emotions, even in public, and did not hide them. He narrates what happened to him:

"That was the hardest time of my entire life, the worst news I ever heard... I tried but I could not hold myself, I cried hysterically, very upset... Oh my God, it was very hard for me. When the physician explained to me that my son would have blood transfusions for the rest of his life and that the scenario was that he could die soon because children with such diseases don't live long... I was totally shocked. I cried 'til I fainted in the clinic. No, nobody with me, I was alone. I was collecting his test results; I didn't expect him having thalassaemia. I was thinking it could be ordinary anaemia... My friend told me, it took about 10 minutes to bring me back." (F.9a)

In three thalassaemia departments, female family members always accompanied the teenage and young adult females with BTM. The reason given in the interviews was that it was socially unacceptable for young adult females to attend hospital on their own, and that they should always be accompanied by their mother, sister or any female figure from their families.

"There is an argument each month. She wants to come to the hospital on her own, but her dad and the oldest brothers said to her clearly, 'no, this is not going to happen. Your mum should be with you when you go to hospital.' She tried to discuss with them many times, but they refused... Then she came to me complaining and said, 'I'm not a child

anymore, I'm 16 years old', and she started crying. I said, 'listen to me, this is our culture and our norms and we have to respect that. Did you ever see any girl go to hospital alone?'... I reassured her, 'I trust you but what should our neighbours say if they saw you going out alone?'. ” (M.7a)

“I have to come with her every month to the hospital, she is still a teenager... No, no, no, I can't let her comes here alone. What would people say about us? She is a girl... You know our society. ” (M.9b)

“I wish she were a boy. At least she could come to hospital on her own when she grew up, but because she is girl I have to accompany her all time to the hospital. ” (M.13b)

It was noticed that in some cases, the mothers were unable to take part in the interviews because their husband did not give permission, either because their husbands refused permission for them to be individually interviewed, or because they did not want them to talk about their family situation. Furthermore, some couples suggested being interviewed as a couple, instead of individually. However, after discussion and explanation of the study's aim and objectives, some of them agreed to take part in the individual interviews.

“Why not? You can interview us together... What is the difference? We are husband and wife and she is our daughter... We can save your time. ” (F.3c)

“Let me ask him first ... You know M [Initial of her husband] will be angry if I don't tell him ... why you didn't interview us at the same time. ” (M.2c)

B. Social stigma

In some families having a chronic illness could cause feelings of shame and stigmatisation which led some parents to hide the fact that their children had been diagnosed with BTM and that they regularly received blood transfusion and iron chelating therapy.

"I did not tell all my family members that my daughter was diagnosed with thalassaemia. Only me, my husband and my family in law knew about her disease and blood transfusions. I didn't want to discuss this with anybody right now. No, no, no, even my close friends. You know how people stigmatized us... You know what I mean? " (M.13b)

"My family in law stigmatised, shamed and accused me of being the one who brought the disease to their children. We fought because of that and we did not talk to each other from that time... You know what they called me? 'The stranger', because I'm the only one who is not a cousin. I'm from a different tribe but all my sisters in law, and my children are the only ones who have thalassaemia in their family." (M.13a)

"My family in law have the culture that all females in the family not allowed to go out of the home on their own... I told her that his doctor said its thalassaemia, and I need to take him for blood transfusion every three weeks. She made fun out of that and told me, 'this is your excuse because you want keep going out... You are the sick one with thalassaemia, not our children. We do not want you here, you stigmatised this family... Go to your family'." (M.9c)

"He blames me that I'm the only one who brought the disease to my child... He said, 'you and your family bring the shame to my daughter with this disease'." (M.8b)

"One of my sisters in law saw my son running in front of our house. She shouted at him, saying... 'Oy... Don't run boy... Do you have the ability to run...? You sick boy like your mother, shame on you... You will die soon'." (M.13a)

In some cases, marriage proposals were withdrawn for unaffected siblings because BTM was present in the family. In some families, proposals were withdrawn regardless of whether the proposed members of the family were known to be carriers of the defective

thalassaemia gene. In the interviews, the participants indicated that socially and culturally, it was not acceptable to get married to a carrier of a genetic disorder.

“I was really worried, not only for her future but also for her sisters... Many marriage proposals were withdrawn when they knew about thalassaemia in our family, and this worried me a lot, because three of them are now at the marriage age but none of their proposed marriages succeed.” (M.16a)

“You know people gossip about our family that we have genetic disorders, but the disease is from God... It is God's will to have it or not... Yes, of course it impacts on the marriage issues in our family. You know people talk. [Silent for minutes] Two proposals for my sisters did not work because of that.” (F.3a)

Some participants stressed how it was socially unacceptable to propose marriage to chronically ill females in Jordanian society. They stated that:

“No one in our society will marry a lady if she known as a thalassaemia carrier.” (F.8c, F.6a, M.9b and F.15a)

“No one proposes marriage to girls with thalassaemia ... It's socially totally unacceptable,” (F.8b, F.10b, M.2c and M.8a)

“I'm the only one who is not related to them. All my sisters in law are from their family... Because of that, my mother in law hurts me many times. Even she knows that her son is also a carrier but she said, 'if my son married a healthy woman, his children would be ok.' She accused me that my daughters will not get married... No one will propose to them.” (M.11c)

“As a man, he can get married at any age and have healthy children. Nobody will question that. But for me as a women, the whole society will say, 'she left her children to

get married, she is not a good mother.' They will shame and stigmatise me... You know, this our culture." (M.1a)

In one case, a mother complained of the anti-social behaviour and discrimination from some relatives and neighbours towards her children. The data showed that such scenarios became worse when parents were not related before getting married. For example, parents did not allow their children to eat, drink or play with children known to have BTM, based on their mistaken beliefs that it is an infectious disorder.

"One of my sisters in law refuses to let her kids play with my thalassaemia sons... She told me one day, 'keep your ill children away, I do not want my kids to get thalassaemia from them.' Can you imagine that? I was genuinely shocked and too frustrated. One day my son came home crying because she told him, 'go away, play with your sick sister, such a pale boy.' I swear to God, that day I did not sleep because of the stress after we had a big fight." (M.13a)

C. Social isolation

Some participants stated that they used to stay at home, while others could attend few or no social activities. Most mothers in the interviews stated that their reasons for not sharing in social activities was that they were overloaded with duty of care for their children with BTM. Participants said that the demands of care resulted in limiting their social activities, in some cases isolating them. Some mothers stated that they did not leave the house except when they brought the children to the hospital, as this example illustrates:

"I do not go out at all... My time is for my children... They need a lot of care and I have no time... You know how much time the household stuff takes, and I have three kids in school and my youngest son has thalassaemia. This all needs a lot of care... I have to stay up late at night to insert the infusion medication and ensure that the machine does not

stop when he moves... You can say I'm socially not active at all... Since the time I had my youngest son, it is difficult for me to handle all these issues.” (M.3b)

“She used to stay home alone. She did not communicate with anybody, always in her room... I told her that this was not helping... This our destiny you have to try and accept that.” (F.1b)

“She deliberately did not accept the dinner invitation in Ramadan because she had read a similar surname to her husband's surname in the patients list... She did not want to meet them because they do not know about her child with thalassaemia.” (M.3b).

A father described similar isolation:

“I stayed home for almost three months after the diagnosis was confirmed... It was hard for me... Hard... Very hard... I stayed in my room alone for days... I smoked and ate in my own room, did not answer any calls... It seems strange but I didn't feel that I was ready to see him... You know, watching your son weak, pale and with the infusion machine pumping him every night, it was killing me from inside... You know what I mean? ... It is not easy.” (F.9a)

It was noted that some fathers resorted to different strategies, such as not staying home, carrying out different activities, visiting their extended family or friends, or spending more time at work. In the interviews, fathers' involvement in caring process for their children was not clear or sufficient enough. Some fathers tended to keep themselves busy away from home in order to keep themselves away and not get involved, as this example illustrates:

“I found that working overtime made me feel better... I go out with my friends, just to kill the time. We have two. I resorted to coming home late on purpose to ensure that everybody was asleep... To be honest, I do not want to see my wife inserting the infusion

medication. I do not want see my son crying, its heart breaking... Yes, of course it's an issue for her [his wife. We quarrel a lot over this issue." (F.9a)

"When I'm upset and stressed I know he used to drive the car just to stay away from home for an hour and then he will be back." (F.10a)

"I stay out of the house for a few hours and sometimes I stay in my shop... When I'm stressed I don't like to be at home with my family." (F.5c)

"I used to go to work and did not come back home 'til night time just to sleep... I did overtime work and sometimes spent the day with friends or visited my sisters... Just to not go back home." (F.1b)

Stigmatisation in the community led some families to face additional social challenges which interfered with their daily activities, limited their mobility and affected their relationships with friends, family members and their own society.

"Because I have two kids with thalassaemia, I stopped going anywhere... I stuck at home because of my in-laws causing trouble for me and my husband... Oh dear, listen and I will tell you how... First, they stopped visiting me, then they asked my husband to divorce me, then they gossiped that I have brought the disease to their family and shamed them and more, more, more... They were very aggressive with me and my children... Oh, I could tell you more and more. They showed me the worst days in my life and the problem is that my husband listens to them." (M.13a)

"At the time my son was diagnosed he was a toddler. Even he did not know he had the disease, but I'm the one who takes the whole responsibility. I have been shamed and stigmatised with time... I stopped talking to many of my relatives because I don't want tell them about my son with thalassaemia. Even when they invited us to share in their social activates I won't go. Because I know they will ask me about my son." (M.8a)

"I did not talk or tell anybody about her health problem, even my family. Only my family in law knows about her situation... I don't need people to shame and stigmatise us."
(M.13b)

In some cases, caring for children with thalassaemia isolated participants from their social life.

"I dedicated myself to my son. I never go out or leave him alone just for fun. No, this is impossible for me. I lock myself at home with my children all time... Some neighbours think I'm not social." (M.1a)

D. Employment issues

Participants raised some issues related to how their work limited the time available to care and to be involved in their children's hospital visits. For example, it was difficult for some fathers to get days off from work to accompany their children for blood transfusions or hospital visits, as the following quotations indicates:

"They are not cooperative with me. If I take my son to the hospital I have to take unpaid leave. I work in private sector, and we have limited days of yearly vacation... But I have to do this because I have two children with thalassaemia and my wife is caring for the other four children at home. They are all still young, and she can't leave them home alone."
(F.10c)

"When his mum is sick, like today, I have to take the day off to bring him here... I can only do that as part of my annual leave, because they refuse to give me days off." (F.12a)

"Only God knows how we suffer... We are both employees, me and my wife. We struggle and face many issues to come for blood transfusion. In the end I had to tell the school manager that I have three children with thalassaemia, and they need regular blood

transfusion, because I have to give him an excuse for why I need to take leave every now and then.” (F.7c)

“I finished a night shift before I came to the hospital for her blood transfusion and I will again go back to work tonight... I have no time to sleep.” (F.12b)

Taking time off work to care for their children is an issue for most of the working fathers and mothers because of their wishes to keep their child’s diagnosis secret, as this example illustrates:

“No... Nobody at my work knows that my son has received regular blood or has thalassaemia... Each time I have to give them different excuse to have time off from work, so that I can bring him to hospital. You know people talk a lot.” (F.3c)

“I have to leave my work and drive to reach hospital for four hours going and back, which means I lose my work for that day, because nobody knows that I have a child with thalassaemia at work.” (F.6a)

E. Gender preferences

Male children were the first preference for the participants. This preference is based on their cultural and social background, the role and the social image of the men and women in their society. It was noted that having sick males was preferable to having healthy females for some families, as these participants claimed:

“Yes, of course it would be better if she was a boy.” (M.17a)

“Girls in our community are already mistreated. I can't imagine what is the situation will be if they diagnosed with chronic illnesses like thalassaemia. Of course their situation will be worse. Because of that I preferred to have a male rather than a female child with thalassaemia.” (M.8a)

"I wish she was a boy... You know caring for boys is easier than girls... Especially when he is sick... You know what I mean." (M.16a)

"Having boy is different than a girl... You know that in our society girls' roles are different... The males can be responsible for themselves, spend time out of the home alone, live alone, get married and work on anything, but this is not the same scenario for girls. She always needs a guardian... Even when you have a sick boy, he is still the man of the house... He can deal with any issue." (F.2a)

"To be honest with you, it would be big problem if the child with thalassaemia in the family was a girl... I have no girls but I feel sorry for those who have girls diagnosed with thalassaemia because their situation will be more difficult and complicated." (F.9a)

"Alhamdulillah [Thank God] I have a boy with thalassaemia, not a girl... I feel so sorry for my brother, his daughter is diagnosed with thalassaemia." (M.6b)

"Of course having boys with thalassaemia is better than girls... Please excuse me for what I'm saying, but girls with thalassaemia could not get married, or get pregnant, but for the boys the scenario is different. They do not have a menstrual cycle, no pregnancy or delivery... For any parents, having boys with thalassaemia is much better than girls... Boys can move freely but all the community eyes are focused on girls." (M.13a)

Mothers in the interviews said that if their first born child was male, it relieved the pressure on the mother, improved the relationship with the husband and family in law, and gave them some peace and stability for many years. Such is the desirability of having a male child.

"I have three girls and my husband argues with me. He needs me to gets pregnant, he needs a brother to the girls... Me too, but my fear is that he will also have thalassaemia... I know I will not have peace with him 'til I have the boy." (M.17a)

“To be honest with you, sometimes I wish I had a boy... You know they accused me of not being able to conceive a boy... Having my son will make my husband at least happy.”
(M.13a)

“My mother in law said, ‘I wish that all of your daughters were sick and he is the healthy one’... God knows how much I want a healthy son but what should I do? This is not my fault.” (M.17a)

Parents believed that caring for females with thalassaemia is more demanding than caring for males in terms of social care, responsibility and decision making, not only in the current time but also in the future.

“Yes, having a boy is better than a girl because girls with thalassaemia will most likely to stay alone in the future which is really an issue... She needs someone to take care of her because no one can accept to get married to a thalassaemia lady.” (F.2a)

“He is a male... He can face this life... I thanked God he is boy not a girl. He is a man, he can get married but for a girl with thalassaemia, she will never get married. It is impossible, this disease for girls is life changing.” (F.10b)

“I have to take care of her for the rest of my life because she is female... She is tired more and needs more care as she grows up.” (M.2b)

Some participants mentioned that they much worried about their girls’ with thalassaemia future and the challenges they could face. Parents of male children with thalassaemia did not have the same scenario.

“Yes, I would prefer that she is a boy... Yes, the boy is different than the girl. Any boy with thalassaemia can get married to any healthy girl but not vice versa... The girls, they have their monthly cycle and if they get married the pregnancy could really be a risk for her health. But she can't avoid it, you know our society.” (M.17a)

"I'm not worried about A [Initial of his son] but all my worries are about R [initial of his daughter]. She may not get married [silent for minutes]... Who will propose? Who will agree to marry a lady with thalassaemia? Having a boy with thalassaemia is of course better than a girl." (F.1b)

"Because they are boys and in the future they will be men... but for the girls getting this thalassaemia, they have to deal with many health issues and pregnancy is the most important... You know... I'm happy that the only daughter we have is a healthy one." (F.14a)

F. Insecure marital relationship

Participants highlighted different marital challenges resulting from their duty of caring for children with BTM. Parents exposed various feelings which developed over time, such as insecurity in their marital relationships, financial challenges and ambiguity in their responsibility as parents and as carers to their children.

"All our problems started when we discovered that our son has thalassaemia." (M.13a)

"My family in law talked to him to have a second wife. I know this will happen one day because he lately changed. We quarrel daily... I stated it clearly to him many times... I told him, 'if you are planning to have a second wife, please divorce me first'... I do not want him anymore and I do not want an unpleasant surprise one day... I have had enough." (M.17a)

"I did my best for him but he did nothing. This disease is not my fault. I know he denies that but he is also a partner in this. [Silent for minutes] What is written in my blood tests is written in his tests. We both carry the gene. It is not only me who is responsible for our children with thalassaemia. We discussed this many times and nothing changed." (M.2b)

“No, I don’t think we can continue like this. I think it just a matter of time and we will divorce. He is not good for me as a husband and for the kids as a father. I feel like I’m oppressed with him. No, I’m not happy at all.” (M.9c)

“We still do not talk to each other. I felt that things between me and my family in law come to the end. Even my husband has changed a lot. He used to care more but these days he is always angry and we argue many times.” (M.13a)

G. Being a caregivers

Parents were considered the only carers for their children with thalassaemia, both inside and outside the home. It was noticed that it was usually mothers who took the leading role in child care. Most of the children with BTM in the hospital were accompanied by their mothers, and few was by their fathers, as stated by the following participant:

“Yes, most mothers take the responsibility to care for their child with thalassaemia but this is unfair. It should be shared between them. He is also responsible like her. Both are carriers of the gene and passed to their child. It is unfair for the mother to be the victim.” (M.1a)

“No, he [her husband] never accompanies her to the hospital or even gives her any medication. I’m doing everything for her... He gives me money and says he’s busy... [Silent for minutes] He’s always busy... To be honest, he does nothing, he’s always busy.” (M.2b)

“All what I care for now is my K [initial of her son]. I just want him to take the blood and the medication ‘til the time they will do the operation... His future is mine now.” (M.1a)

“He never ever accompanied him to the hospital or took the responsibility to follow up his case with any physician... I’m the one who does all this... He is not the type of caring father for his family.” (M.13a)

Some mothers complained of the limited involvement of their husbands in their children's care. They stated that fathers tended to keep themselves busy most of the time and leave them alone in this mission.

"I have always accompanied my son to the hospital for almost the last five years. He has never brought him for any test or for blood transfusion... He is busy most of the time... Always he has his own excuses... You know men." (M.17a)

In another scenario, a few fathers refused to care and look after their children just because they had thalassaemia:

"He left the legal child custody for his son because he is sick, but not for his daughter because she is healthy. I told him either take the two of them or none of them... We agreed and we did a legal statement under one condition: that I cared for both my son and daughter 'til the time my son had the bone marrow transplantation. After that he takes the legal custody for them... He doesn't want to care for a sick child. We argued about this many times after the divorce... While our child is sick he is mine but when he is healthy after the operation, he will take him." (M.8b)

"First he refused to do the blood tests. I tried with him many times. I told him that the doctor said both of us need to do it. I paged him many times. I told him, 'for God's sake... They need to diagnose him because they told me he could have a cancer.'... I really struggled with him but thank God after three days he did the test. Since that day he never ever did anything for his child... Talk to him or play with him, never even when he came back from work. He sits in his room to not see his son with the infusion machine." (M.9c)

Another mother reported how her husband refuses to be involved in his child's hospital visits or even in any types of child care, even when he is not busy. As the following mothers claimed;

“Her dad brought her once to the hospital, but I accompany her each time... No, he is not working. He is retired four years ago. He stays home. No, not very busy, but this is a mother’s duty... Women can do this better than men.” (M.1c)

“My husband is not helping me at all. Sometimes he doesn’t even give me the daily expenses for his kids... He did not show any care and compassion to our children, even when he is on break on Friday. He never asks about him or accompanies him to hospital. No, no, when I asked him why he did not answer me... No, he is doing nothing.” (M.9c)

“My husband refuses to accompany me to the hospital when I take ‘A’ [initial of her son] for blood transfusion. He said, ‘you are better than me to stay with A in the hospital.’ He drives us to the hospital and will come back to take us home.” (M.6b)

“Yes, he is here waiting outside in the car park... He refuses to come with me to the department. Usually he escorts us to the hospital and goes to visit his friends or wait in the parking ‘til we finish, then he will be come to take us back home.” (M.4a)

“He refuses to see them or even stay. He travels a lot, just meets them for one day only.” (M.8b)

Participants indicated that the basic role of caring for children without BTM was different from that of one with the condition. For instance, dealing with daily medication and frequent hospital visits were considered as extra duties requiring adequate knowledge and up-to-date training. However, some parents expressed concern because they felt they were not well prepared and trained to care for chronically ill children. It worth mentioning that parents in the interviews did not focus on the psychological status of their children as the following examples shows.

“I have two sons with thalassaemia, A and H. I have to stay home most of the time to care for them and play with them when their brothers and sisters are at school ... We are at

home most of the time. Everyone goes to either work or school. It not an easy job to care for your healthy children and more difficult when they chronically ill... I have to take more care over his food, what he eats and drinks, and of course to give him his daily infusion medication.” (M.13a)

“My daughter keeps asking me many questions and sometimes I don’t know what to answer her... She is a teenager... It is hard for me to deal with all her requests... Demanding for everything... You know what I mean? She doesn't have any patience. I don’t know [Silent for minutes]” (M.6c)

“Going and coming to the hospital is not easy with time. You feel tired, driving for long distances and sometime using public transportations. It's really not easy... I have been doing this for ten years.” (F.6a)

In some families, parents decide who will accompany the child to the hospital based on the child’s gender and age. Mothers usually accompany girls at all ages, and fathers accompany male children when they are teenagers.

“Because she is female... If she was a male I think he could accompany her to the hospital, but you know this is our culture. Mothers care for daughters and fathers care for sons.” (M.19a)

“I talked to his dad to start accompanying him to hospital... He is a young adult you know, he is fifteen this year... I can't keep coming with him, he is a man.” (M.8a)

“She is the youngest... Yes, it is me who looks after her... But ‘til now I can’t stand to see them insert the needle for blood transfusion... Usually I wait outside the door.” (M.2c)

“Sometimes I feel really tired from the weekly hospital visits because I live in Ajloun [a city in the northern region]/ I have to take two to three transportations on the way... No,

she is only two years old, I'm the one to care and look after her... No, I don't think her dad can do that. I don't even think he knows how to do it.” (M.17a)

The data showed that in a few exceptional cases fathers shared in their children's care. However, the care depended on the child's gender and age. For example, some fathers were involved in outside home care such as looking after their children's academic achievements in school, attending school meeting with their young adult children, and organising some social activities with them.

“He is a smart boy, his dad visits his school regularly... We need his teachers to be more aware for his activities, you know school teenagers can be really violent... We gave them his father's mobile number in case of an emergency.” (M.9c)

“I usually go to visit him at school at the beginning of the academic year and explain to his teacher about his situation, and I also keep check on him every now and then.” (F.3a)

“She is good in school, smart and active. She also goes shopping at the nearest shop to our house.” (M.9b)

“I take him with me to all of our family social activities... I need him to grow up to become a man.” (F.1b)

“I always visit her at school and follow up with her teachers and I usually ask them to care for her more, and that makes her feel happy more.” (M.7a)

“I visited him in school several times and I explained to them about his disease... They are really good, they understand his needs... I need him to be a man. I take him with me when I'm visiting family or shopping.” (F.5b)

“I usually take him to social meetings in our family, shopping and sometimes to the Friday prayer... I need him to learn how to deal with people.” (F.2a)

Some families stated that it was socially unacceptable for men to take a leading role in caring for their children, because culturally it was seen as a duty for women. Most of the fathers' caring role was limited to the teenage male children, and also mainly focused outside the home. I noticed that most of the hospital chaperones were mothers who accompanied their children. The following participants claimed:

"Women are better at caring for their children than men... When I bring her to the hospital for blood transfusion... I spend more than seven hours at each visit... Men, they do not have patience for this... They are not good at all in this kind of job. Yes... Yes this is our duty as mothers." (M.17a)

"It's me who looks after and does everything them... He is busy at work and you know men are not always able to care for children. This is our job, the mother's." (M.2b)

"This is why we are mothers... To care and look after for our children." (M.16a)

Some families were struggling with the administration of the infusion medication. For example, some had issues with the insertion of the sub-cutaneous needle. First, some mothers revealed that they had problems with the insertion site rotation which can affect the effectiveness of the iron chelating medication. Second, participants were distressed by the feeling that they were causing pain to their children, especially when started crying. This reported more frequently with toddlers and younger children with BTM. Other parents had issues dealing with the machine itself, including the alarm, batteries and other minor technical errors. This caused worry for some parents and gave them extra stress.

"I used to wake up all night waiting for the infusion machine to finish. N [initial of her son] sometimes wakes up when the alarm goes off which disturbs his sleep... I don't know why the alarm goes off. I switch it off and on again and again." (M.8b)

“He always cries, especially when we come to the hospital... Do you know what? The hospital visits were sometimes funny and sad. One day we brought him to hospital for blood transfusion and he refused to get out from the car because he knew we are going for blood transfusion which he did not want... He made me laugh [smile and giggling], then I asked him why did you come with us? I know he just wanted to go out in the car. The needle for him is punishment.” (M.6b)

“The oral tablets saved us a lot because we struggle with the iron infusion machine... Especially with my son. You know what he used to do what when he is angry? Remove the machine. He said, ‘I don’t want the medication.’... He used to cry a lot because we connect the machine whether he likes it or not... Sometimes we wait ‘til he falls asleep and we switch it on and again, when he wakes up he removes the line, and we wait and connect it again when he falls asleep and we used to stay like that for the whole night.” (F.1b)

Compliance with the medication, whether the infusion iron chelation or the oral form, was an issue for some parents. As revealed in the interviews, some parents did not understand the importance of giving the daily medication.

“To be honest with you, I did not give her the infusion medication every day; she’s had it only twice... I could not be able to see her in pain... It is not easy to inject her daily... I’m very soft hearted and the previous two times I was crying with her... In hospital I wait outside when they insert the need for blood transfusion... I can’t stand see the needles and blood.” (M.11b)

“I was afraid to insert the needle wrong because he refused to let me insert it in his abdomen and I used to insert it in his hands for long time... He moves a lot in his sleep so I keep waking up to make sure the whole infusion finished.” (M.6b)

Some mothers described their experiences with inserting the oral form of the iron chelating medications:

“She is now taking the tablet forms but she didn't take them daily... I told her many times to take it but the problem is that she didn't listen to me. She doesn't like their taste... She said, ‘it makes me sick every morning’ but I told her: its ok, you need it. It's important for your health.” (M.9b)

“He is a teenager and sometimes refuses to take his oral medication. We’ve talked to him many times but it’s really hard to convince him... Because he also takes other medications because he is also has hepatitis.” (M.4c)

6.6.2.2. Sub-category 2.2: Faith

In the interviews participants showed that their faith, including religious beliefs and practices, helped most to positively cope and have some acceptance of what they faced in their situation.

A. Religious beliefs

Participants in this study coped with their situation through their faith. Their religious beliefs assisted them to cope through spiritual power, which helped them to accept their situation as carriers of the defective gene. Furthermore, their faith assisted them to accept having and caring for a child with a life threatening genetic disorder. Participants showed different interpretations and understanding of their situation based on their religious beliefs. Some parents understood and accepted the fact as their destiny, as the following mothers express:

“It is my destiny... It’s God work for me.” (M.1a)

“This is our destiny. Thank God for everything, we can’t do any things. I feel that God always supports us... This is the life you suffer here but the big reward is in the afterlife.”
(M.11b)

“I was desperately praying every day... I know this is our destiny... and only God can change it.” (M.6b)

“This what God needs us to have... he keeps telling me, don't worry. I just say ‘Alhamdulillah’ [Thank God] this is our destiny.” (M.7a)

“Thank God... He is [her husband] able to cope and adapt well because of his religious beliefs. I think the situation could be worse if he was not religious man.” (M.6b)

Participants' religious beliefs assisted them in accepting their situation as their destiny, rather than objecting to the life they must adapt to, as these fathers expressed:

“I do believe that this is God’s test for us. The Noble Quran God said, ‘Nothing shall ever happen to us except what Allah has ordained for us’... This is our destiny... Alhamdulillah [Thank God].” (F.2a)

“It’s our destiny in this life ... What Allah brings to your life is something out of your hands... You don't control it.” (F.5b)

“Yes, my faith... It is only my prayers and strong faith in God that helped me to keep calm and hold on. This is a test from God for us.” (F.2a)

Some participants thought that their situation could be test from God, but not a punishment, and that by obeying God’s orders they could pass this test and be rewarded in this life or in after life. These participants claimed that with God, you always win:

“This test from God to us... All I can say is that ‘may Allah cure and bless her health and all children with thalassaemia.’” (M.17a)

“No, no, no, I trusted him [her husband] because he has strong faith in God and believed that this is God’s will for us and God always chooses the best for him and for me too. This is what keep us going on in this life.” (M.1a)

“I know this is a test from Allah to me and to my family... I’m sure Allah will cure her totally ‘inshallah’ ... I always keep my prayers for her.” (M.3b)

Some parents considered that all disorders and illnesses are God’s will and that they should therefore be submissive to God’s will. Parents believed in predestination and that they should not complain about what God does and chooses for them in their life, whether it was bad or good. These beliefs were based on their faith that they would be rewarded either later in this life or in the afterlife. For example:

“You know all illnesses and health come from Allah, and Allah can cure them. We all need to be more patient and accepting... It is ‘God’s will’ for me and my children... Yeah, when Allah chooses you something in this life such as disease that means that Allah tests your strength and your faith... When you accept and obey Allah, Allah gives you and rewards you in the afterlife.” (M.13a)

“This disease is God’s work no one can stop it... This is God's will for us.” (M.17a)

“Death and life are in Allah's hands. We can't object to that.” (M.11b)

Participants also believed that God cures all diseases and illnesses, whether acquired or obtained, and regardless of the severity of the disease and the stage the patient was in. Participants used some quotations from the Holy Quran to support their believed, for instance:

“I have strong faith in God, that this is what God need us to go through in this life. It is our destiny... Everything in this life is planned and sent from God.” (M.1a)

“I believe strongly in God... I believe that one day God will cure her because God loves her and all children... It is just a test for us in this life... God can totally cure her one day, I believe in that.” (M.7a)

Some participants cited statements from the Holy Quran as evidence that Allah is the only one who is capable of curing, supporting and blessing people with health. However, people needed to have strong faith in Allah and comply with the recommended treatments and the required medications, as one father stated:

“I have strong faith that Allah chooses me for this purposefully and Allah will enable me to cope and give me strength in this. You know in the Holy Qur’an, Allah said, ‘And if Allah should touch you with adversity, there is no remover of it except Him. And if He touches you with good - then He is over all things competent’ [The Holy Qur’an, Al-’An’am. 17:7].” (F.3c)

“What should I do? I give my child the daily medication and I take him to blood transfusion regularly but I know it is all in Allah’s hands...you know in the Holy Quran, Allah said, ‘And when I am ill, it is he who cures me’ [The Holy Qur’an, Ash-shu’arā’. 80:19]. The Poets...I’m sure one day Allah will cure him.” (F.10b)

B. Religious practices

Participants in the interviews reported that their experiences caring for children with BTM transformed their life and had a great impact on them. They observed many religious duties in order to assist themselves and their children to adjust to the new family situation. Parents carried out different religious rituals, such as meditation as part of their daily prayers, and frequently reading chapters from the Holy Quran. It was also apparent that some parents were more positive or resigned than others and expressed more enthusiasm in performing these religious duties, as well as other life activities. For example:

"I read every day part of the Holy Quran. I pray and cry at night to Allah to cure him [silent for seconds]... You know what I did last week in Ramadan [fasting month]? I sat with my son after I finished my prayer and I asked him to repeat after me the healing prayer... I know Allah loves children and listens to them because they are honest and pure... Last year I asked his grandma when she went on pilgrimage to Mecca to do a 'Doa'a' [mean praying], prayer especially for God to cure him." (M.11a)

"I spend days and nights crying, and 'til now I keep crying every now and then... Before a few days in Ramadan I was praying with him and I told him, 'you yourself pray to God'... God loves children and listens to their prayers." (M.13a)

"I'm calmer when I'm in prayers and doing 'Doa'a'. It was relieving... makes me feel more strong, you know what I mean? God listens to you and knows about you and that makes me happy because God will help me, if I ask or not... All we need is strong faith in God." (F.3a)

Some parents used holy water from the 'well of Zamzam' in Mecca, in the hope it could assist in the treatment process and even lead to a cure. It is worth mentioning that some participants used Zamzam alongside the chelating therapy to decrease the level of accumulated iron in their children's body, as these examples illustrate:

"God cures all types of illnesses, I do believe in that, and because of that I bring him 'Zamzam' [holy water from Mecca] and I give it to him in the early morning every day for around three to four months... A friend of mine said 'Zamzam' is good to decrease the blood iron level, he used it with his son." (F.9a)

"I went on a pilgrimage. I visited Mecca and I prayed many times to have a healthy son, a brother to A.A [Initial of her son] and to cure A.A. from his disease, and I do believe that will be soon, Inshallah. I give them Zamzam daily." (M.6a)

Participants in the interviews showed that having children with BTM impacted on their attitudes and behaviours. For instance, some parents started to behave more religiously, not only towards their family members but also towards their community in general. Parents become more attached to the concepts of forgiveness, alms-giving, calming, helping others and being good citizens, as expressed by one mother:

“Since we had our son with thalassaemia, we have changed a lot... It is something inside you that changes... It changes your spirit... My husband and I agreed to increase the alms-giving, to give ‘Zakah’ yearly to help the poor, ill and the needy... And I asked my husband to put ‘Sadaqa’ [give money for charity and needy people] in the Mosque at Friday prayers... That means giving some money to the poor people you know... If you help others Allah helps you in return... When you do it for God, always God rewards you.”
(M.5c)

Parents often reacted positively to bearing and enduring the pain which is a part of their experience of caring for their children. They have the attitude of not complaining to others about their situation, which are culturally and religiously considered unacceptable behaviours. Furthermore, parents tended to be long-suffering and made sense of the situation by changing their behaviour. They preferred to keep calm and silent, bearing in mind that illness is something from Allah and as such, everyone is obliged to accept it:

“I prefer to keep silent, I do not complain to anyone... I know that only Allah knows my intention and what I have... It is not good to keep talking about it... My husband also told me, ‘do not complain except to Allah’... When praying you can ask Allah all what you want... But not complaining to people because they cannot help you... Traditionally, we say, ‘To complain to anyone is humiliating except Allah’... You know what I mean. I stopped complaining to friends and relatives as it will not help. Only Allah can help us.”
(M.4c)

6.6.2.3 Sub-category 2.3: Satisfaction with

In this sub-category, the participants expressed their satisfaction with the health care services their children with BTM received in the department. Furthermore, participants showed that they were happy with the premarital tests which launched in Jordan for any engaged couples. The data showed that most of the participants were happy with the social support from their families and friends, and with the social activities which helped them to cope with their situation.

A. Health care services

The participants were satisfied with the availability of current health care services provided for their children in government hospitals, such as the free health insurance and conservative treatments. According to the following participants:

“Yeah, it is an excellent service. We had the health insurance from the time she was diagnosed at the hospital. They offered everything, and most importantly the blood because... she is dependent on blood transfusion now, the medication and all the tests and treatments she might need... No, we didn’t pay anything at all.” (M.6b)

“Yes they are very good. They are organised, the blood transfusion is on time and everything is clean. Sometimes there is a meal available at lunchtime.” (M.13a)

“The service is good. Everything’s available, the blood and the medication.” (F.3a, M.7a, F.14a and F.6a)

“Wallah [swear to God] they are doing their best in this department. I’m very satisfied with their services.” (F.1b)

“The blood units for transfusion are always available. We have no problem with that.” (M.13b, F.5c, M.9b and M.18a)

Some participants were satisfied with the care provided in the departments, including the availability of both nurses and physicians and quality of the care provided, as the following participants claimed:

“The health care provided and the staff are very good. They care for our children... they did many blood tests and give them the blood on time. They are really good... We don’t have problem with it.” (F.2a)

“The service is ok... The staff are always busy but they are good. They have the sense of caring, and they’re very cooperative especially, when I come late or when I miss blood transfusions. They give me a reminder phone call.” (F.9a)

“The nurses are very good but very busy because there are many children with thalassaemia. You have to wait to talk to them.” (M.3C)

Other mothers claimed:

“Yes, the medication is always available, and I also asked her physician to give her medication because she was not gaining much weight.” (M.17a)

“The nurses are good... They helped me with registration when I came here the first time, I was totally lost... Each time I come here they were available, although they look busy, but we chat sometimes.” (M.16a)

“The nurses are good but always busy and overloaded... They work all the time... I watch them coming and going all day... You don’t find time talk to them.” (M.6b)

B. Pre-marital tests

Parents showed their support for the pre-marital counselling programme which was launched in 2004. Parents considered the pre-marital tests an excellent chance to prevent

having more children with BTM, to prevent engaged couples from having to live through the same experience, and to allow anybody to determine their carrier status:

“There is no excuse for the unmarried couples now... You know what I mean... Anyone can now know if he/she is a carrier of thalassaemia or not. The test was free, they don’t have not pay anything even if they want to repeat it, which is good for them ... I wish it had been there when I got married.” (M.3b)

“Yes, I’m happy about the tests. At least my children will not suffer the same way I did.” (M.11a)

“Yes, that was good... These days everybody has the chance to know if he/she is a carrier or not... Not like us.” (F.1b, F.10a and M.1c)

“Sometimes I worried about my children, but I said to myself, no need, there are many premarital tests available these days so anybody can checked and know if they are carriers or not.” (M.16a)

The participants were satisfied with the health and social activities that were provided to patients with BTM and their families. Most of these activities were organised by the Jordanian Thalassaemia and Haemophilia Society (JTHS) in collaboration with the JMoH, and supported and funded by community organisations and non-governmental organisations:

“Each year in ‘Ramadan’ we receive an invitation for breakfast... I used to attend, it was really good... For me it is a chance to meet parents, and the kids were very happy as they received good food and gifts to celebrate ‘Eid-Al-Fitr’.” (M.6b)

“I always encourage my son to share in such activities... it really helps him to socialise.” (F.7c)

"I attended the last meeting with the Jordanian Thalassaemia and Haemophilia Society which helped me to meet mothers with children at the same age as my son, and we still communicate sometimes." (M.2c)

C. Social activities

Parents stated that the organised activities were connected with, but not limited to, the 'International Thalassaemia Day' celebration, which is also organised yearly, and national conferences and workshops for children with BTM and their families. Parents stated that they were aware of most of these activities, which they also considered a source of knowledge on up to date therapeutic methods, techniques and new medications:

"They do parties or things like celebrations on that day... Yes, it was good. Everybody met, talked, ate food, then we went back home... I'm happy for the children, they have fun... It was a nice break from the daily routine." (F.1b)

"They taught me how to insert the needle, I had never ever in my entire life handled a needle. I was terrified at the beginning but now I'm used to doing it." (M.4c)

Another father said:

"I read their announcements in the sitting room and at the end of the corridors... Yes, if I have time I will go they usually celebrate on this day." (F.3b)

In addition, parents welcomed the opportunity to meet socially with other parents which the organised events provided:

"I met her in the last workshop... We talked for hours... This is why I like attending such meetings." (M.3b)

"I like to attend such activities... We meet and talk... Seeing other mothers makes me feel that I'm not alone in this... You know what I mean?" (M.18a)

Attending the organised activities was considered a social support for parents and their children, as they met people living with similar experiences, shared their experiences and discussed issues:

“I meet mothers with their children whose conditions were far less serious than my son’s, and mothers whose children’s conditions are more acute than that of my child... That was encouraging for me, that my son can grow, live more and become an adult like them... I told him, ‘See, you are not the only child, there were many children who look like you’.”
(M.9c)

“Yes, in that meeting I met a mother. She showed me her son and she told me how she struggled with him to take the medication... I said in my heart, oh thank god my son is much better.” (M.11c)

“I met her in the last breakfast during Ramadan and we are still in contact. She had boy and girl diagnosed with thalassaemia at the same age as my children... That surprised me, she lives in the next flat to her family in laws and struggled with them like me... Oh dear, I felt like we both suffered with this disease.” (M.13a)

The only negative responses were at the BBHC in Al-Zarqa, where some participants expressed their unhappiness with the health centre structures, the access to the building and the size of the departments:

“They moved us to this building. It was far away from the city centre, if you don’t have car you have to take two transportations... As you can see, they located the department on the third floor with no lift... I swear to God I was breathless when I used all these stairs... I do not know how my son, who has anaemia, can do it.” (F.7c)

“The department is located on the third floor... How can disabled children come up here when there is no elevator in this building? ... Can you imagine! ... All the parents have to

carry their children up the stairs... Why they don't locate it on the first floor? The space is too limited: only two treatment rooms and the doctor's clinic." (F.8c)

"For me it's easy because I have a car and I can leave my business to drive them to the centre for blood transfusion, but for other families it is really hard... You need to take two transportations or hire a taxi which can be expensive." (F.3c)

Some participants were not happy with the amount of time of the paediatrician in the BBHC spent on duty, as he attended the clinic for only a few hours a day. In addition, participants complained that some required blood tests were not performed in the centre so they had to keep moving between the centre and the hospital during the day if any blood tests were ordered:

"If you need to see the physicians you have to wait... I have been waiting for an hour... The services were unacceptable... If you need to perform any blood tests, you have to do it in the main hospital and come back to the centre... You know what I mean... It is all money and time consuming." (F.8c)

The limited space available in the BBHC was mentioned as one of the issues in the participants' interviews:

"The centre is full of women who come with their children and there is no space for men. Usually I sit here and close the curtains... It's really unacceptable, what should I do with women in the same room?" (F.4c)

"I can't bring him with me because there is not enough space... You see sometime they place two children in the same bed." (F.8c)

"The centre is too small, only two rooms. I prefer to come early." (M.1c)

D. Social support

Most participants were satisfied with the social personal support they received from partners, family, friends and relatives. For many participants, this was considered to be the basic and first line of support they received. Participants communicated and chatted individually and within groups as they expressed their feelings and talked about their concerns and experiences. This social support helped parents to adapt positively to their situation. It also assisted some in overcoming the impact of the social stigma they faced.

Couples supported each other, expressed their feelings to each other and in some cases made plans to share the responsibilities, which was one of the techniques used for coping between participants. This was reflected positively in parents' relationships as a couple:

"I was crying in my room, then my husband sat beside me and calmed me... We talked and discussed our son's therapy... He told me about the details of thalassaemia therapy and that there is a cure method of conducting an operation... We agreed to go ahead with donor matching tests... I felt his talk relieved me and gave me some hope that my son will be cured one day, but to be honest I'm still hesitant about the operation." (M.1c)

"This is what God needs us to have... He keeps telling me not to worry and saying 'Alhamdulillah' [Thank God], this is our destiny." (M.7a)

"He is always there for his son. Actually I feel they are like friends... He also helps me a lot and this makes things much easier for me... Oh dear, I don't think I can manage without him." (M.5a)

"I love my husband and he also does. We are connected and care for each other... I don't think I will leave him people as advised me to do... No, I'm happy with what we have even though it is a boy with thalassaemia. This is our destiny, we have to face it together." (M.8a)

“His family asked him to have a second wife after our son was diagnosed with thalassaemia but he told them, ‘I care for my wife and I don’t want leave her to face all this alone’.” (M.1a)

This study showed that mothers talked more than fathers to their family, friends, neighbours and relatives to express their feelings and seek support, even from their relatives and in laws, as the following examples explain:

“I was with my mother in law... I was so frustrated... She stays with me in hospital... She is really like my mother, listens to me and is always there for me... I do love her... Yes, she always asks how I’m doing and my child, especially when he’s received blood.” (M.6b)

“I phoned my family in law and when I told them the bad news after 30 minutes they all came to support us. It is not easy... We were all shocked and surprised. My cousin said, ‘Inshallah I hope it’s not a serious disease’... They started talking to us and calmed us because my husband and I were panicking... It is not easy for us to know that our son has thalassaemia... Dear it is a really hard experience.” (M.8a)

Friends were considered important to the participants’ social support system. Listening and spending time with friends helped the participants to cope and adjust to the unique experiences they faced, as these mothers claimed:

“We have been friends since high school... I do not talk to anybody except her... She is more than a sister to me... She lives nearby but my family are far away. When I’m feeling sad I visit her and we talk for hours.” (M.9c)

“When I’m upset I call her and we talk. She is a good friend to me.” (M.18a)

Support from family members and regular contact with other parents caring for children with BTM provided support and played a major part in the coping mechanisms adopted by parents, as these participants claimed:

“I live in Ajlun ⁷ and my family in Irbid. I visit them after I have been to hospital with my daughter for blood transfusion in Irbid... I stay overnight and leave the next day... This is my only time to talk to my mum... I’m the only female born in my family, I have no sisters... My mother is the only person I trust and talk to. She is my mum, my friend, my sister and my world... It is hard to handle this alone.” (M.17a)

“I talk to my mum. She is my best friend she always help me.” (M.13a)

“My sister lives far away but we talk for hours when I need her.” (M.7a)

Neighbours and relatives were also considered as part of the social support available to parents. In the interviews some participants received their only support from their neighbours, especially those who had lived through the same experiences before.

“She saw me often during my trips back and forth to hospital, she is my next door neighbour... Her son died of thalassaemia two years before... I did not know that ‘til one day we had a talk at the bus stop and she told me. Since then we have become closer... She told me how she cared for her son for years and years and she said, ‘I know just how you feel’... She is really good, often passes by to ask about my son, advised me, we spend hours talking... Crying together... Laughing together... She is really... really... good, I always pray for her late son.” (M.17a)

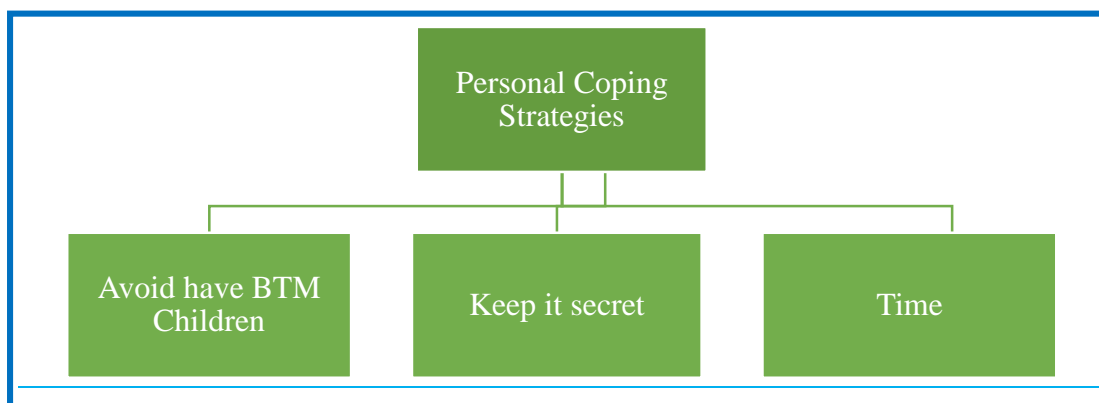
“We used to go and come together from hospital and now she is like my sister... We talk and sometime we cry. [Smiling and giggling] She helped me a lot... She is not only my neighbour, she is my really like sister.” (M.8a)

⁷ Ajlun: A hilly town in the north of Jordan, located 76 kilometres (around 47 miles) North West of Amman. (Jordan departments of statistics, 2013)

6.6.3 Core Category 3: Personal Coping Strategies

The data showed that parents used various coping strategies in order to reduce and tolerate the demands of caring for their children (see figure 10). In the interviews, participants showed that their coping styles ranged between cognitive, behavioural and emotional. Mothers and fathers revealed that they used various personal coping strategies, which were designed and framed by their cultural and religious beliefs. This core category is composed of three sub categories: ‘avoid having more children with BTM in the family’, ‘keep it secret’, and ‘time’.

Figure 10 Core category 3. Personal Coping Strategies



Source: Author (2013) *the data in the figure was generated from the research findings.

6.6.3.1 Sub Category 3.1: Avoid having children with thalassaemia.

Parents stated that knowing about their status as carriers of the thalassaemia gene and caring for a child with BTM were the two reasons that stopped them having more children in the family.

“I told my wife I don’t need more children at all... She discussed the antenatal tests, how they are available these days many times... Then I told her that even the idea of antenatal tests is unacceptable... I’m done... There is no room for this discussion... I was so upset.”

(F.9a)

“The first thing I asked my husband after my daughter was diagnosed is how to prevent pregnancy and stop having another child with thalassaemia.” (M.6b)

“Yes, it is not like before... Our sleeping nights are now different [sleeping nights: their sexual relationship]. I really became scared of pregnancy. I try hard to avoid it.” (M.5a)

Participants in the interviews revealed that they tried various methods to not have another children with thalassaemia in the family including changing their marital status, abortion and family planning. Participants used various family planning methods to prevent further pregnancies, such as oral contraceptives or the Intra Uterine Device (IUD).

“The difference between my second born and the third is six years. I was afraid to have another child with thalassaemia.” (M.14a)

“It was not easy. I faced many challenges with my husband and my family in law. I was totally shocked, upset and stressed... You know that the feeling that your husband doesn’t need you to be the mother of his children at all... I felt like he rejected me... He told me, ‘I don’t need children anymore.’ He refused for me to get pregnant at all ‘til now. We have many problems because of this and ‘til now I’m still using the loops [IUD].” (M.13a)

“I told her that we have to go for the tubal ligation operation. We do not need more children, we don’t need to struggle with another child with thalassaemia.” (F.6a)

“I have three children with thalassaemia major and now I have twins... They are healthy... We do not need more children... We did the tubal ligations. We don’t need more risk to have another child with thalassaemia major in the family.” (F.15a)

“She used helix [IUD], but because of the bleeding the doctor advised her to use the pills [oral contraceptive]. I think there is something going wrong as she discovered she is pregnant.” (F.10c)

The data showed that some parents' coping strategies could be in conflict with their partner's needs.

"I do not want to get pregnant... My daughter is only two years old... I used helix... But to be honest with you, my husband has asked me many times to remove it. Because we have three girls, ah [long sigh], he need a boy... I told him, 'let us wait at least 'til she is five'... But we quarrel a lot for that... He did not accept it and the problem is that my mother in law support him and they keep making comments and gossiping about me. [Silent for minutes]. It is not easy." (M.7a)

A. Abortion

Participants perceived abortion differently. Some mothers used abortion as a last resort against having more children with thalassaemia major; others did not accept the idea of induced abortion at all, considering it religiously and socially unacceptable. The data showed that few couples used abortion as a method of avoiding having another child with BTM. Some participants stated that after the positive result of the CVS confirming that the unborn child had BTM, they decided to terminate the pregnancy after counselling.

"We did the test twice and they confirmed to us it was an affected pregnancy, and we did not have any other option... It was a hard decision but we had to go for it. [Silent for a moment]. At first my wife refused, and then I consulted many religious leaders in the community. Only one gave us permission to go through abortion, because the pregnancy was still in the early gestational weeks." (F.12a)

"Yes... My husband asked me to have an abortion but I told him I don't want it. Abortion is forbidden... It was an unplanned pregnancy and we didn't know if it was a baby with thalassaemia... Oh dear, we quarrelled a lot... He believed that abortion is not forbidden if the unborn child has thalassaemia, but for me, no, I do not believe in that. I asked many religious leaders and they said, 'no, it's not allowed in cases of thalassaemia.'" (M.7a)

“There were many fatwa from different religious leaders about abortion... Some said it can be done in cases of thalassaemia and others said, no, it’s only allowed before 40 days. It was confirmed of having thalassaemia or any problems. To be honest I was so confused... I phone called them after I watched a television programme in Ramadan, then I took my decision.” (M.8a)

“The prenatal tests take a long time and after that you have to go through abortion, which I refused to do because it is forbidden religiously which is really so stressful... It is awful to wait for the unknown.” (M.6b)

“I can't do it. They told me it is forbidden to abort my baby... I don't want to do a big sin in my life like this... No, no, I can't do that.” (M.13a)

The mothers who went through the termination expressed enduring feelings of sin for killing their unborn baby, stress for doing a socially and legally unacceptable procedure, and worry about the outcome of the termination. In addition, they also expressed fear of going through this experience again. The two mothers described the termination as unwanted and stressful experiences. According to the following participants:

“It was awful and stressful... Very hard for me to go through that. I was upset and stressed. I keep praying to God for forgiveness. [Head down and silent for a moment]. It is not easy, the feeling of sin in following me all time. I don't know why.” (M.5a)

“She was very terrifying and so stressed and the first time she refused... It is not an easy decision for both of us. The feeling is so bad... Like you have sinned by killing your child... Which God gives you” (F.12a)

“No... I hope I will not do abortion again... It was an awful experience, the feeling of sin and pain is still in you... When I think back, sometimes I wondered why I did it... You know that bad feeling... When you feel just upset and questioning yourself.” (M.1c)

Other participants still religiously and culturally debate the issue.

“She discovered that she was two months pregnant. We visited the physician and we asked for an abortion... We did not want to have another child with thalassaemia... No, we did not carry out any tests... We reached the level where we even did not want to check. We were already shocked and stressed enough, we just do not want any more children... Even though the whole family and some of my friends objected to our decision.” (F.1a)

“Both of our families disapproved our decision to have an abortion but what we can do? We don’t have any other options.” (F.12a)

B. Change in marital status

There were two participants who got divorced as a result of having a first born child with BTM. Participants used divorce as a coping strategy to end their relationship with the carrier partner, and usually they re-married and started a new life because of the risk of having another child with thalassaemia in the family. For example:

“She was my cousin. We had our first child after a year of our marriage. He was diagnosed at the age of eight months and since that time the problems were never ending. We fought almost daily and we ended up getting divorced. I did not want it to happen because of our sick son but after my family convinced me I did it. She left my son and remarried. He was only twenty months and I had a full time job. He was just a baby and I have no time to care for him. All my friends and family advised me to get re-married. The second time around, I carried out the premarital test to confirm that my second wife is free, not a carrier, because I know that I’m a carrier... I do not want to repeat my first experiences.” (F.4c)

“We had really big problems, and we fought many times. My brother had eleven boys and the other one had six boys, and I have only one boy with thalassaemia. All my sisters and

friends of mine insisted on me to have a second wife and to be honest with you, yes, this what I did. I don't have any other option... I don't want to have more children with thalassaemia.” (F.1b)

“He neglected me and his son, we had a clash every day... I moved to my family home because he accused me of being the one who brought thalassaemia to our son and he keeps blaming me... After a few months he divorced me.” (M.3b)

“After two years of caring for her child with thalassaemia she asked for divorce and refused the legal child custody because she wanted to get remarried and travel with her new husband... She phones them once every two or three months but not on regular basis, no.” (M.4c)

Another mother narrated her story about the impacts of thalassaemia on her marriage and how her life changed because of having a child with thalassaemia:

“We were not related before we got married but after my son was diagnosed with thalassaemia, because of my husband's shock he didn't talk to me. I have been caring for our son alone...He neglected me and we had a big clash. I left him and moved to my family home because he was accusing me of being the one who brought the disease to our son after a few months he divorced me ...I didn't asked for any compensation all I wanted was to have the legal custody for my son after two years I remarried and till now I'm caring for my son, he did not meet his son for the last eight years he even did not bother to ask about him.” (M.8b)

Two participants stated that as a result of having children with BTM their husbands have second wives. In the two cases, the husband did not divorce the first wives, and there was one case where the wife asked for a divorce when her husband took a second wife. It was noticed that the number and the gender of the affected children with thalassaemia were

major factors when the decision was made by the couples to end or change their marital relationship.

“In the first place he refused to do the blood test... He accused me of being the one who brought thalassaemia to my son and daughter... After I had my daughter, the last born, he started behaving strangely. He did not talk to me a lot, he was always busy, and my mother in law told me that he was planning to get a second wife... The second born is a healthy boy but my husband wants more healthy children... He told his fiancé that he is free, not carrying any genetic disorders, and I was the only carrier who brought the disease to the family... I showed her the blood tests through my mother in law, but she didn't believe me and they got married.” (M.2b)

6.6.3.2 Sub-Category 3.2: Keep it secret

Some participants tended not to tell anybody, even their own family, about their child being diagnosed with thalassaemia because it is an inherited genetic disorder. Parents preferred to keep the matter secret or limited to few close people, and felt that this helped them to avoid the social stigma and its implications, and to cope better.

“Nobody knows that my son is diagnosed with thalassaemia.” (M.8b)

“We agreed, me and my husband, to not talk about it to people. We only informed my family in law because we lived in the next apartment... My family know she is sick but they do not know it is thalassaemia.” (M.13b)

“One of my sisters in law has a son with thalassaemia. They didn't tell anybody about it, but I saw them in the thalassaemia department many times... You know, we are in the same department, she cannot hide it anymore.” (M.8a)

“Nobody knows that my son has thalassaemia... Most people know that my son is sick and he needs blood every now and then.” (F.6a)

The reasons given by participants who did not disclose that their children have thalassaemia were that it would socially stigmatise them, which could impact the whole family, not only the child with thalassaemia. Parents prefer to keep it secret as a way of coping and decreasing the possibility of being under social pressure.

"I don't like to talk about it or complain to anybody... I preferred to keep it on my own... You know, in our community everybody gives you that pitying look... which I can't bear."
(M.9b)

"Some people socially stigmatise you and the whole family. Because of that we did not want to tell many people about it... None of our relatives or neighbours know about our son and daughter with thalassaemia. It's just our both families." (F.1b)

"No, no, no, we do not talk about it... None of our relatives know that our son has thalassaemia. We have three daughters at the marriage age, and that could impact on them. You know how people these days look at you if you have any genetic disorders."
(M.6b)

"Even though my brother in law is educated, he instructed his wife to not say that his daughter is a thalassaemia carrier, not even to us. He doesn't want his family to be socially stigmatised." (M.8a)

Fathers revealed that the number of cigarettes they used daily had increased since their child was diagnosed with BTM. This helped them to calm down and cope with their stress. Most fathers stated that this was the case, especially in the first years when they had a high level of stress after their child was diagnosed.

"I used to smoke one pack daily but since that event in the family... Yes, now I smoke more, up to two packs and sometime three packs per day... I know not only my wife is

angry but also my mum, but what should I do? It is me, when I'm not feeling ok, I smoke."
(F.10a)

"Yes, smoking was increased at that time... To be honest, I noticed myself how heavy a smoker I became. [Head down]. I'm not happy, so stressed and depressed." (F.9a)

"No, I don't like to complain to anybody. I love to keep everything for myself and to the cigarettes... Yes, I'm a smoker... About one to two packs a day." (F.6c)

"I used to smoke occasionally, but now I'm a smoker... It was not easy for me to discover that my three boys have thalassaemia. I had never heard about thalassaemia before, can you imagine? It was shocking news. [Head down and low voice tone]. I could not believe it. I have three children with thalassaemia and guess what? They were all diagnosed within a year, one after another." (F.14a)

Some children with BTM were also influenced by their parents' coping strategies:

"He started smoking last year and this annoyed me a lot. I told him, 'you are already sick' but he did not listen to me... He said everybody smokes, not only him. Even his dad."
(M.2b)

"I told her many times not to cry in front of her because when she saw her mum crying she sat beside me and cried." (F.3c)

"When he saw me praying, he started repeating after me and moving his hands exactly the way I did." (M.13a)

6.6.3.3 Sub-Category 3.3: Time

Time was mentioned in the interviews as one of the participants' coping strategies. Over time, parents coped much better with their situation.

“From time to time things change a lot, and you know, every time you come to the department you learn something new.” (F.3a)

“I saw children with thalassaemia for the first time of my life when I visited the thalassaemia department. They look different... There I was, shocked, wallah [I swear to God]. I did not realise that I was crying... Tears just flowing down my face... I was really very upset... One mother said to me, ‘don't worry, you will used to it with time. This is because it is your first visit.’ ... She is right, I am used to it now.” (M.11a)

“With time things become more clear and organised for the whole family.” (M.1a)

The interview data showed that most participants described the first year of their child's diagnosis as the worst and most stressful time. Parents in this year have to deal with many issues, such as the frequent hospital visits for their child's blood tests and transfusions, learning how to insert the medication, especially the iron chelation pumps, and facing the fact that they were carriers.

“Yes, the first months were the most stressful. My wife and I were worried about our new born and ‘A’ [initial of his child with BTM] and we do not know how to manage. We have to send him to my mum. My wife was very angry and upset and she was crying in each time we went to the hospital. They did many blood tests because they misdiagnosed him. It took them up to five months to confirm that he has thalassaemia. It's not easy at all but now things are better. He is much older and I can work with him.” (M.5b)

“I was in hospital almost every day... Oh dear, it was very hard. He cried when they did blood tests and I was crying with him... No, no, things were very hard for both of us, we were shocked... It is not expected. Oh dear, the first year was the hardest but with time we handle it much better.” (M.11c)

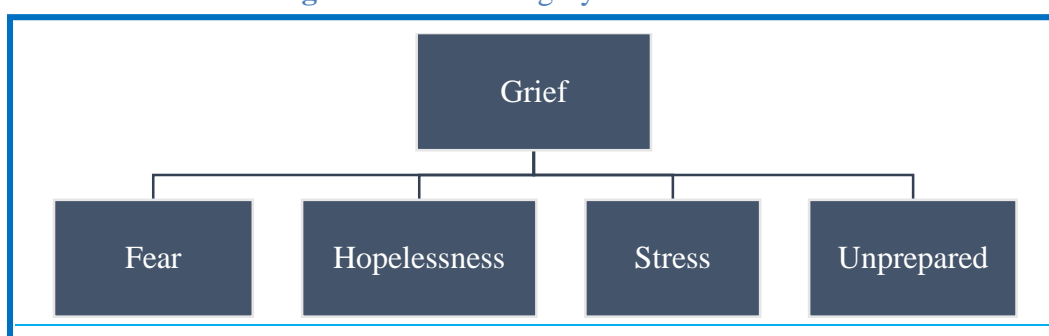
“It took us around a few weeks to settle down, and then things in our house went back to regular life.” (F.3c)

“You know, the years pass and you start feeling and being ok... I have been coming to hospital now for five years. It has become easier for me and also for G [initial of her son]. The first six months are the worst.” (M.2c)

6.6.4 Core Category 4: Grief

This core category is composed of four sub-categories: fear, hopelessness, stress and being unprepared (see figure 11). These categories represent participants’ feelings.

Figure 11 Core category 4. Grief



Source: Author (2013) *the data in the figure was generated from the research findings.

6.6.4.1 Sub-Category 4.1: Fear

Participants in the interviews expressed their fear of many issues related to having and caring for their children. Some mothers expressed that their fear focused on the unplanned pregnancies and having a second child with BTM, which for them is the ultimate fear, as these examples show:

“I did not know that... I was shocked. I have been busy with my son [the first child diagnosed with BTM] at that time and when I missed my cycle I did the test and I discovered I was pregnant... I was really terrified. The first thing that came to mind was

that the baby would have BTM. I didn't plan for this pregnancy, it just happened... What can I say? Alhamdulillah [Thank God].” (M.1c)

“I was terrified of getting pregnant because I do not want another child with thalassaemia. Oh God, I had this fear for the whole pregnancy.” (M.2c)

“We are afraid that the second pregnancy will also be thalassaemia. Because of that we did the abortion.” (F.1b)

“I was terrified that my unborn baby would also have the same problem.” (M.6b)

“Having a child with thalassaemia makes you live in continuous grief and fear. [Silent for a moment]. You have the daily medications and lifelong blood transfusions and you are lucky if your child does not have some complications, which is rare.” (M.4c)

Participants feared the death of their children. Many parents had witnessed the death of patients with BTM in the same department, in some cases friends of their children. As these examples show:

“He was close friend to the late K, God bless his soul [K is a child with BTM who died at the time this study was conducted], and that makes me more worried and more afraid about him. He has no other friends, all of his friends are from here [thalassaemia department] ... He does not communicate with other children his age.” (F.5c)

“I know they do not live for a long time... What should I say? [Silent for a moment]. I don't know what to say, but thinking about that scares me a lot.” (M.17a)

“It's hard when you witness the death of your son. It's more difficult than witnessing the death of your dad... I learned a lesson from my dad when my brother died of cancer and I saw how it's really hard for him to cope and deal with the sadness. Because of that, when I think I could also lose my son I become like a crazy man.” (F.10c)

“You know how stressful that is... Watching your child die slowly and you can do nothing.”
(F.7c)

“I saw him many times crying on his own and this made me feel very angry and upset. He was asking, ‘why me? Why am I different? Why am I is only one who will die soon?’ I tried to talk to him and support him but sometimes it was too difficult for me. [Silent for a moment]. It is heart breaking... Do you know what I mean?” (F.5c)

“It's awful. When you think he could die soon, it's very hard... Can you believe that they told us children with thalassaemia usually don't live long? They die around the age of 20, when they start enjoying their life... It's hard to know that your son, the one you care for all these years, could die at this age. I could not accept this idea at all.” (M.5a)

“I cry all the time... They told me that he could die soon. Children with such a disease don't live long.” (M.11c)

“They told us he is chronically ill and will receive blood for the rest of his life... [Silent]. When you hear that about your son... I felt totally down, stressed, and scared. The first thing to come to my mind was that he could soon die from all this blood.” (M.1c)

“Children with such types of disease in their blood do not live long. They reach maximum up to fifteen or maximum up to twenty, then they start changing and die. [Silent for a moment].” (F.6a)

Parents feared BTM complications and the changes in their children's physical appearance, such as skin colour, facial pigmentation and body structure.

“The first thing that shocked me on my first visit to the thalassaemia department was seeing the patients with facial pigmentation, protruded abdomens. They look totally different... Oh my God... It was really shocking... When I thought that my daughter would

look like them, I genuinely cried... I told my husband, 'we have to do the bone marrow transplantation as soon as possible'. I cannot imagine her being like this... To be honest, I wish I had not seen them. I think they should separate patients based on their age and not keep them all in the same room... What do you think?" (M.13b)

"We regularly ask the physician about the impact of the thalassaemia and in which year his skin will change. We saw many children in the hospital... Oh dear, they really look different with time." (M.7a)

"I did not want my son to look like them... You know, their head structure is different, their skin colour and there were many pigmentations in their faces... I did not expect the disease do this to them. I felt so sorry for them." (M.8a)

"Their physical appearance looked different... Their body structure is smaller than their peers and you see their upper jaw protruding now which is not nice at all for the girls. [Sad and low voice]. This drives me crazy. I don't want that appearance for my child." (M.13a)

"Lately she has refused to come with me to visit our relatives. She has become too shy... Yes, I think because of her face. I saw her using the mirror a lot... She is around thirteen. You know how girls at this age become so sensitive to their skin, hair and their general appearance... I talk to her but to be honest with you I'm still worried about her." (M.16a)

"I gave her my mother's name 'A' [initial of her daughter] because she has her eyes. We expected her to look like her, very beautiful... But now with the iron chelating everything changes. See how her face looks and she has become skinnier." (M.2b)

Some parents also showed their concern toward their children's growth and developments.

"He has some brown colour in his face. I am really concerned but to be honest what worries me more is that he looks smaller than his brothers..."

Shorter than any other family members... Some relatives treat him like the youngest and this annoys him a lot. He keeps telling them, 'No, I'm the oldest'." (M.9a)

"I told my sister, 'he did not grow up like his brother'... He is now thirteen but he looks nine years old... One of the teachers did not believe that he is thirteen. We have to explain to the school teachers about his condition." (M.13b)

Some parents felt that they had lost the physical appearance and identity of their children due to BTM condition as quoted.

"Sometimes I think how she will look, if she is not having all these changes from thalassaemia ... That makes me feel really very sad, upset and cry sometimes." (M.7a)

"Yes, sometimes I feel like I wish to know how he will look... I mean without these changes in his face and teeth." (F.9a)

"No, I don't wanted her to be like the children we saw in the thalassaemia department. I was shocked ... They look different from their mothers. I need her to be exactly what she is meant to be... I don't know, but that upsets me more and more with time." (M.13b)

Some mothers expressed fear about the termination of their pregnancies affected with thalassaemia. Mothers stated that abortion is religiously forbidden, and socially and culturally it was unacceptable in Jordan for them.

"No, no, no... I could not even think about abortion... You know, in our society and religion it is a big sin to kill your unborn baby... I'm afraid if I did it Allah would punish me and my family in this life and also in the afterlife... No." (M.11a)

"I wanted to be pregnant but I'm hesitating. I don't want to have another child with thalassaemia... I can't have an abortion... I don't know what to do." (M.13a)

6.6.4.2 Sub-Category 4.2: Hopelessness

Many parents felt that there was no hope that in their children's future they would be cured or have ordinary life like other family members. Parents stated that the thalassaemia disrupted their children's chances to continue with their study and work, or get married and have their own families. Participants felt that thalassaemia could haunt their children in the future.

"Of course there is fear that he may not be able to work or get married. [Silent for a moment]. I don't want him to stay alone." (F.2a)

"You know, I don't see her having any future with this chronic illness. She dropped out of school last year which means she has no work, and marriage is something impossible for her... She will always be in hospital with regular blood transfusions. This is the fact and I have to accept it." (M.9b)

"I don't expect that, she is girl and has thalassaemia... Study and work would not be appropriate... Not expected for someone in her situation to get married." (M.17a)

"I don't know what to say, but as they said, his situation is different. [Silent for a moment]. He could not live for more than twenty years. I really don't know. He has a heart problem and had two spleen operations because of the disease. [Sad and soft voice]... He has no future." (F.6a)

"No, no, no, I don't think he can work... I know that and I don't care about him having a job... I just wanted him to be ok, at least to stop taking the blood... I saw many children in these departments who died even after they had the operation, which is what worries me." (F.1b)

"I didn't see any future for him... They told me, 'patients with thalassaemia usually don't live for long as usual... Most of them die soon.'"

[Head down and slow voice for few minutes]. You know how stressful that is... Watching your child die slowly and you can do nothing.” (F.7c)

“I have seen many patients in the departments go through the bone marrow operation but they came back after few months for blood transfusion. I felt sorry for them... I do not want my son to go through all this for nothing.” (F.8c)

Participants had feelings of hopelessness regarding the possibility that their children’s situation could improve or change.

“Nothing’s in our hands. We can do nothing... We don’t have many options.” (F. 14a)

“Nothing’s in our hands to do, nowhere to go... We just wait... There is no hope for him to get back to normal.” (F.6a)

“This disease is different because patients have limited chances in life.” (F.6a)

6.6.4.3 Sub-Category 4.3: Stress

Parents expressed in the interviews that their stress increased with time. Stress levels differed according to various factors such as the child’s age, gender and order of birth in the family, as well as social and financial support.

“Caring for a chronically ill child is so stressful. Oh my God, it is so tiring... I was feeling bad, crying almost every day... He is only two years old and has to have a blood transfusion every two weeks... I’m not complaining, Alhamdulillah [Thank God], but I’m so upset, you know what I mean? But I don’t know.” (M.17a)

“You know, I can’t find suitable words to describe how I’m feeling... I do believe that no words can exactly express my feelings... Stressed, tired, frustrated, afraid, sad and upset... I don’t know.” (M.18a)

"You know that feeling... when you are feeling so sad and frustrated... Sometimes I cry. I can't handle all this stress." (M.1c)

"It is really hard. Very, very, very, sad and frustrated. You know like when you are so happy and excited for having a child then suddenly all this happiness was taken by knowing that your child has thalassaemia." (F.7c)

"I just want to live as much time with him as much as I can. [Silent for a moment]. I feel like I don't want him to go... You know what that mean? I know everybody will die one day, but I don't know what to say." (M.5a)

Some participants revealed mixed feelings towards their children.

"He was worried. He asked me many times to reassure him that the blood tests results for our last born is normal... He kept asking me, 'is this the final result? Will it not change in the future? Are you sure of that?'... Oh my God, he was so stressed'." (M.8a)

"It's really very hard to be describe. I don't know what to say... I'm not capable of finding the appropriate words to describe how I felt... [Silent for a moment]. You know, I was like speechless, suffocated, and breathless ...I was always crying. I could not even stand on my feet, I was shaking. I just sat on the nearest chair." (M.17a)

"I was totally shocked. I cried loudly on my way home. I walked like a crazy woman and all the people stared at me... I was panicking... I don't know how I reached my home... Yes, I was on my own... I felt like I'm suffocated. I could not breathe or talk, just cry and shout... It was the worst day of my life. I felt like I was about to die that day." (M.9c)

The nature of thalassaemia impacted on the participants' feelings and their emotional status.

"You know what broke my heart? When she looks pale, tired, powerless. Even she did not

play or move a lot like her sisters in those days... She looks fragile. I know by that time that she needs blood.” (M.17a)

“The idea that he have thalassaemia just upset me and made me feel so stressed [Silent for a few minutes]. I really feel sorry for him.” (F.9a)

“It was the worst news for me. I could not handle it. [Silent for a moment]. I was very upset... I felt that my legs could not hold me any more... I woke up on the clinic sofa. My husband told me that I fainted after crying and they put me on the sofa ‘til I came back.” (M.5a)

“I was very shocked, angry and upset... We decided we did not need to have any more children.” (F.1b)

“I was angry, upset and depressed for around one month after she was diagnosed... It is not easy for me but what should I say? This is our destiny, we can't object to it... I always cry.” (F.10b)

Some parents raised their concerns about the initial misdiagnosis and the delay in confirming the diagnosis of thalassaemia. Parents were unhappy with the time taken to confirm the diagnosis, which reached six months in some cases. For example:

“It took more than four months to confirm that she has thalassaemia. Can you imagine that wasted time? Each lab revealed different results... And every time we got more confused... She was misdiagnosed many times. Listen to their story, they said it could be jaundice, then it was iron deficiency anaemia, and she took iron supplements. Finally, after three months they said no, she has thalassaemia. It is really frustrating, isn't it?” (M.5a)

“The health care centre referred us to the hospitals because they did not know what caused her anaemia. Then the hospital said, ‘her case is normal but because her blood is

not improving'. They referred us again to another hospital. It took them three months to confirm that she has thalassaemia and that was after we did the blood tests, me and my husband." (M.17a)

Some participants also felt disturbed and unhappy with the quality of their child's life, as this mother stated:

"It is lifelong suffering... You are in pain every single day of your life without any positive promise of a total cure. We have been waiting for more than four years to do the bone marrow transplantation and we are still waiting... Can you believe that our number on the waiting list is 70 and this number has not changed for all the last year? I do not know if I can wait for much longer... I'm so stressed." (M.8b)

Some parents still questioned why this happened to them. Other still do not understand why they were the only ones in the family having health issues with their children. Participants' feelings of frustration were clear during the interviews.

"Why only me in the whole family?" (M.3b)

"Why my son?" (M.8b)

"All my sisters are married and have healthy children except me. Why me?" (M.6c)

"We were both shocked that we were carriers... You know... Oh my God, I can't believe it... [Silent for a few seconds]. Nobody from either family even believes it or has any disease like this." (F.10b)

It was noticed from the interviews that some fathers tried to hide their emotions and show that they coping with their situation. Some of them insisted on not complaining as it is not socially acceptable for men to complain.

"No, it was ok... I'm ok, it was just his mother who keeps crying... No, for me, I don't cry, I'm fine." (F.14a)

"No, men do not cry." (F.3a, F.15a and F.1b)

"I'm ok...I'm fine, it is just his mother who makes things a big issue... She is always complaining." (F.6c)

6.6.4.4 Sub-Category 4.4: Unprepared

Mothers felt that they were overloaded and unprepared to care for children with BTM. They felt bored by the routine of frequent hospital visits, blood transfusion and medication administration. In addition to caring for their ill children, mothers were also responsible for dealing with everyday life events. Socially, mothers were considered the primary carers for themselves and the family members in health, illness and wellbeing.

"To be honest, I'm really feeling tired... You know I have three children I need to feed, wash, clean and send to school every day. You have to do the homework as well, which is never ending when you have kids. [Smiling and laughing]. Maybe you will not believe me if I tell you for the last two years I have not attended any social activities... I didn't expect all this in my life." (M.17a)

"We were all surprised that she has thalassaemia and will take blood... We didn't expect that... You know that feeling when you are waiting for the first baby... Then they tell you he is ill and he will receive regular blood transfusions at hospital... I was genuinely shocked, frustrated and very upset. I did not know why he is sick, or how to care for my boy. Can you believe that it's hard? Oh dear, that is too much, not only for me but also for any other mother, isn't it." (M.11b)

Not only mothers but also fathers expressed that as a couple they were not ready to have a child with BTM and to care for him/her in the family, because of all required duties and responsibilities.

“It is a hard experience for both the mother and the father to care for their chronically ill child with thalassaemia. To take him to hospital, do many blood tests and on the top of that they need time to understand what it is. It is not easy for us at all.” (M.8a)

“It is the hardest time and the biggest shock of my entire life... Even after the diagnosis of his youngest brother with a neurological disorder. That was easy for us, not like the time of his diagnosis. No, it was the hardest time of our life.” (M.1a)

“It was really hard for me to accept the idea that my son is ill. To be honest it took me around year to understand that he has thalassaemia because I refused the idea from the beginning. I was shocked. It was really, really hard.” (M.5a)

Most of the participants were shocked to discover that their children had thalassaemia because they were not prepared. As the following example showed:

“It was bad news I was really shocked... Very hard to hear that. [Silence for a moment].” (F.6a)

“It is really hard... Until now we are still shocked. It is not easy to see your younger daughter suffer from such disease. She has to take daily medication, frequent blood tests and transfusions... I'm feeling really sorry for her. I don't think I, as an adult, can handle all these issues.” (F.8c)

“I was totally shocked... I kept crying, felt really very upset... It was hard, very hard.” (M.7a)

Parents felt a sense of helplessness as they had to accept the available therapy and the way the health authorities dealt with chronic haematological disorders. Parents felt they were unable to help their children to overcome the disorder or even to stop or minimise the complications. This is because parents had to wait for many years for the opportunity to undergo BMT, which is the only hope for them to have their children back to normal. In some cases the parents had to wait even when a donor became available. This waiting ranged from three to six years on average because of limitations in financial support and the availability of health services.

“This is your son and you don’t know what to do... I felt like my hands were tied... We have to wait for the bone marrow transplantation. I don’t know for how long we will wait, you know... We have been waiting for four years. Sometimes I feel like it is not even going to happen.” (M.2b)

“I don’t know what to do... We are just holding on and waiting... God’s chosen something for us... I have no idea what the future holds for us. We wish that they could do the operation soon.” (M.9c)

Some participants, especially the mothers, stated that crying was their only coping strategy to deal with their situation. However, in some ways it might have helped them to release the pressure of having to provide constant care for their children. Participants cried when they talked about their children’s condition to others and sometime cried alone.

“My worries and fears are internal. I rarely show my feelings to anyone... I don’t like it, especially with my family and my kids... I prefer to cry where there is nobody around me.” (F.6c)

“It is hard for a man to cry... But I know some can cry when they are on their own but of course not in front of others.” (F.10a)

“If I cry, that would not be in front of anybody... We are human and sometimes you really feel it... But for women, they are soft hearted, they cry any time in any place. But for men, no.” (F.6c)

“When I.A [initial of his son] had the spleen operation, I felt totally down. That was the first time of my entire life I cried like this.” (F.10c)

“I was hysterically crying outside the clinic and felt dizzy, then I fell on the floor fainting... It was really the worst moment of my life.” (F.9a)

6.6.5 Parents' Attitudes and Perceptions

Participants' revealed various attitudes, behaviours and perceptions toward children with BTM based on their experiences. Some parents perceived their children with BTM as ordinary or 'normal' children. As the following examples.

“I see her like any other normal girl. Like her sisters, she is able to eat, play, move and she is able of doing many things on her own.” (M.17a)

“No, she is a normal girl. I treat her like any normal girl, especially in front of her sisters but I always support her to eat more... She has a very slim body.” (M.7a)

“My son is a normal boy like his peers, thank God. He is academically even ahead of them I'm proud of him ... His only problem is his face shape and personal appearance...” (M.8a)

“No, I treat him like others. I never ever make him feel he is sick or different. He is a normal child... I treat him like a normal child... He is not different to any other family members.” (F.3a)

“He is like an ordinary child. He can do many things which any child his age can do.” (F.2a)

Many participants revealed that they consider their children with BTM to have a high intelligence quotient 'IQ' and a unique personality with outstanding academic achievements in school.

"K.S [Initial of her son] is an outstanding student. He is very clever. Children with thalassaemia have special cognitive abilities, more than the regular children. Their IQ is higher... God takes something from them and gives them back something else instead. He is really good. All the teachers like him..." (M.1a)

"Her academic achievement is really good. Even socially, everybody who met her loved her." (M.18a)

"I feel like their IQ is higher than regular children. They are usually cleverer than ordinary children. My son's academic achievement is really higher than his brothers." (F.10b)

"She is a smart, active girl. She goes to her school alone... She studies hard, helps me at home and sometimes she also does the shopping for us." (M.11b)

"I think he is just an ordinary child. I don't feel he is different from his teens... His dad treated him different, not like his brothers. Actually he spoiled him a lot." (M.5a)

"All my three children have thalassaemia, but they are very smart. I have M, G and A [Initial of his sons]; M he is the first rank in his class, G, his academic performance is very good and A, he is doing really well. The school teacher is happy with him." (F.14a)

Some parents tended to spoil their children with BTM more than other children in the family; treating them differently, bringing more gifts, and answering all their requests.

"She is the only one who accompanies me wherever I go, and at any time she is always with me, not like her sisters." (M.17a)

“I care more for B.A [initial of his son]. My wife said, ‘you spoil him a lot’, because I have to take him with me anywhere I go, for any social activities, shopping, sometimes just for spending time out, and I bring him many gifts...” (F.9a)

“I bring him many gifts games and take him out with me a lot. Doing that makes me feel that I’m doing some compensation to him.” (F.6a)

Participants in the interviews showed their satisfaction with the premarital test. Most of them believed that any carrier couples should not get married, so that they would not live the same experience they had, and to decrease the number of children with BTM.

“Those who knew that they were carriers and insisted on getting married... Sorry to say it, but I have to say they don’t love each other. If you still insisted on going ahead and taking a risk to have a child with thalassaemia ... They really do not know how bad the situation is and what kind of stress they will face... All I have to say for them is to stop it, don’t do it.” (F.9a)

“Yes, every couple should do the premarital tests because the suffering is not worth the risk. When you know the disease’s impact and complications, you realise it is not worth the risk... Get married and have a child with thalassemia, it is really not worth it. Most people only know that a child with thalassaemia needs blood, but they don’t know how parents suffer caring and looking after them... Injecting your child with infusion medication for eight hours daily is not easy at all.” (F.10b)

“The couples carrying the thalassaemia gene when they get married, love is the one thing on their mind. However, they don’t know that this disease can make them hate each other and the life style they could have... Don’t make this mistake in your life. This is my message to them all.” (M.1a)

"I just need them to think logically, not emotionally. It is not an easy experience for any parents... To see your son suffer and know that you are the one who contributed to that... No, they need to rethink their decision seriously." (F.2a)

"The premarital tests are available and free. If you are both carriers, don't get married... Believe me, you don't want to live the experience of caring for a child with thalassaemia." (F.6c)

"I think they were selfish... To think only about yourself and ignore the fact that you put your beloved child at risk of having thalassaemia... Taking lifelong blood transfusion and medications... I think they do not understand what having a son means." (F.9a)

Some parents behave overprotectively of their children, based on their belief that they were acting in the best interest of their vulnerable children.

"His mother spoils him a lot and sometime I feel she overprotects him which I don't like... She kept instructing him, don't do this, don't do that. She does not allow him to do anything. She does not allow anybody to touch him or even think to hit him, even if that was just kidding. She never punishes him, even when he is making a mistake or being naughty with his brothers." (F.3a)

"Sometimes I let him play with other children but I keep an eye on him and I keep checking on him frequently... He has to play in front of my eyes, not far away." (M.1a)

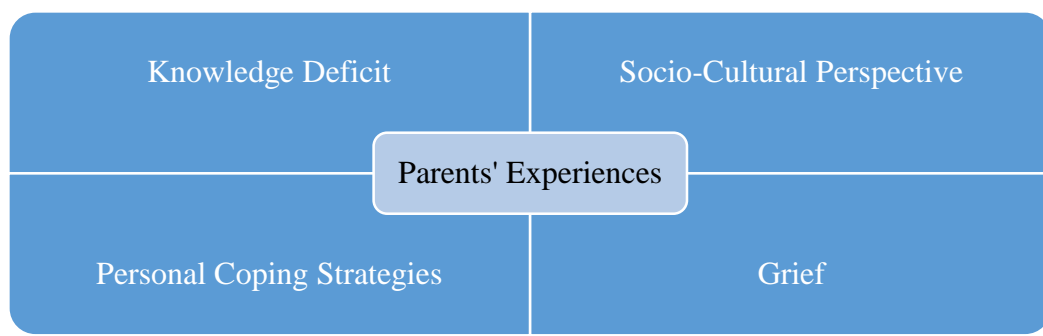
"He is not allowed to play out of the home... He only plays with his cousin in our garden." (M.11c)

"I don't allow him to play outside home, I can't... There are many risks. I can't trust the social environment. I have to protect him. If something happened to him, I will not forgive myself at all." (M.8b)

6.6.6 Summary of the Experiences and Coping Categories

The data showed that Jordanian parents of children with BTM had a lack of knowledge associated with various socio-cultural barriers, and experienced emotional burdens and feelings of grief (see figure 12).

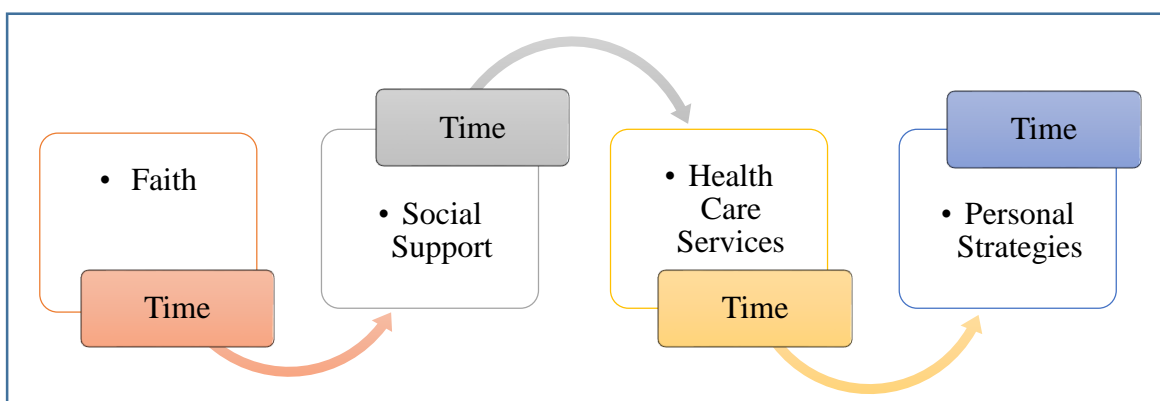
Figure 12 Core Categories of Parents' Experience



Source: Author (2013)

However, the data showed that Jordanian parents' faith, and the social support they received, together with the quality of the health care services for their children, assisted them in coping with their situation over time (see figure 13). In addition, the findings highlighted a variety of personal coping strategies, which were developed over time.

Figure 13 Parents' Coping Strategies



Source: Author (2013)

6.7 Participants' Recommendations

The participants in this study made some recommendations and suggestions which were captured during their interviews:

1. Participants suggested that premarital tests should take place only in specific recommended laboratories to maintain the credibility and validity of the tests, and to avoid any potential inaccurate results:

"We were all shocked, even the paediatricians, because we did the premarital tests. But because the test was inaccurate we have now girl with thalassaemia. I think the whole premarital test should be conducted in laboratories which are controlled by the ministry of health only, not private sector... To stop them messing with people's lives and giving them wrong results." (M.13b)

"The government should only allow such tests to be carried out in specific laboratories where the results are valid, because it is important. Come people decide on their marriage and future life based on these tests." (F.12b)

"After two weeks they told us that the premarital tests were inaccurate and our son has thalassaemia... It was a big shock to all of us... They should not allow for any laboratory to do such tests. It should be performed by the ministry of health only." (M.11c)

2. Participants suggested that the governmental health services should offer mandatory antenatal screening tests to the known high-risk families, free of charge:

"Most antenatal screening tests are costly but at least they help you to know what I'm having... To be honest, each carrier family should do those tests." (M.1c)

"Not all parents can afford to have these tests... The government should offer this for free to the families with such problems. Then they can decide what they want to do." (F.10a)

3. Group therapy. Some participants recommended that discussion and chatting with other parents who share the same life experiences supported them and their children, and had a positive impact on their experiences:

“You know, it is good to hear from parents who’ve had children with thalassaemia before you... You don’t feel you are the only one suffering and they tell you their story.” (M.11b)

“I meet many mothers in the department. It is the only place we regularly come to and we are friends now. We chat sometimes about our children and life events... It would be good if they arranged regular meetings for all mothers... I could meet more and we could talk more and more.” (M.2c)

4. Participants suggested that families caring for children with BTM should receive some financial assistance, whatever their monthly income and their financial status:

“It costs because you come here every three weeks and you know, our only income is my husband’s salary and he gives me only 2 JD [Jordanian Dinar] for the whole day, which is not enough. I wish the government could financially assist by paying for families... Wallah [I swear to God], sometimes I have to ask for loans from friends.” (M.3b)

“We live in Al-Tafila [a town in southern Jordan]. Usually we have to drive more than three hours to come here... It costs about 20 JD for each visit. Sometimes in winter we have to leave home at four in the morning to be here at eight and we leave at about seven in the evening. At least if they pay for us the transportation, because we have to hire a taxi for the day, and you know the petrol costs these days.” (F.5b)

“I can afford the cost but I know many families cannot. The government should meet the cost for each family caring for their child with thalassaemia.” (F.1b)

5. Participants recommended that the JMoH should use the media to raise community awareness, minimize social stigma and instruct carrier couples to not get married. This would decrease the number of children with BTM in the community.

“The problem is in the media... Thalassaemia is not presented well for the community. They only focused on cancer... If you asked most people, they know about cancer, but few or none know about thalassaemia.” (F.10b)

“I think we need more community awareness about thalassaemia, but my advice to any new couples is that they should doing the tests in a public lab, not private one, because they are not accurate.” (M.11c)

“I think it is all about the media and the law... They need to focus more on thalassaemia, and be more assertive and prevent any carrier couples from getting married... They can go to talk in mosques and schools, especially for women.” (F.7c)

“To be honest with you, increased community awareness is the key... Educate fathers and mothers who had have daughters and sons who need to get married... To instruct them and support them to take the appropriate decision in their life, because they are going to suffer if they have a child with thalassaemia.” (F.6c)

“They can have talks in Friday prayers or even in special meetings, to discuss with this health problem. It’s really not easy to care for children diagnosed with thalassaemia... Proposed couples should understand what to expect in the future... They should be more assertive with them.” (M.4c)

6. Some participants suggested that the JMoH could offer the families travel services to the thalassaemia departments. This would especially benefit working parents who struggle to find time to take their children for blood transfusions:

“My suggestion is for an assigned special bus to take all children with thalassaemia for blood transfusions in hospital, and any other tests, at a time agreed between the nurses and their families, and then bring them back home. Because there are many working parents struggling with time to send their children for blood transfusions... Which is loaded and stresses them more... By doing this the children will be cared for by the nurses, and the parents will not be stressed and worried about them... Exactly how they do with the paralysis children.” (F.10b)

“It will be much better if the hospital sent a car to take children with thalassaemia for blood transfusions... They can stay on their own without their mothers, especially the ones who are over seven years ... You know, sometimes you really need some help.” (F.2a)

6.8 Conclusion

In this chapter, the findings have been presented from the forty semi-structured interviews with Jordanian parents of children with BTM: twenty fathers and twenty mothers. The chapter has presented parents' experiences and their coping strategies of caring for their children, supported by quotations. In addition, the researcher's field observations, memos, and notes were presented in this chapter. Parents' experiences and coping strategies were mainly influenced by their social values, culture and religion. Parents experienced a knowledge deficit as they revealed many things they did not understand about BTM, such as their family history, how to care for children and how to plan for future pregnancies. Parents described how the culture placed demands on their daily life, and how they had to accept much of this because of the cultural norms found in Jordan. Parents experienced feelings of overload, unpreparedness and grief because of gender preferences, the roles and duties at home and work, all shaped by culture. They expressed a sense of unhappiness and helplessness toward their children's illness. Fear of the future and hopelessness also shaped the parents' feelings. Despite all of the challenges that were experienced by this sample of Jordanian parents, they expressed happiness with their roles as caregivers and were satisfied with the health care services their children received in hospital. It was noted that parents' faith and religious practices were the major adaptation mechanism used by the participants in this study.

Chapter Seven: Discussion

7.1 Introduction

This chapter discusses the research findings in relation to the existing literature. The chapter will be presented in four parts. Part one presents the genetic screening services; part two is about socio-cultural perspectives; part three discuss participants' emotional experiences; part four will focus on participants' coping strategies. The discussion will address the impact of the culture, society, religion and gender on parents' experiences and coping strategies. Conclusions are drawn at the end of the chapter.

7.2 Part One: Genetic Screening Services

This section will discuss the participants' knowledge, cultural, social and gender themes. This includes knowledge deficits, self-education, and the role of HCPs, as well as the genetic services and counselling available in Jordan.

7.2.1 Knowledge Deficits

The participants' lack of knowledge influenced their experiences and coping strategies of caring for children with BTM. The knowledge deficit limited their access to effective coping strategies which might have been useful in adapting to the care needs of their children. The study found that, irrespective of their educational background, parents experienced a lack of knowledge about BTM. According to the research data, about 73% of the participants had completed high school, 20% had a diploma certificate and 7% had university degrees, indicating that they could all read and write. However, there was no relationship between participants' education level and their knowledge of their own genetic status, family history or the origin of BTM.

Participants from the three hospitals where the data was collected exhibited various levels of knowledge deficit. The findings showed that most parents did not know about their own genetic status as carriers to the BTM gene until they had a child diagnosed with it. A similar finding reported by Sadiq, et al. (2000) found that around 75% of a total 77 Jordanian families of children with BTM did not know about BTM before having their first affected child. Moreover, this was supported by another study carried out by Mrayyan, et al. (2004), who found that around 70% of affected Jordanian families of children with BTM discovered the disorder through its signs and symptoms, and that some families only knew about their genetic disorder and their child's diagnosis by chance. The findings contrast with Rifaya, et al's 2011 study, which found that 80% of the parents of children with thalassaemia in Sri Lanka had adequate knowledge about thalassaemia.

The findings showed that parents were unaware of their own and their family's genetic status. There appears to have been a lack of discussion between family members about inherited genetic disorders and the likelihood of such disorders passing through generations. Such a discussion could have prompted participants to go for premarital screening tests. However, the absence of discussion in families caused them to miss important indicators about the risk of being carriers and of having more children with BTM in the future. According to Bennett, et al. (2002), discussing and knowing about family history is the most cost-effective, simple and comprehensive tool in passing on information between generations. Such discussion with Jordanian families and between proposed couples was culturally not customary. In Jordan, knowing about previous cases diagnosed with BTM in the extended family was probably the only reason that engaged couples sought genetic education and counselling. The findings revealed that only two out of forty participants had carried out the premarital tests, and only because they were aware of the existence of cases in their families.

Participants reported that knowing about the family history could have prompted them to carry out the screening tests and seek medical counselling. That might have helped to prevent their having a child with BTM and reduce the number of BTM-affected members in the family. There were many scenarios in which parents with an unknown family history had a second child before their first-born was diagnosed or before they even knew that they were carriers. This findings were supported by Read and Donnai's 2012 study, which revealed that knowing about family history was one of the reasons why couples sought genetic counselling, and that having this information enabled them to cope, adjust and make the appropriate life decisions. It was important for the HCPs to provide effective interpretation of the family medical history in order to enable the couple to organise their reproductive planning and to help them to make their choices (Read and Donnai, 2012; Bennett, 2012).

Arguably, providing parents with professional health education could place them in a position to be the best primary educators to the children with BTM and family members. This could also positively affect children's ability to adapt to their lifelong disorders. Furthermore, providing mothers with such information was more likely to enhance their understanding, assist them coping and caring for their children, according to Atkin and Ahmad (2000a).

The findings indicated that most parents experienced lack of knowledge and misunderstanding about the progress of their child's condition and the importance of adhering to the treatment. In addition, parents were not aware of the various complications which could affect their children. This could interfere with their caring process, affected participants' caring ability and impact on the health status of their children. In some cases, it interfered with the effectiveness of their children's therapy by increasing the risk of associated complications. For instance, the findings revealed that some parents still faced

challenges with administering daily injections to their children, which left parents, especially mothers, with the feeling of causing pain to their children. Arguably, this led to some mothers not administering the medication regularly either the infusion or oral form, and there were some cases where children were missing some doses and the children's blood tests revealed high levels of iron. Many reasons for this were given in the participants' interviews, including unwillingness to administer the daily needle insertion, the time the infusion machine takes, and the taste of the oral medication. Sustained adherence to iron chelating therapy is important for children with BTM and their families in order to maintain acceptable levels of iron in the body organs, and to decrease the likelihood of complications. Non-adherence to treatment was reported not only in cases of thalassaemia but also in other chronic illnesses. Foster, et al. (2001) found that children diagnosed with Cystic Fibrosis experienced high levels of non-adherence to their required treatments. Arguably, HCPs have the major role in addressing such issues in the health care services.

In the present study, not only was the effectiveness of the medication compromised, but some parents also put their children at significant risk by delaying or missing blood transfusion sessions. From the research observations in the departments, it was found that some parents experiences some challenges and did not turn up even after many reminder phone calls from the nurses and staff. This issue also supported by Atkin and Ahmad (2000a) who highlighted how adherence to the lifelong treatment is a challenge for patients with BTM and their families.

The findings also showed that some participants were not aware of the nature and origin of BTM, or the fact that both parents must carry the defective gene in order to have a child with BTM. In addition, some participants did not fully understand that there is a risk of having a child with BTM in each pregnancy. Arif, et al. (2008) reported similar

findings about Pakistani parents' lack of knowledge of the nature of BTM. It was found that only 15% (n=120) of Pakistani parents knew that thalassaemia was an inherited disorder. However, the findings of Mrayyan, et al. (2004) disagree with this study. Mrayyan, et al. (Ibid) found that most of the Jordanian respondents in their study were aware of the genetic origins of thalassaemia, but that preventive measures to avoid having other affected children were not taken by affected parents. Another study by Wong, et al. (2011) in Malaysia found that the majority of the participants (69.7% out of a total 3723 responding households) knew that thalassaemia was a genetic disorder and that any individual can find out their carrier status through performing blood tests.

Parents in this study also showed varied levels of understanding of the origin of BTM, which impacted on the effectiveness of their caring process and their life decisions. For example, some parents believed that if they had one child with BTM in the family, they could not have another. Others believed that if they had a male with BTM, they would not have a female with BTM, as they thought it was a sex-linked disorder connected with females or males in certain families. Similar lack of knowledge was reported as one of the major themes in Atkin and Ahmad's (2000a) study of families from different ethnic groups in the United Kingdom caring for children diagnosed with sickle cell or thalassaemia disorders. Furthermore, Liem, et al. (2011) found that the caregivers' lack of knowledge about thalassaemia impacted on the child's development, and found that lack of information was a major source of parents' frustration. Another study by Prasomsuk, et al. (2007) found that mothers of children with BTM in Thailand experienced lack of knowledge about thalassaemia, which affected the caring process for their children.

It was noted during the interviews that parents did not report any form of professional health education or counselling. The only information that the participants received about

BTM was in the first few hospital visits, when their first child was diagnosed. Parents claimed that the lack of their knowledge about BTM was a result of the HCPs' failure to give them relevant information on their children's situation. This findings concurs with Atkin and Ahmad's 2000a study, in which the parents of children with thalassaemia and sickle cell disease criticised the HCPs team for not providing them with the basic appropriate information about their children's disorders and for not keeping them updated about the changes in their children's conditions.

It can be said from the data, for those parents who did understand BTM, their knowledge helped them to care, cope and adjust to their situation. In addition, it assisted some parents to provide quality care, minimise complications and decrease the side effects of the treatment. This is supported by Georganda (1990), who argued that parents caring for their children with thalassaemia believed that information and understanding of the illness enhanced their coping and adjustment. In another study, Tsiantis, et al. (1996) argued that fathers with inadequate education levels and the presence of major complications of thalassaemia were predictors of poor family adjustment.

7.2.2 Self-Education

The findings showed that self-education was another coping strategy reported by participants. This could be as a response to the shortage of professional health education. It was noticed from the findings that fathers used the self-education strategy more than mothers. Many fathers stated that reading and educating themselves about BTM helped them to know more about their children situation, thalassaemia and assisted them adapt to their situation, especially at the early stages of diagnosis when they were urged to find out about their child's condition.

However, what is concerning about this strategy is the accuracy of the information used to self-educate, in respect of such a complex medical condition. For example, fathers in the interviews mentioned that they used various websites as resources to educate themselves. Moreover, the complexity of the terminology could have made it difficult for parents to understand the condition and accurately interpret the information. Each child with BTM is unique, which means that every child needs his or her own treatment plan based on age and the stage of their growth and development. Arguably, self-education would be a more effective strategy if combined with professional supervision. It can be suggested that health education sessions should be designed based on each patient's situation in order to avoid overloading parents with unwanted and unnecessary information.

7.2.3 Health Care Professionals' Roles

Participants in this study highlighted the absence of professional support. Few participants mentioned that they received support and counselling from the HCPs in the interviews. Professional health education and counselling plays a major role in reducing parents' stress and facilitating their coping, and it can be argued that when provided with appropriate information, participants will be able to deliver quality care to their children. The importance of professional support was also addressed in several literature such as (Sloper and Turner, 1992; Beresford, 1994; Chamba, et al., 1998; Atkin and Ahmad, 2000b).

It was noticed that in all departments, there was an absence of genetic education and counselling for parents. This raises the issue of HCPs' understanding of their professional roles in practice as health providers, educators, counsellors and advocates to patients with BTM and their families, and to the families at risk of having genetic disorders.

Arguably, nurses have a key role in health education, illness prevention and health promotion through their roles as health providers and educators (Biesecker, 2001) in relation to thalassaemia, and that more could currently be done by nurses in Jordan. This role could be present in terms of parent support, promoting positive adaptations, patient advocacy, education and assistance in decision making (Burton, et al., 2003). Tsiantis, et al. (1996) argued that nurses and HCP teams caring for children diagnosed with thalassaemia and their families need to be prepared for the mental health aspects of their work. In Jordan, nurses' attitudes and perceptions of genetic counselling were discussed by Gharaibeh, et al. (2010). They found that around 86% of 200 registered Jordanian nurses and midwives perceived genetic teaching as not being part of their role, but part of the health genetic services' role and/or the responsibility of other HCPs. Similar findings were reported in another study by Mrayyan, et al. (2004), who found that Jordanian nurses were excluded from genetic counselling programmes and professional education. Furthermore, Gharaibeh and Gharaibeh (2011) argued that Jordanian nurses and midwives had an inadequate level of knowledge about genetic education and obtaining patients' family history, which was considered the easiest way to identify high-risk families, as mentioned earlier. Arguably, this absence of nursing roles in genetic health services impacted negatively on patients and their families. Moreover, it became clear that Jordanian nurses and the HCP teams need to update and enhance their knowledge and experience in genetic counselling, in order to provide quality and comprehensive health services to patients with thalassaemia, the caregivers, and high risk families. In addition, they need to be aware of the complexities of the feelings of parents of children with BTM, and of the emotional burden they experience, in order to respond to their behaviour, care for and support them (Tsiantis, et al., 1982). Donnai and Elles (2001, p. 1050) suggested that the "*genetic services need to listen to the experiences of patients*" in order to be able to provide quality care.

This is not only the case in Jordan. Kronfol (2012) argued that in most Arabic countries there is a need to create a balance between hospitals based health services and primary and community services, where health education and counselling is expected to take place. Kronfol (Ibid, p. 1164) stated that “*the health care practitioners have to work within a team in collaboration with colleagues in primary care, social services and the various health organizations*” in order to focus on patient-centred approach in their services.

While genetic counselling in Jordan was available as a part of the premarital screening programme, it was noticed that this service was not scheduled in the health care plan for patients with BTM and their families. It was not a surprise that only two families mentioned this in the interviews. The findings showed that most of the participants were focused on the support from family and friends, mentioned that they received limited professional support. Similar findings were reported by Rifaya, et al. (2011), where 86% of fifty families of children with thalassaemia in Sri Lanka were reliant on family support. Arguably, the role of the HCPs is to support, empower and assist parents by communicating and better understanding their responses, attitudes and behaviour as families and caregivers to their children. This would improve their ability to deliver quality care, to decrease the psychosocial burden of the disorder, to improve their support to each other and to strengthen their relationship in the face of threat and stressful events (Bruce, et al., 1996; Hunfeld, et al., 1996; Betman, 2006).

However, it can be said that there was an imbalance in power and authority between HCPs and patients with BTM and their families because the HCPs had more specialised and advanced knowledge about the patients’ conditions than their parents did. It can be argued that the HCPs needed to see the patients and their families at the centre of their health care services, as well as to focus on the concept of holistic care. One potential solution

could be for 'in-service training' to be focused on educating and empowering HCPs to achieve this objective.

Furthermore, there was a need to re-conceptualise and re-distribute the balance of power between the HCPs and the service users to reshape the professionals' roles with the patients and their families, while at the same time providing a new emphasis on the provision of advice, counselling and education. In turn, this means empowering parents to make decisions regarding their children's health and assisting them in achieving their goals and meeting their needs. This is also supported by Atkin and Ahmad (2000a), who found that on the one hand, appropriate professional support can enable parents of children with thalassaemia and sickle cell anaemia to cope, and can reduce their stress. On the other hand, if the nurses and HCPs were busy or showed unsympathetic responses, this could make the services part of the problem, and increase the difficulties faced by the parents and their ability to cope with their situation.

7.2.4 Genetic Services

The findings indicated that there were two main reasons for the gap in parents' knowledge: the unavailability of genetic screening at the time most of the participants in this sample got married, and not knowing about their family history in relation to BTM.

Participants lacked knowledge about the availability of the genetic health prevention services and access to such services as antenatal screening programmes and family planning methods, which contributed to their negative experiences and coping strategies. Comparable findings were reported by Gharaibeh and Mater (2009), who found that young Syrian adults (942 university students) had inadequate knowledge and negative perceptions about premarital testing. Better knowledge could help parents to decrease the risk of having another child with BTM in the family, and increase the probability of

having healthy children instead, which was their main aim. In another study, Gharaibeh (2001) found that there was a significant relationship between Jordanian parents' knowledge levels and their perceptions of susceptibility, the severity of genetic disorders and the benefits of counselling and screening programmes.

Participants in the study were satisfied with the mandatory nature of the premarital tests. However, they raised some issues about the validity and reliability of the results in some laboratories. The two couples in this study who had received inaccurate results were surprised and shocked when their first-born was diagnosed with BTM. In addition, having inaccurate pre-marital tests caused unnecessary interruption in the child's treatments. That there were two such cases out of forty participants in this study suggests that there could be many other families in the same position. The situation of the two couples' questions the quality of the health services provided and the care delivered to customers in various health care settings, and especially in the medical laboratories. Furthermore, the inaccurate pre-marital results could mislead and delay the child's diagnosis, as was the case for the two affected couples in this study.

Another important issue raised in the findings is that more than 90% of the participants (38 families) did not know about the available antenatal screening programme in Jordanian health care settings. The findings indicated that only two mothers out of twenty had undergone CVS. Al-Gazali, et al. (2006) stated that the antenatal screening programmes have been available in the Jordanian health care services since 2006. It is worth mentioning that, not only in Jordan but the low rate of uptake for antenatal screening programmes was also reported by Arif, et al. (2008), who found that only 5% of a total of 120 Pakistani caregivers of a child diagnosed with BTM had undergone antenatal screening, and that 5.8% had their other children screened for BTM. In another study, Wong, et al. (2011) found that only 13.6% out of a total of 3723 responding

Malaysian married participants had been screened for thalassaemia. These findings about parents' knowledge about antenatal screening seem to suggest that mothers were taking a high risk in their pregnancy plan. Interestingly, in the interviews some mothers used the word 'gambling' when they were asked about how they planned for new pregnancies after learning that in each pregnancy there was a risk of having a child with BTM. It can be argued that this kind of 'gambling' placed the mothers at risk of having another child with BTM in the family, as well as increasing their stress levels during the pregnancy period as they waited to find out if their unborn baby had BTM or not. It was clear that parents' need to have another child and their preference for a healthy child led them to take great risks.

7.2.5 Genetic Counselling

Surprisingly, the findings showed that most of the participants had the attitude that carrier couples should not be allowed to marry. This attitude, however, is contrary to individual rights and choices, which is the basic idea behind genetic counselling which supported by (Godard, et al., 2003). Some parents in the interviews blamed newly married couples for having children with BTM despite the availability of free pre-marital screening tests; parents stated that carrier couples should not get married, with some parents arguing that by avoiding marriage, such couples would not be at risk of having children with BTM and would not live through the same experiences they had. This finding was similar to that identified by Oseroff (2011), where the prevailing attitude was that carrier couples should not be allowed to marry in order to decrease the risk of having children with BTM in the future. Based on this findings, this study suggested that genetic counselling should be available not only to carrier couples at risk, but also to the parents of children with BTM.

The findings of this study showed that Jordanian carrier couples do not receive the appropriate counselling and are still struggling with limited options to cope with their situation. For instance, termination of affected pregnancies is still illegal. According to Oseroff (2011) the conservative treatment were not available to parents who decided to marry after they had been tested positive for BTM and received counselling. Such parents were expected to take the responsibility of covering their child's treatments. This issue raises concerns related to the rights and freedom of choice of carrier couples, as enshrined in Jordanian law. Arguably, the issue is not only about the availability of counselling sessions, but also the realistic and effective options being given to non-married carrier couples. This study questioning the effectiveness of genetic counselling in Jordan, which focus on the interpretation of premarital blood results and the likelihood of having children with BTM in future. Genetic counselling and education are the most important needs for parents of BTM children, carrier couples and families at risk, and it should be sensitive to religion and cultural belief systems (Bennett, et al., 1999), be non-directive, and assist families to choose options appropriate to their needs (Donnai and Elles, 2001). In addition, the counsellor should try to be neutral as possible in order to avoid interfering with the couple's decisions, and to give them the advantages and disadvantages of each available option (Karetti, et al., 2004).

Educating parents about their family history and the availability of genetic screening programmes would empower them to make their own decisions, with support from the HCPs. Effective education and counselling about available family planning methods and antenatal screening programmes would also help parents to gain a better understanding of genetic disorders and, consequently, would decrease the number of children with BTM in the family. Arguably, educating and empowering parents could affect their social roles and responsibilities through reduced social stigma.

Parents would also be able to take the appropriate decisions regarding their children's treatments options, and assist them in identifying their roles and responsibilities in caring to their families, thereby improving the quality of their children's lives. However, the absence of professional education, counselling and support from HCPs was a fundamental issue in this study, because the only resources some parents had were their family and friends.

7.3 Part Two: Societal and Cultural Perspectives

In this section, societal and cultural perspectives will be discussed in relation to social stigma, consanguineous marriage, parenting experiences, power and authority for both men and women, parents' involvement in care, gender preferences and termination of affected pregnancies. In Jordanian society, cultural and social norms directly influence parents' roles, attitudes and behaviours. Consequently, they impact on the health behaviour of individuals (Leininger, 2002). The findings showed that they determined the roles of mothers and fathers, provided social guidelines, assigned duties and responsibilities for parents inside and outside the family, and distributed power and authority between men and women. Parents were overwhelmed by cultural and social norms, values and beliefs, which in some scenarios seemed to put them under pressure, increase their stress, limit their options and conflict with their needs. This contributed to a negative impact on their experiences and coping strategies.

7.3.1 Social Stigma

Stigma is defined as a discrediting and undesirable attribute, reducing the individuals' status in the eyes of their society (Brown, et al., 2001; Link and Phelan, 2001; Weiss, et al., 2001; Parker and Aggleton, 2003), creating social boundaries between so-called 'normal' and 'outsiders', 'carriers' or 'infected', 'us' and 'them' (Link and Phelan, 2001).

Stigmatisation of parents of children with BTM is well documented in Jordanian society by Mrayyan, et al. (2004), Hamamy, et al. (2007b), Oseroff (2011) and Hamamy (2012). According to Atkin and Ahmad (2000a) social stigmatisation has been reported not only in Asian countries but also among different ethnic minorities and communities such as African, Mediterranean and African Caribbean.

The findings revealed that parents faced stigma in three scenarios: first, for having and caring for children with BTM; second, for being carriers of the BTM gene; third, for being associated with children diagnosed with BTM. In this study, stigma was mainly associated with gender, and in many cases mothers were found to be more stigmatised than fathers. In the interviews mothers stated that they were stigmatised in the community from the time that the premarital screening was carried out and when they gave birth to a child with BTM. Interviewed fathers did not mention that they were stigmatised as strongly as the mothers did.

In order to avoid being stigmatised, some Jordanian parents tended not to talk about their children in public or with family members, relatives and friends. They tried to hide the fact that they had a child with BTM. Furthermore, some mothers stated that they used the duty of caring for their children as an excuse to keep them busy and to not attend to any social activities, in order to avoid the embarrassment of chatting about their children. If they had to participate in any social activities in public, mothers tended not to be accompanied by children with BTM. The same findings were reported by Hunfeld, et al. (2001) in mothers of adolescents with chronic pain, who reported limitations in their social functioning and activities in addition to greater level of personal strain. Consequently, this study found that stigma impacted on parents and particularly mothers' social life and contributed to limiting their activities, relationships and social networking. In some cases it led to parents being isolated, as well as having limited support from

friends, relatives and the society at large. This impact was similar in Liem, et al's 2011 study about Asian and Indian families of children with BTM, in which parents were found to be reluctant to extend their social networks and communicate with others about their children. This is due to social stigma and the lack of knowledge in their community.

The concept of social stigma has been applied to a wide range of different health circumstances, not only to children with BTM; the literature showed that parents of children with other forms of chronic illness and genetic disorders had been stigmatised, in particular those with cancer (Fife and Wright, 2000), mental illness (Phelan, et al., 2000) and urinary incontinence (Sheldon and Caldwell, 1994). In addition, Burnes, et al. (2008) found that African mothers and African Caribbean families with sickle cell disease in Canada were isolated from socialising in groups because of stigma. It is worth mentioning that children with physical and mental disorders were also stigmatised and isolated. Fishman (1994) found that Palestinian children with Down's syndrome were frequently subjected to abuse and were hidden from public view. They did not attend any social activities and were not presented in public society because of social stigma. These findings were reported more in case of females with Down's syndrome than males.

Hiding the fact of having a child with BTM in the family tended to minimise parents' social activities, including spending time with other patients and their families, and prevented them from attending workshops, conferences or social activities designed for such groups. Ratip, et al. (1995) found that 51% of the parents of thalassaemia intermedia patients experienced social isolation. Similar findings were also reported by Gray (2006) in families caring for children with autism, where the families coped through social withdrawal and individualism.

Attending social and professional activities such as conferences and workshops gave the parents and their children a chance to meet and communicate with HCPs, other patients

and caregivers from different backgrounds. Arguably, these meetings could give them an opportunity to share experiences and coping strategies, gain new knowledge and extend their network, all of which could increase social support and collaboration.

Surprisingly, not only do patients with BTM become stigmatised, but also their family members, whether carriers or non-carriers. For example, many parents mentioned in the interviews that marriage proposals for their healthy or carrier daughters were withdrawn because of the stigma attached to having family members with BTM. These findings were consistent with Oseroff's (2011) study, where the stigma in Jordanian society had long-term effects not only on patients but also on their family members.

The findings highlighted some cases in which children and their families faced rejection and shame from their families in law. This was based on their lack of knowledge of and attitudes towards genetic disorders in their community. For example, some cases reported that people believed BTM to be a contagious and they refused for their children to communicate with children with BTM. Furthermore, the changes in children's physical appearances caused them to stand out in the community and resulted in discrimination in some cases. In practice, this raises the issue of community awareness and attitudes towards BTM.

Arguably, some participants in this study preferred consanguineous marriage as their coping strategy, as the best option to avoid social stigma from other families in their community for both their healthy and carriers' offspring. Arguably, this strategy could increase the risk in the next generation not only of having BTM, but also of other inherited genetic disorders and illnesses associated with consanguinity, such as birth defects, and could increase the postnatal mortality rate, this supported by literature such as (Bittle, et al., 1991; Hamamy, et al., 2007a; Bittle and Black, 2010a; Hamamy, 2012).

In Jordan, the premarital screening programme has been integrated into Jordanian culture with a view to minimising stigma towards carrier couples. For instance, if one partner was found to be a carrier of the thalassaemia gene, the laboratories and HCPs attempted not to release the result to the engaged couple or to discuss their status. Instead, they would just tell the couple that their pre-marital results were acceptable, and give them a test certificate to be presented in the court as documentation of their health status, which meant that the couple could go ahead with their marriage plan. This strategy was used to prevent any possibility of shame and stigma. This was particularly the case when women received a positive result, because it was noticed that many men refused to marry carrier women, or avoided proposing to women who had family members known to be diagnosed with BTM.

Strategies to prevent or minimise social stigma in the premarital screening programme were not only adopted in Jordan but also in the Islamic Republic of Iran, where Iranian couples are also required to undergo premarital tests. Samples were taken from the men first, and then from their partners if the result was positive. This strategy was adopted to prevent carrier women from being stigmatised in the community or shamed by their husband or family in law (Samavat and Modell, 2004). Another strategy was adopted in Cyprus, where the test certificate was needed in order to issue the marriage licence. However, the certificate does not indicate the pre-marital results, the blood tests or who was the carrier. It only states that the couple went through pre-marital screening tests and received the appropriate counselling (Zlotogora, 2009).

7.3.2 Consanguineous Marriage

The findings of this study showed that 70% of the participants (28 participants out of 40) had a consanguineous marriage to a first or second cousin. This finding is also consistent with Mrayyan, et al. (2004), who found that the majority of children with BTM in

Jordanian families originated from consanguineous marriage. In addition, similar findings were reported in Pakistan, where most of the parents of patients with BTM had a first cousin marriage (Khattak, et al., 2006). The findings showed that most couples made their marriage decisions based on many factors, such as: (a) the couple's relationship before marriage, whether they were related or not related to each other; (b) whether the couple had been in a love relationship; (c) the couple's socioeconomic status. In one scenario, families with a history of carrying the defective BTM gene, some families could not cancel the marriage proposal after the test produced positive results, even where couples were related to each other or from the same kin. The second scenario was with arranged marriages: where both families arranged the marriage and were responsible for the wedding expenses, they tended to not cancel the marriage proposal whatever the pre-marital tests results.

Despite the health disorders associated with consanguineous marriage, it is strongly preferred and recommended in various communities. It was estimated that more than 20% of the human population prefer consanguineous marriage (Hamamy, et al., 2005). In Arab countries, consanguineous marriage accounts for 25% to 60% of all marriages (Alwan and Modell, 1997; Teebi and Farag, 1997; Al-Gazali, et al., 2006; Christianson, et al., 2006). The prevalence rate in Jordan is 30%-39% (Gharaibeh, et al., 2010; Hamamy, 2012). Recently, the rate of consanguineous marriages in Jordan has begun to decline (Hamamy, et al., 2007b). However, consanguineous marriages were still common in rural communities, as opposed to modern cities, and were mostly associated with younger women with a low educational background (Bittles and Black, 2010b; Oseroff, 2011).

Hamamy (2012) argued that consanguineous marriages are recommended in Jordan for many reasons. It is less expensive, and it is believed that close relatives will be better suited with minimum marriage expenses, thereby minimising future problems with both

sets of families in law. It is thought to help couples to transmit the 'right' social values to the new generation (Sandridge, et al., 2010), as well as to keep heritage and wealth in the same family (Hamamy and Bittles, 2008). The findings showed that consanguineous marriage and parents' relationships before marriage had an impact on the social support they received, particularly from their family in law. The findings highlighted two scenarios. In the first, parents were related to each other before being married (relative couples), and it was noticed that the families in law supported the mothers rather than shaming or stigmatising them. In the second, couples were not related to each other before marriage (non-relative couples). In this case, some mothers faced criticism from their husbands and families in law, who accused and blamed them of being the one with the defective gene and for causing the transmission of the disorder to their children; they were shamed and stigmatised. Similar findings were also reported in Greece, where the fathers of children with BTM tended to blame their wives, who in turn tended to accept the blame and hence take the burden of their children on their 'shoulders' (Anastasopoulos and Tsiantis, 1991; cited in Tsiantis, et al., 1996, p. 200).

The data revealed that in some cases the families in law, and particularly mothers in law took control and encouraged their sons to divorce, separate or take a second wife in order to have healthy children free from thalassaemia. The same issue was raised by Chamba, et al. (1998) among families and caregivers in Asian households. It was also found that Asian mothers criticised their mothers in law for taking a controlling role, rather than caring and supporting them in the process of caring for children with BTM (Atkin and Ahmad's, 2000a). Arguably, this would at times destabilise mother's' ability to cope, increase their stress and the social pressure they faced.

In summary, Jordanian parents in a consanguineous marriages were at risk of having more children affected with other autosomal genetic disorders and genetic defects, not only

thalassaemia which is supported by literature such as (Hamamy, et al., 2007a; Gharaibeh, et al., 2010). It could not be reachable to address such an issue in the community, within certain time, based on the fact that, the benefits of consanguineous marriage and married outside the family, confused many of them. However, consanguineous marriage is not the only factor in such disorders; some literature such as (Ahmed, et al., 2000; Ahmad and Bradby, 2007) argues that making the assumptions about the consanguinity is the major attributable factor cause of some genetic disorders such as thalassaemia, without taking into consideration other factors such as the socio-economic, ante-natal and genetic services could be questionable.

7.3.3 Parenting Experiences

The findings showed that a lack of knowledge of how to care for children with BTM caused parents to experience stress, frustration, feelings of inadequacy and general unhappiness. It can be argued that satisfaction with the childbirth experience may have immediate and long-term effects on the women's health status and her relationship with her infant (Goodman, et al., 2004). For new mothers, caring for the first-born with BTM was challenging and stressful because they were unprepared and felt a lack of control over their situation, which could be linked to low self-esteem. Arguably, there was a risk of harm to the person and to their self-perception. In some cases, parents' perceptions of the meaning of health and genetic disorders were altered. For instance, some parents believed that being a carrier meant that they were unhealthy, and that the carrier mother would be unable to deliver a healthy baby. Carrier parents felt that they had lost their identity as healthy parents, and that they had lost the healthy child they were expecting. The same findings were reported in early literature. For instance, Tsiantis, et al. (1982) found that parents caring for children with BTM experienced denial, guilt and anxiety over death, and loss of their children, which could also cause stress among other family

members. Having a first-born child with BTM places new parents in a process of long-term grieving, stress, and uncertainty about the future. The findings showed that parents felt that being a carriers and caring for a child with BTM limited their happiness in experiencing parenting for the first time in their lives. Some parents felt frustrated as their role shifted from being parents to focus more on the role of carers to their child. Goodman, et al. (2004, p. 213) argued that “*satisfaction with childbirth experience also has implications for the health and well-being of women and her new born*”. Furthermore, knowing that there was a probability of having another affected child with BTM in subsequent pregnancies added more stress to the couple’s new experience as parents. In addition, some mothers revealed that lack of knowledge about antenatal genetic screening programmes and the fear that a second pregnancy might result in another affected child negatively impacted on their marital and sexual relationship with their partner.

In the interviews, parents reported that the time spent caring for children’s medical needs impacted adversely on their family function and social life. A substantial body of literature such as (Ahmad and Atkin, 1996; Gill and Modell, 1998; Atkin and Ahmad, 2000a; Sapountzi-krepia, et al., 2006) reports that thalassaemia can have negative social and psychological implications for individuals, parents and families. For instance, some mothers reported that they were physically exhausted and uncomfortable with the frequent hospital visits as they used public transportation, travelled long distances, in some cases from one city to another, and spent more than six hours in hospital for their children’s blood transfusion. Similar findings were reported by Mazzone, et al. (2009), who found that the mothers of children with BTM had lower scores in their quality of life, and in the physical domain: mothers reported feelings of fatigue, pain and discomfort because of their constant care to their children. Arguably, this could be because they are the primary caregivers and because of the nature of the care.

Mothers had to provide constant care, and the lack of involvement from fathers added more to their responsibilities. This is congruent with the Jordanian cultural and social norms, where the basic role of the mother is to care for the whole family, and particularly the children. Mothers caring for children with BTM experienced not only physical but also psychosocial burden, as reported in Prasomsuk, et al. (2007). In addition, Politis (1998) and Goldbeck, et al. (2000) argued that there is a high psychosocial burden associated with the consistence of treatments for patients diagnosed with chronic illnesses and their families.

Some participants in this study mentioned that they faced a financial burden as a result of the demands of caring for their children with BTM. Financial problems were reported also by parents of children with BTM in United Kingdom by Clarke, et al. (2009), who found that despite the free therapy and the financial benefits available for the patients in the United Kingdom, families reported a range of financial concerns.

7.3.4 Involvement in Children's with BTM Care

In this study, the findings indicated that parents felt that they were playing a major role in supporting children with BTM to adapt and in decreasing complications occurring with time. Mothers in this study showed that their involvement in caring had a positive impact on their relationship with the HCPs, more so than for fathers. This positive relationship may have a positive impact on mothers' understanding of the importance of the blood transfusion. This in turn improved their attendance at the blood transfusion sessions, and their compliance with the treatment required for their children. Rifaya, et al. (2011) reported similar findings in Sri Lanka, where parents of children with thalassaemia were satisfied with the doctor and nurse-patient relationship in terms of the available management, support and health guidance.

Mazzone, et al. (2009) also reported that the mothers' involvement in their children's care in a therapeutic setting, and found that the positive relationship with the HCPs was important for the children's health status. In addition, involvement of the family in the child's care has a positive impact on families' coping strategies and family function. Mothers felt they were professionally supported when they were involved in their children's treatment.

In addition, involvement of both fathers and mothers has a positive impact on the families' coping strategies, partner support and marital management. Similar findings were reported by Gavin and Wysocki (2006), who found that more paternal involvement in the illness management of children with chronic medical conditions was associated with healthier maternal, marital and family functioning. Other studies such as Hanson, et al., (1988) and Harris, et al., (1999) highlighted the significance of availability of both fathers and mothers in their children's lives. They argued that young adults diagnosed with various chronic illnesses from families with absent fathers may demonstrate poor compliance with treatment, poorer psychological adjustment and a lower health status than those whose fathers were present.

Despite the positive impact on mothers of involvement in care, there were also some negative issues present in their interviews, mainly because they were taking the leading role in their child's care. Most of the mothers were found to bear the brunt of the management process, both practically (Quittner, et al., 1992) and emotionally (Goldbeck, 2001), more than fathers did. Fathers' involvement in caring for children with BTM was reported as being minimal, in both fathers' and mothers' interviews. Some mothers were not happy with their husbands not being totally involved in the children's care. However, fathers mentioned that time constraints and work overload were the reasons for their limited involvement.

The same issues reported in Ratip, et al's (1995) study, they found that 25% of parents caring for thalassaemia intermedia patients had limited time to devote to work because of the continuity of care they provided, and were unable to concentrate and work effectively due to worry.

Some fathers in this study felt that the children's care was their wives' responsibility. This attitude was found among most fathers, despite different employment and educational backgrounds. From the research findings, most of the children with BTM were diagnosed at an early stage of their childhood; the average age at diagnosis was 9.5 months (see section 6.3.6 table 20) which indicates that mothers were the first to lead the caring role for children with BTM. Tsiantis, et al. (1996) found that parents of children with BTM reported having more difficulties with the younger children than the older. Arguably, this could be related to the fact that when their children were diagnosed, the parents were not prepared and did not yet know how to adjust adequately to the children's situation. It was noted from the findings that fathers' levels of involvement were connected to child's age, gender and the phase of the disorder. For instance, there were some fathers who were involved in the care of their male children, more than female, and tended to be more involved in the care of older children, while mothers took more responsibility of caring for younger children with BTM. In summary, from the interviews it can be argued that fathers' roles, responsibility and involvement in caring for children with BTM were unclear for both members of the couple.

Gender is one of the issues connected to fathers' involvement in hospital visits and caring for children with BTM. I noticed from the research findings and memos that, most thalassaemia departments were originally part of paediatric wards, or were located in paediatric hospitals, and that their staff were considered part of the paediatric wards. Most of these staff were female nurses; there was only one male nurse out of ten working in

the three thalassaemia departments at the time this study was carried out. During the data collection period, it was noted that this gender inequality in the staff could impact on fathers' involvement, because it was noticed that many fathers considered thalassaemia departments to be areas for women and children only. In practice, it could be that a more equal gender balance among nurses and HCPs in thalassaemia departments would encourage fathers to be more involved in their children's care.

7.3.5 Gender Preferences

The findings revealed that in some cases mothers preferred a son with BTM to a healthy daughter. Surprisingly, some parents expressed that it was better for the healthy or carrier child in the family to be a boy. However, it did not matter so much if the girl was diagnosed with BTM or other disorder. Gender preferences revealed by some participants were due to many social and cultural reasons:

- (a) Culturally, men were considered the sources of power and authority in the family;
- (b) Men had a legal, social and financial responsibility towards all female members;
- (c) Socially, men had more freedom and mobility in the community than women.

It was argued in the interviews that having a male child in the family decreases the social pressure on mothers from their family-in-law, and secured their status more in the marital relationship. This finding was also supported by studies of Al-Qutob, et al. (2003) and Al-Akour, et al. (2009), who stated that in the Jordanian community, males were preferred to females in social, health, and labour contexts. In another study, Al-Akour (2009) found that when the gender known prenatally in Jordanian families the mean birth weight of male new-borns was significantly higher than that of female. The findings addressed the fact that having males in the family is considered a positive attribute for carrier mothers.

Having no male child in the family placed marital status at risk through social challenges such as divorce or separation. This risk could be worsened if there was more than one male child in the family with BTM. The findings indicated that participants with one or no male children were under social pressure to have more. The study found that there were many reasons for parents' desire to have more healthy children. Unfortunately, some families argued that having more healthy children would give parents more hope and increase the chance that matching donors could be found in the family. This could support parents to decide on the BMT for their child. For others, the motivation was to disprove the myth, shame and stigma attached to carrier mothers, who were criticised for being unable to conceive a healthy child. For some participants, having a healthy male figure in the family is necessary for future financial and social support, based on the socio-cultural belief that the male figure in the family is the source of social power, wealth, support and authority. In Jordanian society, large family size is preferred (Hamamy, et al., 2007b). This preference increases toward males, which directly impacts on the number of children in families. Findings reported by Khalaf, et al. (2008) also demonstrate that gender roles, tradition, family loyalty and social pressure impact on the number of children in the Jordanian family. Furthermore, in the same study Khalaf, et al found that knowledge about family planning and access to family planning services also have an impact on the number of children a family have. It can thus be argued that parents' knowledge deficit about access to and affordability of antenatal screening tests, coupled with the unavailability of termination of the affected pregnancy with BTM, left parents with limited options to cope with their situation, as well as leaving them with difficulty in meeting their need of having more healthy children in the family.

7.3.6 Termination of the Affected Pregnancy

In Jordan, there was intense religious, political, legal and socio-cultural debate on terminating affected pregnancies with BTM (Oseroff, 2011). Two mothers out of the forty in this research used abortion as a coping strategy. The two mothers stated that they struggled to get a 'Fatwa'⁸ to allow for termination. This findings indicated that the mothers undergoing termination of pregnancy faced strong social criticism and shame, not only from the community but also from their family members and close friends. The two mothers who went through the termination expressed enduring feelings of sin of killing their unborn baby, stress of going through a socially and legally unacceptable procedure, and worries about the outcomes of the termination the affected pregnancy with BTM on their health. In addition, they also expressed the fear of going through this experience again; the two mothers described the terminations as unwanted and stressful experiences. Deciding to terminate the affected pregnancy with BTM was for them a brave and strong decision, which they had to make on their own, with reluctant support from the husbands and without any form of social and professional support.

In Jordan the debate about termination of affected pregnancies with thalassaemia increased after the successful adoption of termination as part of the health genetic services in some Muslim countries. For example, selective abortion was allowed in Iran if the foetus was diagnosed with BTM (Strauss, 2009); this strategy has decreased the numbers of newly registered children with BTM (Oseroff, 2011). A reduction of 90% in the incidence of BTM was also reported in Sardinia, because of the adoption of a community education programme, including as free screening tests and selective abortion (Zlotogora, 2009; Oseroff, 2011).

⁸ Fatwa: legal ruling given by a recognised religious scholar in answer to questions on a matter of importance. (Hussain, 2011)

It appears that the Jordanian participants in this study were divided between their own unmet needs and expectations, as well as;

1. Social stigma and criticism associated with termination;
2. The legal and religious debate about termination of affected pregnancies with BTM;
3. The limited professional support, education and counselling.

In practice, it can be argued that the sexual and reproductive health of carrier women is basic to their quality of life. Health care policies need to be reviewed and evaluated, taking into consideration the impact of cultural and religious background on health in the Jordanian society (Ayaz and Yaman-Efe, 2008). In Jordan there are many legal restrictions on abortion, which is only allowed in two scenarios. The first is when the pregnancy is considered life threatening to the mother, or likely to put the mother's health at serious risk.

The second is, which stated also by the Islamic 'Sharia Law' allows termination, when the foetus is diagnosed with either malformation or congenital abnormalities which are not amenable to treatment. In 1991, a fatwa was passed which allowed abortion to be performed before 120 days of gestation if the foetus is found to be malformed or to have congenital anomalies (Hessini, 2007). There are two Jordanian public laws (numbers 21 of 1971 and 54 of 2002) allow termination of pregnancy (UN-Public Health Law, 2011) concurrent with this fatwa. This fatwa was adopted in Jordan and many other Muslim countries (Al-Gazali, et al., 2006). However, it seem that the interpretation of the fatwa varies according to the individual's beliefs, socio-demographic background, religious adherence and the context of their life experiences (Ahmed, et al., 2008).

The law gives Jordanian women the right to choose to terminate pregnancies in the two aforementioned scenarios. However, each case must be assessed individually, evaluated and approved by two licensed gynaecologists before the termination can proceed. In addition, written consent must be obtained either from the pregnant mother, or from her husband or legal guardian if she is unable. Anyone performing abortion outside of these two scenarios is subject to prosecution, which could result in a lengthy prison sentence.

7.3.7 Power and Authority

Socio-cultural and religious factors shape and draw the lines of power and authority within families in the Jordanian community. Arguably, men have more power and authority than women in relation to taking a major decision in life and in setting family rules and regulations, including those related to their children's health. For instance, it was noted that many women had to get permission from their husband to participate in this study. For some female participants, their husband's permission was essential before signing the consent forms or recording the interviews. Another scenario stated by mothers was that their husbands were the only one in the family who had the authority to make decisions on any medical or surgical procedures for the children with BTM and other family members. In cases where the father was not available, only a male figure in the family could give authorisation, and not the mother of the child. This raised the issue of gender inequality in relation to the parents' roles and responsibilities in caring for the children with BTM and gave a picture of the scope of fathers' and mothers' involvement in family health related decisions.

Gender inequality was present in many areas of Jordanian life. To be accepted as good fathers and mothers, and to fulfil their social role in the family and in the community, participants were expected to carry out certain social duties, and to present certain attitudes and behaviours.

Women were expected to be wives and mothers responsible for caring for children and handling household matters, and men were expected to secure employment to be able to financially support their families. Although this attitude is still dominant in Jordanian society, over time there seem to have been some changes and modifications in women's and men's social status, roles and responsibilities. These changes are found more among the modern generation, where the woman's role has expanded to being partners in many other aspects of life in family and society. In practice, mothers' experiences and coping strategies in this sample were different from those of fathers, in terms of their perceptions, roles and duties. Traditionally, mothers tend to take the leading and central role in caring for their children. Consequently, this could eventually lead to mothers relinquishing their paid jobs if they were employed, in order to concentrate on child care (Olsson and Hwang, 2001). The findings showed that all mothers were homemakers; none of them were employed. However, the situation was different for fathers: around 65% had a full time job, 20% had a part time job and 15% were retired or had their own business. Mothers were unemployed despite their educational background, which was found to be more advanced than fathers. The data reveals that around 20% of the mothers, compared to 17.5% of the fathers, had a high school certificate, and around 15% of the mothers compared to 12.5% of fathers had a university degree. This findings also consistent with Yamouri's 2010 study which showed that there was no relationship between women's educational background and employment rate in Jordan. It was noted that despite Jordanian women's educational achievements, only a minority participated in the workforce. This finding is found to be reliable with the World Bank Report (2004) *"Gender in the Middle East and North Africa"*, which indicated that around 26.5% of Jordanian women with university degrees were unemployed, versus 9.1% of Jordanian men. Another supported study by Miles (2002) found that the unemployment rate among Jordanian females was double that of males. It is worth mentioning that, men and

women's employment status influenced on their roles as a fathers and mothers as well as the available time to care for their children with BTM.

7.4 Part Three: Emotional Status

Part three discusses parents' disclosure of the emotional impact of caring for children with BTM. It will cover their satisfaction, emotional burden and grief.

7.4.1 Satisfaction

Parents disclosed positive experiences in terms of their satisfaction with the health care services, the social support they received and their roles as caregivers. Parents stated that they were satisfied with the health care services for many reasons: (a) they improved the quality of their children's life and in some cases minimised or delayed complications; (b) they facilitated parents' roles as caregivers of their children; and (c) they had a positive impact on parents' perceptions of the disorders and children with BTM. Parents reported that they were happy with the safe regular blood transfusions, iron chelating therapy, immunisations and free health insurance for their children. Similar findings were reported by Rifaya, et al. (2011, p.16) in Sri Lanka, where 90% of parents of children with thalassaemia were satisfied with the current available treatments.

In the interviews parents emphasized that they were satisfied with the Jordanian health care services because they facilitate their role as caregivers. For example, the preparation of prescriptions by the physicians made it easier for parents to collect medications, which saved their time by making it available when they accompanied the children for blood transfusion. The data also disclosed that most mothers were satisfied with the support, and management they received and the relationship they had with the staff in thalassaemia departments. For instance, most mothers showed appreciation of the reminder phone calls they received from nurses for their children's blood transfusions, and of the flexibility of

the nurses' schedules. In addition, participants were happy with the scheduling and accessibility of the required immunisations, which served to protect the children from some blood-borne diseases. These findings are in contrast with Prasomsuk, et al's 2007 study in Thailand, where mothers of children with BTM expressed that they were unhappy with the quality of the health care services. Thai mothers expressed that going to the local hospital for blood transfusion was time consuming and annoying.

Some participants in this study were satisfied with the social support they received from partners, friends and extended families, which facilitated their coping and adaptation. This is also supported by Baldwin and Carlisle (1994) and Atkin and Ahmad (2000a). Such social support could be the only support parents received, assisting them in coping and in accepting their situation over time. Psycho-social support is essential to the families caring for children with BTM. Tsiantis, et al. (1982) argued that it necessary in order to assist them in providing comprehensive care.

In some cases, mothers and fathers expressed their satisfaction with their roles as a caregiver to their children. They reported that involvement in the caring plan inside and outside home had a positive impact. It can be said that this satisfaction was based on their feeling of doing their duty and taking their responsibility of being 'a good mother' or 'a good father'. Recognising parents' emotional status would enable them to have a better understanding of their own feelings and those of their partners. Arguably, this could have an impact on family cohesiveness and the marital relationship, which could in turn help them to cope positively as couples and as individuals. In addition, knowing parents' emotional needs would assist the HCPs to provide them with appropriate care, support, education and counselling. Katz (2002a) found that parents caring for a chronically ill child are entitled to have emotional, practical and social support in order to adapt successfully to their experiences.

7.4.2. Emotional Burden

Parents in this study experienced various types of emotional burden, such as anxiety, fear, anger, stress, denial, worry, hopelessness, guilt, frustration and unhappiness. Such emotions were reported in literature. For instance, emotional distress, anxiety and the fear of losing the children with BTM were reported by mothers and families in several literature such as (Hoch, et al., 2000; Fisher, 2001; Chambers, et al., 2001; Sapountzi-krepia, et al., 2006). Denial, guilt and anxiety were reported by Sapountzi-krepia, et al. (2006). In addition, Eccleston, et al. (2004) and Jordan, et al. (2008) found that parents of adolescents with chronic pain reported high levels of stress, anxiety, depression and impaired emotional function.

Mothers in this study expressed their worries about their children's physical appearance, including their skin colour and body structure. Similar worries were expressed by mothers caring for children with BTM in Thailand (Prasomsuk, et al., 2007). Some parents expressed feelings of helplessness over the progress of the disorder, the presence of complications and the life-long treatments. This feeling increased their distress and worry about their children's current health status and their future. These findings were also supported by Atkin and Ahmad (2000a), who found that parents of children with BTM and sickle cell anaemia in the United Kingdom felt helpless and socially isolated. In addition, guilt and frustration are widely reported by children with BTM and their families in the literature such as (Baldwin and Carlisle, 1994; Atkin and Ahmad, 2000a; Sadiq, et al., 2000; Atkin and Anionwu, 2010; Ahmed, et al., 2013). In another study in Sri Lanka, Nahalla and FitzGerald (2003) argued that children with thalassaemia have to regularly attend hospital for blood transfusion in order to survive, which creates a lot of emotional burden for their families. In another study Ghanizadeh, et al. (2006) found that approximately 49% of 110 Iranian thalassaemia major subjects and their families suffered

from depression, and 62.7% had anger and irritability because of their situation. Studies into psychosocial issues faced by the children with BTM and their families discussed the body image and its impact on the affected children and their families. For instance, Atkin and Ahmad (2000a) discussed how the compliance to chelation therapy affected a young person's sense of self and social image, which could result in social isolation.

Some parents in this study expressed their feelings through crying, social withdrawal and grief. Kubler-Ross (1997) argued that expressing feelings could help parents and caregivers to reach the stage of acceptance and be more able to manage their own situation with passage of time. Surprisingly, the findings showed that some participants of teenage children with BTM had feelings of guilt, anger, stress, denial and frustration as in the first year when the children were diagnosed. The first year following their children's diagnosis was described by some families as the hardest time they ever faced, and the feelings still presented a challenge later in life. According to Atkin and Ahmad (2000a), the feelings and stress experienced in the period immediately after diagnosis were not confined to this period, and could continue to be demanding over time. Arguably, having and caring for children with BTM could impair families' social and emotional wellbeing (Liem, et al., 2011), increase the psychological burden (Gill and Modell, 1998) and cause prolonged grief in their lives (Davis and Schultz, 1998; Betman, 2006).

It can be argued that hiding and ignoring their emotions for many years could lead parents to reach a state of incongruence with reality, which in turn could influence their behaviour, thoughts and emotional status (Davis and Schultz, 1998). From the findings, it appeared that some parents had internally refused to adjust to their situation. The idea of caring for and living with affected children was not totally recognised by some participants; they were still living in the past and many of them still had not reached internal acceptance. Their stress was captured in their expression of negative perception. It can be argued that

parents' internal dialogues were not fully answered, and if these feelings were not managed, they could be at risk of developing into psychological or mental problems. This support by Khairkar, et al. (2010) they argued that social anxiety and depression placed parents of chronically ill children at serious risk of mental and psychological disorders.

Surprisingly, some parents stated that they were unprepared in caring for their children even after several years of diagnoses. In practice, this raised the issue of the availability of the assessment of parents' psychological status and social wellbeing to be a caregivers to children with BTM. It can be argued that there is a need to focus on psychosocial therapy for such parents, particularly during the first year following the disclosure of the family's genetic status and the confirmation of the child's diagnosis. The findings also showed that most participants with young adult patients tended to be worried about their children's health in future, and feel hopelessness about their potential to secure employment and be able to raise families. This findings are supported by Aydinok, et al. (2005). Parents felt anxious and scared that their children would need to be financially supported for the rest of their lives because of their inability to secure a job or acceptable income, and would need somebody to care for them because of the risk that they would be unable to have their own families. Arguably, this could be because of the limited social services for this group, and the unavailability of a social care and management plan to address these issues added to their families' fear and concern.

7.4.3 Grief

Parents' grief was one of the core categories of this study's findings. Grief is known as a dynamic, ongoing process controlled by the experiences of loss (Bruce, et al., 1994) and influences parents' attitude, emotions and behaviour. Grief reported in several literature among caregivers who experienced fear of their children's death, helplessness, unpreparedness and anxiety. This was not only the case with BTM, but also with different

haematological disorders and various chronic illnesses such as sickle cell anaemia (Compas, et al., 2001), schizophrenia (Davis and Schultz, 1998), mental disability (Bruce, et al., 1994) and cystic fibrosis (Dushenko, 1981; Bluebond-Longer, 1996; Betman, 2006). The findings of this study showed that participants experienced feelings of grief in the sense of losing their healthy children to chronic illness. Parents felt that they had lost their healthy children and were afraid of losing them completely through sudden death. It was noticed that over time, BTM changed their children's physical appearance and their body structures. For instance, some children have a bronze colour, large flat face bones and protruding teeth. Some parents expressed grief over not knowing how their children were 'supposed' to look like, had they been healthy. They also felt that their children had lost their future, in terms of getting a job, an educational degree or the opportunity to have their own family in the future.

The parents' fears were presented in the interviews in two forms. The first fear was of losing their children through sudden death, which was described as the biggest fear because participants witnessed the death of other patients in the department, who were friends of their children. Participants argued that this feeling was prolonged and became more demanding with time. For some parents, the fear of sudden death was associated with the feeling of hopelessness, as they felt that there was no hope for their children's cure. This findings was also supported by Aydinok, et al. (2005) and Pruthi and Singh (2010). Although death had not occurred, parents were keen to keep their children for as long as possible by improving their health status, giving them the required medications, accompany them to blood transfusion and maintaining their wellbeing by caring for and supporting their diet and protecting them from accidents and injuries. For a few parents, these concerns and fears had a positive effect. They utilised the available time with their children effectively and positively, on the assumption that their children might die at any time.

Such parents tended to spend as much happy and productive time as possible with their children, because it was believed that their life span was limited. This positive attitude also impacted on parents' daily moods and behaviour.

The second fear was of BTM as a result of the chronicity of the disorder burden, progression, morbidity, the complications, the lifelong treatments and its side effects. BTM complications were reported as one of parents' fears, as in some cases parents saw that complications could disable their children, increase their risk of having to undergo invasive procedures, and cause the need to administer more medications. Similar findings reported by Mazzone, et al. (2009), who found that the nature of the disorder and its complications were the main factor causing a psychological burden to patients and their families. In addition, Klein, et al. (1998) found that the early presence of clinical deterioration, regular blood transfusion and frequent invasive procedures caused significant suffering for children and their families. Parents worried about their children's future because they witnessed other children with thalassaemia in the same departments with various complications such as heart and spleen disorders. The same concerns about children's future and their health status were found by Prasomsuk, et al. (2007) when they interviewed mothers of children with BTM in Thailand.

This study findings showed that some parents tried overprotecting their children with BTM. It can be argued that participants' focus on overprotection could be one of their ways to adapt and to decrease the negative impact of BTM on their children, or due to worries, fear and the feeling that their children were vulnerable to many risks. Some participants dedicated themselves to protecting their children from any harm by minimising the risk of common health problems related to sports such as injuries, bleeding, trauma or fractures. For example, mothers revealed that they tried to limit their children's school and social activities. Similar findings were reported by Mazzone, et al.

(2009), who found that an overprotective attitude was often experienced by mothers of children with BTM. In another study, Tsiantis, et al. (1996) argued that overprotective behaviours from parents caring for children with BTM was part of either pathological or adaptive denial of the burden imposed by the illness.

Another overprotection behaviour from parents was to spoil children and try to meet all their needs, whatever their financial situation, or sympathise more with them. It can be argued that, this response could affect other family members, and could result in unintended neglect of the needs of other families' members and especially their siblings, which is also supported by Tsiantis, et al. (1996). It can be argued that this behaviour could also result in more financial constraints on the family budget. This findings is also in accord with Foster, et al's 2001 study, which found that parents of children diagnosed with cystic fibrosis experienced high level of parental involvement for their younger children and older teenagers' care, resulting in less attention to their siblings while the patients' needs take priority.

7.4.4 Grief and Gender

Grief is an individual experience, even among people experiencing the same loss. This study found that cultural, social norms and religion influenced both parents' grief and their emotional responses to their situation. The findings of this study indicated that only one father reported crying in public after he was informed that his child had BTM, compared to many women who reported that they had more opportunities to express their feelings. It was noticed from the data that women were allowed culturally to express their grief through crying and screaming in public, a finding which is also supported by Davis and Schultz (1998) and Betman (2006). However, the same would not be acceptable for men. Socio-cultural norms dictated that men had to be appear more emotionally controlled and competent and avoid expressing their feelings in public (Jacobs, et al.,

1986; Betman, 2006). As mentioned earlier, parents' social roles and responsibilities affected their emotional responses and grieving (Bruce, et al., 1994; 1996). The findings showed that sources of fear, grief, anxiety and unhappiness were present in mothers' experiences more than those of fathers. It could be argued that the mothers spent more time with children than fathers did, as they considered the primary caregivers and were thus more expressive of their emotions. Betman (2006) argued that the amount of time fathers and mothers spend with their chronically ill children determines the amount and the frequency of the stress they faced and the risk of experiencing grief. Furthermore, men's and women's perceptions had an impact on their experiences and grieving. Arguably, this could be because individuals perceived life events differently; either negatively or positively based on their knowledge, experiences, social and cultural background, which is also supported by (Katz, 2002b; Betman, 2006).

Another area highlighted by mothers in this study was the fear of having another child with BTM, unplanned pregnancy, abortion, stigma and social conflicts with their families in law. Inconsistencies with families in law could be expressed threats resulting in changing mothers' marital status through divorce, separation or their husband taking a second wife. It was noticed that the socio-cultural barriers mothers faced in this study complicated their experiences, added to their fear, grief and increased their stress levels. For instance, some mothers had conflicting feelings about having a termination of their affected pregnancy with BTM, while at the same time wanted more children in the family.

7.5 Part Four: Personal Coping Strategies

This section highlights the personal coping strategies used by fathers and mothers in adapting to their situations. The findings showed that parents' coping strategies were affected by their faith, socio-cultural background, gender and time. In addition, the child's characteristics and the social support parents received also shaped their coping strategies.

7.5.1 The Coping Process

Coping strategies were identified as efforts to reduce the negative events in life where there was physical and psychological pain (Snyder, et al., 1987). There is no standard way to treat or reduce threats; rather, a coping strategy is an individual's way of managing life situations (Van Heck and De Ridder, 2001). Moreover, coping is known as an active, multidimensional process (McCubbin, et al., 1996) and refers to the ways in which people deal with stress (Goldbeck, 2001). In this study I made no distinction between parents' coping as negative or positive, because everyone copes differently under the same conditions in order to reduce, control or minimise the sources of stress, whether internally or externally. This was also supported and reflected in the literature such as (Folkman, 2001; Stroebe and Schut, 2001; Betman, 2006).

Parents in this study showed various ways of coping. In some cases it depended on their child's growth and development stage, age and phase of BTM. This is also supported by Hall and Docherty (2000), who suggested that there are many variables underlying parents expressed emotion, so both parent and patient characteristics and the interaction between them must be assessed and examined. However, some literature such as (Beresford, 1994; Atkin and Ahmad, 2000b) seems to suggest that coping with the psychological consequences of the disorder was not directly related to the severity of the child's health condition. Hall and Docherty (2000) argued that there is an interaction between parent coping style and schizophrenic patient behaviour.

The findings showed that fathers and mothers presented a wide range of dissimilar coping strategies to adapt to their situation. Similar findings were reported by Goldbeck's 2001 study, in which a dissimilarity in coping was found between fathers and mothers caring for children with cancer, which could impact on other family members. However, the findings also showed that there are some similar strategies used from both fathers,

mothers and couples. It was noticed from the findings that the religion was the dominant similar strategy. This finding supported by Goldbeck (Ibid) study, which is found that the strongest similarity between mothers and fathers coping strategies seemed to be religion. Furthermore, the findings revealed that some participants in this study had adopted various personal coping strategies at different stages from the time their child's diagnosis was confirmed, extending into adulthood. It can argued that caring for children with BTM is an ongoing active process requiring range of knowledge and skills in each stage. Some participants described their coping as negative, while others considered them to be on the positive side, this could be related to the variation in participants' backgrounds and characteristics. However, living and coping with haematological disorders such as thalassaemia is "*a complex and dynamic process*" (Atkin and Ahmad, 2001, p. 625) for the patients and their caregivers.

7.5.2 Coping Models

The findings indicated that participants adopted the following models in their coping strategies: (a) the engulfment model; (b) the balanced-boundary model; and (c) the medical model (Twigg and Atkin, 1994; Lewis and Meredith, 1988). The participants either adopted one of them or alternated between them with time.

A. The Engulfment Model

The findings showed that most mothers in this study were totally involved and dedicated their lives to caring for children with BTM. They fell more into the engulfment model, in which care for the children becomes the centre of their life, than fathers did. Atkin and Ahmad (2000a) found that there was a correlation between engulfment and the burden of the child's condition. They found that the engulfment increased when the child's condition deteriorated and reduced when it improved. The findings showed that some

mothers found it difficult to separate themselves from their child's situation. They dedicated themselves to care for their children, and limited entertainment and social activities. In addition, they restricted their engagements with family members, friends and the community in order to care for their children. This became more obvious when the children had blood transfusion sessions, surgical interventions or medical procedures. For instance, some mothers in this study cried, were stressed, expressed denial and were upset during their children's blood transfusion sessions, which is described by some as the 'day of sadness'.

B. The Balanced-Boundary Model

The findings showed that fathers tended to be in the balanced-boundary model more than mothers did. In this model, the participants were able to maintain a balance between ongoing care for children with BTM and their own lives. Lewis and Meredith (1988) argued that caregivers could maintain some autonomy by separating themselves from their situation. The findings showed that fathers tended to keep up with their work and social activities more than their wives did. Similarly, Atkin and Ahmad (2000a) argued that men were more able to keep a balance and sense of autonomy than women when they care for children with BTM.

C. The Medical Model

Most participants in this study coped through embracing the medical model. This finding is supported by literature such as (Battiato, 1990; Darr, 1990; Atkin and Ahmad, 2000a). In this model, parents adhered to the medical health instructions and treatments including blood transfusion, iron chelating therapy, required immunizations, mineral supplements and diet instructions. Overall, this enhanced their children's health status and improved the quality of their life. This was also suggested as one of the positive coping strategies used by parents in caring for their sickle cell children (Hill, 1994a, p.155).

The study found that embracing their role as caregivers was one of participants' coping strategies, through:

1. Sharing in their children's therapy by administering the medications (the iron chelating infusion or the oral form) at home;
2. Accompanying them to blood transfusions, which gave them the feeling of control and choice in assisting their children.
3. Managing their children's diet, exercise and daily activities.

The findings showed that participants' involvement in home care for their children with BTM encouraged and positively influenced their coping and decreased the feelings of guilt. Similar findings were reported by Betman (2006) in parents caring for children diagnosed with cystic fibrosis. It can be argued that parents who engage with their children's health care plan and who embrace the medical model can have an opportunity to increase their knowledge and experiences of treatments and complications, through spending more time and communicating more with the nurses and HCPs. In addition, it could help parents to know how to utilise the available health services. Ahmad and Atkin (1996) argued that the stability and the steady progress in patients' health status could also give more credit to the medical model, which reflects the findings of this study. Despite acknowledging that caring for their children is their primary social and cultural role, some mothers claimed that their husbands relied totally on them. This increased mothers' feeling of coping on their own and taking responsibility alone, instead of being shared between them as partners and parents.

7.5.3 Coping and Gender

It was noted from the research findings that parents' individual coping behaviours were based on the gender and personality. For instance, fathers in this study tended to use practical behavioural coping strategies more than mothers did. Reading, smoking or

changing their marital status are examples of the fathers' coping strategies. However, mothers' strategies tended to be more emotional and spiritual. For instance, crying, expressing feelings of anger, praying and reciting the Holy Qur'an. However, some mothers also had some behavioural coping strategies, such as using contraceptives to prevent more pregnancies and isolating themselves socially. It was clear that the difference in mothers' and fathers' coping was not only behavioural but also cognitive. The study found that mothers' response and understanding of BTM as a haematological disorder were different from those of fathers. For instance, it was noted that mothers had more negative attitudes towards their experiences, than fathers had.

Interestingly, women used a wider range of coping styles and strategies than men did, which supported by (Katz, 2002b; Betman, 2006). However, Mastroyannopoulou, et al. (1997) argued that the emotional style, which was used commonly by women, can place them at high risk of having psychosocial or mental disorders.

This study revealed that participants differed in their coping and adjustment. For instance, some parents coped and adjusted effectively to their situation while others apparently did not. Fathers and mothers in the interviews showed different coping strategies towards children with BTM based on many factors, such as their knowledge, experiences, socio-cultural and religious background. Folkman (2001) argued that personal characteristics and the social environment influence individual coping strategies, which also contribute to successful adaptation to psychological stress. Utilising all available mechanisms helps to achieve stability and to enable the individual and the families to function successfully. Folkman (2001) found that parents' dynamic coping changed over time, based on the stage that their children were in as well as the circumstances of their social life. In addition, BTM progress and the complications of their child's was found to be one of the factors

alongside compliance with the treatment and the quality of the health services used (Baldwin and Carlisle, 1994).

A. Mothers' Coping

The findings showed that most mothers aimed at not having another child with BTM in the family but rather assist their children and family members adapting to their situation. Some mothers' coping strategies mainly focused on avoiding having further pregnancies to minimise the risk of having another child with BTM. To achieve this, mothers can access abortion as part of the genetic services programmes of many countries worldwide, but not yet in Jordan. The findings showed that two mothers in this study had an abortion as a last resort after failing to avoid further pregnancies. However, most mothers avoided abortion in order to escape the social stigma, shame, the sin and cultural pressure which are associated with the termination of pregnancy, as discussed early in this chapter (see section 7.3.6).

The findings revealed that crying was one of the mothers' main emotional coping strategies to express their feelings. Furthermore, crying was evident in cases where the mother was still in a state of denial, grief and rejection of their situation. In the interviews, four mothers cried while they were expressing their feelings of sadness, self-blame and grief for having and caring for children with BTM; despite their crying mothers chose to carry on with the interviews. This raised issues about mothers' psychological wellbeing and their ability to care and support their family members. Such mothers with prolonged sadness and stress had negative perceptions of their experiences. This was also found in Betman's 2006 study, in which it was found that mothers' negative perceptions were associated with self-blame for passing the genetic defect to their children.

In the social domain, to avoid stigma, mothers used various personal coping strategies, such as isolation, disengagement, limiting social activities and hiding the fact that they

have and caring for children with BTM. This finding is in accord with previous studies among other chronically ill population. For instance, Davis, et al. (1998) found that maternal adjustment in fifty two mothers of children with congenital heart disease was associated with high level of daily stress.

B. Fathers' Coping

The data showed that fathers mainly tended to keep themselves busy with work and stay away from home which it could be as one of their coping behaviours with their situation. In addition, some fathers used reading, smoking, social isolation and, for some, change in their marital status as their way of adaptation. However, some fathers struggled to meet their needs and cope with the socio-cultural pressure related to the gender preference in society. This was more pronounced in cases where the only male child in the family diagnosed with BTM, and issues arose of having a second wife in order to have a healthy male child. This strategies were supported by several literature such as Lillie-Blanton, et al. (1993), Katz (2002b) and Betman (2006) which argued that men's coping strategies tended to fall more in the cognitive and behavioural domains.

The findings showed that fathers experienced traditional, cultural and social pressures to appear well and to be able to cope and show their ability to adapt to their situation. Most fathers in the interviews said that, they have to keep saying that "*I'm ok*", "*I'm fine*" or "*I'm doing well*", even when they were not. Some of them struggled to hide their feelings and emotions, to ensure that they had the ability to cope with their situation. Complex socio-cultural issues and fathers' fear of not fulfilling their expected roles in the family, as well as their fear of being unable to cope, in many cases could resulted in fathers hiding the real issues with which they faced. For instance, fathers' employment and the limited time were mentioned as some of the barriers that limited their involvement in accompanying their children in hospital.

The data showed that two mothers who were not related to their husbands before marriage, were divorced when they had a child with BTM. The mothers stated that the reason given by their husband was that they had not known that they were carriers of thalassaemia gene. In other cases, two mothers were abandoned by their husbands, who took second wives following the birth of the children with BTM. This indicated how thalassaemia impacted negatively on the marital relationship. This contradicted the findings of Tsiantis, et al's (1996) study, which found a very low of family break-ups in Cyprus, Greece, Italy and the United Kingdom. Tsiantis, et al. (Ibid) argued that this could indicate that thalassaemia had a binding effect on the family where the couples were known to be carriers. In other chronic illnesses such as sickle cell disease, Hurtig (1994) found that the parents and their affected children reported variance in quality of relation but a broad base of positive relations. Hurtig (Ibid) argued that the knowledge and the social support from the community made significant contributions to the positivity in that relationships.

This study highlighted important issues which emerged from the findings, including that there was no forum for fathers to discuss and express their feelings. Even inside their own families, they were expected to take the supportive masculine role and show their ability to handle any family challenges. In addition, men's roles, duties and responsibilities in Jordanian culture in terms of caring for chronically ill children were not adequately addressed in the media, education and in the community. The situation was reflected in fathers' coping strategies, such as going out to spend time with friends. Arguably, this could indicate that fathers expressed their limited communication not only in their experiences but also in strategies for coping and dealing with other family members. In summary, it can be stated that the less time fathers spent with their children, the less they expressed their emotions towards them (Davis and Schultz, 1998).

Fathers in the interviews mentioned that their primary role was to support their wives and family members. A similar finding was reported by Stinson, et al. (1992), who found that men had difficulty receiving support, and that this was related to their expected social role. This role is to be strong, to control their emotions, and to give support to their partner and family members in times of stress and when needed. For mothers, the scenario was different, as they were more emotional and socially active, and sought support from others.

Most fathers demonstrated their ability to control emotions in front of others when the child's diagnosis with BTM was confirmed and found out that they were carriers. Some fathers stated that this was the most difficult and stressful period in their life. A similar discussion was found in Cook's 1988 study of men's ability to control their feelings in public and handle themselves in crises and stressful situations. Arguably, emotional control was an important coping strategy for men, improving their self-confidence and giving them the ability to control different stressful situations.

C. Couples' Coping Strategies

The data showed that mothers and fathers coped individually, and for some couples their experiences and coping strategies were correlated. Folkman (2001) argued that an individual's coping strategies were influenced by their relationships, personality and life experiences. Furthermore, fathers' and mothers' emotional well-being were highly correlated, as stated by Tsiantis, et al. (1996).

Men usually appeared to be less affected by emotion than women did. They tried to cover their emotions by keeping themselves busy, which was one of the mothers' sources of worry in this study. Some mothers accused their husbands of not caring and not effectively sharing in children's care. It could be argued that the mothers needed to understand that this behaviour, for some men, could be a way of adapting and coping with their situation. Lack of knowledge about the differences in partners' coping strategies

could affect their support to each other and their understanding of their partners' behaviour. For some couples, this could result in a gap in their marital relationship and parenting status. This might be the reason why it is important for each side at least to understand their partner's coping styles, in order to carry on positively and effectively. This gap in the participants' knowledge could impact on their role as carers and the quality of care they delivered to the children with BTM. A similar finding was reported by Copeland and Clements (1993) and Betman (2006), who argued that the lack of knowledge and misinterpretation of the partner's coping style and strategies had implications on marital relationships and family management. Parents need to identify their own and their partner's coping strategies to be able to evaluate their available options and choose the best way for them to cope, adapt and adjust to their situation as partner and caregivers. Melnyk, et al. (2001) found that empowering parents and educating them about problem solving techniques could assist them in understanding and developing better coping strategies.

Interestingly, the findings showed that parents' coping strategies, knowledge and understanding impacted on children's coping with their situation. For example, some mothers in the interviews complained that their teenage children with BTM become smokers, who probably copied their father's way of coping with stress. Arguably, this could be another reason why parents' coping strategies need to be evaluated by nurses and HCPs in order to assist them to cope effectively and positively.

Social isolation as a coping strategy used by both fathers and mothers could limit parents' access to available information and support from the extra-hospital community. The findings indicated that most fathers in this study tended to keep their network limited to their partner and occasionally to some family members. In addition, fathers rarely sought extended social support or help. The scenario was different for mothers, whose social

networks were found to be more extended, as noted in the interviews. The findings revealed that mothers felt freer than fathers feel to talk about their children's condition and to ask for support from their partner, friends and family members. Fathers were found to be reluctant to seek support from outside family members or from HCPs. Interestingly, most fathers in the interviews focused on the idea that their role was to be the one who gives support but does not receive it. Liem, et al. (2011) found that Asian and Indian families in the United States of America experienced limited social support resources, and had a desire for privacy and not to communicate about their children's health condition. Their perception that others lacked knowledge of BTM was the reason given for not seeking support or discussing their children's issues.

7.5.4 Religion as a Coping Strategy

The data showed that all participants in this study were from the Muslim community. Unfortunately, none of the participants was a Christian, so it was not possible to capture the impact of Christian beliefs on coping. However, Kelleher and Islam (1996) and Hill (1994b) stated that various religious beliefs had an impact on coping strategies. In addition, the phenomenon of using religion as a coping strategy is not only confined to Islam, but is also reported across various religions, such as Christianity, Hinduism, and Judaism (Selway and Ashman, 1998). The findings showed that most participants emphasised that their faith gave them strength, which was intrinsic to their coping strategies. Similar findings supported by the literature such as (Bywaters, et al., 2003; Diken, 2006; Michie and Skinner, 2010). Not only in case of thalassaemia but Gray (2006) argued that some families relied on their faith to cope with caring for their children diagnosed with autism.

Members of the Jordanian community are considered strong religious believers. Religion affects most aspects of life, including socially, politically, economically and in terms of

health. Since Jordan is predominantly a Muslim country, there are many rules and regulations issued based on Sharia Law. It is worth mentioning that religious beliefs, practices and cultural understanding were embedded, regulated, and influenced parents' lives. Hirschman (2004) argued that religious values support traditional beliefs and patterns related to gender issues and customary practices. The findings presented that participants adopted various religious beliefs and practices dealing with their situation. For instance, parents believed that God can cure any health illnesses or disorders, whatever their complexity, at any time. This gave some parents the strength to keep a positive attitude toward their situation and the hope that their children with BTM would return to normality and begin to live healthy. A similar finding was reported by Weisner, et al. (1991), who found that religion impacted on and positively affected families' experiences.

Parents' cognitive coping was composed of beliefs and perceptions, developed from their religious background and based on their knowledge and experiences. Religious practices were more evident at times of crisis and stress. In such instances, parents increased their prayers, recitation of parts of the Holy Qur'an and doing more charity, which supported them emotionally, improved their understanding, empowered them spiritually, and decreasing their feelings of guilt. Likewise, Atkin and Ahmad (2000a) found that in mothers of children with sickle cell disease, coping with the symptoms of their children's illness was enhanced through their spiritual strength gained through the prayer. Arguably, parents' faith and trust in the available medical treatments resulted in a positive attitude toward their children.

Based on their religious beliefs, most of the participants in this study accept their situation as part of their 'destiny'. Most of them believed it was God's will, and therefore could not be questioned. It can be argued that such beliefs minimised their feelings of guilt and

answered the “why me?” question. This findings supported by Ahmed, et al. (2013), who argued that religious beliefs empowered parents and gave them positive perspectives toward their situation. Bryant, et al. (2011) and Ahmed, et al. (2013) found that parents of a child with BTM socially stigmatised, and therefore for some of them a perception that having a child was a punishment from God developed with time. Interestingly, in this study participants believed that God was not punishing them, but testing them in this life, and that their perception and behaviours could decide if they were able to pass the test or failed. They believed that a big reward awaited them either in this life or in the afterlife, with blessings from God if they were patient, accepting of their situation, and behaved according to their religion. The findings showed that mothers focused on religious beliefs and practices as a way of coping, which gave them a feeling of internal peace, that they were supported and blessed by God, and that their suffering and pain would be rewarded. This resulted in positive attitudes toward their experiences in general, which helped them to maintain the provided care to their children with BTM. Parents’ faith strengthen the relationship with their children, in terms of social support, physical care and positive attitudes toward them. In addition, faith resulted in behaviour change, as some parents stopped complaining about their situation because reassurance came from God ‘the almighty one’. In addition, parents’ spiritual strength due to their faith led them to behave patiently, helped some of them reach acceptance level with the passage of time, and assisted other to adapt more positively.

Participants’ positive attitudes increased their collaboration and communication with nurses, HCPs and other parents in the departments. Consequently, it led to the sharing of more information. Furthermore, this study showed that parents used a variety of religious practices to treat their children. It can be said that, religious practices empower the couple's role as a caregivers to the children with BTM, brought emotional stability to their life, and increased their marital satisfaction and family relationship.

It also noticed that religious activities were conducted by parents to assist, support their children and empower them spiritually. These activities carried out by parents themselves or with their children. For instance, some parents reading the Holy Qur'an frequently, visit 'Mecca' for pilgrimage and performing special prayers. In other scenario, parents performing special prayers with their children and giving them the holy water 'Zamzam', which was believed to reduce the level of iron in their blood. Comparable findings were reported by Fiese and Tomcho (2001), who they found that marital satisfaction was related to religious holiday practices, when couples found themselves closer to the ritual meanings and the routine practices. They also found that connections between family members were generated through various religious practices. In addition, faith affected religious parents' emotional adjustment and their perceptions of their children. However, participants in this study revealed some diversity, even within families, since fathers' and mother's beliefs and preferences were unique and individual. Some participants felt that caring for their chronically ill children empowered them emotionally and socially, and gave them focus and meaning in their lives.

Participants' faith impacted on their decision making, in carrying out the antenatal diagnostic tests and terminations of affected pregnancies by BTM. The findings showed that some participants believed that termination of affected pregnancies, was a sin, citing some statements from the Holy Qur'an as evidence that selective abortion was indeed forbidden, unethical and illegal. For some participants, termination of an affected pregnancy meant killing an unborn child, a belief which stopped some parents undergoing the antenatal diagnostic tests. For instance, many participants mentioned the following statements from the Holy Qur'an:

“Whoever, has spared the life of a soul, it is as though he has spared the life of all people. Whoever, has killed a soul, it is as though he has murdered all of mankind.” (The Holy Qur’an, al-Ma`idah. 32:6).

“Kill not your offspring for fear of poverty; it is we who provide for them and for you surely, killing them is a great sin.” (The Holy Qur’an, al-Isra`.31:15)

The debate about termination of affected pregnancies was confusing to most participants in this study, because of the fact that different religious parties have different stances toward abortion. In the absence of a ‘fatwa’ in the Jordanian health care services and support from the religious leaders in the community, the findings exposed that parents had limited choices which could lead to unpleasant decisions. The open debate about termination of thalassaemia-affected pregnancies left parents to make the choice on an individual level. Abortion in the case of foetus deformity was for some parents the best choice. However, for parents of children with thalassaemia, it was not an available option at the time this research carried out.

The findings revealed that it was considered acceptable for parents to go through antenatal genetic tests. However, some parents indicated that it was pointless, as abortion was an illegal procedure and was religiously perceived as immoral. This finding was similar to the findings of other studies such as (Bryant, et al., 2011; Ahmed, et al., 2013) on genetic tests and counselling, which found that in many Muslim communities, the genetic screening tests were accepted, but that termination of the pregnancy was considered immoral and unethical in case of affected pregnancy with BTM. It can be argued that participants’ attitudes toward termination of affected pregnancies was greatly affected by their religious values and beliefs. The same findings were reported by Alkuraya and Kilani (2001) when they interviewed 32 Saudi families with hemoglobinopathies, where the majority 81.3% accepted the prenatal diagnosis and 87.5% refused the idea of abortion

as an initial response to the question and 96.4% stated that religious reasons for their rejection of the abortion. Another supported study by Ahmed, et al. (2000) found that Pakistani parents sought 'Fatwa', religious decrees to terminate pregnancies only in cases of severe foetus disorders, but not in case of BTM. The same issue also reported in Malaysia, where Wong, et al. (2011) found that 63.4% out of a total of 3723 responding Malaysian participants were unsupportive of the selective termination of fetuses diagnosed with BTM.

7.5.5 Parents' Understanding of their Child's 'Normal' - 'Abnormal' Status

The findings of this study showed that participants' perceptions of and attitudes toward children with BTM were varied. Some parents were aware that their children would never be the same as before the diagnosis, and expected them to die at a certain age. Arguably, this perception could be as a result of the side effects of iron chelating therapy and the complications. For other parents, this perception was based on previous knowledge, and experiences of witnessing the death of other children in the same department. Some other participants believed that the BMT the only cured method could treatment their children but they stated that their children would never be normal again even after having the operation. They believed that their children would continue to receive certain medications and perhaps occasionally blood transfusion. Furthermore, some participants accepted that children with BTM were physically not as well developed as their healthy peers. However, some considered them as normal in terms of their physical ability because they could play with friends and siblings, were successful in their academic performance at school, and could independently perform daily living activities both inside and outside home, as could other ordinary children of their age. Other parents perceived their children as normal due to their physical appearance, in cases where there was no skin pigmentation or other changes in body structure. Some participants argued that the absence of skin pigmentation

minimised the social stigma that they could face, this was supported by Darr (1990). Similar findings were reported by Eiser (1994) for mothers caring for children diagnosed with sickle cell disease. In Eiser's study, normalisation, positive framing and optimism were found to be effective as coping strategies by some parents caring for their chronically ill children. However, Hill (1994b) argues that for some parents, normalisation was a type of denial of the diagnosis and progress of BTM. Arguably, normalisation could be both way for some participants to cope with their children's situation, and for others, a denial of their situation.

Based on the literature reviews (see section 2.6.1), it can be said that some of the children with BTM often experienced challenges regarding their growth and development. The findings indicated that some parents tried to compensate for the feeling that they had 'lost' a healthy child by arguing that the children with BTM had more ability than the healthy ones. For example, mothers insisted that their children's academic achievements were more advanced than those of healthy children. In other cases, parents stated that the children with BTM had special capabilities, outstanding performance, qualifications and academic strengths that enabled them to access education and develop socially better than ordinary children.

7.5.6 Time

Participants showed that over time, they were able to obtain more information and gain a better understanding of their child's situation, which helped them to adjust positively to their new situation. For some participants, time was the main factor in coping with their situation, as over time their acceptance increased and they learned more about various effective coping strategies. This finding was also supported by (Atkin and Ahmad, 2000a) who found that with time, parents adapt effectively.

In interviews, parents' narrated their life story, which started for most of them from the first year following their child's diagnosis. Participants argued that with time, they became more tolerant, and had better understanding of their child's condition and the caring process. Arguably, parents' ability to cope more effectively over time could also be connected to the social support and the treatments their children with BTM had. From their stories, most parents argued that the most critical time for them was the first year after their child's diagnosis. Arguably, this year could therefore be the essential time when social support, education and counselling were needed the most. The same arguments was made by Tarkka, et al. (1999), who found that social support and aid from public health nurses were positively correlated with how well first time mothers coped with their situation. In conclusion, the findings showed that participants' faith and the social support they received, with the passage of time, assisted them to cope effectively with their situation.

7.6 Conclusion

The study findings reflected participants' experiences and coping strategies in relation to the day-to-day issues of children with BTM. Parents' experiences and coping strategies were affected by the constant changes in their child's health status. The research findings were focused on the participants' knowledge, emotional status, their personal coping strategies, and the impact of the social, cultural and religious values on their experiences and coping strategies. The discussion in this chapter presented how the research findings support and challenged some of the literature. Furthermore, the discussion highlighted the areas which need to be addressed by the nurses and HCPs to support and empower parents in their social process and their journey in caring for children with BTM. The suggested recommendations to the various stakeholders will be summarised in the next chapter.

Chapter Eight: Conclusion

8.1 Introduction

The study was conducted with the aim of gaining a better understanding of Jordanian parents' experiences and coping strategies in caring for children with BTM.

Specifically, the research questions were:

- What are the key experiences of Jordanian parents of children with BTM?
- In what ways does caring for a child diagnosed with BTM impact on the parent's life?
- What are the coping strategies of Jordanian parents of children with BTM as described by the parents themselves?

The recommendations to various stakeholders are presented along with general conclusions.

8.2 Summary of the Study Findings

This study filled the gap in the literature; support and challenge previous findings. Through explored the experiences and identified coping strategies of Jordanian parents of children with BTM and highlighted the impact of the culture, religion and the social norms on parents' experiences and coping strategies. The findings revealed that caring for children with BTM was a challenging and uncomfortable experience for most participants. Parents' negative experiences were seen to be related to their lack of knowledge of the condition and its treatment, the psychological burden and socio-cultural barriers, as well as lack of health education, support and counselling from nurses and HCPs. However, the positive side of parents' experiences related to the satisfaction with health care services, being a caregivers and the social support. It is possible that parents

of chronically ill children are more likely to openly express their dissatisfaction with the child's situation, simply because of the amount of experience they are likely to have had. In addition, negative experiences were related to the nature of the disorder itself and the day-to-day requirements of caring for their children. For instance, the children were totally dependent on blood transfusion and iron chelating therapy meaning that they needed constant care. More than this, their constant care demand caused parents to worry about their children current status and their future. These concerns were exacerbated by socio-cultural restrictions on their private life and the lack of emotional support from health care workers. These findings reflect the work of other researchers (c.f. Mazzone, et al., 2009; Liem, et al., 2011) but the real depth of parental suffering is laid bare in this present study.

The availability of social support and the accessibility of health care services played a major role in supporting and assisting parents to cope effectively with their situation. The findings showed that participants coped through adopting a variety of strategies. Some parents coped through engulfment⁹, others through the balancing-boundary model¹⁰, and most parents embracing 'the medical model'¹¹ in compliance with medical advice. Parents' faith had a positive impact on their ability to cope. Parents found some comfort in knowing that their child's condition was God's will and part of his destiny for them all as a family. This belief diminished feelings of self-condemnation and self-blame. For example, parents believed that God could cure their children, and if this did not happen in this life, they and their children would be greatly rewarded in the afterlife. It is worth mentioning that most participants stated that with time: (a) they developed more positive

⁹ Engulfment Model, in which the participants care for their children becomes the centre of their life. (Twigg and Atkin, 1994; Lewis and Meredith, 1998).

¹⁰ Balancing-boundary Model: The participants were able to maintain a balance between on-going care for their children and their own lives. (Twigg and Atkin, 1994; Lewis and Meredith, 1998).

¹¹ Medical Model: In this model, the care givers adhered to the medical health instructions and treatments. (Twigg and Atkin, 1994; Lewis and Meredith, 1998).

attitudes, (b) expanded their knowledge and (c) gained better understanding of their children's situation.

8.3 Answering the Research Questions

The three research questions designed for this study were as follows:

8.3.1 Question Number One

What are the key experiences of Jordanian parents of children with BTM?

On the one hand, parents revealed that their experiences were positive because of the:

1. Free medical insurance and conservative treatments for their children;
2. Accessibility of the premarital screening programme;
3. Social support they received from their partners, families and friends;
4. Their role as caregivers to the children with BTM inside and outside the home.

On the other hand, parents revealed that their experiences were negative because of:

1. The lack of knowledge about their own health history on whether or not they were carriers of the defective gene; most parents in this study learned about the disorder only when they had a first child born with BTM;
2. The lack of understanding about thalassaemia itself: participants showed inadequate understanding of the nature, origin, clinical manifestations and complications of BTM;
3. The socio-cultural barriers, which included stigma and social pressure, which also extended to all family members;
4. The limited support and counselling parents received from the HCPs.

8.3.2 Question Number Two

In what ways does caring for a child diagnosed with BTM impact on the parent's life?

1. The study found that having and caring for children with BTM causes an important psychological burden on parents;
2. BTM impacted on parents' perceptions towards their children's health status. Some participants feel that they had lost the healthy children they had expected in the family. Moreover, with the passage of time, parents experienced continued losses because of the changes in children's physical appearance, the complications of BTM, or sudden death;
3. The socio-cultural barriers limited parents' social activities and led some to social isolation in an attempt to avoid stigmatisation.

8.3.3 Question Number Three

What are the coping strategies of Jordanian parents of children with BTM as described by the parents themselves?

The coping strategies revealed in this study were as follows:

Mothers' coping strategies were:

1. Avoiding pregnancy not to have more children with BTM in the family;
2. Termination of the affected pregnancies, although this was sparingly used because of the socio-cultural and religious beliefs;
3. Expressing their feelings, through crying to gain a sense of emotional relief.
4. Communicating and chatting about their situation and seeking social support.

Fathers' coping strategies were:

1. Reading about thalassaemia;
2. Smoking: some fathers stated that their smoking habits increased due to increase their stress level;
3. Changing marital status: some fathers change their marital status by getting a divorce or separation, or by having a second wife;
4. Spending more time either at work or with friends.

Shared strategies used by both mothers and fathers as a couple:

1. 'Keep it secret'; hiding the fact that they were carriers or had a child with BTM.
2. Social isolation was used in order not to communicate, interact with or talk about their children with BTM in public.

8.4 Study Recommendations

Based on the research findings and considering the study limitations, the following recommendations are offered, to encourage more attention to the experiences and coping strategies of Jordanian parents of children with BTM. The recommendations are addressed to multidisciplinary team including health care and social services, community members, researchers and to the education system. Greater inter-professional collaboration and a new focus on the emotional welfare of such families could better support, empower and enable these families to fulfil their life goals and achieve wellbeing. The multidisciplinary team need to adopting a comprehensive approach, and to work towards placing the children and their families at the centre of their care plan, focussing on partnership and collaboration with each other. Arguably, the multidisciplinary team has the ability to empower these families and to advocate for their rights in the health system and in the community.

8.4.1 Short Term Recommendations

This study recommends that there is a need to:

1. Improve on and encourage fathers' involvement in hospital care. For instance, some modifications in the daily work schedule to make the health services available either at weekends or in the evening so that fathers are better able to attend with their children.
2. Consider gender balance in staffing, as the availability of male nurses may have an impact on encouraging fathers' involvement in hospital care.
3. Highlight the parents' psychosocial needs, their understanding and interpretations of the received information.
4. Conduct educational and counselling sessions to give these families the opportunity to clarify their own issues and to have their questions answered. These sessions could be offered in various forms; individual, couple and groups depending on their social, cultural and religious background as well as based on their health care plan.

8.4.2 Medium Term Recommendations

This study recommends that there is a need to:

1. Review the medical laboratories' rules and regulations, in order to maintain the accuracy and credibility of genetic screening tests.
2. Increase the awareness about family needs among nurses and HCPs. This would impact positively on nurses' knowledge, attitudes and understanding of their role as educators, counsellors and advocates. This should enhance their ability to support and provide quality care for these children and their families.

3. The social services should broaden their scope of work to include more social activities for these families, focus on social environments, home visits, children's relationships and community integration and cohesion. In order to integrate the children and their parents more into the community. In addition, they need to incorporate cultural, social, traditional and religious values as appropriate in each individual's management plan to mitigate the socio-cultural barriers.
4. Introduce health education modules into the nursing curriculum.
5. Encourage the community and religious leaders to openly discuss issue relating to chronic medical conditions in children. The leaders can encourage the meaning of citizenship in the community, such as encouraging people to undergo genetic screening tests and taking an active role in blood donations. In addition, religious leaders can help to articulate, from a spiritual point of view, the advantage performing the pre-marital and antenatal tests. The leaders and faith organisations can provide spiritual in-depth education and counselling to individuals, targeting at-risk populations in order to discuss the health related topics in collaboration with HCPs. For example, the issue of 'Fatwa' on terminations of affected pregnancies and clarifying the stand of religion from consanguineous marriage.
6. Utilise the national activities and holidays to bring more attention to genetic health disorders. These occasions can be used by conducting awareness campaigns and offering volunteers to work with children with BTM and their families, such as:
 - a. 8th of May, the 'international thalassaemia day';
 - b. 'Ramadan', the fasting month;
 - c. New Year's and Christmas Day celebrations;
 - d. Eid Al-adha and Eid Al-Fitr; Muharram/New Year;
 - e. Independence Day.

7. Conduct further research based on the issues raised in this study. For instance:
 - a. A study to explore nurses' and HCPs' experiences dealing with children with BTM and their families and compare them with those of the parents of BTM with children.
 - b. A study to explore the impact of BTM on siblings and other family members.
 - c. The suggested future research could be on 'how HCPs and/or social workers could meet the need for psychosocial support for the parents' of children diagnosed with BTM.
 - d. The future studies could identify 'how the health care services can better utilise culture and religion in health education and genetic counselling'.

8.4.3 Long Term Recommendations

This study recommends that there is a need to:

1. Discuss the ability of the JMoH to adopt the policy of offering free antenatal screening to high risk families.
2. Adopt community health screening programmes to give an accurate rate of the prevalence of BTM in the Jordanian community.
3. Arguably, nurses are considered one of the most important change agents in the area of community health and education, the scope of Jordanian nurses' roles need to be reviewed, improved and expanded. Consideration should be given to nurse specialist roles in community health, paediatrics and thalassaemia.
4. Utilise private and public media such as the TV, radio, internet websites and newspapers, to target the younger and older generations to raise awareness of genetic health disorders.

8.5 Conclusion

In conclusion, this study provided the parents of children with BTM an opportunity for their voice to be heard. The study offered insight into Jordanian parents' experiences of caring for children with BTM and their coping strategies. The data were collected through face-to-face, semi-structured interviews with forty participants. Twenty mothers, and twenty fathers were recruited from three thalassemia departments located in the main Jordanian cities: Irbid, Amman and Al-Zarqa. Some issues raised are supported by earlier literature such as (Gharaibeh, 2001; Atkin and Ahmad, 2000b; 2000a; Prasomsuk, et al., 2007; Oseroff, 2011; Mrayyan, et al., 2004; Hamamy, et al., 2005; 2007; 2012). However, data provide new insights into the experience of Jordanian parents of children with BTM, particularly in the way parents felt unprepared for providing their children with the care they needed, their lack of knowledge and the emotional burden inherent in the task of being a parent.

Parents felt that they had been inadequately prepared for taking care of their children. This is in spite of recommendations made by several studies such as (Mazzone, et al., 2009; Atkin and Ahmad, 2000b; 2000a; Sadiq, et al., 2000) that more emotional and informational support should be provided for parents caring for children with BTM. Both mothers and fathers in this study emphasised the importance of health education, preparation and support which should be started from the time they knew they were carriers to the defective gene and at the time their children were first diagnosed with BTM.

Most Jordanian parents in this study were shocked because they did not know about thalassemia until their child was first diagnosed with the condition. Participants' emphasised that their faith and social support assisted them to cope effectively and adapt to their situation with time. Overall, this study has highlighted that parents' negative

experiences were mainly due to their lack of knowledge, socio-cultural restrictions and inadequate professional support. In spite of these negative experiences, parents expressed satisfaction with the social support, the health care services and their role as caregivers to their children.

This study sought to raise nurses, HCPs and the community's awareness of BTM and other haematological genetic disorders, through exploring participants' experiences and identifying their coping strategies as well as highlighting the impact of religion and culture. This study can be used to encourage the multidisciplinary team to identify the gap in parents' knowledge and address their needs. Furthermore, this study provides HCPs with a better understanding of parents' emotional and psychological needs. In much the same way, increasing parents' understanding of their emotional response to their situation may well empower them to make better life decisions and in this way improve the quality of life for their children, for themselves as parents and importantly for Jordanian society as whole.

Appendix 1 and 1a: Literature on Thalassaemia

Literature on Thalassaemia								
Date	References	Title of the study	Country	Design	Sample	Setting	Focus of study	Limitations of study
2013	Ahmed, S., Bryant, L., Ahmed, M., Jafri, H., and Rashid, Y.,	Experiences of parents with a child with Down syndrome in Pakistan and their views on termination of pregnancy.	Pakistan	Qualitative used the interviews.	30 mothers and fathers of children with Down Syndrome.	Northern Pakistan via a centre providing schooling, speech therapy, Physiotherapy, medical and psychological assessment for children and young adults with intellectual disabilities.	To explore parents' experiences of their child with Down Syndrome in Pakistan and their views on abortion for the condition.	The study limited to one geographical area.
2012	Al-Sweedan, S., Khabourb, O., and Isam, R.	Genotoxicity assessment in patients with thalassemia minor.	Jordan	Quantitative-collect blood and urine samples from participants in hospital.	43Participants, 18 Thalassemia Minor, 18- Normal Healthy and 7 BTM, Excluded females.	Hospitals Northern region in Jordan	To assessed genotoxicity in the lymphocytes of thalassemia minor subjects using sister chromatid exchange and chromosomal aberration assays.	Small sample size.

2011	Liem, R., Gilgour, B., Peligra, S., Mason, M., and Thompson, A.	The impact of thalassaemia on Southeast Asian and Asian Indian families. In the United States: A qualitative study.	USA	Qualitative- Ethnographic semi-structure interviews, 1-on-1 interviews used the guidelines.	14 southeast Asian and Asian Indian parents of children with transfusion depended thalassaemia.	Hospital	To describe the challenges, including sociocultural and socioeconomic barriers faced by an urban immigrant population in the USA affected by thalassaemia major.	Agreement related to the application of some codes was low. This may be due to language barriers. The interviews were not carried out with both parents, and were limited to Chicago only.
2011	Wong, L. P., George, E., and Tan, J. A. M.	Public perceptions and attitudes toward thalassaemia: Influencing factors in a multi-racial population.	Malaysia	Quantitative- A cross-sectional	A total of 3723 responding households.	Computer-assisted telephone interview survey.	To determine differences in public awareness, perceptions and attitudes toward thalassaemia in the multi-racial population in Malaysia.	1. All data were collected via self-report. 2. All data were collected via telephone interview including households with fixed-line telephones interviews. Socio-economically disadvantaged groups were under-represented.
2011	Bryant, L., Ahmed, S., Ahmed, M., Jafri, H., and Raashid, Y.,	‘All is done by Allah’. Understandings of Down syndrome and prenatal testing in Pakistan.	Pakistan	Mixed method Methodology combines quantitative techniques and analysis with broadly qualitative approaches to sampling and pattern interpretation.	A sample of health professionals, researchers and parents of children with the condition.	Parents of a child with DS (n =30) were recruited and staff working at the Centre (n = 6). Health professionals and researchers attending a research workshop in a local University Hospital (n = 29).	A centre for people with learning disabilities and local hospital.	Limited to one limited area All participants lived in or nearby a large city in Northern Pakistan.

2011	Gharaibeh, H. F., and Gharaibeh, M. K.	Factors influencing health-related quality of life of Thalassaemic Jordan children.	Jordan	Quantitative-cross sectional study; used 'PedsQoL' Questionnaires through interviews.	211 Participants; 128- Thalassaemic children and 85 healthy children control group, age between 8 and 18 years.	Two thalassaemia unites in governmental hospitals (85 from northern hospital and 50 from middle hospital and four public schools.	The study highlights the negative impact of thalassaemia on the quality of life of children, especially in terms of physical well-being and school achievement.	The variation in the two geographical areas has the possibility to influence on the study outcomes.
2011	Heydarnejad M. S., Dehkordi A., and Dehkordi K.	Factors affecting quality of life in cancer patients undergoing chemotherapy.	Iran- Tehran	Quantitative, use Questionnaire	200 cancer patients	Tehran Hospital	To evaluate the QoL of cancer patients with solid tumours and at the different chemotherapy cycles.	The study was limited to one hospital.
2011	Gharaibeh, H. F., and Gharaibeh, M. K.	Factors influencing health-related quality of life of thalassaemic Jordanian children.	Jordan	Quantitative- A cross-sectional study	211 participants; 128 thalassaemic children and 83 healthy children between the ages of 8 to 18 years.	Thalassemia Units in two Hospitals and four public schools.	To assess the health-related quality of life of Jordanian children with thalassaemia, using PedsQoL questionnaires.	Research limited to two geographical areas.
2011	Irshaid, F., and Mansi , K.	Status of thyroid function and iron overload in adolescent and young adults with beta-thalassemia major treated with deferoxamine in Jordan.	Jordan	Quantitative	72 participants; 36 BTM patients frequent blood transfusion aged 12-28 years and matched controls.	Thalassaemia Unit at Princess Rahma Educational Hospital, Irbid, Jordan.	To evaluate the status of thyroid functions and iron overload by measurements of serum free thyroxine (FT4), triiodothyronine (FT3), thyrotropin (TSH) and serum ferritin level.	Small sample size. The study could be carried out with yearly interval to detect the subclinical thyroid dysfunction cases.

2011	Ahmmad, S., Mubeen, S., Shah, S., Mansoor, S.	Parent's opinion of QoL in Pakistani thalassaemia children.	Pakistan	Quantitative across-sectional study used questionnaires.	221 thalassaemic patients age between 4-12 years old, 61% boys.	10 centres in Karachi, Lahore and Multan (blood banks and hospitals)	To find out the physical, social, psychological life aspects and overall quality of the life among thalassaemic children in Pakistan.	The majority in the research sample was male children.
2011	Rifaya, M. I., Rajapaksa, S. K., Prematilaka, G., and Hettiarachch, N.	Socio-demographic and psychological aspects of children with thalassaemia.	Sri Lanka	Quantitative-observational study descriptive - use questionnaires.	50 thalassaemic children, admitted for monthly blood transfusion.	Paediatric units of Teaching Hospital Kandy.	To identify the socio-demographic and psychological aspects of thalassaemia.	The study limited to one geographical area.
2011	Abdallah, M., Fawzi, M., Al-Maloul, S., El-Banna, N., Tayyem, R., and Ahmad, I.	Increased oxidative stress and iron overload in Jordanian B-thalassaemic children.	Jordan	Quantitative	80 participants (40 children with BTM and 40 match control group) all children under 13 years old.	Hospital.	To evaluate the TBARS in β -thalassaemic children compared to controls together with compensatory increase in superoxide dismutase (SOD) activity and decrease in catalase (CAT) activity.	Sample size limited.
2011	Nusair, Z., Al-Wraikat, A., Abu Al-Shiekh, N., Kofahi, S., and Zoubi, M.	The frequency of iron deficiency anaemia and thalassamia trait among children: experience at Prince Rashed Bin Al-Hassan Military Hospital.	Jordan	Quantitative-blood sample was obtained from participants.	1,012 participants (range age children 6 months to 14 years).	Thalassaemia departments of the Military Hospital in the North of Jordan.	To determine the frequency of IDA and thalassaemia traits among children attending the Paediatric Department.	Sample limited to the children who attend the departments only. The study did not focus on the feeding process and racial differences which could contribute to the anaemia.

2010	Hazza'a, A. M., Darwazeh, A. M., and Museedi, O. S.	Oral 'Candida' flora in a group of Jordanian patients with β -thalassemia major.	Jordan	Quantitative	100 participants; 50 patients diagnosed with BTM and 50 age- and sex-matched controls.	Thalassaemia Centre at Princess Rahma Hospital in Irbid.	To assess the oral Candida colonization in a group of patients with thalassaemia major both qualitatively and quantitatively.	One geographical area in north Jordan.
2010	Khairkar, P., Malhotra, S., and Marwaha, R.,	Growing up with the families of b-thalassemia major using an accelerated longitudinal design.	India	longitudinal design	100 children with BTM and their 150 parents, both groups were subdivided further so that each group represented the continuum of longitudinal course. The sampling was done for a period of 16 months from January 2004 to April 2005.	Paediatric Centre, Postgraduate Institute of Medical Education and Research (PGIMER), Chandigarh.	To construct the picture of developmental epidemiology for psychosocial aspects in families of patients diagnosed with BTM attending a tertiary care hospital in north India.	The study did not include late adolescents in a later age group (15-17 yr) which could have provided an expanded and better picture of developmental epidemiology. Poor validity of Reaction to Illness Questionnaire and non-usage of the structured diagnostic instrument to make ICD-10 diagnoses in parents were also the limitations.
2010	Gharaibeh, H., Oweis, A., and Hamad, K. H.	Nurses' and midwives' knowledge and perceptions of their role in genetic teaching.	Jordan	Quantitative descriptive cross-sectional design.	200 registered nurses and midwives.	Three maternal and child health hospitals located in the northern part of Jordan.	To explore nurses' and midwives' knowledge and perceptions of their role in genetic teaching.	Limited the research to one geographical area.
2010	Pruthi, G., and Singh, T.	Psychosocial burden and quality of life in parents of children with thalassemia and cerebral palsy: A comparative study.	New-Delhi	Quantitative descriptive study. WHOQoL-BREF (Murphy et al., 2000). Used semi-	60 caregivers, aged 18 years and above, with children having confirmed diagnosis of BTM/ Cerebral	Two service agencies in Delhi.	To investigate, the psychosocial burden and QoL among parents having children with BTM and Cerebral Palsy.	Small sample size

				structured interview.	Palsy, aged 4 years and above.			
2010	Sandridge, A. L., Takeddin, J., Al-Kaabi, E., and Frances, Y.	Consanguinity in Qatar: knowledge, attitude and practice in a population born between 1946 and 1991.	Qatar	Qualitative Face-to-face interviews 70-item structured questionnaire.	Three native Arabic-speaking medical students with 362 Qatari employees.	Qatar institutions	To estimate the prevalence of consanguinity among Qataris and to assess their knowledge of the risks and their attitudes towards the practice and to test the acceptability of sixteen Likert-style questions within the Qatari population.	Access limited to the abstract.
2009	Al-Akour, N. A., Khassawneh, M., Khader, Y., and Dahl, E.	Sex preference and interest in preconception sex selection: a survey among pregnant women in the north of Jordan.	Jordan	Quantitative- A self-reported questionnaire.	600 pregnant women.	Seven representative main maternal and child health centres in the north of Jordan.	The study describes the sex preference and interest in employing sex selection techniques among pregnant women in northern Jordan.	The study was limited to one geographical area.
2009	Clarke, S., Skinner, R., Guest, J., Darbyshire, P., Cooper, J., Shah, F., Roberts, I., and Eiser, C.	Health-related quality of life and financial impact of caring for a child with Thalassaemia Major in the UK.	UK	Quantitative a cross-sectional assessment.	A total of 22 families. Limited age of their children with thalassaemia between 8-18 years old.	Three UK Paediatric Haematology and Bone Marrow Transplant centres in: London, Birmingham, and Newcastle.	To determine HRQoL in children with TM living in the UK, and the impact of caring for a child receiving National Health Service treatment on family finances.	Limitations include the relatively small sample, and reliance on mothers' reports with few father involvements in the study. The study is not therefore representative for younger children.

2009	Mansi, K., Aburjai, T., Barqawi, M., and Naser, H.	Copper and zinc status in Jordanian patients with a-thalassemia major treated with Deferoxamine.	Jordan	Quantitative	42 Patients with thalassaemia (20 male and 22 females) range age 'between' (4-14).	Thalassaemia centre at Princess Rahma Hospital in Irbid.	To evaluate the serum copper and zinc in Jordanian Thalassaemic patients.	One geographical area in northern Jordan.
2009	Gharaibeh, H., and Mater, F.,	Young Syrian adults' knowledge, perceptions and attitudes to premarital testing.	Syrian	Quantitative	942 university students	Tishreen University	To identify young Syrian adults' knowledge, perceptions and attitudes about premarital testing.	One university -limited geographical area.
2009	Al-Sweedan, S., Jaradat, S., Iraqi, M., and Beshtawi, M.	The prevalence of factor V Leiden (G1691A), prothrombin G20210A and methylenetetrahydrofolate reductase C677T mutations in Jordanian patients with beta-thalassaemia major.	Jordan	Quantitative	200 Participants (100 patients diagnosed with BTM and 100 Control Group).	Thalassaemia Units in Hospitals.	To detect the factor V-leiden, prothrombin and methylenetetrahydrofolate in children with BTM.	Access limited to the abstract.
2009	El-Akawi, Z., Al-Remawi, H., and Al-Namarneh, K. H.	The relationship between the type of mutation in the globin gene and the type and severity of sickle/beta-thalassemia disease in Jordanian patients.	Jordan	Quantitative	22 Patients with Sickle/ BTM (10 males and 12 females) age between 3-23years.	Thalassaemia Centre at Princess Rahma Hospital in Irbid. Northern region.	To give better understanding of the molecular mechanisms that influence the severity of the disease.	Small sample size and limited geographical research area.
2009	Mazzone, L., Battaglia, L., Andreozzi, F., Romeo, M., and Mazzone, D.	Emotional impact in B-thalassaemia major children following cognitive-behavioural family therapy and quality of life of care-giving mothers.	Italy	Quantitative - used Child Behavioural Checklist (CBCL), Children Depression Inventory,	28 outpatients with a diagnosis with BTM and 28 control group.	Hospital and Paediatric Clinic.	To evaluate the compliance with chelation treatment in children with BTM after a session programme of	Small sample size of the study.

				Multidimensional Anxiety Scale for Children, Emotionality, Activity Sociability and Shyness Scale (EAS) and World Health Organization Quality of Life (WHOQOL-BREF) questionnaires used in various stages of the study.			CBFT; to assess behaviour, mood, and temperament peculiarities of patients, compared to healthy subjects; to analyse QoL of care giving mothers.	
2008	Abu-Ghoush, M.	Subtypes of Alpha Thalassaemia diagnosed a medical centre in Jordan.	Jordan	Quantitative - Blood sample collected.	430-Alpha Thalassaemia.	Princess Iman Centre for Research and Laboratory Sciences.	The study helps in the prediction of the phenotype severity by identifying the genotype of HbH patients.	The research limited to one geographical area.
2008	Arif, F., Fayyaz, J., and Hamid, A.	Awareness among parents of children with thalassemia major.	Pakistan	Quantitative Across-sectional study - interviewed using a pre designed questionnaire.	120 care takers	Civil Hospital Karachi.	To determine the awareness among parents of children with thalassaemia major (TM) regarding the disease.	The majority was of low socioeconomic class and 66.7% were illiterate.
2008	Khalaf, I., Abu-Moghli, F., Callister, L., and Rasheed, R.	Jordanian Women's Experiences with the Use of Traditional Family Planning.	Jordan	Qualitative-descriptive 32 semi-structured, open-ended questions.	Six focus groups with women of childbearing age (18 - 44 years of age; n = 51).	Maternal child health clinic in the northern, central, and southern Regions.	To explore the issues and challenges related to the use of Traditional family planning among Jordanian women.	Using focus groups could impact on the participants' responses as the topic is personal experiences about using the TFP methods.

2008	Burnes, D., Antle, B., Williams, Ch., Cool, L.	Mothers raising children with sickle cell disease at the intersection of race, gender, and illness stigma.	Canada	Qualitative- used the long interviews	10 participants and a four-month post-interview with half of the participants. Canadian mothers of African and Caribbean.	---	To understand the under researched experience of raising a child with sickle cell disease.	Access limited to the abstract.
2008	Ahmed, S., Hewison, J., Green, J., Cuckle, H. S., Hirst, J., and Thornton, J. G.	Decisions about testing and termination of pregnancy for different foetal conditions: a qualitative study of European White and Pakistani mothers of affected children.	UK	Qualitative	19 Pakistani and European women in West Yorkshire, UK.	NHS Genetics Department who either had a child with a genetic condition or had terminated a pregnancy for a genetic condition within the last 5 years.	To explore the reasons for and against prenatal testing and termination for a range of conditions in women from two different ethnic backgrounds.	The relationship between educational level and attitudes was not explored in this study.
2008	Van den Tweel., van den Tweel, X. W., Hatzmann, J., Ensink, E., van der Lee, J., Peters, M., Fijnvandraat, K., and Grootenhuys, M.	Quality of life of female caregivers of children with sickle cell disease: a survey.	Netherlands	Quantitative- cross sectional study, used the TNO-AZL Adult Quality of Life questionnaire.	54 caregivers of children with sickle cell disease and 28 caregivers of a control group.	Outpatient Clinic	To evaluate the quality of life of caregivers of children with sickle cell disease.	Most of the participants in this study have low social economic statuses which limited the study generalisation.
2008	Mansi, K., and Aburjai. T.	Lipid profile in Jordanian children with B-thalassaemia Major.	Jordan	Quantitative- Blood sample collected.	46 Participants 26 patients with BTM and 20 controls group, 14 males and 12 females.	Thalassaemia Unit at Princess Rahma Educational Hospital in Irbid.	To investigate the lipid pattern in Jordanian children with BTM.	Limited sample size and the geographical area.
2008	Alqaddoumi, A., Kamal,	Molecular spectrum of Alpha-	Jordan	Quantitative	286 Participants 572 chromosomes)	Princess Iman Centre for Research and	To define the spectrum of α -thalassaemia	Research setting the whole sample from one

	N., and Shbailat., T.	thalassaemia in Jordan.			were studied among which 29 were HbH disease patients.	Laboratory Sciences.	determinants existing in Jordan.	centre limited to one geographical area.
2008	Ayaz, S., and Yaman-Efe., S.	Potentially harmful traditional practices during pregnancy and postpartum.	Turkey	Qualitative-questionnaire was used to gather information during face-to-face interviews.	121 women	Hospitals	To identify potentially harmful practices of married women during pregnancy, delivery and postpartum.	Access limited to the abstract.
2007	Abu-Ekteish, F. M, Al-Rimawi, H. S., Al-Ali., M. K., and Shehabi, I. M.	Pulmonary function tests in children with beta-thalassaemia major.	Jordan	Quantitative-Blood test and pulmonary function tests.	40 children with BTM, 23 males and 17 females.	Thalassaemia unit, Princess Rahmah Teaching Hospital.	To describe the type of lung impairment in thalassaemic children.	One geographical area used.
2007	Shaligram, D., Girimaji, S. C., and Chaturvedi, S. K.	Psychological Problems and Quality of Life in Children with Thalassaemia.	India - Bangalore	Quantitative-A cross-sectional design. Questionnaires	39 children (8-16 years old) with BTM. 23 boys and 16 girls.	Department of Psychiatry.	To assess psychological problems and QoL in children with thalassaemia.	The research sample is mainly from lower socio-economic group. The small sample size, the participant's background could impact on the research outcomes.
2007	Prasomsuk, S., Jetrisuparp, A., Ratanasiri, T., and Ratnasiri, A.	Lived experiences of mother caring for children with thalassaemia major in Thailand.	Thailand	Qualitative-in-depth interviews.	15 mothers with thalassaemic children who had BTM.	Udonrthani Centre Hospital.	To explore mothers' experiences with thalassaemic children. To understand and represent mothers beliefs and attitudes about the illnesses and explore mothers	The research sample limited to mothers of blood transfusion children with BTM, and the interviews were conducted during the time their children received blood transfusion, give the participant compensations could

							feelings about day to day care for their children with BTM.	impact on the study outcomes.
2006	Ismail, A., Campbell, M., Ibrahim, H., and Jones, G.	Health related quality of life in Malaysian children with thalassaemia.	Malaysia	Quantitative-cross-sectional design. Interviews.	78 patients with thalassaemia interviewed and 235 healthy controls. The mean age for patients and school children is 11.9 and 13.2 years.	Hospitals and schools in Kuala Lumpur	To investigate if children with thalassaemia have a lower quality of life in the four dimensions as measured using the PedsQoL 4.0 generic Scale Score: physical, emotional, social and role (school) functioning compared to the healthy controls allowing for age, gender, ethnicity and household income.	The study limited to one geographical area conducted in one centre.
2006	Khattak, I., Khattak, S., and Kan, J.,	Heterozygous Beta thalassaemia in parents of children with Beta thalassaemia major.	Pakistan	Quantitative-collect blood sample	100 families having children with beta thalassaemia major.	Lady Reading Hospital Peshawar in Pakistan.	To find out the pattern of transmission of beta thalassaemia in the affected families.	The study was limited to one hospital.
2006 a	Hazza'a, M. A., and Al-Jamal. G.	Dental development in subjects with thalassaemia major.	Jordan	Quantitative	88 participants 44 Children with BTM; 29 males and 15 females and 44 match sex and age match control group.	Departments of Orthodontics of the Faculty of Dentistry- Jordan University of Science and Technology.	To evaluate the dental development of patients with BTM compared it with unaffected children.	One geographical area used.

2006 a	Al-Rimawi, H. S., Jallad, M. F., Amarin, Z. O., and Al-Sakaan, R.	Pubertal evaluation of adolescent boys with beta-thalassaemia major and delayed puberty.	Jordan	Quantitative-Controlled clinical study.	33- Patients diagnosed with BTM	Tertiary referral teaching hospital.	To examine the hormonal status of the hypothalamic-pituitary-gonadal axis in adolescent males with beta-thalassaemia major.	Limited sample size and the geographical area.
2006	Gavin, L., and Wysocki, T.	Associations of paternal involvement in disease management with maternal and family outcomes in families with children with chronic illness.	USA- Florida	Quantitative-Cross-sectional designed.	A sample of 190 heterosexual couples.	Children's Clinics in Jacksonville and Orlando, Florida.	To measure of the amount and helpfulness of paternal involvement in paediatric disease management and to explore the association between father involvement and other aspects of family functioning.	Limited sample size.
2006	Khurana, A, Katyal, S., and Marwaha, R. K.	Psychosocial burden in thalassaemia.	India	Qualitative-structured interviews.	50 adolescents affected with thalassaemia (25 males and 25 females).	Thalassaemia Transfusion Unit of the Division of Paediatric Haematology Advanced Paediatric Centre, Nehru Hospital.	To determine the presence of disease burden in the psychosocial life aspects of Indian adolescents affected with thalassaemia.	Covers some psychosocial aspects.
2006 b	Al-Rimawi, H. S., Abdul-Qader, M., Jallad, M. F.,	Acute splenic sequestration in female children with sickle cell disease in the North of Jordan.	Jordan	Qualitative-interviewed.	77 patients with sickle cell disease were identified. Their ages ranged	Hospital - department.	To evaluate the rate of acute splenic sequestration in patients with	Access limited to the abstract.

	and Amarin, Z. O.				between 2 and 18 years.		sickle beta-thalassaemia and sickle cell anaemia.	
2006	Gray, D. E.	Coping over time: the parents of children with autism.	Australia	Qualitative-longitudinal study- Ethnographic methods that emphasized in depth interviews and participant observation.	28 parents (19 mothers and 9 fathers) of children with autism.	Treatment centre for autism.	To investigate the coping of the parents care for their children with autism.	The small sample size.
2006	Sharghi, A., Karbakhsh, M., Nabaei, B., Meysami, A., and Farrokhi, A.	Depression in mother of children with thalassaemia or blood malignancies: a study from Iran.	Iran	Quantitative-cross-sectional study questionnaires used in two parts; the first was completed by interviewers and the second is the BDI completed by the mothers themselves.	294 mothers of children with thalassaemia, blood malignancies and a control group.	Children age less than 15 years old treated in the Hospital Medical Centre (The major paediatric hospital of Tehran University of Medical Sciences).	To investigate if mothers of children with thalassaemia or blood malignancies have higher scores of depression compared with a group of control mothers.	The study was limited to one medical centre.
2006	Al-Qaddoumi, A. A.	Co-inheritance of alpha and beta-thalassaemia in a Jordanian family.	Jordan	Qualitative - Case Study	4- Children with BTM. Their parents are double heterozygotes for alpha and beta-thalassaemia.	Hospital	To describes the haematological and the molecular data resulting from the interaction between alpha and beta-thalassaemia determinants in a Jordanian family.	The limited sample size.
2006	Barakat, L., Alderfer, M.,	Posttraumatic Growth in Adolescent Survivors of Cancer	USA	Quantitative-baseline and	150 families, data were collected from 150 teen	Participant's home and hospital.	To describe posttraumatic growth	The measure of PTG used in this study was not standardized;

	and Kazak, A.	and Their Mothers and Fathers.		post interventions.	survivors, 146 mothers and 107 fathers.		following childhood cancer survival.	positive changes were not validated by other informants.
2006	Sapountzi-Krepia, D., Roupa, Z., Gourni, M., Mastorakou, F., Vojiatzi, E., Kouyioumtzi, A., and VanShall, S.	A qualitative study on the experiences of mothers caring for their children with thalassaemia in Athens, Greece.	Greece	Qualitative-semi-structured questionnaire obtained during a 3 months period.	19 mothers who have children with thalassaemia.	Hospital	To investigate the caregiving experiences of mothers of children with thalassemia. Using a semi-structured questionnaire.	Small sample size in the study which also limited to one geographical area.
2006 b	Hazza'a, A. M., and Al-Jamal G.	Radiographic features of the jaws and teeth in thalassaemia major.	Jordan	Quantitative	100 participants 50 diagnosed with BTM and 50 control group.	Thalassaemia Centre at Princess Rahma Hospital in Irbid, and the Teaching Dental Centre of Jordan University of Science and Technology.	To compare the radiographic changes and root and crown-body length of the mandibular first permanent molar in a group of thalassemia patients with control group matched for age and sex.	The study limited to one geographical.
2005	Hamamy, H., Jamhawi, L., Al-Darawsheh, J., and Ajlouni, K.	Consanguineous marriages in Jordan: why is the rate changing with time?	Jordan	Qualitative-study used questionnaire-structured interviewed.	1032 individuals who are diabetic patients registered at the NCDEG.	The NCDEG in Amman.	To explore the secular trend in consanguinity in Jordan and the subtypes of consanguineous marriages that may be undergoing a change.	The participants limited to one setting.
2005	Al-Rimawi, H. S., Jallad, M. F., Amarín, Z. O., and	Hypothalamic-pituitary-gonadal function in adolescent females with beta-thalassaemia major.	Jordan	Quantitative-blood sample were collected from the two groups.	31 beta-thalassaemia major females aged between 13 and 22 years and	Thalassemia unit, Princess Rahmah Teaching Hospital.	To evaluate the function of the hypothalamic-pituitary-gonadal axis in	The mismatch in the participants' number and the control group.

	Obeidat , B. R.				in 12 control females aged group.		adolescent female patients with beta-thalassaemia major.	
2005	Aydinok, Y., Erermis, S., Bukusoglu, N., Yilmaz, D., and Solak, U.	Psychosocial implications of thalassaemia major.	Turkey	Mixed Methods- Qualitative- Interviews used the Symptom Distress Checklist 90 (SCL-90) with the patients and Quantitative- filled the CBCL by their mothers.	38 patients with BTM; 20 girls and 18 boys aged between 6 and 18 years old and their mothers.	Paediatric Haematology Department of Ege University Hospital, Izmir.	To determine the psychosocial features of the patients with TM and their mothers and to disclose whether the psychological status of the patients contribute to the compliance with the therapy.	Two third of the mothers come from low socioeconomic status which could impact on their responses and affected the research outcomes.
2005	Al-Wahadni, A., Qudeimat, M. A., and Al-Omari, M.	Dental arch morphological and dimensional characteristics in Jordanian children and young adults with BTM.	Jordan	Quantitative	24 patients who suffered from β -thalassaemia major (mean age = 13.9 ± 3.1 years) and an unaffected control group matched for dental age, sex, and incisor and molar relationships.	Thalassaemia centre at Basma Hospital, Irbid, and four primary and secondary schools.	To examine the arch dimensions of Jordanian patients with β -thalassaemia major in comparison with an unaffected control group.	Small sample size and the limited in the research setting to one centre.
2004	Karetti, M., Yardumian, A., Karetti, D., and Modell, B.	Informing Carriers of β -Thalassaemia: Giving the Good News.	UK	Qualitative- used interviews included administration of a psychological scale.	28 carriers of beta-thalassaemia interviewed immediately after counselling.	---	To explored the value of informing beta-thalassaemia carriers of the advantages, as well as the disadvantages of carrier status.	Limited access to the abstract.

2004	Mrayyan, M., Al-Omary, O., and Saber. A.	Jordanian Families' knowledge about thalassaemia and their attitudes toward genetic counselling.	Jordan	Quantitative - descriptive study – Questionnaire.	100 families with thalassaemic children.	Three Governmental hospitals.	To assess the knowledge of Jordanian families about thalassaemia and their attitudes toward genetic counselling.	Small sample size, the sample selected non-randomly from the three hospitals. Limited the hospital to only governmental type excluded the military and private types.
2004	Chapple, A., Ziebland, S., and McPherson, A.	Stigma, shame, and blame experienced by patients with lung cancer: qualitative study.	UK	Qualitative-study-interviews.	45 patients with lung cancer include men and women as well as young and old.	General practices, oncologist, chest physicians, and support groups.	To draw on narrative interviews with patients with lung cancer and to explore their perceptions and experience of stigma.	Low responses from the participants and their background and health history could impact on the study outcomes.
2004	Goodman, P., Mackey, M., and Tavatoli, A.	Factors related to childbirth satisfaction.	USA	Quantitative-correlational descriptive study- use questionnaires	60 low-risk post-partum women, aged 18- 46 years, with uneventful vaginal deliveries of healthy full-term infants.	Two medical centres in the south-eastern United States	To examine the multiple factors for their association with components of childbirth satisfaction and with the total childbirth experience.	The sample size was relatively small and non-randomly selected, thus restricting the statistical inference of the results, so that the findings are not generalizable to all postpartum women.
2004	Eccleston, C., Crombe, Z, G., Scotford, A., Clinch, J., and Connell, H.	Adolescent chronic pain: Patterns and predictors of emotional distress in adolescents with chronic pain and their parents.	UK	Quantitative-Used questioners.	80 adolescents and accompanying parents.	Specialized tertiary care chronic pain management service.	(1)To examine emotional distress in adolescent chronic pain patients, with an additional focus on how patients cope with chronic pain, (2) to examine emotional distress in the accompanying	1. The participants were recruited from a tertiary-care national referral centre. 2. These results are based on cross-sectional data from related samples. 3. A number of the measures used were developed with non-pain populations and/or with younger children. Although they were the

							parent, with a specific focus on the potential stress of parenting, and (3) to examine the relationship between how adolescents attempt to cope with pain and the potential role of coping on adolescent and adult emotional distress.	best available instruments, their use may have introduced levels of measurement error that inflate the possibility of type II error.
2004	Lutz, M. J., Barakat, L. P., Whitley, K. S., and Ohene-frempong, K.	Psychological Adjustment of Children with Sickle Cell Disease: Family Function and Coping.	USA	Quantitative	73 caregivers and 23 children age between birth to 18 years admitted to a haematology acute care unit for pain or fever associated with sickle cell disease.	Children's hospital on the East Coast of the United States.	To determine the effects of coping style and family functioning on children's adjustment to sickle cell disease.	Access limited to the abstract.
2003	Harteveld, C. L., Yavarian, M., Zorai, A., Quakkelaar, E., Van-Delft, P., and Giordano ¹ , P. C.	Molecular Spectrum of a Thalassaemia in the Iranian Population of Hormozgan: Three Novel Point Mutation Defects.	Iran	Quantitative-collected blood samples from the participants over 2 months.	660 randomly	Hospitals	To describe the molecular spectrum of a-thalassaemia mutations in a population sample of new-borns in the South-Iranian province of Hormozgan.	Some families could be consanguineous marriage.
2003	Nahalla, C. K., and FitzGerald, M.	The impact of regular hospitalization of children living with thalassemia on their parents in Sri Lanka:	Sri-Lanka	Qualitative-	10 parents.	Thalassaemia unit of a large hospital in a north-west	To describe what it means to have a child with thalassaemia regularly	Small sample size there is a need for more representative sample needed.

		A phenomenological study.				province of Sri Lanka.	attending hospital for blood transfusion.	
2003	Al-Qutob, R., Mawajdeh, S., Allosh, R., Mehayer, H., and Majali, S.	The effect of parental knowledge of foetal sex on birth weight. A study from Jordan.	Jordan	Quantitative	A sample population of 1,195 women (cases, n = 640; control, n = 555) were studied in relation to their knowledge of the sex of the foetus.	Three hospitals in Amman.	To determine the effect of the knowledge of prenatal foetal sex, through the use of ultrasound, on infant mean birth weight and the proportion of low birth weight babies.	The study limited to one geographical area.
2003	Bywaters, P., Ali, Z., Fazil, Q., Wallace, L. M., and Singh, G.	Attitudes towards disability amongst Pakistani and Bangladeshi parents of disabled children in the UK: considerations for service providers and the disability movement.	UK	Qualitative-study semi-structured interviews.	19 Pakistani and Bangladeshi families.	The locality in East Birmingham Family Service Unit, Birmingham.	To explore whether there is a valid basis for the negative stereotypical views held by some professionals and service providers about minority ethnic communities' attitudes to and care of disabled children.	The limited sample size in this study.
2002	Abu-Alhaija, E., Al-Wahadni, A., and Al-Omari, M.	Uvulo-glosso-pharyngeal dimensions in subjects with BTM.	Jordan	Quantitative - Cephalmetric radiographic – measurements taken from all participants.	15- Subjects with BTM; 8 males and 7 females and 15 subjected control group matches the age and sex.	Hospital-radiology departments.	To investigate cephalometrically the Uvulo-glosso-pharyngeal dimensions in subjects with BTM.	Small sample size.

2002	Zahed, L., Nabulsi, M., and Tamim, H.	Attitudes toward prenatal diagnosis and termination of pregnancy among health professionals in Lebanon.	Lebanon	Quantitative-used questionnaire	75 participants; geneticists, family doctors, paediatricians and obstetricians/ Gynaecologists.	2 main hospitals in Beirut.	To assess the attitudes of health professionals towards prenatal diagnosis and termination of pregnancy, for a series of genetic, non-genetic and non-medical conditions.	The Small sample size and the limited study setting to one geographical area. The participants' background and the professional facilities which could affected on their responses.
2002	Baker, B. L., Blacher, J., Crnic, K., and Edelbrock, C.	Behaviour Problems and Parenting Stress in Families of Three-Year-Old Children With and Without Developmental Delays.	USA	Quantitative	Parents of 225 three-year-old children with or without developmental delays.	Hospital and out clinic	To examined early evidence of behaviour problems in children with or without developmental delays and the relative impact of cognitive delays and problem behaviours on their parents.	Limited access to the abstract.
2002	Al-Wahadni, A. M., Taani, D. Q., and Al-Omari, M. O.	Dental diseases in subjects with beta-thalassaemia major.	Jordan	Quantitative-Descriptive study.	124 subjects 61 Patients with thalassaemia and 63 healthy controls.	Dental Clinical oral examinations	To determine whether thalassaemia associated with an increase in the severity of periodontal disease and dental caries.	The participants' oral hygiene and type of the food could impacted on the result.
2002	Caro, J., Ward, A., Green, T., Huybrechts, K., Arana, A., Wait, S.,	Impact of thalassaemia major on patients and their families.	Cyprus, Egypt, Greece, Hong Kong, India, Iran, Italy, Jordan,	Quantitative	1,888 questionnaires	Hospitals in the 10 countries.	To describe the burden of thalassaemia major and its treatment, in terms of	Limited access to the abstract.

	and Eleftherion, A.		Taiwan, and the UK.				prevalence of iron-overload-related complications, direct and indirect costs, and the patient's physical and social well-being.	
2002	Abu-Alhaija, E., Hattab, F., and Al-Omari, M.	Cephalometric measurements and facial deformities in subjects with BTM.	Jordan	Quantitative	54 Thalassaemic subjects 37; 24 males and 13 females. Their age 5-6 years. Compare to 37 normal control group.	Dental centre of the Jordan University of Science and Technology - Irbid.	To identify cephalometric and facial feature of patients with BTM.	Limited geographical area.
2002	Miles, R.	Employment and unemployment in Jordan: the important of the gender system.	Jordan	Qualitative-study Focus group interviews.	Only participants who were currently working or looking for work were recruited. Groups of single and married women were convened separately in each of the area and focus groups of single and married men were conducted.	Amman, Madaba, Marka and Baqa'a.	To investigates how the gender system influences employment and unemployment patterns in Jordan.	The participants' education background could impact on the study findings.
2002 b	Katz, S.	When the child's illness is life threatening: Impact on the parents.	Israel	Quantitative - study used four questionnaires.	80 fathers and 80 mothers of children fill the questioner separately	A major hospital in the Tel-Aviv area.	To investigate the impact on parents of children with life threatening and parents of children with non-life	Limited sample from one setting.

							threatening chronic illnesses measured satisfaction with social support received, perception of the impact of the child's illness, and coping behaviours.	
2002	Louthrenoo, O., Sittipreechachar, N, S., Thanarattanakor, N, P., and Sanguansermsri, T.	Psychosocial problems in children with thalassaemia and their siblings.	Thailand	Mixed Method	82 children with thalassaemia, 20 siblings, and 50 control children without a chronic illness.	Hospital	To evaluate psychosocial problems in children with thalassaemia and their siblings.	Limited access to the abstract.
2002	Ray, L.	Parenting and childhood chronicity: Making visible the invisible work.	Canada	Qualitative	30 families with 34 children who had chronic health conditions participated. 30 mothers and 13 fathers were interviewed.	28 chose the family home and 2 mothers preferred to be interviewed at work.	To validate a model describing the work required to raise a child with a chronic health condition with a sample of parents providing theoretically diverse care. The model, Parenting and Childhood Chronicity.	---
2001	Olsson, M. B., and Hwang, C. P.	Depression in mothers and fathers of children with intellectual disability.	Sweden	Quantitative-used the Beck Depression Inventory (BDI).	216 families with children with autism and/or intellectual disability.	Urban and rural communities in the south-west of Sweden.	To investigate the prevalence and severity of parental depression in families with	The study relies one single administration of the BDI which could limit the knowledge about severity of the depression.

							children with disabilities, as compared with a group of control families.	
2001	Goldbeck, L.	Parental coping with the diagnosis of childhood cancer: gender effects, dissimilarity within couples, and quality of life.	Germany	Quantitative	108 parents out of 54 complete families participated in a prospective study.	University Clinic Ulm	The main purpose of the study was to compare maternal and paternal coping styles and to investigate relationship of parental coping patterns to quality of life for parents and children.	Small sample size and heterogeneous diagnostic groups.
2001	Chambers, M., Ryan, A. A., and Connor, S. L.	Exploring the emotional support needs and coping strategies of family carers.	Northern Ireland	Qualitative- two focus group interviews, each group comprising seven family carers.	14 participants	In the local health board area.	To explores the emotional support needs and coping strategies of family carers. This paper focuses specifically on the emotional support needs and coping strategies identified by group members.	Limited sample size.
2001	Foster, C., Eiser, P., Oades, P., Sheldon, C., Tripp, J., Goldman, P.,	Treatment demands and differential treatment of patients with cystic fibrosis and their siblings: patient, parent and sibling accounts.	UK	Qualitative-	8 patients, 8 mothers, one father and 8 siblings.	Home interviews.	To investigate the impact of CF and treatment demands on patients, their mothers and siblings.	This study involved a small number of patients and siblings varying in age from middle childhood to late adolescence.

	Rice, S., and Trott, J.							
2001	Fiese, B. H., and Tomcho, T. J.	Finding meaning in religious practices: The relation between religious holiday rituals and marital satisfaction.	USA	Quantitative - interviewed to completed measures of religious holiday practices (current family and family-of-origin) and marital.	120 couples, married 9 years on average, satisfaction.	Home Interviews	To examined the relation between marital satisfaction and religious holiday ritual practices.	The sample was relatively homogeneous in regard to race and religion, representative limited geographical area. the relatively low alpha level found for husbands' and wives' reports of roles and routine may have affected our findings comparing the relative contribution of meaning a above and beyond routines.
2001	Sadiq, M. F., Eigel, A., and Horst, J.	Spectrum of B-Thalassaemia in Jordan: Identification of two novel mutations.	Jordan	Quantitative - collect blood samples from all participants.	A total of 240 B-thalassaemia alleles relating to 127 unrelated patients- 113 Transfusion dependent b-thalassaemia and 14 S/b-thalassaemia patients.	Thalassaemia units -hospitals.	To identify the mutations of BTM in Jordan.	The patients investigated in this study limited to the northern part of Jordan.
2001	Alkuraya, F. S., and Kilani, R. A.	Attitude of Saudi families affected with haemoglobinopathies towards prenatal screening and abortion and the influence of religious ruling (Fatwa).	Saudi Arabia	Quantitative-descriptive study.	32 families were interviewed using a pre-structured questionnaire.	The outpatient clinic or accompanying their child in the ward. In the King Khaled University Hospital (KKUH), and from two Ministry of	To examine the attitude of Saudi families affected with hemoglobinopathies towards prenatal diagnosis and abortion, and to evaluate the effect of	The study limited to one geographical area, Riyadh city. Limited sample size.

						Health hospitals in Riyadh.	education on religious ruling on such attitudes.	
2000	Sadiq, F., Rimawi, H., and Haddad, L.	Psychosocial and economic study of families with B thalassaemic children in northern Jordan.	Jordan	Qualitative- Used interviews	77-Families multi-transfused thalassemia children. The interviewed families had a total of 107 affected children.	Hospital in Northern Jordan	To assessed the knowledge and attitudes of the affected families toward family planning, the complications of the disease, and the screening of the heterozygote condition before marriage.	The study limited to one geographical area.
2000 a	Atkin, K., and Ahmad, W.	Family care-giving and chronic illnesses: how parents cope with a child with a sickle cell disorder or thalassaemia.	UK	Qualitative- in-depth interviews	37 parents; 17 couples of a child with thalassaemia and 25 parents; eight couples of a child with sickle cell disease. The eventual sample included 34 mothers, 25 fathers and three guardians for example: an uncle, brother and sister-in-law.	7 localities in the North of England.	To discusses the impact of caring within the context of coping: the materials, resources and strategies at personal, social and professional levels, which are found helpful in providing care.	Small sample size.
2000 b	Atkin, K., and Ahmad, W.	Pumping iron: compliance with chelation therapy among young people who have thalassaemia major.	UK	Qualitative- in-depth interviews with participants twice over a six months.	25 Young people with thalassaemia; age range (10-19 years) and 26 Young people with sickle cell disease. The sample included 12 males and 13 females with	Six locations in the Midlands and Northern England.	To provide detailed understanding of young people experiences of living with a genetic condition.	Small sample size.

					variety of ethnicity background.			
2000	Hoch, C., Gobel, U., and Janssen. G.	Psychosocial support of patients with homozygous beta-thalassaemia.	Germany	Qualitative	10 afflicted adolescents and young adults aged between (15 and 27 years).	Hospital	To get to know the reasons for the unsatisfactory compliance with therapy, to promote the exchange of experience how to deal with the disease and its treatment, to give comprehensive medical information and to improve in this way the own responsibility and the compliance with therapy.	Limited access to the abstract.
2000	Goldbeck, L., Baving, A., and Kohne, E.	Psychosocial aspects of beta-thalassaemia: Distress, coping and adherence.	Germany	Qualitative	43 patients with thalassaemia major (3 to 26 years old).	Hospital	To describes the patients' perspective, their typical coping strategies, health related locus-of-control-beliefs and psychosocial influences on adherence.	Limited access to the abstract.
2000	Fife, B. L., and Wright, E. R.	The dimensionality of stigma: A comparison of its impact on the self of persons with	USA Indiana	Qualitative	206 participants (130 persons with HIV/AIDS and 76 persons with Cancer).	Three private medical practices in the city.	To compare the effects of the stigma associated with HIV/AIDS and	The study limited to one geographical area.

		HIV/AIDS and cancer.					Cancer on self-stem, body image and personal control.	
2000	Hall, M., and Docherty, N.	Coping style and schizophrenic patient behaviour as predictors of expressed emotion.	USA	Qualitative	44 parents were assessed using the Camberwell Family Interview and the Strategic Approach to Coping Scale.	---	To examined relationships between levels of expressed emotion in relatives of individuals with schizophrenia and the coping strategies these relatives employ.	Limited access to the abstract.
1999	Babiker, M. M., Bashir, N., and Sarsour, N.	Prevalence of thalassaemia in school children in north –eastern Badia, Jordan.	Jordan	Quantitative- blood sample collected from the subjects.	1020- School Children.	29 Schools serving 32 villages in the North –eastern Badia.	To identify the prevalence of thalassaemia in the Jordanian school children in north- eastern Jordanian Badia.	The study limited to one geographical area.
1999	Harris, M. A., Greco, P., Wysocki, T., Elder-Danda, C., and White, N. H.	Adolescents with diabetes from single parent, blended and intact families: Health-related and family functioning.	USA	Quantitative - study the data collected through used different questionnaires.	119 adolescent 12–16.75 year olds with type 1 diabetes mellitus (DM1).	---	To examine family composition as it related to health status, treatment adherence, and parent–adolescent relationships.	Limited access to the abstract.
1999	Tarkka, M. T., Paunonen, M., and Laippala, P.	Social Support Provided by Public Health Nurses and the Coping of First-Time Mothers with Child Care.	Finland	Quantitative- Longitudinal study: use questionnaires.	254 mothers	Health care clinic.	To look at the factors related to the first time mother’s coping with child care when her child is 3 months old.	The socioeconomic background of the sample could impacted on the study results.

1998	Gharaibeh, N., Al-Sheyyab, M., and Batieha, A.	Detection of b-thalassemia carriers in Jordan.	Jordan	Quantitative-collected blood sample from the participants.	751-Subjects; 249 university students and 502 subjected selected from the premarital screening programme.	Clinical - Laboratory and Jordan University.	To determine the real prevalence of thalassaemia carriers in Jordan, using our own cut off points, and to develop a better understanding of this disease.	The study limited to one geographical area.
1998	Davis, D., and Schultz, C.	Grief, Parenting and Schizophrenia.	Australia	Quantitative - study used Structured questionnaire.	16 mothers -father dyads of children with schizophrenia.	Emailed the questionnaire to their home.	This study aimed to (a) validate the presence of grief in mothers and fathers of children with schizophrenia, and (b) explore whether the hours of parental contact with the child influences the strength of grief reactions.	All subjects were members of the Schizophrenia Fellowship of Victoria. This suggests that participants were particularly active in their efforts to cope with their situation which could be impact on their responses. Cope with their situation.
1998	Klein, S., Sen, A., Rusby, J., Ratip, S., Modell, B., and Olivieri, N. F.	The psychosocial burden of Cooley's anaemia in affected children and their parents.	Canada - Toronto	Qualitative-structured interview-used questionnaire.	Three groups of respondents: (1) parents answering questions about their children (under 16), (2) parents answering questions about themselves, (3) children (age 7 to 15 inclusive) answering questions about themselves.	Outpatient clinic at the Hospital for Sick Children in Toronto.	To identify the psychological burden of Cooley's anaemia in affected children and their parents.	The number of participants not clear indicated in this study.
1997	Mastroyanno poulou, K.,	The impact of childhood non-	UK	Quantitative	93 mothers and 78 fathers of children	Home	To assessed Mental health,	The variation in the children condition

	Stallard, P., Lewis, M., and Lenton, S.	malignant life-threatening illness on parents: Gender differences and predictors of parental adjustment.			with a life-threatening non-malignant condition.		family functioning, effects on employment and relationships, coping style, and perceptions of prognosis.	could present different outcome.
1997	Gravelle, A. M.	Caring for a child with a progressive illness during the complex chronic phase: parents' experience of facing adversity.	Canada	Qualitative-phenomenological study - used interviews.	11 parents; five mothers and three Couples. The affected children ranged in age from 26 months to 16 years and all lived at home.	The Muscular Dystrophy Association of Canada (Columbia branch), and two community health departments near Vancouver.	To explore the day-to-day experiences of parents caring at home for a child with a progressive life-threatening illness at a certain point in their illness trajectory.	Small sample size.
1997	Morris, J., Blount, R., Cohen, L., Frank, F., Madan-Swain, A., and Brown, R.	Family Functioning and Behavioural Adjustment in Children with Leukaemia and Their Healthy Peers.	USA	Quantitative-used two questionnaires the CBCL and FES.	33 children with leukaemia and their parents; 22 males and 11 females and 32 healthy children; 22 males and 10 females.	Cancer Care facility in the university.	To examine the association between family functioning and behavioural adjustment for children with leukaemia and their healthy counterparts.	Small sample size.
1996	Sunna, E. I., Gharaibeh, N. S., Knapp, D. D., and Bashir, N. A.	Prevalence of haemoglobin S and beta-thalassaemia in northern Jordan.	Jordan	Quantitative	2,290 volunteers were evaluated to determine the prevalence of HbS and beta-thalassaemia and 568 new-born samples were collected from the umbilical and analysed for the	3 areas of Northern Jordan.	To determine the incidence of HbS and beta-thalassaemia in the Northern Jordan.	The study limited to one geographical area.

					presence of HbS using electrophoresis.			
1996	Bruce, E. J., Schultz, C. L., and Smyrniotis, K. X.	A longitudinal study of the grief of mothers and fathers of children with intellectual disability.	USA	Qualitative-Longitudinal study.	49 mothers and 49 fathers.	---	To investigate report's findings based on annual interviews conducted over a three-year period. Longitudinal outcomes on measures used to define grief largely confirmed the original findings.	The access limited to the abstract.
1996	Hunfeld, J. A. M., Mourik, M. M., Passchier, J., and Tibboel, D.	Do couples grieve differently following infant loss?	Netherlands	Quantitative-study used Prenatal Grief Scale.	13 couples who lost an infant due to a major congenital anomaly.	---	To assess couple grief using the Prenatal Grief Scale.	The access limited to the abstract.
1996	Tsiantis, J., Dragonas, Th., Richardson, C., Masera, G., and Spinetta, J.	Psychological Problems and adjustment of children with B-Thalassaemia and their families.	Cyprus, Greece, and Italy and UK	Mixed Method Quantitative and Qualitative. Semi-structured Interviews and Questionnaires used.	Families (N= 188) with children aged 6 to 14 years suffering from g-thalassaemia Major and teachers.	Health clinics	This study aims were two-fold: a) to systematically investigate the psychosocial problems experienced by families with affected children 6 to 14 years of age, as well as the family's adjustment to the effects of 13-	The study limited sample size and geographical area. The teacher in this study were nominated by the children in the school.

							thalassaemia major, and b) to compare these psychosocial problems and the families' adjustment across a number of cultures where the disease is prevalent: Cyprus, Greece, Italy and the United Kingdom.	
1995	Bashir, N. A.	Serum zinc and copper levels in sickle cell anaemia and beta-thalassaemia in North Jordan.	Jordan	Quantitative-study	28 patients with beta-thalassaemia and 15 patients with sickle cell anaemia of 3-10 years of age compared with 25 age-matched controls.	Hospital and schools.	To compare the level of serum zinc in Sickle Cell Anaemia and patients with BTM.	Patients' health stage and their food could impact on the patients Zenic levels.
1995	Gazmararian , J. A., James, S. A., and Lepkowski, J. M.	Depression in black and white women; the role of marriage and socioeconomic status.	USA	Quantitative-The data collected by Centre for Epidemiology Studies Depression from the Americans Changing Lives survey from the research centre in Michigan.	534 black and 836 white women, 25 to 64 years old.	Home questionnaire	To investigated the degree to which the relationship between race and depression in US black and white women is modified by socioeconomic and marital status.	The participants' background could impact on their responses.
1994	Sadiq, M. F., and Huisman, T. H.	Molecular characterization of beta-thalassaemia in north Jordan.	Jordan	Quantitative-collected blood sample.	43 patients with beta-thalassaemia major and five with HbS-beta-	Hospital	To study the beta-thalassaemia	Limited the study to the geographical area

					thalassaemia, aged 6 months to 24 years.		mutations in 91 chromosomes.	
1994	Fishman, R. B.,	Changing attitudes to Down's Syndrome.	West-Bank	Qualitative	---	---	To evaluate the attitudes toward down syndrome in the Palestinian community.	Limited access to the abstract.
1994 b	Hill, S. A.,	Motherhood and the obfuscation of medical knowledge: The case of sickle cell disease.	USA	Qualitative in-depth interviews.	29 African American mothers.	---	To examines how low-income African American mothers of children with sickle cell disease cope with the reproductive implications of having passed a genetic disease on to their children.	Access limited to the abstract.
1994	Bruce, E. J., Schultz, C. L., Smyrniotis, K. X., and Schultz, N. C.,	Grieving related to development: A preliminary comparison of three age cohorts of parents of children with intellectual disability.	UK	Qualitative	58 parent dyads but significant gender-related differences.	Cohort 1 comprised parents with children aged 1–4 years; Cohort 2 comprised parents with children aged 5–10 years; and Cohort 3 comprised parents with children aged 11–21 years.	Employed a developmental framework to compare 3 age cohorts comprised of 58 mother–father dyads of children or young adults with intellectual disabilities.	Limited access to the abstract.
1994	Akasheh, M. S.	Graves' disease mimicking beta-thalassemia trait.	Jordan	Qualitative-Case study.	One participants	Queen Alia Hospital-Amman.	To draws attention to haematological	Small sample size.

							changes occurring in Graves' disease that risk being misinterpreted by the unwary physician.	
1994	Hurtig, A. L.	Relationships in families of children and adolescents with sickle cell disease.	USA	Qualitative-study- Used interviews and assessments of children and adolescents with sickle cell disease and their parents.	70 families	---	To assess the quality of family relations, the degree to which sickle cell disease has impacted on these relations, and the variable which contribute to these relations.	The access limited to the abstract.
1993	Al-Hader, A., Bashir, N., Hasan, Z., and Khatib, S.	Thyroid function in children with beta-thalassaemia major in north Jordan.	Jordan	Quantitative-collected blood sample from participants.	90- Patients with BTM; 51 Boys and 39 girls. 2-10 years old.	Hospital Thalassemia unit, Princess Rahmah Teaching Hospital.	The present study was undertaken in an attempt to evaluate basal thyroid function in children with -thalassaemia major in North Jordan by measuring the basal serum levels of tri-iodothyronine (T3), thyroxine (T4), and thyroid-stimulating hormone (TSH).	Sample Size and limited to the northern area.

1993	Bashir, N., Al-Hader, A., and Al-Shareef, L.	Cortisol levels in children with haemoglobinopathies in north Jordan.	Jordan	Quantitative-collected blood samples from participants.	100 children; 50 males and 50 females, between the ages of 3 and 10 years.	Hospital Thalassaemia unit, Basma Teaching Hospital.	To evaluate the Cortisol levels in children with haemoglobinopathies in north Jordan.	Small sample size and limited to one geographical area.
1993	Copeland, L. G., and Clements, D.B.	Parental perceptions and support strategies in caring for a child with a chronic condition.	Canada	Qualitative-used questionnaires.	38 fathers and mothers (19 paired parents) who had children with chronic conditions.	---	To compare fathers' and mothers' perceptions of a child's chronic condition and to compare strategies used by fathers and mothers to support themselves during critical times.	Limited access to the abstract.
1992 a	Bashir, N., Barkawi, M., and Sharif, L.	Sickle Cell/Beta-Thalassemia in North Jordan.	Jordan	Quantitative	50-Patients with Sickle Cell/BTM. 3-9 years old.	Princess Basma Teaching Hospital.	To investigate the feature of children with Sickle Cell / BTM.	Limited sample size.
1992 b	Bashir, N., Barkawi, M., Sharif, L., Momani, A., and Gharaibeh, N.	Prevalence of hemoglobinopathies in north Jordan.	Jordan	Quantitative-collected blood sample from participants.	1,000 subjects, 2-80 years old.	Hospital in northern Jordan.	To identify the prevalence of hemoglobinopathies.	Limited Geographical research area.
1992	Sloper, P., and Turner, S.	Services needs of families of children with severe physical disability.	UK	Quantitative	107 families of young children with severe physical disability.	---	To investigate families service contacts and needs for help.	Access limited to the abstract.
1992	Quittner, A. L., Opiari, L. C.,	The impact of caregiving and role strain on family life:	USA	Quantitative - used three questionnaire.	20 mothers caring for an infant or toddler with CF	Home recording to the daily activities.	To compared daily activity patterns and	The access limited to the abstracts.

	Regoli, M. J., Jacobsen, J., and Eigen, H.	Comparisons between mothers of children with cystic fibrosis and matched controls.			and 20 matched control mothers.		extent of role strain between mothers caring for an infant or toddler with cystic fibrosis (CF) and matched control mothers.	
1992	Stinson, K. M., Lasker, J. N., Lohmann, J. and Toedter, L. J.	Parents' grief following pregnancy loss: A comparison of mothers and fathers.	USA- Lehigh Valley/ Pennsylvania area.	Qualitative - Longitudinal study Interviews –used the prenatal grief scale.	56 couples	Home interview - the participant recruited from: 16 private clinics, 1 freestanding midwifery centre, 4 hospital clinics, local health bureau and social services agency.	To identify the differentiations between men and women grief following pregnancy loss.	Increased the sample size and more diverse need.
1991	Barkawi, M., Bashir, N., and Sharif, L.	Sickle cell-thalassemia in a Jordanian family.	Jordan	Qualitative- Case study.	One family	Hospital	To differentiating sickle cell-thalassemia from the sickle cell disease, and to identify the prognosis and the varieties in clinical manifestations.	Small sample size.
1991	Bashir, N., Barkawi, M., and Sharif, L.	Prevalence of hemoglobinopathies in school children in Jordan Valley.	Jordan	Quantitative	456- Healthy Children 6-10 years old.	Schools	To identify the prevalence of hemoglobinopathies in Jordan Valley.	Limited the study to one geographical area.
1991	Weisner, T. S., Beizer,	Religion and families of children with	USA	Qualitative-used interviews.	102 families with 3-5 years old children with	---	To evaluate the religion role in family of	Access limited to the abstract.

	L., and Stolze, L.	developmental delays.			development delays.		children with developmental delay life.	
1988	Cook, J. A.	Dad's double binds, rethinking fathers' bereavement from a men's studies perspective.	USA	Qualitative-study used Interviews and questionnaires were used to gather qualitative data from the participants.	55 men whose children had died 10 months to 5 years previously.	---	To address the issues of how men experienced their emotional adjustment to the death of a child from cancer, as well as how they dealt with the normative imperatives of the bereaved father role.	Access limited to the abstract.
1988	Hanson, C. L., Henggeler, S. W., Rodrigue, J. R., Burghen, G. A., and Murphy, W. D.	Father- absent adolescents with insulin-dependent diabetes mellitus: A population at special risk?	USA	Mixed method- Adolescents and their mothers completed several self-report and observational instruments.	30 intact families and 30 father-absent families.	---	To evaluate whether family structure is associated with the psychosocial functioning and physical health of adolescents with insulin-dependent diabetes mellitus.	Access limited to the abstract.
1986	Jacobs, S., Kasl, S., Ostfeld, A., Berkman, L., and Charpentier, P.	The measurement of grief: Age and sex variation.	UK	Qualitative - study Structured Interviews.	44 male and 70 female acutely-bereaved spouses (aged 46 years and over) were interviewed 1 month after the loss of their spouse.	---	To examine age and sex variation in the expression of grief among recently widowed persons, using a structured assessment of separation anxiety,	Access limited to the abstract.

							Numbness/ disbelief, and depression.	
1982	Tsiantis, J., Xypolita- Tsantili, D., and Papadakou- Lagoyianni, S.	Family reactions and their management in a parents group with beta-thalassaemia.	Greece	Qualitative - group discussion.	15 families, each with one child with beta - thalassaemia.	Outpatient transfusion department.	To assessed parents of Beta- thalassaemia major children reaction and their managements.	Limited sample size.

Appendix 1a: Articles, Books and Literature Review Papers.								
Date	References	Title of the study	Country	Design	Sample	Setting	Focus of study	Limitation of study
2012	Hamamy, H.	Consanguineous marriages; Preconception consultation in primary health care settings.	Jordan	Article	---	---	To highlighted the role of the health care setting role in related to the consanguineous marriage.	---
2012	Read, A., and Donnai, D.	What can be offered to couples at (possibly) increased genetic risk?	UK	Article	---	---	To review the reasons why a couple might seek specialist genetic counselling about a possible reproductive risk and the options available to them.	---
2012	Kronfol, N.	Historical development of health professions' education in the Arab world.	Lebanon	Article	18 Arab Countries.	---	To reviews the historical development of health professions' education in the Arab countries, highlighting the role that the World Health Organization.	---
2012	Bennett, R.	The family medical history as a tool in	USA	Article	---	---	To reviews standardized pedigree symbols, clues to identifying	---

		preconception consultation.					“red flags” in family history (with a focus on preconception genetic counselling), the pedigree as a psychosocial tool, and resources for obtaining a medical family history.	
2012	Newton, K., and Lamarche, K.	Take the challenge: Strategies to improve support for parents of chronically ill children.	Canada	Article	---	---	To help clinicians better understand these parental experiences; by increasing clinicians’ awareness, strategies can then be used, which will improve the outcome for the child, parents, and siblings.	---
2011	Oseroff, B.	The Ethics of Prevention: counselling, consanguinity, and premarital testing for Beta-Thalassaemia in Jordan.	Jordan	Thesis Qualitative - used interviews.	Interviews with thalassaemia and non-thalassaemia participants.	Amman Comprehensive Health Clinic.	To evaluate the Jordanian prevention program, paying special attention to possible ethical implications.	The number of interviews is not much clear in this study.
2010	Bittles, A., and Black, M.	The impact of consanguineous on neonatal and infant health.	UK	Article	---	---	To assess the influenced of consanguineous on reproductive behavioural.	---
2010	Michie, M., and Skinner, D.	Narrating Disability, Narrating Religious	USA	Literature reviews descriptive study.	Analysed data from a 2004 semi-structured	These women were recruited through existing studies at the	To examine the place of religion in the narratives of mothers of children	The lacked data on fathers’. In addition, although our final sample

		Practice: Reconciliation and Fragile X Syndrome.			interview conducted with a subset of 60 mothers, an interview designed, ranged in age from 22 to 49 years, with an average age of 36. Thirty-eight were Protestant, 12 were Catholic, 3 were Jewish, 2 held some other religious affiliation, and 5 had no religious affiliation.	University of North Carolina-Chapel Hill (UNC) and UNC's online fragile X participant research registry.	with fragile X syndrome.	included families from across the United States and from a range of incomes and education levels, we cannot claim our sample was representative of U.S. families who have an identified child with fragile X.
2010	Yamouri, N.	Gender in the Middle East and North Africa. MENA Strategy for Gender Work.	World Bank	Article	---	---	To discuss the gender issues in the employments.	---
2009	Strauss, B. S.	Genetic counselling for thalassaemia in the Islamic Republic of Iran.	Iran	Article	---	--	To evaluate the genetic counselling programme for thalassaemia in Iran.	---
2009	Zlotogora, J.	Population programs for the detection of couples at risk for sever monogenic genetic diseases.	Cyprus	Article	---	---	To review the genetic detection programmes for the couple at risk foe sever monogenic.	---
2009	Hamamy, H., and Bittles, A.	Genetic clinics in Arab communities: meeting	Jordan	Article	---	---	To identify the genetic services in the Arab communities and its	---

		individual, family and community needs.					impact on the individual, family and community.	
2008	Jordan, A., Eccleston, C., and Crombez, G.	Parental functioning in the context of adolescent chronic pain: a review of previously used measures.	UK	Descriptive and evaluative literature review.	4,225 articles, generating a total of 73 eligible studies.	The studies were conducted of all measures used with parents of adolescents aged 11-18 years experiencing chronic pain.	To examine the use of instruments which assess the functioning of individuals who parent an adolescent with chronic pain.	(1) Some studies did not explicitly state their inclusion of parental participants in the abstract or title. (2) Our necessary cut-off date excluded recent instruments. (3) The use of the WHO (1948) taxonomy to classify measures. (4) The deliberate omission of observational measures that assess parental functioning and behaviour in the context of adolescent chronic pain. (5) Many of these studies were not designed with parental functioning as the primary outcome, which may account for the instrument selection.
2007	Hamamy, H., and Al-Hait, S.	Premarital screening program for Beta-	Jordan	Articles	----	---	To initiate a nationwide intervention	---

		thalassaemia in Jordan.					program for the control of BTM.	
2007	Hamamy, H., Al-Hait, S., Alwan, A., Ajlouni, K.	Jordan: Communities and Community Genetics.	Jordan	Article	---	---	To evaluate the factors impact on community genetic disorders.	---
2007	Chen, J. Y., and Clark. M. J.	Family function in families of children with Duchenne muscular dystrophy.	---	Article	---	---	To investigates the relationships of child- and family-related variables with family function in families with children who have Duchenne muscular dystrophy.	Access limited to the abstract.
2007	Hessini, L.	Abortion and Islam: policies and practice in the Middle East and North Africa.	Middle East and North Africa region.	Article	21 Muslim countries.	---	To provides an overview of legal, religious, medical and social factors that serve to support or hinder women's access to safe abortion.	---
2006	Al-Gazali, L., Hamamy, H., and Al-Arrayad, S.	Genetic Disorders in the Arab World.	Jordan	Article	---	---	To identify the effect of genetic disorders in the Arab countries and the preventive programmes.	---
2006	Diken, I. H.	An Overview of Parental Perceptions in Cross-Cultural Groups on Disability.	Turkey	Article	---	---	To examine studies on parental perceptions on disability among families of children with disabilities across varied traditional cultural groups, including Mexican American, Chinese American,	---

							Arab, and Jewish communities.	
2006	Heijnders, M., and Van Der Meij, S.	The fight against stigma: an overview of stigma-reduction strategies and interventions.	UK	Literature Review Study.	The search was limited to English and Dutch documents published in peer-reviewed journals after 1990.	Using Science Direct, PubMed and Psych-Info.	To identify work done to date on stigma-reduction strategies and interventions.	---
2006	Betman, J. E. M.	Parental Grief when a Child is diagnosed with a Life Threatening Chronic-Illness. The Impact of Gender, Perceptions and Coping Strategies.	New Zealand	Thesis Qualitative Designed - used questionnaire	37 mothers and 15 fathers.	The National Cystic Fibrosis Association.	To investigate whether the grief experience differed for mothers and fathers and the impact that perceptions and coping have on both these gender differences in grief and on grief in general.	---
2006	Christianson, A., Howson, M., and Modell, B.	A global report on birth defects/ The hidden toll of dying and disable children.	Global report in the middle and low income countries.	Report WHO	---	The data on the birth prevalence of birth defects collected in middle- and low-income countries.	To provide global estimates of birth prevalence for serious birth defects of genetic or partially genetic origin.	---
2004	Samavat, A., and Modell, B.	Iranian national thalassaemia screening programme.	Iran	Article	---	---	To evaluate the Iranian experiences in thalassaemia screening programme.	---
2004	Hirschman, C.	The role of religion in the origins and adaptation of immigrant groups	USA	Article	---	---	To identify the role of the religion and how it is impacted on the immigrant groups.	---

		in the United States.						
2003	Qubbaj, W.	Approaches towards the Prevention of Thalassaemia in Jordan.	Jordan	Thesis Quantitative Descriptive Designed.	100 Families	---	To explore different approaches towards the prevention of thalassaemia.	---
2003	Major, D.	Utilizing role theory to help employed parents cope with children's chronic illness.	USA	Article	---	---	To utilise the 'role theory' to help the unemployed parents cope with their chronically ill children.	---
2003	Burton, H., Shuttleworth, A., and Metcalfe, A.	Genetics education for nurses, midwives and health visitors.	UK	Literature Review Study.	---	---	To identify the nurses, midwives and the health visitors role in genetic education, identify the possible to develop new interventions to detect, prevent, treat and manage conditions with a genetic component.	---
2003	Godard, B., Ten Kate, L., Evers-Kiebooms, G., and Ayme, S.	Population genetic screening programmes: principles, techniques, practices, and policies.	Amsterdam - Netherlands	Review the existing professional guidelines, regulatory frameworks and other documents related to population genetic screening programmes in Europe.	51 experts from 15 European countries.	The European Society of Human Genetics Public and Professional Policy Committee.	To examines the professional and scientific views on the principles, techniques, practices, and policies that impact on the population genetic screening programmes in Europe.	---

2002	Cowan, L.	The epidemiology of the epilepsies in children.	USA-Oklahoma	Article manuscript	---	---	To summarize what is currently known about the epidemiology of the childhood epilepsies and to identify promising areas for further population-based studies.	---
2002	Leininger, M.	Culture Care Theory: A Major Contribution to Advance Transcultural Nursing Knowledge and Practices.	USA	Article	---	---	To focused on the major features of the Culture Care Diversity and Universality theory as a central contributing theory to advance transcultural nursing knowledge and to use the findings in teaching, research, practice, and consultation.	---
2002	Meleski, D.	Families with chronically ill children: A literature review examines approaches to helping them cope.	USA	Article	---	---	To examine the approaches used to help families cope with chronically ill children.	Access limited to the abstract.
2002	Angastiniotis, M.	The adolescent thalassaemic. The complicant rebel.	Italy	Literature Review Study	---	---	To examine how various published studies have viewed the adolescent with thalassaemia and to draw conclusions about the necessity for supportive	Limited access to the abstract.

							services for the patients and their families.	
2001	El-Shanti, H.	The impact of genetic disease on Jordanian: strategies towards prevention.	Jordan	Articles	---	---	Focused on the causes and preventive methods of the genetic disorders Suggestion.	---
2001	Melnyk, B., Feinstein, N., Moldenhouer, Z., and Small, L.	Coping in parents of children who are chronically ill: Strategies for assessment and intervention.	USA	Article	---	---	This article will: (a) review stressors of childhood chronic illness for parents over time; (b) provide a summary of tools, (c) delineate important nursing assessments, (d) review interventions that have resulted in improved parental coping outcomes, and (e) describe a theoretical framework that can be used to assess and intervene with parents of chronically ill children.	The access limited to the abstract
2001	Van Heck, G. L., and De -Ridder, D. T. D.	Assessment of coping with loss: Dimensions and measurement.	USA Washington D.C.	Chapter of the book.	In: M. S., Stroebe, R. O., Hansson, W., Stroebe, and H. Schut, ed.	Handbook of Bereavement Research Consequences, Coping and Care.	American Psychological Association.	---
2001	Folkman, S.	Revised coping theory and the process of bereavement.	USA Washington D.C.	Chapter of the book	In: M. S. Stroebe, R.O. Hansson, W.	Handbook of Bereavement Research.	American Psychological Association.	---

					Stroebe, and H. Schut, ed.	Consequences, Coping and Care.		
2001	Stroebe, M., and Schut, H.	Models of coping with bereavement: A review.	USA Washington D.C.	Chapter in the book	In M. S. Stroebe, R. O. Hansson, W. Stroebe, and H. Schut, ed.	Handbook of Bereavement Research. Consequences, Coping and Care.	American Psychological Association,	---
2001	Zahed, L.	The spectrum of β -thalassaemia mutations in the Arab populations.	Lebanon	Article	---	---	To review the molecular basis of β -thalassaemia in various Arab countries and the distribution of the mutations.	---
2001	Biesecker, B. B.	Goals of genetic counselling.	USA	Article	---	---	To recommends use of genetic counselling sub- specialties as a framework for considering different. Client needs and thus different counselling goals and specific aims in the reproductive, paediatric/adult, and common disease settings.	---
2001	Altshuler, L. L., Cohen, L. S., Moline, M. L., Kahn, D. A., Carpenter, D., and Docherty, J. P.	Treatment depression in women.	USA	Special Report on the Expert Consensus Guideline Series.	Survey send to 40 national experts on women's mental health issues, 36 (90%) of whom completed it.	Home	To bridge the gap between research evidence and key clinical decisions.	---
2001	Donnai, D., and Elles, R.	Integrated regional genetic services: current	UK	Article	12 UK health regions and international	---	To describe how the benefits of this rapidly expanding	---

		and future provision.			comparisons reported in recent scientific and official publications.		knowledge are being brought to the UK population as genetic services, and how they may develop in the future.	
2001	Compas, B. E., Connor-Smith, J. K., Saltzman, H., Thomsen, A. H., and Wadsworth, M. E.	Coping with stress during childhood and adolescence: problems, progress, and potential in theory and research.	---	Literature Review Study.	Studies of the association of coping with symptoms of psychopathology and social and academic competence are reviewed.	---	To review the progress and issues in the study of coping with stress during childhood and adolescence.	Access limited to the abstract.
2001	Fisher, H. R.	The needs of parents with chronically sick children: A literature review.	UK	Literature Review Paper	8 research studies that were carried out from 1987 to 1997, written in the English language.	All studies were carried out from the naturalistic paradigm and yielded rich data.	To provide HCPs with an enhanced knowledge of the needs of parents with chronically sick children.	The limited number of the studies reviews.
2001	Gharaibeh, H.	Parental knowledge, attitudes and practices in relation to thalassaemia in northern Jordan.	Jordan	Thesis Qualitative – used pre and post questionnaire	36- Parents	Hospital	To assessed parents' knowledge and attitudes. As well as evaluate their practice in relation to thalassaemia.	One geographical area.
2001	Link, B. G., and Phelan, J. C.	Conceptualizing stigma.	USA New York City.	Review papers	---	---	To define stigma as the co-occurrences of its components- labelling, stereotyping, separation, status loss and discrimination.	---
2000	Katz, S.	Busy Bodies: Activity, Aging	Canada	Article	---	---	To examines the theoretical and	---

		and the Management of Everyday Life.					practical aspects of activity in the gerontological field, and considers how activity has also become a keyword in radical and popular vocabularies for narratives of the self.	
2000	Sadiq, M., Rimawi, H., and Haddad, L.	Psychosocial and economic study of families with beta thalassaemic children in northern Jordan.	Jordan	Article	----	---	To identified the psychosocial and economic impact of thalassaemia on family of children with BTM.	---
2000	Phelan, J. C., Link, B. G., Steuve, A., and Pescosolido, B.	Public conceptions of mental illness in 1950 and 1996: What is mental illness and is it to be feared.	USA	Literature Review Study	---	---	To compare the definitions of mental illness between 1950 and 1996.	---
1998	Chamba, R., Ahmad, W., and Jones, L.	Improving Services for Asian Deaf Children: Parents' and Professionals' Perspectives.	UK	Book.	Available from British Library Document Supply Centre.	---	--	---
1997	Alwan, A., and Modell, B.	Community control of genetic and congenital disorders.	Egypt WHO-EMRO office.	Book	EMRO Technical Publications series.	---	---	---
1997	Teebi, A., and Farag, T.	Genetic Disorders among Arab Populations. Oxford Monographs on Medical Genetics.	USA	Book	New York: Oxford University Press.	---	---	---

1997	Kübler-Ross, E.	The Wheel of Life: A Memoir of Living and Dying.	USA New York City.	Book	New York: Scribner	---	---	---
1998	Selway, D., and Ashman, A. F.	Disability, religion and health: A literature review in search of the spiritual dimensions of disability.	Australia	An historical and cross-cultural overview.	---	---	To explores the realm of disability, religion and health, and draws together literature from a variety of sources to illustrate the diversity of the sparse research in the field.	This review search limited area in the field of endeavour in search of the spiritual dimensions of disability.
1998	Gill, P., and Modell, B.	Thalassaemia in Britain: A tale of two communities - Births are rising among British Asians but falling in Cypriots.	UK	Article	---	---	To introduce thalassemia in British communities.	---
1998	Politis, C.	The psychosocial impact of chronic illness.	Greece	Literature Review Study.	---	Data based	This paper is primarily concerned with homozygous thalassaemia major. The milder intermedia syndrome is itself a chronic disease, whose patients and their families may well be subject to the same forces as are discussed here, but its psychosocial aspects have been much less studied than is the case with thalassemia major.	---

1997	Eiser, C.	Adaptation to Chronic Childhood Illness.	USA	Articles	---	---	To evaluate the adaptation to chronic childhood illness.	---
1996	Ahmad, W., and Atkin, K.	Ethnicity and caring for a disabled child: the case of children with sickle cell or thalassaemia.	UK	Descriptive articles.	---	---	To provide an overview of this area within the broader context of childhood disability and chronic illness, and ethnicity and health.	---
1996	Bluebond-Langer, M.	In the Shadow of Illness. Parents and Siblings of the Chronically Ill Child.	USA	Book	Princeton University Press.	---	---	---
1996	McCubbin, H. I., Thompson, A. I., and McCubbin, M. A.	Family Assessment: Resiliency, Coping and Adaptation. Inventories for Research and Practice. Madison.	USA	Book	Wisconsin: University of Wisconsin Publishers, pp. 407-447.	---	---	---
1996	Kelleher, D., and Islam, S.	How should I live? Bangladeshi people and non-insulin-dependent diabetes.	UK	Chapter of Book	In: D. Kellerher, and S. Hilliers., Researching Cultural Differences in Health, p. 220.	---	---	---
1996	Martin, C., and Nisa, M.	Meeting the needs of children and families in chronic illness and disease. A greater role for the GP?	Australia	Literature Review Study.	---	Medline electronic database.	To define chronic disease and illness. To describe 'non categorical' dimensions or common features of different chronic diseases in	---

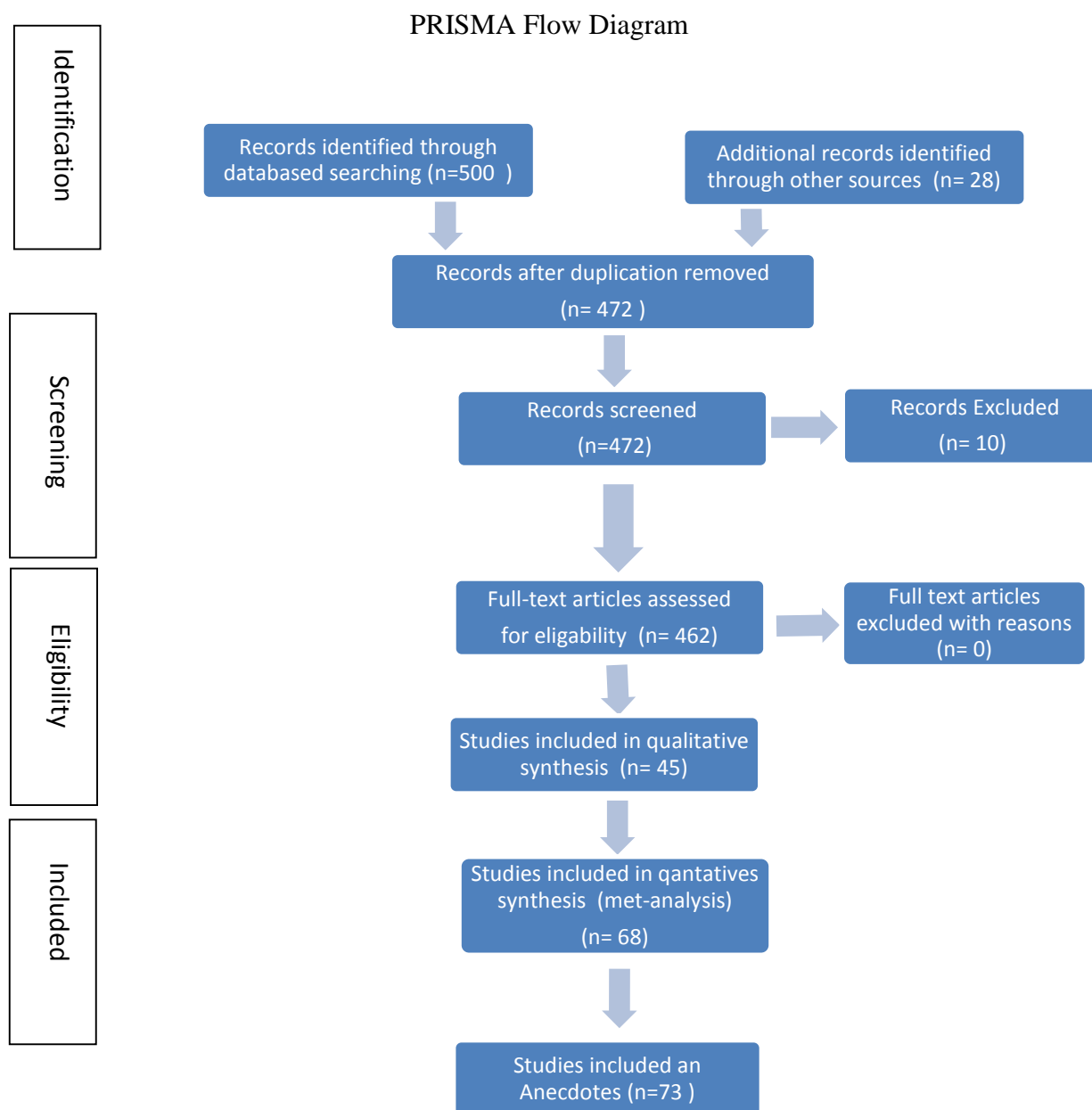
							childhood and their impact on the child and family involved. To explore needs for care and the role of the general practitioner in providing this care.	
1994	Baldwin, S., and Carlisle, J.	Social Support for Disabled Children and Their Families.	UK-Edinburg	Book	---	British Library Document Supply Centre.	---	---
1994	Beresford, B.	Resources and strategies: how parents cope with the care of disable child.	UK	Literature Review Study.	---	---	The study focus on research which clarifies the relationships between coping resources, coping strategies and outcomes.	---
1994	Meyer, D. J., Vadasy, P. F., and Fewell, R. R.	SIBSHOP: A Handbook for Implementing Workshops for Siblings of Children with Special Needs.	UK- London	E-Book	---	---	Online: Available at: http://files.eric.ed.gov/fulltext/ED270906.pdf .	---
1994	Midence, K., and Elander, J.	Sickle Cell Disease: A Psychological Approach.	UK- Oxford	Book	---	---	---	---
1994	Twigg, J., and Atkin, K.	Carers Perceived: Policy and Practice in Informal Care.	UK	Book	Buckingham: Open University Press.	---	---	---
1994a	Hill, S. A.	Managing Sickle Cell Disease in Low Income Families.	USA	Book	Philadelphia: Temple University Press.	---	---	---

1994	Sheldon, K., and Caldwell, L.	Urinary incontinence in women: Implications for therapeutic recreation.	USA	Literature Review	---	---	To presents a review of the literature concerning the causes and effects of urinary incontinence (UI) in community-dwelling mid-life and older women in the USA.	Access limited to the abstract.
1994	Beresford, B.	Resources and strategies: how parents cope with the care of disable child.	UK	Literature Review	---	---	This review focused on research which clarifies the relationships between coping Resources, coping strategies and outcomes.	---
1993	Eiser, C.	Growing Up with a Chronic Disease The Impact on Children and Their Families.	UK	E-Book	---	---	Online available at: http://books.google.co.uk/books .	---
1993	Lillie-Blanton, M., Anthony, J. C., and Schuster, C. R.	Probing the meaning of racial/ethnic group comparisons in crack cocaine smoking.	USA	Literature Review Study.	The 1988 NHSDA interviewed 8814 individuals residing within households in the USA. Subjects were selected using a multistage area probability sampling of all residents aged	Data Based	To probe the meaning of reported racial and ethnic group differences in the prevalence of crack cocaine smoking and to estimate the degree to which crack cocaine smoking is associated with personal factors specific to race/ethnicity.	Access limited to the abstract.

					12 years and older.			
1992	Wallander, J. L., and Varni, J.	Adjustment in children with chronic physical disorders: Programmatic research on a disability-stress-coping model. Chapter in book.	USA	Book	Chapter In La Greca, A., Siegel, L. J., Wallander, J. L., and Walker, E. G., 1992.	Stress and Coping in Child Health, United States of America. pp. 279-298. The book.	---	---
1991	Bittles, A., Mason, W., Greene, J., and Rao, N.	Reproductive behaviour and health in consanguineous marriage.	USA	Article	---	---	To identify the connection of reproductive behaviours and health with related to the consanguineous marriage.	Limited access to the abstract.
1990	Battiato, I.	Psychological aspects within the family of thalassaemic subjects.	Italy –Catania	Article	---	---	To identify the psychological aspect within the family of thalassaemic subjects.	Limited access to the abstract.
1990	Darr, A.	The social implication of thalassaemia Among Muslims of Pakistani Origin in England; Family Experience and Service Delivery.	UK	Thesis- PhD	---	---	To explore Pakistani Muslims origin in England of thalassaemia subjects and identifies the social implications.	---
1990	Eiser, C.	Chronic Childhood Disease: an Introduction to Psychological Theory and Research.	UK	E-Book	Cambridge University Press.	---	Online available at: http://books.google.co.uk/books .	---

1990	Georganda, E. T.	The Impact of Thalassaemia on Body Image, Self-Image, and Self-Esteem.	Greece-Athens	Descriptive-Article.	---	---	To discuss the impact of the thalassaemia on body image, self-Image and self – esteem.	---
1988	Lewis, J., and Meredith, B.	Daughters Who Care: Daughters Caring for Mothers at Home.	UK	Book.	Publisher Routledge: London and New York.	---	---	---
1981	Dushenko, T. W.	Cystic fibrosis: A medical overview and critique of the psychological literature.	USA	Article	---	---	To description of CF symptoms, complications, and their diagnosis is followed by an overview of medical and nonmedical treatment.	Access limited to the abstract.

Appendix 2: PRISMA Flow Diagram



Source: Adopted by Moher, et al. (2009).The data in the figure was generated from the research findings.

Appendix 3: Ethical Approval Forms
Form 3.1: University of Hull Ethical Approval Letter



Ms Khetam Al-Awamreh
Faculty of Health and Social Care
University of Hull

FACULTY OF HEALTH
AND SOCIAL CARE
T: 01482 464524
E: p.a.pearcey@hull.ac.uk

04 May 2010

OUR REF 031

Meeting date 29 March 2010

Dear Khetam

Re: Your proposal

Thank you for submitting your amended application for approval of your study to the Faculty Ethics Committee. I am pleased to inform you that, after consideration, the committee are delighted to approve your study and you may begin data collection with immediate effect.

Yours sincerely


Dr Pat Pearcey
Chair, Research Ethics Committee

cc. file/JJ/PD

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Vice - President's Office
 جامعة آل البيت
 AL al-BAYT UNIVERSITY
 مكتوب نائب الرئيس
 الرقم : ٤٠١/٢٨
 التاريخ : ١٥ رجب ١٤٣١ هـ
 الموافق : ٢٨ / حزيران / ٢٠١٠ م
 لطفاً للايعاز المذكور
 مراجعة د. عبد الرؤوف
 دراسة العلم على هاشم
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 تحية طيبة وبعد
 فارجو أن أنقل إلى معاليكم بأن الطالبة سقنم المومارية والتي تدرس الدكتوراه في التمريض في
 جامعة Hull University في المملكة المتحدة ترغب في إجراء دراسة في استراتيجيات وراثة
 The experiences and coping strategies of parents of children with beta thalassemia major in Jordan: Aquilative investigation.
 أودع التحريم بالواقعة بالإيعاز لتسهيل مهمة مسؤوليها على العيادات والبيانات اللازمة لذلك
 شاكراً لمعاليكم تعاونكم مع جامعة آل البيت .
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 أ. د. هاشم الماسحيسند
 الدكتور
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 E-Mail: info@alalbayt.aabu.edu.jo
 Web Sit: http://www.aabu.edu.jo
 مقر الجامعة : الطرقة (٢٠٢) فاكس : ٦٢٩٧٠٢٥ (٠٢) ص ب (١٣٠٤٠) المرق ٢٥١١٣ المملكة الأردنية الهاشمية
 Al al - Bayt University, (Mafraq) Tel. (02) 6297000 Fax. (02) 6297025 P.O.Box (130040) Mafraq 25113 The H.K.of Jordan

Form 3.3: Jordanian Ministry of Health Ethical Approval Letter


وزارة الصحة

الرقم م.ب. ١ / لجنة اخلاقيات / ١٤٤٨٥
التاريخ
الموافق ١٠ / ١١ / ٢٠١٩

مدير تطوير الموارد البشرية

تحية طيبة وبعد ،،،

اشاره لكتابتكم رقم تطوير / متدربين / ٥١٣٨ / تاريخ ٢٠١٩/٧/٢٠
بخصوص البحث المقدم من طالبة الدكتوراه / ختام محمد عبد الله العوامره .

بعضوان :

"تجربة الوالدين في رعاية الابن المصاب بمرض التلاسيميا وطرق تأقلمهما في الاردن"

يرجى التكرم بالعلم بأنه تم عرض البحث على لجنة اخلاقيات البحث العلمي
وقد قررت اللجنة الموافقه على اجراء البحث المشار اليه اعلاه ، بعد ان قامت الباحثة بأجراء
التعديلات المطلوبه .

للتكرم بالاطلاع واجراءاتكم لطفا .

واقبلوا الاحترام

رئيس لجنة اخلاقيات البحث العلمي
الدكتور عبد الهادي البريزات
المساعد المدير لشؤون التقنية

ص ب / رس
وزارة الصحة
مديرية تطوير الموارد البشرية
٢٠١٩ / ١١ / ١٠
الرقم: ٨٥٥٥

الملكية الأردنية الهاشمية
علاف: ٢٢٠٠٠٢٢٠ فاكس: ٩٦٢٢ ٦ ٥٦٨٨٢٧٢ ص.ب: ٩٦٢٢ ٦ عمان ١١١١٨ الاردن. الموقع الإلكتروني: www.moh.gov.jo

Form 3.4: Ethical Letter from Jordanian Ministry of Health


وزارة الصحة

الرقم
التاريخ
الموافق ٢٠١٠ / ٨ / ٣١

..... مدير مستشفى

تحية طيبة وبعد ،،،

ارفق طيا صورة عن كتاب رئيس لجنة اخلاقيات البحث العلمي رقم
م ب ١/لجنة اخلاقيات/١٤٤٨٥ تاريخ ٢٠١٠/٨/٣٠ بخصوص الموافقة لطالبة الدكتوراه
ختام محمد عبد الله العوامره على اجراء بحث بعنوان :-

" تجربة الوالدين في رعاية الابن المصاب بمرض التلاسيميا وطرق تأقلمهما في الاردن "

وذلك عن طريق اجراء مقابلة للأباء والأمهات المراجعات للمستشفيات الحكومية او
القيام بزيارة لمنزل الطفل المصاب وإجراء المقابلة في المنزل في حال تعذر اجراء المقابلة في
المستشفى .
كذلك اجراء مقابلات مع الممرضات العاملات في اقسام التلاسيميا من ذوي الخبرة في
رعاية مرضى التلاسيميا .

ارجو التكرم بالاطلاع والايجاز لمن يلزم تسهيل مهمة الباحثة المذكورة في اجراء
البحث اعلاه .

واقبلوا احترامي ،،،

مدير تطوير الموارد البشرية

الدكتور أيوب السيادة

نسخة / الملف

عدد الباحثين (١)

الملكمة الأردنية الهاشمية
عانت ١١١١٨ الأردن. الموقع الإلكتروني: www.moh.gov.jo
هاتف: ٥٢٠٠٢٣٠ فاكس: ٥٦٨٨٣٧٢ ص.ب: ٨٦ عمان ٩٦٢٢ ٦


Form 3.5: The Ethical Research Committee in the Jordan Ministry of Health

لائحة الوقائع

وزارة الصحة

رقم الملف ورقم العاملة	Code: MOH REC 700033 رقم الكتاب وتاريخه		
من رئيس لجنة أخلاقيات البحث العلمي بخصوص البحث المتم من طالبة الدكتوراه ختام محمد عبيد العوامر			
الرقم	التاريخ	إلى	المشروعات والتوقيعات
١٧٥٦	١٧/١٢	عصاوية أخلاقيات البحث العلمي الدكتور محمد الفاعوري	<p>لجنة طبية ولجنة أخلاقيات البحث العلمي التي تم طلبها من قبلكم للمرة الثانية على البحث المقدم من طالبة الدكتوراه ختام محمد عبيد العوامر بعنوان:</p> <p>عقوبة الوالدين في رعاية الابن المصاب بمرض التلاصق وطرق تأهيلها في الأردن</p> <p>للتكريم بالاطلاع والمعالجة تبين انكم حول الموضوع لتتأكد على ضرورة ذلك من أفراد اللجان وأقبلوا امرنا</p> <p>رئيس لجنة أخلاقيات البحث العلمي</p> <p>الدكتور عبد الهادي البريدات</p> <p>كتبه: محمد عبيد العوامر</p> <p>تاريخه: ١٧/١٢</p> <p>المراجعة: ١٧/١٢</p>

Form 3.6: Ethical form to the ABGH in Amman


وزارة الصحة

الرقم
التاريخ
الموافق ٢٠١٩ / ٧ / ٢١

مدير مستشفى البشير
رئيس لجنة أخلاقيات البحث العلمي

تحية طيبة وبعد ...

أرفق طياً صورة عن كتاب رئيس جامعة آل البيت رقم ٣٠٤٣/٢/٤ تاريخ ٢٨ / حزيران / ٢٠١٠
بخصوص طلب السماح لطالبة الدكتوراة الآتية ختام محمد عبدالله العوامرة إجراء دراسة في مستشفيات وزارة
الصحة بعنوان :-

(تجربة الوالدين في رعاية الإبن المصاب بمرض التلاسيميا وطرق تأقلمهما في الأردن)


وذلك عن طريق إجراء مقابلة للآباء والأمهات المراجعات للمستشفيات الحكومية أو القيام بزيارة لمنزل
الطفل المصاب وإجراء المقابلة في المنزل في حال تعذر إجراء المقابلة في المستشفى .

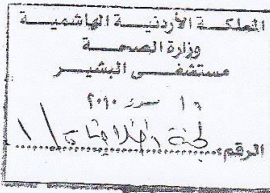
وكذلك إجراء مقابلات مع الممرضات العاملات في أقسام التلاسيميا من ذوي الخبرة في رعاية مرضى
التلاسيميا .

أرجو التكرم بالاطلاع وإعلامي رأيكم حول إمكانية الموافقة .

واقبلوا الإحترام ...

مدير تطوير الموارد البشرية


الدكتور أيوب السيادة



نسخة / الملف
ع ش
ع

الملكية الأردنية الهاشمية
وزارة الصحة
مستشفى البشير
١٦ سرر ٩٠١٠
الرقم
لجنة الأخلاقيات

الملكية الأردنية الهاشمية
www.moh.gov.jo الموقع الإلكتروني عمان ٨٦ ب. ص ٩٦٢ ٦ ٩٦٨٨٢٧٢ فاكس ٩٦٢ ٦ ٥٢٠٢٢٠ هاتف

Appendix 4: Research Documents in Arabic
Form 4.1: Invitation Letter for the Fathers.

"رسالة دعوة للمشاركة في الدراسة"

أخي المشارك

تحية طيبة و بعد.....

جامعة "ال البيت" الأردنية , جامعة "هل" البريطانية و أنا الباحثة "ختام العوامرة" أنا الآن أقوم بدراستي للحصول على درجة الدكتوراه من جامعة " هل " البريطانية و هذا البحث هو متطلب اساسي في الدراسة لذا نتوجه بالدعوة لك للمشاركة في هذا البحث الذي يهدف لمعرفة و استكشاف تجربة الوالدين قيامهما في رعاية ابنهما المصاب بمرض التلاسيميا و كيفية تأثير ذلك و أيضا شرح طرق تأقلمهم مع هذا الوضع في الأردن.

أرجو ان تقرأ بدقة و تأني قبل اتخاذك القرار بالمشاركة بالدراسة البحثية أو الرفض و إذا كان لديك أي أسئلة أو استفسارات أرجو ان لا تتردد في طرحها.

سوف تحصل على نسخة نموذج الموافقة بلأشتراك في الدراسة بلأضافة الى نموذج المعلومات التفصيلية للدراسة , و إذا أردت المزيد من التوضيحات فلا تتردد بلأتصال بالباحثة على العنوان المذكور في أسفل الصفحة.

شكرا جزيلاً لوقتكم قرأت هذه المعلومات

طالبة الدكتوراه: ختام العوامرة

هاتف أرضي: 027250745

هاتف خلوي: 07777495149

البريد الإلكتروني :

Kta112001@yahoo.com

K.M.Al-Awamreh@2009.hull.ac.uk

أربد / الأردن

شاكرين حسن تعاونك

Form 4.2: Invitation Letter for the Mothers.

"رسالة دعوة للمشاركة في الدراسة"

أختي المشارك

تحية طيبة و بعد.....

جامعة "ال البيت" الأردنية , جامعة "هل" البريطانية و أنا الباحثة "ختام العوامرة" أنا الآن أقوم بدراستي للحصول على درجة الدكتوراه من جامعة " هل " البريطانية و هذا البحث هو متطلب اساسي في الدراسة لذا نتوجه بالدعوة لك للمشاركة في هذا البحث الذي يهدف لمعرفة و استكشاف تجربة الوالدين قيامهما في رعاية ابنهما المصاب بمرض التلاسيميا و كيفية تأثير ذلك و أيضا شرح طرق تأقلمهم مع هذا الوضع في الأردن.

أرجو ان تقرأي بدقة و تأني قبل اتخاذك القرار بالمشاركة بالدراسة البحثية أو الرفض و إذا كان لديك أي أسئلة أو استفسارات أرجو ان لا تترددي في طرحها.

سوف تحصلين على نسخة نموذج الموافقة لأشترك في الدراسة بالإضافة الى نموذج المعلومات التفصيلية للدراسة , و إذا أردت المزيد من التوضيحات فلا تترددي بالاتصال بالباحثة على العنوان المذكور في أسفل الصفحة.

شكرا جزيلاً لوقتكم قرأت هذه المعلومات

طالبة الدكتوراه: ختام العوامرة

هاتف أرضي: 027250745

هاتف خلوي: 07777495149

البريد الإلكتروني :

Kta112001@yahoo.com

K.M.Al-Awamreh@2009.hull.ac.uk

أربد / الأردن

شاكرين حسن تعاونكم

Form 4.3: Consent Form

"إقرار الموافقة بالأشتراك في الدراسة"

عنوان الدراسة: تجربة الوالدين في رعاية أبنهما المصاب بمرض التلاسيميا وطرق تأقلمهما في الأردن.

اسم الباحثة: ختام العوامرة - طالبة دكتوراه

الرقم السري للمشاركة:.....

أختي المشاركة / أخي المشارك الرجاء وضع علامة (*) في المربع المقابل للجملة المناسبة لك و من ثم التوقيع في

المكان المخصص لذلك إذا تمت موافقتك:

1. أقر أنني قد قرأت وفهمت "ورقة المعلومات التفصيلية" الخاصة بالدراسة المذكورة أعلاه, وكانت لدي الفرصة بأن أطرح أي سؤال للاستفسار و حصلت على الأجوبة المناسبة لجميع تساؤلاتي ()

2. أفهم بأن مشاركتي في هذه الدراسة اختيارية, و بكامل أرادتي وأنني أمتلك حق الانسحاب في أي وقت وبدون ذكر الأسباب أو التبرير و بدون اي مسائلة مع عدم التأثير على الرعاية الصحية المقدمة لي أو و لأبني أو التأثير على عملي و حقوقنا القانونية ()

3. أنا أعلم بأن الباحثة و المشرفين على البحث سوف يتعاملون مع المعلومات المعطاه لهم في الدراسة بسرية تامة ()

4. أفهم بأن بعض الملاحظات والمعلومات المتوفرة عن أبنني في المستشفى والمتعلقة بمشاركتي في الدراسة قد تحتاج الباحثة لقراءتها, لذا فأنا أسمح للباحثة بالاطلاع على الملف الطبي عند الحاجة ()

5. أنا أوافق على المشاركة في الدراسة المذكورة أعلاه ()

اسم المشاركة:..... التاريخ:...../...../..... التوقيع:.....

اسم الباحثة:..... التاريخ:...../...../..... التوقيع:.....

شاكرين حسن تعاونكم

Form 4.4: Research Information Sheet for Mothers

تجربة الوالدين في رعاية أبنهما المصاب بمرض التلاسيميا وطرق تأقلمهما في الأردن

"ورقة المعلومات التفصيلية الخاصة بالدراسة"

عنوان الدراسة: "تجربة الوالدين في رعاية أبنهما المصاب بمرض التلاسيميا وطرق تأقلمهما في الأردن".

عزيزتي المشاركة: أود دعوتك للمشاركة في هذه الدراسة, ولكن قبل أن تتخذي قرار المشاركة, نجد أنه من الضروري أن تعرفي لماذا تجرى هذه الدراسة, وماذا تتضمن, وما هو المطلوب منك إذا اشتركت فيها.

نرجو من حضرتك أن تأخذي الوقت الكافي لقراءة المعلومات التي سنذكر بعناية, دقة, و تأني. وإذا وجدت معلومة غير واضحة أو أن لديك أسئلة أرجو منك طرحها وسأقوم بالإجابة عليها وتوضيح المعلومات غير الواضحة.

هدف الدراسة: تهدف هذه الدراسة البحثية إلى التعرف على تجربة الوالدين في رعاية أبنهما المصاب بمرض التلاسيميا وطرق تأقلمهما في الأردن .

سبب اختيارك للمشاركة: لأنك أم لشخص مصاب بمرض التلاسيميا في الأردن أو لأنك ممرضة تعملين في قسم التلاسيميا لأكثر من عام.

حرية المشاركة في الدراسة: إن المشاركة في هذه الدراسة اختيارية وليست إجبارية, فلك حرية الاختيار في المشاركة أو عدمها. إذا رغبت في المشاركة فسوف تأخذين ورقة المعلومات هذه للاحتفاظ بها, و التوقيع على نموذج الموافقة للمشاركة. وما زلت تتمتعين بحق حرية الانسحاب من الدراسة في أي وقت بدون ذكر الأسباب.

وقرارك في المشاركة أو عدم المشاركة لن يؤثر على الرعاية الصحية المقدمة لك أو لابنك في المستشفى و لن يؤثر على عملك في المستشفى.

دعم الدراسة: هذه الدراسة مدعومة مالياً من قبل جامعة "ال البيت" في الأردن ومن "الباحثة" بالإضافة الى جامعة "هل" في بريطانيا.

إذا اشتركت في الدراسة: لا يوجد أضرار أو أذى قد يلحق بك أو بأبنك ولا بعملك من جراء المشاركة في الدراسة. كما أن جميع المعلومات التي ستجمع في الدراسة ستحفظ وتعامل بسرية تامة, و لن يتم ذكر الأسم, الكنية, أو العنوان, بل سيتم التعامل برقم لكل مشاركة و بذلك لن تكوني معروفة للآخرين.

إذا اتخذت قراراً بالمشاركة: سوف يتم الاتفاق على تاريخ يوم معين و وقت لإجراء مقابلة معك في مكان من اختيارك (البيت أو المستشفى) , حيث سأطرح عليك بعض الأسئلة ومن ثم أعطيك الوقت الكافي للإجابة عليها بكل حرية.

ستقوم الباحثة بتسجيل المقابلة في غرفة من اختيار المشاركة من أجل الراحة ستستغرق المقابلة حوالي ساعة من وقتك و ستكون المشاركة مرة و احدة , ستكون المقابلة باللغة العربية و لك الحق ان توقفي التسجيل في اي وقت تشاءين . خلال ذلك الوقت ستقوم الباحثة أيضاً بتدوين بعض الملاحظات على دفتر خاص لذلك.

نتائج الدراسة: سيتم تحليل نتائج الدراسة و تقدم على شكل مدونة خاصة الى جامعة "هل" البريطانية من أجل الحصول على شهادة الدكتوراة و في المستقبل نتمنى أن أستطيع نشر النتائج من هذه الدراسة في مجلات علمية. والمعلومات التي ستجمع و النتائج سوف تستخدم لتكون قاعدة معلومات لخطط التنمية الصحية المستقبلية لمرض التلاسيميا في الأردن.

مراجعة الدراسة: تم أخذ الموافقة على إجراء الدراسة من قبل اللجنة الأخلاقية في جامعة "هل" في إنجلترا بريطانيا و جامعة "ال البيت" في الأردن بالإضافة الى "وزارة الصحة الأردنية".

السرية الخصوصية لهذه الدراسة:- سيتم تسجيل المقابلات في غرفة هادئة مستقلة في مكان من اختيار المشاركة و سيتم تحليل النتائج من قبل الباحثة و للمحافظة على السرية سيتم حفظ التسجيل و جميع المعلومات في كمبيوتر خاص بالباحثة و لن يستطيع أحد استخدامه, و جميع الملاحظات المدونة في دفتر خاص ستحفظ في ملفات و خزائن بالبحث لا يمكن الوصول اليها الا الباحثة.

و سيتم مسح وازالة و أتلاف جميع المعلومات المتعلقة بالبحث بعد انتهاء الدراسة و استخراج النتائج

إذا كان لديك أي سؤال أو استفسار فلا تتردد في الاتصال مع الباحثة:

طالبة الدكتوراه: ختام العوامرة

هاتف أرضي: 027250745

هاتف خلوي: 07777495149

البريد الإلكتروني :

Kta112001@yahoo.com

K.M.Al-Awamreh@2009.hull.ac.uk

أريد / الأردن

شكراً جزيلاً على حسن تعاونك

Form 4.5: Research Information Sheet for Fathers.

تجربة الوالدين في رعاية أبنهما المصاب بمرض التلاسيميا وطرق تأقلمهما في الأردن

"ورقة المعلومات التفصيلية الخاصة بالدراسة"

عنوان الدراسة: "تجربة الوالدين في رعاية أبنهما المصاب بمرض التلاسيميا وطرق تأقلمهما في الأردن".

أخي المشارك : أود دعوتك للمشاركة في هذه الدراسة, ولكن قبل أن تتخذ قرار المشاركة, نجد أنه من الضروري أن تعرف لماذا تجرى هذه الدراسة, وماذا تتضمن, وما هو المطلوب منك إذا اشتركت فيها.

نرجو من حضرتك أن تأخذ الوقت الكافي لقراءة المعلومات التي ستذكر بعناية, دقة, و تأني. وإذا وجدت معلومة غير واضحة أو أن لديك أسئلة أرجو منك طرحها وسأقوم بالإجابة عليها وتوضيح المعلومات غير الواضحة.

هدف الدراسة: تهدف هذه الدراسة البحثية إلى التعرف على تجربة الوالدين في رعاية أبنهما المصاب بمرض التلاسيميا وطرق تأقلمهما في الأردن .

سبب اختيارك للمشاركة: لأنك أب لشخص مصاب بمرض التلاسيميا في الأردن.

حرية المشاركة في الدراسة: إن المشاركة في هذه الدراسة اختيارية وليست إجبارية, فلك حرية الاختيار في المشاركة أو عدمها. إذا رغبت في المشاركة فسوف تأخذ ورقة المعلومات هذه للاحتفاظ بها, و التوقيع على نموذج الموافقة للمشاركة. وما زلت تتمتع بحق حرية الانسحاب من الدراسة في أي وقت بدون ذكر الأسباب.

وقرارك في المشاركة أو عدم المشاركة لن يؤثر على الرعاية الصحية المقدمة لك أو لابنك في المستشفى.

دعم الدراسة: هذه الدراسة مدعومة مالياً من قبل جامعة "ال البيت" في الأردن ومن "الباحثة" بالإضافة الى جامعة "هل" في بريطانيا.

إذا اشتركت في الدراسة: لا يوجد أضرار أو أذى قد يلحق بك أو بأبنك من جراء المشاركة في الدراسة. كما أن جميع المعلومات التي ستجمع في الدراسة ستحفظ وتعامل بسرية تامة, و لن يتم ذكر الأسم, الكنية, أو العنوان, بل سيتم التعامل برقم لكل مشارك و بذلك لن تكون معروف للآخرين.

إذا اتخذت قراراً بالمشاركة: سوف يتم الاتفاق على تاريخ يوم معين و وقت لإجراء مقابلة معك في مكان (البيت أو المستشفى), حيث سأطرح عليك بعض الأسئلة ومن ثم أعطيك الوقت الكافي للإجابة عليها بكل حرية.

ستقوم الباحثة بتسجيل المقابلة في غرفة من اختيار المشارك من أجل الراحة ستستغرق المقابلة حوالي ساعة من وقتك و ستكون المشاركة مرة و احدة, ستكون المقابلة باللغة العربية و لك الحق ان توقف التسجيل في اي وقت تشاء. خلال ذلك الوقت سأقوم أيضاً بتدوين بعض الملاحظات على دفتر خاص لذلك

نتائج الدراسة: سيتم تحليل نتائج الدراسة و تقدم على شكل مدونة الى جامعة "هل" البريطانية من أجل الحصول على شهادة الدكتوراة و في المستقبل نتمنى أن أستطيع نشر النتائج من هذه الدراسة في مجلات علمية.

والمعلومات التي ستجمع و النتائج سوف تستخدم لتكون قاعدة معلومات لخطط التنمية الصحية المستقبلية لمرض التلاسيميا في الأردن.

مراجعة الدراسة: تم أخذ الموافقة على إجراء الدراسة من قبل اللجنة الأخلاقية في جامعة "هل" في إنجلترا
بريطانيا و جامعة "ال البيت" في الأردن بالإضافة الى "وزارة الصحة الأردنية".

السرية الخصوصية لهذه الدراسة:- سيتم تسجيل المقابلات في غرفة هادئة مستقلة في مكان من اختيار المشارك و
سيتم التحليل من قبل الباحثة و للمحافظة على السرية سيتم حفظ التسجيل و جميع المعلومات في كمبيوتر خاص
بالباحثة و لن يستطيع أحد استخدامه و جميع الملاحظات المدونة في دفتر خاص ستحفظ في ملفات و خزائن بالبحث
لا يمكن الوصول اليها الا الباحثة.

و سيتم مسح وازالة و أتلاف جميع المعلومات المتعلقة بالبحث بعد انتهاء الدراسة و استخراج النتائج.

إذا كان لديك أي سؤال أو استفسار فلا تتردد في الاتصال مع الباحثة:

طالبة الدكتوراه: ختام العوامرة

هاتف أرضي: 027250745

هاتف خلوي: 07777495149

البريد الإلكتروني :

Kta112001@yahoo.com

K.M.Al-Awamreh@2009.hull.ac.uk

أريد / الأردن

شكراً جزيلاً على حسن تعاونك

تجربة الوالدين في رعاية أبنهما المصاب بمرض التلاسيميا وطرق تأقلمهما في الأردن

أسئلة توضيحية بناء على أجابة الشخص في المقابلة:

1. هل من الممكن أن تخبريني عن المرة الأولى التي علمت بها أن طفلك مصاب بمرض التلاسيميا؟
2. ماذا حصل من تطورات عندما علمت أن طفلك لديه فقر دم و عندما تم تشخيصه بمرض التلاسيميا ؟ ماذا أخبرك الأطباء ؟ كم من الوقت استغرق تشخيص طفلك بمرض التلاسيميا ؟
3. ما هو شعورك عندما تم تأكيد تشخيص طفلك بالمرض؟
4. ما هو شعورك برعاية طفل مصاب بالتلاسيميا ؟ هل هو شعور مختلف ؟ اذا كانت أجابتك نعم ما هو الاختلاف؟ هل ما زال نفس الشعور من وقت التشخيص ام اختلف ؟
5. هل يحتاج طفلك المصاب بالتلاسيميا رعاية مختلفة عن اخوانه او اخواته ؟ ما هو الاختلاف ؟
6. هل تعتبرين طفلك المصاب بالمرض بحاجة الى دعم عاطفي أكثر من غيره ؟ ما هي طبيعة هذا الدعم ؟ وكيف تقدمين ذلك الدعم؟
7. هل يحتاج إلى رعاية خاصة في حياته الاجتماعية ؟ في مدرسته , علاقته بأصدقائه , بأقربائه أو في مواقف أخرى ..
8. ما هي الأعمال و الواجبات التي يقوم بها طفلك لوحده دون مساعدة ؟
9. ما هي توقعاتك لمستقبل طفلك ؟
10. هل تشعرين انه طفلك مختلف في حالة عدم إصابته بالتلاسيميا ؟
11. هل تعتقدين أن طفلك قادر على تحقيق أمالك و طموحاتك في المستقبل ؟ على تحقيق ما هو متوقع له ؟
12. هل تعتقدين أن وجود طفل مصاب بالتلاسيميا يؤثر على العائلة ؟ و صحة الأسرة بشكل عام ؟ إذا كانت إجابتك نعم ؟ ما هو شعورك تجاه ذلك ؟
13. ما هو تأثير الحاصل على الأسرة بوجود طفل مصاب بمرض التلاسيميا في البيت ؟

أسئلة توضيحية في المقابلة:

1. ما هو دورك كأم أو أب في رعاية طفلك المصاب بالتلاسيميا هل يختلف الدور مع الأطفال الآخرين في الأسرة ؟ إذا كانت الإجابة نعم أرجو توضيح هذا الاختلاف ؟
2. هل أنت راض عن الطريقة التي تعامل بها طفلك ؟ إذا كانت الإجابة نعم ؟ أرجو توضيح ؟ لأسباب ؟ و لماذا الاختلاف ؟
3. هل أنت راض عن الرعاية الطبية التي يتلقاها طفلك ؟ إذا كانت الإجابة نعم أو لا ؟ أرجو عطاء الأسباب؟
4. ما هي الأمور التي تعتقد انه يجب تغييرها في الرعاية الطبية ؟ هل لديك اقتراحات ؟

Appendix 5: Research Documents in English
Form 5.1: Research Cover Letter

Dear Participant

As you have agreed to participate in a research study entitled by ‘The Experiences and Coping Strategies of Jordanian Parents of Children with Beta-Thalassaemia Major’.

I would like to take this chance to thank you in advance for your time and collaboration to carry out this study. You will receive an information sheet and you are asked to sign the consent form, to show your agreement for me to complete the demographic data and the conduct. If you have any queries or concerns regarding the study, please do not hesitate to contact me at the address below.

Khetam Al-Awamreh
Faculty of Health and Social Care
Room 124 Dearne Building
University of Hull
HU6 7RX
K.M.Al-Awamreh@2009.hull.ac.uk
Tele: 0044-1482-46 4532
Fax: 0044-01482-464695
Mobile: 00447858300215

Sincerely

The Experiences and Coping Strategies of Jordanian Parents of Children with Beta-Thalassaemia Major

You are being invited to take part in a research study. Before you decide to participate it is important for you to understand why the research is being done and what it will involve. Please take the appropriate time to read the following information carefully and if there is anything that is not clear, do not hesitate to ask the researcher or if you would like more information.

Please take your time to decide whether or not you wish to share in this research study.

The purposes of this study are:

1. To explore the experiences of Jordanian parents of children with beta thalassaemia major and how caring for patients with beta thalassaemia impacts on the parents' life.
2. To find out the coping strategies that the Jordanian parents of children with beta thalassaemia major used, as described in their words.

You have been selected to take part in this study as a father or mother of a child with beta thalassaemia major and your child has no other chronic medical condition, if you decide to participate you will be given an information sheet and you will be asked to sign the consent form, and after all this you are still free to withdraw from this study at any time without giving a reason.

Be assured that your decision to take part or not will not affect your child's state as patient and will not affect the standard of care your child receives. If you agree to take part as a participant in this study, I will arrange for an interview which will take from 30 to 60 minutes. In this interview you will be asked questions about your experiences and coping strategies used. Feel free to decide the most convenient place and time for you to be interviewed either at home or at the hospital.

This interview will be recorded on 'audio tape' and I will take notes, I do not think there are possible risks for you to participate in this research study. However, the potential advantage is that the information collected could be used to improve and develop health services for children with beta thalassaemia and their families. All information which is collected in the interview will be treated as highly confidential. Your name and address will be removed; each interview will be given a special code in the research. Quotations may be used when the results are published in scientific journals but your name will not be used at all after analysis stage.

The results will be written into a thesis which will be available to read at the University of Hull Library, will also be some documents written in as an article in the scientific journal, which will be available if you order a copy.

This study is supported and approved by the University of Hull, United Kingdom, Al al-Bayt University in Jordan and Jordanian Ministry of Health.

For further information, contact the researcher at the following in United Kingdom and in Jordan.

In United Kingdom:

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In Jordan:

Khetam Al-Awamreh
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Fax: 962-2-6297052
Mobil: 00962777495149

If you have any concerns regarding the study please do not hesitate to contact the address below in Jordan.

Dr Ibrahim Ramahi. Secretary General. Research Ethics Committee (IRB) of Ministry of Health., Amman-Jordan iramahi@hotmail.com telephone number: (00962796699988) JORDAN.

Best Regards

Form 5.3: Consent Form

Title of project: The Experiences and Coping Strategies of the Jordanian Parents of Children with Beta-Thalassaemia Major.

Name of Researcher: Khetam Al-Awamreh

1. I confirm that I have read and understand the information sheet dated in (2010) for the above research study and I have had the opportunity to ask any questions. ☐
2. I understand that my participation is voluntary and that I'm free to withdraw at any time, without giving a reason, without any affected all of my medical and legal rights. ☐
3. I consent (agree totally) to the interview being recorded on audio tape. ☐
4. I consent (agree totally) to the interviewer taking notes during my interview. ☐
5. I agree to take part in the above research study. ☐

Name of participant:

Date/...../ 2010

Signature

Please tick in this box if you would like to receive a copy of the result of this research study at the end of it.

Please complete your contact details below if you would like to receive a summary of the study's conclusions upon completion of the project.

.....
.....
.....
.....

Thank You

Form 5.4: Demographical Data Sheet for Parents

Demographical Data Sheet for Parents

-Name: -Code Number :

-Hospital Name:

-Parents Number:

-Date and Day of the interview:

-Home address:

-Participant's Name:

-Participant's Nickname:

-Other name:

-Relation to the child:

1. Father.
2. Mother.
3. Other

-Participants' marital status:

1. Married.
2. Widow.
3. Divorce.
4. Other

-Work status:

1. Full time job.
2. Part time job.
3. Not working.

-Place of work:

1. Inside home.
2. Outside home.

-Relationship before marriage:

1. Relative couple.
2. Cousin relative couple.
3. Non-relative couple.

-Pre-marital Counselling:

1. Done
2. Not Done.
3. Don't know about the pre-marital counselling
4. Other

-Child Gender:

1. Male.
2. Female.

-Age of the child:

-Is he/she attending school?

1. No.
2. Yes.

If your answer is YES which school level he/she now:

-Age of child's diagnosis with beta thalassaemia major:

-How many times has he/she received blood at hospital:

-What is his/her birth order in the family?

1. The oldest one.
2. The youngest one.
3. Others:

-Dose he/she receive iron chelating therapy?

1. No
2. Yes

If yes what type dose he/she receive and how many times per/week...

-Dose he/she complain of any other chronic illnesses?

1. No.
2. Yes.

If yes what is the name of the disease:

-Do you have another family member diagnosed with beta Thalassaemia Major?

1. Yes.
2. No.

-Participant's educational level:

1. High school.
2. Diploma degree.
3. University degree.
4. Master degree.
5. Doctoral degree.
6. Other

Thank You

Form 5.5: Prompt Questions in English

The following are some of the prompt questions used in the interviews.

1. Can you let me know more about the first time your child was diagnosed with beta Thalassaemia major?
2. What happened between the first times your first child diagnosed that he/she had anaemia and confirmed that he/she had beta-thalassaemia major? What the health professionals said to you? How long the diagnoses of beta-thalassaemia major did take?
3. Tell me more about your feeling when your child was confirmed diagnosed with beta Thalassaemia major?
4. How do you feel about looking after and caring for your child after diagnosis? Is it different or not? If yes what were these feelings? Since the time has passed since your child was diagnosed?
5. Is looking after beta-thalassaemia major children different compared to one who does not have? What extra care do you give your child?
6. Do you feel that your child with thalassaemia needs more emotional support than others? What additional support? In what way?
7. Do you feel that your child needs more care in 'school, social relation friends or relatives and work, than other children?
8. What things do you not let your child do because of the thalassaemia?
9. What are your expectations for your child's future?
10. Do you think that your child would be different if he/she was not diagnosed with beta-thalassaemia?
11. How do you think your child will fulfil his/her potentials? Do you think your child needs your help?
12. Do you think having a child with beta thalassaemia major affects your and family health? If yes, how does it affect? And how do you feel about this?
13. How does having a child with beta-thalassaemia impact on the rest of the family?
14. Tell me more about your role as father /mother, dealing with family having a child diagnosed with beta-thalassaemia? Is it different? How you cope with that?
15. Are you happy with the way you deal with your child? If yes or no why?
16. Have you found the professional team useful? In what way?
17. What will make your child's situation and yours better? Please give suggestions.

Appendix 6: Pilot Interview.

Sample form the Research Pilot Study

Interview Code: **A.M.3**

Participant...**Um-A.B**

Hospital Name: **(PRGH)**

Date and Time: **30 August 2010 at 10:45**

-Me: First of all I want to thank you for giving me your time and taking part in this study before we start I want to introduce to you myself and my research to you my name is 'Khetam Al-Awamreh' I'm currently postgraduate research student, today I want to interview you and talk about your experiences and coping strategies as a mother of child diagnosed with beta thalassaemia major and I want to thank you for signed the consent form ...if you have any question please do not hesitate to asked at any time and I would love to read with you the information sheet ... if that it is ok with you ...

-Mother: My pleasure ... No I'm ok with that...yes I'm ok

-Me: I just need to remind you that you are chosen to take part in this study because you have son diagnosed with Beta thalassaemia major

-Mother: Yes my oldest son A.B

-Me: I really appreciate that a lot, you are ok with the recorders, it is voice recorder to keep the original of the interview and I can listen to that later and write it down. However, I can assured you that nobody will listen to this except me and the transcript sheet will translated into English language and I only and my academic supervisors will have access on that, of course your name will not mentioned. I will give the interview a code number, is that ok with you ...

-Mother: yes no problem you can record.

-Me: in between I may need to write few notes to not forget what we talk about is that ok with you ...

-Mother: yes you can dear, I know student always has to write down something hahaha (she smile and we both giggle about it) me: oh dear yes many writing ...hahahhahah (we both giggle) ok the recorder is now on.

Note: write on the sheet the code number, date and the time of the interview.

-Me: can we start first by filling the demographic data sheet.

-Mother: yes thank you I just need pen.

-Me: I have one ...there ... if you wish I can write it down for you

-Mother: Yes that is better ... you asked the questions and I give you the answers.

-Me: ok then if that what you prefer... let us start ...

Note: we fill in the demographic data sheet... give it the same code to keep it with the notes sheet of the interview.

-Me: Can you tell me about your experiences as a mother of a child with beta thalassaemia?

-Mother: First of all may be [Sobhan Allah] [it is expression used when people showed surprised] it is hard to receive the news and it was hard for me to believe that my first born son has thalassaemia ... 'I'm a mother' [silent for seconds] ... I believed in God and 'I have strong faith' this help me to be more patient and give me strength to accept the situation it is not easy... very stressful time for me and my husband... Oh my God... When we know about the diagnosed my husband cannot handle it but I'm stronger than him ... which to be honest I did not expected ... I keep telling myself... It is disease like any other disease ... anybody could have disease and that it is ...is in it?

-Me: I can see ...

-Mother: In fact it is took me time to understand and accepted the matter not like my husband. at first he did not accept the fact that our son has BTM at all ... it is really so hard for him ...his reaction influences me as well... add more stress ...more tired, feeling down, always angry, shouting for any things even if there is nothing he keep say life is so hard I don't know what happened with him ...oh dear that was the worst time I ever have in my life...what I should tell you... can you imagine I have A.B [her son] and I was pregnant and on the top of that I was going and coming to the shops for securing house stuffs...while he is visiting his friends ... oh..[move her hands and the tone and the tens of her voice change ...As she insisting how things some time comes was unfair] he used to spent the whole day with his friends.

-Me: can you please explain to me more about that you said 'I was pregnant'?

-Mother: Yes after I have A.B I breastfeed him for one year and six months then I discover I was pregnant then I stop the breastfeeding as the health centre told me ... they said is not good to keep breastfeed when you are pregnant so I stop and give him bottle feeding

-Me: that when A.B diagnosed with thalassaemia?

-Mother: yes they diagnosed him while he was one year and three months

-Me: Ok ...Do you know that you and your husband were a thalassaemia carries?

-Mother: No ... No ... No we all get surprised even it was the first time for us to know what is thalassaemia, when they told us it is thalassaemia we thought that it is type of blood cancer we did not know what thalassaemia is? Because they said: he will receive regular blood transfusion.

My husband comes home and he told me that: 'our son has cancer'... you imagine how it was hard for me. I was crying then he saw me freaking so he call my mom to come and he called [Hamate] [Hamate; is word used in common language mean: her mother in law]

But he did not understand what the doctor told him, she told him that he has blood disease and he need blood transfusion so B.S [the initial of her husband name] though it was cancer ...no no no he shocked, he didn't try even try to know more or asked the doctor what that mean or have more details about the disease.

-Me: Ok ... then your husband told you that your son has cancer

-Mother: he was thinking that he has cancer and after three days, my brother in law talk to his friend; he has friend work in hospital as a nurse and he explain to him the results when we realise that it was thalassaemia not cancer.

-Me: what did you and your husband after that?

-Mother: we took him again to the paediatrician clinic in Rahma Hospital [Princess Rahma Government Hospital] to see the haematologist and they asked us to take appointments because A.B blood was very low...They told us 'we need to give him blood now as an urgent matter'...they admitted him to the hospital for blood transfusion... he stayed for three days...

- Interview guide for Parents in English

1. Can you please tell me what is your experiences having and caring for a child diagnosed with beta thalassaemia major?
2. How have you coped with situation having and caring child diagnosed with beta thalassaemia major?

- Interview guide for Parents in Arabic

1. ما هي / كيف تصف تجربتك في رعاية طفلك المصاب بمرض الثلاسيميا ؟

2. كيف تأقلمت مع الوضع كأب /كأم لطفل مصاب بمرض الثلاسيميا ؟

Appendix 8: The Researcher's Presentations.

- The following are some of my presentations in 2011 and 2012.
 1. The Department Presentation in January 2012 at the University of Hull.
 2. The 12th International Conference on Thalassaemia and the Haemoglobinopathies and the 14th TIF International Conference for Patients and Parents, Antalya, Turkey - May 11-14-2011.
 3. The International Conference on Qualitative Research on Nursing and Health. Chiang Rai, Thailand, December 20.

عمان – مستشفى البشير

اليوم الاثنين

التاريخ ٢٠١٠-٩-٣

-ختام : أرحب بك أبو ... مرة أخرى وأشكرك على إعطائنا وقتك وأشكرك على الموافقة للمشاركة في هذه الدراسة. أحب أن أعرفك على نفسي مرة أخرى, أنا ختام طالبة دكتوراه في بريطانيا.

هدف الدراسة كما أخبرتك وكما شرح في ورقة المعلومات هو دراسة تجربة الأم والأب وكيف يتعايشون مع مرض التلاسيميا, وأنا في اعتقادي أن الأم والأب هم أكثر الأشخاص الذين يعيشون هذه التجربة مع. لذلك أرجو منك خلال الوقت الذي سنقضيه في المقابلة أن تشرح لنا تجربتك مع المرض ؟

-الأب: طبعاً أنا مثل أي أب يخاف على ابنه تفاجئت بهذا المرض, ولم أسمع عنه من قبل, وعندما تزوجت لم يكن هناك فحص ما قبل الزواج لمرض التلاسيميا, ولم يكن هذا الأمر معروف في بلادنا آنذاك كما أن عدد الإصابات كانت خفيفة, وقد صدر قرار وجوب إجراء فحص التلاسيميا قبل الزواج بعد زواجي.

وعندما أنجبنا ... لم ألاحظ عليها أي شيء يدل على أنها مصابة بمرض التلاسيميا.

-ختام: هل ... هي طفلتك الأولى؟

-الأب: نعم, هي طفلي الأولى, وعندما أنجبنا ... وفي شهره الأول أحسست أنه ليس بصحة جيدة ولونه أصفر, في الشهر الثاني راجعت مدينة الحسين الطبية لأنني كنت أملك تأمين صحي لي ولعائلتي هناك, كان هناك الدكتور ... والدكتور ... والدكتور ... على حالته لكن بالدرجة الأولى الدكتور ... كان هو المشرف الرئيسي على حالته, ولقد أجرينا ... عدة فحوصات, ما يقارب 72 فحص مخبري.

-الأب: اصفرار في وجهه وكان دمه ضعيف, وقد أعطوه وحدة دم, ولم يتم تشخيص ... في البداية على أنه مصاب بالتلاسيميا لأن الطبيب استبعد هذا الاحتمال لأنه لم يكن في عائلتنا أحد مصاب بمرض التلاسيميا, وحتى عندما سألني الطبيب لم أكن أعرف ما هو التلاسيميا.

-الأب: ولكن كنت ألاحظ أنه كان يشكو من ضعف في الدم, في النهاية أجرينا له فحص التلاسيميا وكانت النتيجة موجبة.

-ختام: لماذا طلب الطبيب فحص التلاسيميا؟

-الأب: لأننا أجرينا جميع فحوصات الدم لمعرفة سبب ضعف دمه وكانت نتائجها جيدة وطبيعية, فاقترح علينا الطبيب أن نجري له فحص التلاسيميا.

وأخبرنا الطبيب أنه إذا ضعف الدم مرة أخرى فلا بد أن نجري له فحص التلاسيميا, بعد ساعتين من إعطائه وحدات الدم تم إجراء فحص التلاسيميا له وكانت نتيجته عالية. وبعد أسبوع راجعنا المستشفى وتم إجراء فحص التلاسيميا ... مرة أخرى فتبين أنه مصاب بمرض التلاسيميا.

-ختام: هل تم التشخيص فوراً؟

-الأب: نعم تم تشخيصه فوراً.

-ختام: هل كان داخل المستشفى وقتها؟

-الأب: لا، لقد أجرينا له الفحص وعلى أثرها تم إدخاله المستشفى لليوم التالي لإعطائه وحدة دم

-الأب: تم تبليغي أنا أولاً... لأنه تم إخراج ... من المستشفى في اليوم التالي وأنا راجعت المستشفى بد أسبوع من أجل الحصول على نتائج فحوصات الدم.

-الأب: الطبيب هو الذي بلغني بالنتيجة لأن التبليغ بالنتائج ليس من اختصاص المختبر وإنما من اختصاص الطبيب.

-ختام: كيف تلقيت الخبر آنذاك؟

-الأب: بشكل طبيعي لأنني لم أكن أعرف ما هو مرض التلاسيميا وقتها، أما الآن فانا أعرف ما هو مرض التلاسيميا لأنني تعايشت معه وكأنه الآن قد تم تبليغي من قبل الطبيب، فبعد عام من المراجعات الطبية للمستشفى عرفت ما هو مرض التلاسيميا. لو كان عندي معرفة مسبقة بمرض التلاسيميا كان من المؤكد أن أتفاجأ لكني لا أعرف ما هو مرض التلاسيميا وما هي مضاعفاته.

-الأب: لقد شرح لي الطبيب عن مرض التلاسيميا بشكل عام وأنه قد يحتاج إلى وحدة دم كل شهر أو كل فترة معينة حسب حاجة الجسم وحسب نقصان كريات الدم الحمراء في الجسم.

-ختام: هل بلغت زوجتك بعدها؟ كيف كانت ردة فعلها؟

-الأب: مثل أي أم... فمهما كان الأب قوياً من الصعب ان تكون الأم مثل الأب وليس أمامها إلا أن تستوعب الأمر.

أمضت شهر وهي مكتئبة ولكن هذه إرادة الله ولا يستطيع أحد أن يعترض عليها.

-الأب: لا، لأنه لا يوجد أي أحد في العائلة مصاب بهذا المرض وليس لديها أي فكرة عنه ولكنها أم، فمثلاً لو أخبرتها بأن أحد أولادك مصاب بصداع ستبدأ فوراً بالبكاء هذه طبيعتها، لكن مضاعفات مرض التلاسيميا لا تعرف عنها شيء، حتى مرض التلاسيميا قبل 11 عام لم يكن معروف كما هو معروف الآن ولم يكن لدى الناس أي فكرة

-ختام: هل تتمنى لو أنه كان في ذلك الوقت توعية أو فحص مبكر للتلاسيميا؟

-الأب: أكيد، ومادام هذا المرض كان موجوداً في الماضي كان يجب على الجهات المختصة توعية الناس له.

-الأب: طبعاً، ستتغير أمور كثيرة للأفضل وستتغير قرارات كثيرة.

-الأب: أتوقع أنه لو كان الفحص موجود وقتها ستكون ردة الفعل من قبل الطرفين برفض الزواج إذا كانت نتيجة الفحص سيئة.

-الأب: سيكون أيضاً لديهم حجة أيضاً بأنهم يستطيعون فحص الجنين في أول شهرين من الحمل ونستطيع عنئذ اتخاذ القرار المناسب ولكن برأي هذا خطأ لأن نتيجة فحص الجنين لا تكون ١٠٠%.

لأن فحص الجنين في أول شهرين من الحمل نتيجه غير مضمونة حيث احتمالية الخطأ تكون ٩٠% مثل ما حدث مع والد ...

-ختام: ما هو الفحص الذي تقصده؟ هل تقصد فحص الجنين في أول شهرين من الحمل؟

-الأب: لا، ولكن ما أريد قوله هو أنه ما دام هناك احتمالية أن يكون الفحص خاطئ ولذلك لا يمكنك أن تضمني النتيجة مثلما حدث مع والد... ..

-الأب: نعم أكيد، فحص ما قبل الزواج التلاسيميا يكون مضمون ولا يوجد هناك مجال للخطأ.

-ختام: إذا أنت تنصح الأشخاص المقبلين على الزواج بأن يجرو فحص ما قبل الزواج التلاسيميا؟

-الأب: أجل، لأن المعاناة التي عشتها لا تستحق المخاطرة، فعندما تتمعن في مضاعفات مرض التلاسيميا تجد أنها تجربة لا تستحق أن تغامر في الزواج من أجلها نعم أكيد، لأنه ليس فقط أنت الذي ستعاني، وإنما طفلك أيضاً سيعاني.

-ختام: هل يعاني الأب والأم من المرض؟

-الأب: طبعاً، إذا كنت أنت تعاني من أجل ابنك، فتخيل كيف ستكون معاناة ابنك لأنه سيتحمل مضاعفات المرض الكثيرة.

Appendix 10: The Field Notes Sheet

[illegible]

Couple Interviews; First Interview

Amman, ABGH

Tuesday, 14 Sep 2010, 10:00

Typed on the day:

in the ninth in the morning, the door opened, inside the corridor children with BTM waiting with their mothers in them chatting and playing ...I noticed that there are few fathers waiting in the outside areas where is the main department entrance waiting for their children to walk inside....'*Alsalm Alikom ...welcome back...you are with us today, how are you doing? hope your study good inshallah*' said a nurse from the station when I walk inside the room ... I replied: '*wa alaikum al salam yes all good inshallah*'...The room was full of many files and documents, the nurse reviewed and arranged the patients files to send them to the paediatrician clinic as they have appointment today. The nurse told me that they have to follow up with the haematologist also but that was when needed it is not like a regular appointments for all children diagnosed with BTM.

Today I'm so exciting to work because I have appointment to interviews couples who agree to take part in the research ...I hope they will manage to be on time, because they told me that they are coming from the south area in Amman ... I know, how far this area from the ABGH and delay in the traffic early morning...but any way, I will have enough time to take breakfast I still have 20 minutes ...

...*Good morning ...'can you please tell them I need the key for the interview room...yes the one in the behind area'* ... I asked the staff in the reception office...ok ...thanksI walked inside to check the interview room and wait inside I still have 10 minutes ...

He walk inside the room...holding the research documents in his hand ... I noted that he is calm and silent ... few minutes then I asked him ... how you are today morning? Alhamdulillah ...I'm ok ... he replied ... then I asked how the transportation today hope it was ok for you? ...I know early morning it is really rushed... then he is open up talking about how driving this day become today and how crazy the people become ... they do not care about the speed.

He is looks frustrated from what he is been witness in the road, the speed people drive and how risk it was ...I think few minutes good to relieve the participant to prepare them before starting the interview ... do you fancy coffee or tea ? I asked: I think I need to give him more few minutes he is look upset and need to talk about the transportation

...Then I asked: how much time do you spend on the road to reach here?

He reply: can you imagined more than two hours ...I replied: I see ... yes sometime its take really too long ... then I said: thanks a lot for you accept my invitation to share in this study ... let me not to delay you and save your time... is this the invitation letter in your hand? He said: yes the one I had from the nurse station ... good I want to thank you for giving me your time “He looks more relax and start talking ...” then I asked: are you ok for us to start the interview

Notes on the interview:

1. He talk freely, calm ... I don't know if he is sad ...??? ... His voice tone low and quiet ... no it could be this is his normal mood ?? He was not like this when we agree on the interview date and time ...??
2. He did not talk about the financial difficulty in the interview.
3. He repeated the words 'Hard time' alternatively with 'stress time' and 'not good time' in the interviews
4. His focused was on how many blood tests... I think he is not happy with procedures because of the delay in his daughter diagnosis of having BTM...

Personal Feeling:

- a. I'm happy that I managed to conduct interviews with couple and finished on agreed time...
- b. The breaks good and refreshing ...
- c. No problem with the interview room booking ... good relax ;-)
- d. Still have ten minutes for the second interview...

Appendix 12: Children's Play Room

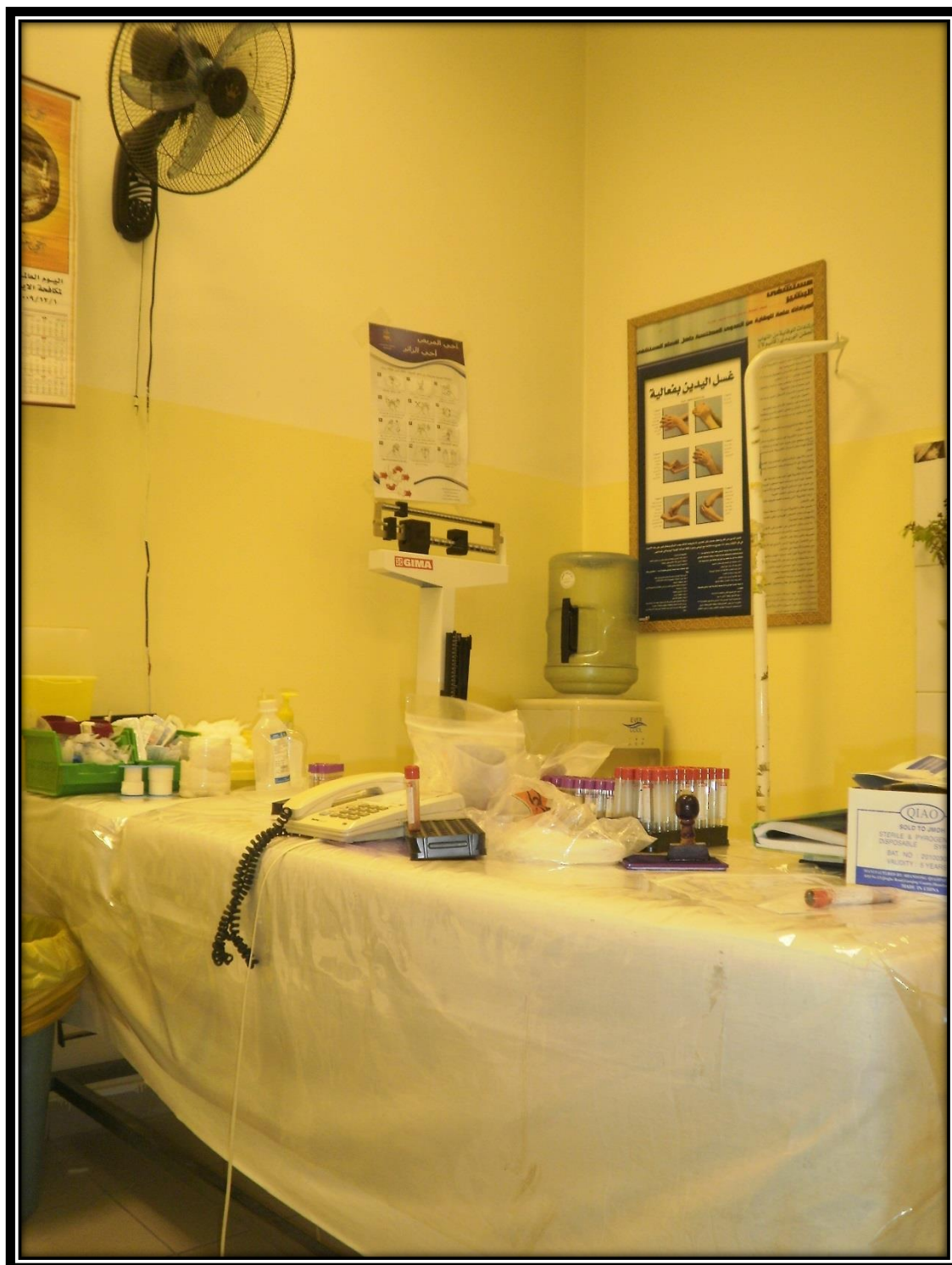
Figure 14 Children Play Room 1 in Thalassaemia Department



Figure 15 Children Play Room 2 in Thalassaemia Department



Figure 16 Treatment Room



Appendix 13: The input of the participants into each theme

Parents' Experiences and Coping Themes													
Core-Categories	Knowledge Deficit			Sociocultural Perspectives			Personal Strategies			Grief			
Sub-categories	Health History	What BTM is?	Genetic health care services	Satisfied with	Faith	Socio-cultural Barriers	Avoid having more children with BTM.	Keep it secret	Time	Fear	Hopelessness	Stress	Unprepared
Participants: Princess Rahma Teaching Hospital (PRTH)													
M.1a	X	X	X	X	X	X	X	X	X	---	---	X	X
F.2a	X	X	---	X	X	X	X	---	X	X	X	X	X
F.3a	X	X	X	X	X	X	---	---	X	X	---	X	X
M.4a	exc	exc	exc	exc	exc	exc	exc	exc	exc	exc	exc	exc	exc
M.5a	X	X	---	X	X	X	---	X	X	X	---	X	X
F.6a	X	X	X	X	X	X	X	X	X	X	X	X	X
M.7a	X	X	---	X	X	X	---	---	X	X	---	X	X
M.8a	X	X	X	X	X	X	X	X	X	X	X	X	X
F.9a	X	X	X	X	X	X	X	---	X	X	---	X	X
F.10a	X	X	X	---	X	X	X	---	X	X	X	X	---
M.11a	X	X	X	X	X	X	X	---	---	X	X	X	X
F.12a	X	X	X	X	X	X	---	X	X	X	---	X	X
M.13a	X	X	---	X	X	X	X	---	X	X	X	X	X
F.14a	X	X	---	X	X	X	X	X	---	X	X	X	X
F.15a	X	X	X	X	X	X	X	X	X	X	X	X	X
M.16a	X	X	X	X	X	X	X	X	X	X	X	X	X
M.17a	X	X	X	X	X	X	X	---	X	X	X	X	X
M.18a	X	X	X	X	X	X	X	X	---	X	X	X	X
Participants: Al-Basher Governmental Hospital (ABGH)													
F.1b	X	X	X	X	X	X	X	X	X	X	X	X	X
M.2b	X	X	X	X	X	X	X	X	X	X	X	X	X
M.3b	X	X	X	X	X	X	X	---	X	X	---	X	X
M.4B Ex	exc	exc	exc	exc	exc	exc	exc	exc	exc	exc	exc	exc	exc
F.5b	X	X	X	X	X	---	X	---	X	---	---	X	X

M.6b	X	X	X	---	X	X	X	X	X	X	---	X	X
M.7b Ex	exc	exc	exc	exc	exc	exc	exc	exc	exc	exc	exc	exc	exc
M.8b	X	X	X	X	X	X	X		X	X	X	X	X
M.9b	X	X	X	X	X	X	X	X	X	X	X	X	X
F.10b	X	X	X	X	X	X	X	---	X	X	--	X	X
M.11b	X	X	X	X	X	X	X	X	X	X	X	X	X
F.12b	X	X	X	X	X	X	---	X	X	X	---	X	X
M.13b	X	X	X	X	X	X	X	X	X	X	X	X	X
Participants: Blood Bank Health Centre (BBHC)													
M.1c	X	X	---	X	X	X	---	X	X	X	X	X	X
M.2c	X	X	X	X	X	X	X	X	---	X	X	X	X
F.3c	X	X	X	---	X	X	---	X	---	X	X	X	X
M.4c	---	X	X	X	X	X	X	X	X	X	X	X	---
F.5c	X	X	X	X	X	---	X	---	X	X	X	X	X
F.6c	X	X	X	X	X	X	X	---	X	X	X	X	X
F.7c	X	X	X	X	X	X	---	X	---	X	X	X	X
F.8c	X	X	---	---	X	X	X	X	X	---	X	X	X
M.9c	X	X	X	X	X	X	X	X		X	X	X	X
F.10c	X	X	X	X	X	X	X	---	X	X	X	X	X
M.11c	X	X	X	X	X	X	X	X	---	X	X	X	X

*Participant: M = Mother and F = Father.

*Hospital Code: A= PRTH, B= ABGH and C= BBHC.

*Number of the interviews: (1, 2, 3 and et al)

*Excluded the interviews from analysis after data cleaning: exc

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