

**School of Nursing and Midwifery**

**The Lived Experience of Adolescents with Haematological Malignancies in  
Jordan: An Interpretive Phenomenological Analysis Study**

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**This thesis is presented for the Degree of  
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of  
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**Declaration**

To the best of my knowledge and belief this thesis contains no material previously published by any other person except where due acknowledgment has been made. This thesis contains no material which has been accepted for the award of any other degree or diploma in any university.

Signature: .....

Date:.....

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## ABSTRACT

This thesis explored and documented the lived experiences of Jordanian adolescents with haematological malignancies (HMs). The study explored how these adolescents described their cancer journey throughout the different stages and how these experiences shaped the adolescents' behavioural responses and coping strategies. A literature review revealed a paucity of bio-psychosocial care studies in this area conducted in Arab countries when compared to western countries. Furthermore, the available research was dominated by quantitative studies, with a dearth of research focused on adolescents with HM. Such a paucity of literature and limited understanding of adolescents' experiences of living with HM has the potential to compromise the quality of care provided to this group of patients. This study contributes to the understanding of adolescents' lived experiences and factors that facilitated or inhibited the experience through an in-depth descriptive account.

A prospective longitudinal study using an interpretative phenomenological analysis methodology explored the lived experience of 14 Jordanian adolescents with haematological malignancies during the first six months following their diagnosis. In this study, in-depth interviews were the main method of data collection. A total of 27 face-to-face, semi-structured interviews were completed and each interview took on average 75 minutes. Each interview was transcribed verbatim and the data analysis occurred using the interpretive phenomenological analysis method first described by Smith in 1996. The data from transcribed interviews were managed using ©QSR NVivo8 software for qualitative data analysis.

The results of the analysis of data were reported under three main themes depicting the participants' experiences, which were the "silence of HM", "life is changing", and "ways of coping". The analysis indicated that initially the participants received little information and had limited communication with their parents and health team members to assist them to understand what was happening to them. This resulted in the participants experiencing increased levels of distress and feelings of confusion as they were left alone to comprehend the cause of their physical problems. With the onset of cancer treatments, the bio-psychosocial side effects of the chemotherapy became one

of the most distressing factors for participants affecting, as it did, all aspects of their lifeworld and generating uncertainty about their futures. Again, participants reported limited support from health team members during this critical stage. This led to difficulties in overcoming the unpleasant experiences associated with chemotherapy and cancer, for example, the alteration in their body image. Nevertheless, the participants were able to adapt and live with their illness with the use of various coping methods. For example, they used their Islamic belief to empower themselves, while playing down the severity of their illness. Some of them used hospital resources, such as the creativity room at the hospital to assist them to cope with the daily impact of their illness and maintain a sense of normality.

The results of this study were consistent with previous research findings, highlighting a number of areas requiring further attention from Jordanian health planners and health team members responsible for caring for adolescents with haematological malignancies. For example, health team members need to place emphasis on the provision of psychosocial care for adolescents in order to prevent the development of co-morbidities during the illness journey. Health team members should also adopt a family centered approach to care to reduce the stress and concern of both the adolescents and their parents. In general, health team members, communities and schools need to work in collaboration in order to effectively provide adolescents with holistic care. The findings have added significantly to existing knowledge and understanding of the spiritual and psychosocial needs of adolescents during this time, particularly because this is the first qualitative research study conducted in Jordan in this area of health care.

This thesis has limitations of which one was that due to hospital policy some of the participants' parents attended the two data collection periods and their presence may have impacted of the experiences expressed. The thesis concludes with a discussion of practice changes and future research projects in this area. Additional longitudinal, qualitative and prospective research studies are needed to explore the lived experiences of adolescents with HM to further identify the bio-psychosocial developmental changes that they experience during their illness journey.

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### ABBREVIATION USED IN THIS STUDY

<b>AIDS</b>	Acquired Immunodeficiency Syndrome
<b>AYA</b>	Adolescents and young adults
<b>CAYA</b>	Children, adolescents and young adults
<b>CBC</b>	Complete Blood Count
<b>CDC</b>	Centers for Disease Control and Prevention
<b>CIA</b>	Central Intelligence Agency
<b>CSF</b>	Cerebrospinal Fluid
<b>CVP</b>	Central Venous Catheter
<b>ESR</b>	Erythrocyte Sedimentation Rate
<b>GP</b>	General Practitioner
<b>GVHD</b>	Graft versus host disease
<b>HM</b>	Haematological Malignancies
<b>ICU</b>	Intensive Care Unit
<b>IPA</b>	Interpretive Phenomenological Analysis
<b>KHCC</b>	King Husain Cancer Center
<b>MOH</b>	Ministry of Health
<b>MSc</b>	Master of Science
<b>NCI</b>	National Cancer Institute
<b>PhD</b>	Doctor of Philosophy
<b>RN</b>	Registered Nurse
<b>SA</b>	Saudi Arabia
<b>SIOP</b>	The International Society of Paediatric Oncology
<b>UAE</b>	United Arab Emirates
<b>USA</b>	United State of America
<b>WHO</b>	World Health Organisation

## CHAPTER 1

### INTRODUCTION AND BACKGROUND

#### 1.1: Introduction

Adolescence is a time of great change and significance in the human life cycle. At this stage, each adolescent strives to establish their identity and self-image, and to begin the process of separating from their parents and becoming autonomous (Paus, Keshavan, & Giedd, 2008). They also begin to experience significant physical and mental changes. Both the adolescents and their families experience this stage of the life cycle with a range of emotions, pleasure, challenges and difficulties (Kroger, 2007; Lerner & Galambos, 1998). Facing a life threatening disease such as cancer compounds the challenge of adolescence for both the individual and their family (Bleyer, 2002).

Over several decades there have been improvements in all aspects of cancer treatment, for example, improvements in chemotherapy, radiation, and surgical outcomes (Horner et al., 2008; King Husain Cancer Centre [KHCC], 2000). As a result, there has been an increase in patient survival rates and a decrease in the mortality rates associated with cancer (Horner et al., 2008; Jordanian Department of Statistics, 2008). For example, by 1990, the survival rate of cancer patients had increased almost three times (80%), up from 25% in the 1960's (Kreitler & Arush, 2004). The increased survival rate was found in most childhood cancers and related to increased chemotherapy effectiveness, sensitivity and other changes in practice due to the outcomes of global collaborative research programs in this area (Kreitler & Arush, 2004). However, the improvement in survival rates for people affected with cancer must be separated from the negative physical, spiritual and psychosocial outcomes that they experience during the treatment journey (Ballenger et al., 2001; Collins et al., 2000; Houtzager, Grootenhuis, Caron, & Last, 2004; Stechlin & Beach, 1966; World Health Organisation [WHO], 2009).

This thesis used an interpretative phenomenological analysis to detail the physical, spiritual and psychosocial experience of Jordanian adolescents diagnosed with haematological malignancies (HMs). The study explored how these patients' perceived

the experience and how their interpretations shaped their behavioural responses during the first six months following their diagnosis of a haematological malignancy.

This chapter will outline the aetiology of haematological malignancies, the epidemiology of these disorders, the developmental stage of adolescence, the identified gaps in caring for adolescents who have a haematological malignancy, the need for this study and the significance, purpose and objectives of the research. The assumptions that I made as a researcher prior to commencing the study are also documented along with definition of terms used in this study, a summary and overview of the organisation of the thesis.

## **1.2: Haematological malignancies**

Haematological malignancies are idiopathic diseases that can be defined as any malignancies originating from blood, bone marrow cells and lymph nodes (Centers for Disease Control and Prevention [CDC], 2011; Mosby, 2006). The definite aetiology of haematological malignancies is unknown but they seem to be associated with a number of different risk factors (Children's Hospital and Health System, 2011; Deschler & Lübbert, 2006; KHCC, 2011a; Macmillan Cancer Support, 2011e, 2011f; The Nemours Foundation, 2011), for example, genetic factors (Ross, Spector, Robison, & Olshan, 2005). It is currently known that the incidence of leukaemia is increased in identical twins and in syndromes of chromosomal abnormality, such as, Down's syndrome (Wiseman, Alford, Tybulewicz, & Fisher, 2009). Furthermore, pollution and other environmental factors appear to play a significant role in the increased risk for the development of these types of cancer (Lee et al., 2009; Pitot & Loeb, 2002; Weng et al., 2008; Weng, Tsai, Chiu, Wu, & Yang, 2008). Examples of environmental risk factors are smoking during pregnancy, nuclear radiation and exposure to benzene that are used in some industries. In addition, haematological malignancies can be traced to nutritional factors such as alcohol consumption during pregnancy, eating foods high in animal fat, or low intake of fibre, and consuming small amounts of fruit and vegetables (Latino-Martel et al., 2010; Ma et al., 2010; Vainio & Weiderpass, 2006). Moreover, some theories link the development of leukaemia to certain types of viruses. For example, leukaemias are associated with human T-cell lymphotropic virus type 1 (HTLV-1) (Schmiegelow, Vestergaard, Nielsen, & Hjalgrim, 2008).

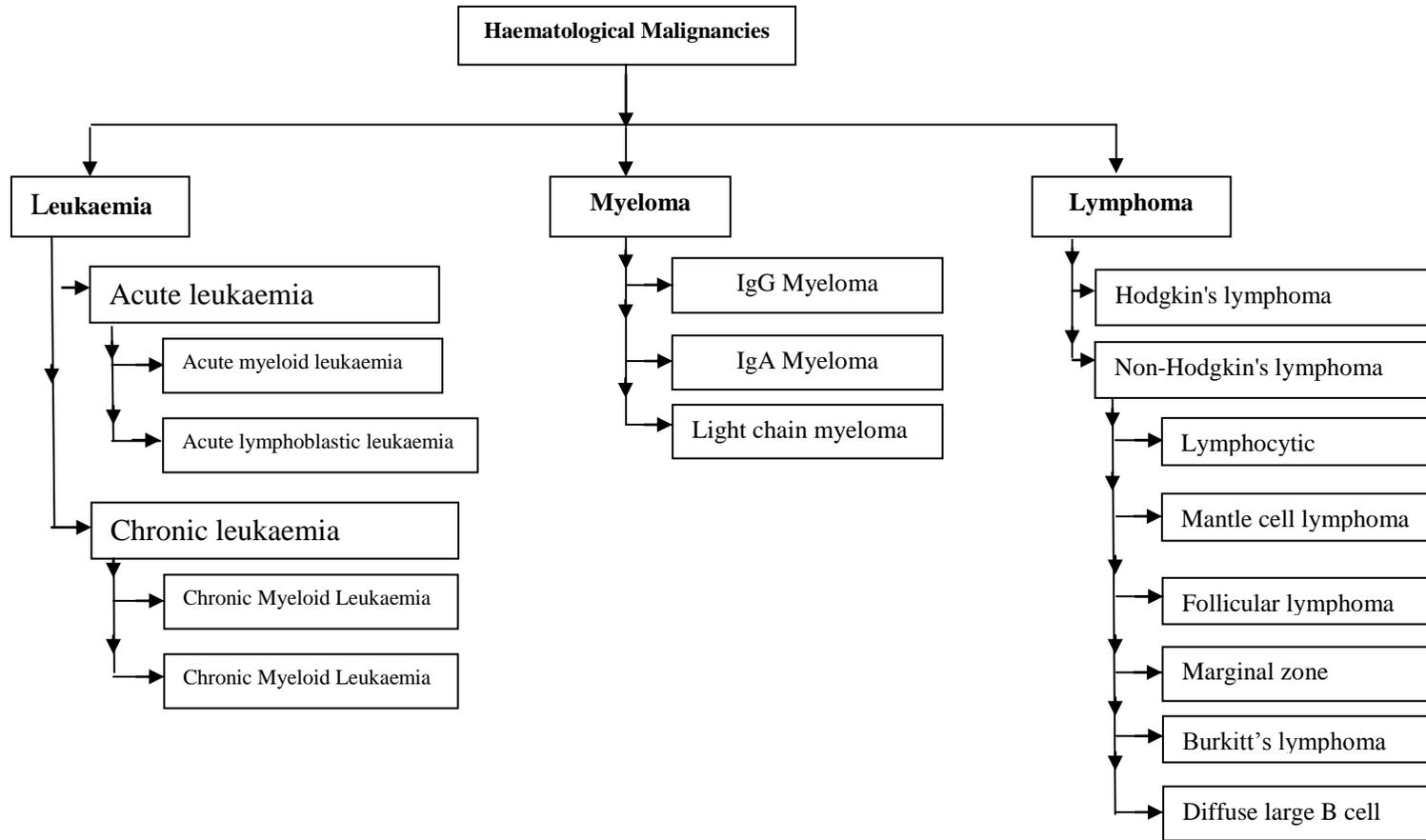
The CDC in (2011) classified haematological malignancies into three main groups of disorders: 1) Leukaemias, 2) Lymphomas; and, 3) Myelomas. This classification depends on the type of blood cells involved in each of the disorders which are summarised in figure 1.1 (KHCC, 2011c; Thomlinson & Kline, 2005).

### **1.2.1: Leukaemias**

Leukaemias are a major group of haematological malignancies associated with the uncontrolled proliferation of white blood cells, characterised by the accumulation of malignant white cells in the bone marrow and peripheral blood which causes bone marrow failure and leads to anaemia, neutropenia, and thrombocytopenia (Ball & Lelek, 2003). Leukaemias can be divided into acute and chronic subtypes on the basis of the speed of growth and spread of the disease, and these two subtypes are further subdivided into myeloid or lymphoid, according to the abnormal cell type involved (see figure 1.1) (Macmillan Cancer Support, 2011a, 2011b, 2011c, 2011d, 2011f; Smeltzer & Bare, 2004; Thomlinson & Kline, 2005).

In acute leukaemia, the onset of the disorder is sudden with symptoms often occurring within a few weeks. White blood cell (WBC) development is halted at the blast phase level (early cell production phase), so that most WBCs are undifferentiated or remain as blasts. Once identified, acute leukaemia progresses very rapidly and in many cases, without aggressive treatment, death occurs within weeks to months (Lanzkowsky, 2011). In chronic leukaemia the symptoms emerge over a longer time period, which may be from months to years and the majority of WBCs produced are mature (Cassidy, Bissett, & Spence, 2002; Lanzkowsky, 2011).

In general, leukaemias can be diagnosed by a variety of different diagnostic tests, for example, a complete blood count (CBC) to diagnose normochromic normocytic anaemia, blood film which typically shows variable number of blast cells, a lumbar puncture to sample cerebrospinal fluid (CSF), X-ray, and liver and renal function tests (Cassidy et al., 2002; Lanzkowsky, 2011).



*Figure 1.1:* Types of haematological malignancies

### **1.2.2: Lymphomas**

Lymphomas, another type of haematological malignancy, are a heterogeneous group of diseases caused by malignant lymphocytes that usually accumulate in lymph nodes and cause characteristic clinical features of lymphadenopathy (swelling of the lymph node) (Lanzkowsky, 2011). Lymphomas are classified into two subtypes, Hodgkin's lymphoma and Non-Hodgkin's lymphoma (Cassidy et al., 2002; Hartlapp et al., 2009; Lanzkowsky, 2011; Thomlinson & Kline, 2005).

Hodgkin's lymphoma (HL) is a cancer of the lymphatic system characterised by proliferation of different giant, multi-nucleated cells (Reed-Sternberg cells) and is the third most common type of cancer worldwide in males and females aged between 10 to 14 years. However, it is very rare for children to have Hodgkin's lymphoma (Cassidy et al., 2002; The Nemours Foundation, 2011). Non-Hodgkin's lymphoma is a more common malignant tumour of the lymphoid system (B or T cells). Non-Hodgkin's lymphoma is the sixth most common cancer in the United States and ninth in Australia (Australian Institute of Health and Welfare [AIHW], Cancer Australia & Australasian Association of Cancer Registries, 2008; National Cancer Institute [NCI], 2008). This group of haematological malignancies can occur in people of any age but mainly affects people who are older than 60 years of age (Cassidy et al., 2002; Thomlinson & Kline, 2005). In summary, lymphomas can be diagnosed based on a full blood count, an erythrocyte sedimentation rate (ESR), serum uric acid level, liver biochemistry, serum immunoglobulin, chest X-ray, computed tomography (CT) scans of the chest, abdomen and pelvis, bone marrow aspiration biopsy are always performed, and lymph node biopsy (Cassidy et al., 2002).

### **1.2.3: Myelomas**

Myelomas are cancers of plasma cells, a type of B lymphocyte important in the production of antibodies (Cassidy et al., 2002; Gahrton, Durie, & Samson, 2004). The Deoxyribo Nucleic Acid (DNA) in these plasma cells is damaged and as the bone marrow is found in multiple areas of the body (e.g. in the spine, skull and pelvis), the disease is often called multiple myeloma (The Cancer Council New South Wales, 2008; Thomlinson & Kline, 2005). The type of myeloma depends on the particular type of

immunoglobulin that the myeloma cells produce. The most common type is IgG, which accounts for about 60% to 70% of all cases of myeloma. The less common type of myeloma is IgA and it accounts for about 20% of cases (Cancer research UK, 2010). The major signs and symptoms accompanying the diagnosis of multiple myeloma are anaemia, breathlessness, tachycardia, low immunity, weight loss, and kidney failure (The Cancer Council New South Wales, 2008; Thomlinson & Kline, 2005). Myeloma is diagnosed based on blood and urine tests, CT scan, X-ray, magnetic resonance imaging (MRI), bone marrow biopsy, and cytogenetic tests (Cassidy et al., 2002; The Cancer Council New South Wales, 2008).

#### **1.2.4: Treatment of Haematological malignancies**

Globally, the treatment for haematological malignancies is similar and specific interventions depend on the type of disorder. In general, the treatment is divided into three types which are: 1) advanced specialised treatments; 2) complementary treatments; and, 3) adjunct treatments.

The first type of treatment is the advanced specialised treatments and these include chemotherapy, radiation, surgical intervention and bone marrow transplants (Deschler & Lübbert, 2006; KHCC, 2011b; Pizzo & Poplack, 2006; Whelan, 2003). Chemotherapy agents are cytotoxic drugs which are administered to reduce the growth and the spread of the cancer cells (Perry, 2008). However, cytotoxic drugs destroy both benign and malignant cells and have severe side effects which include but are not limited to vomiting, fatigue, alopecia, impotency, digestive system problems (Burstein, 2000; Jakobsen & Herrstedt, 2009; Perry, 2008; Ramirez et al., 2009). Bone marrow transplants (BMT) are also commonly used to treat haematological malignancies, and these are used when the traditional treatments such as chemotherapy fail (Atkinson, 2004; Eapen et al., 2007). BMT take place after the diseased bone marrow or stem cells is purposely destroyed and healthy bone marrow is then transfused from a donor into the affected person (Atkinson, 1997, 2004; Varricchio, 2004). BMT has many adverse effects which include pain, fatigue, fever, headaches and graft versus host disease (GVHD) (Liu & Hockenberry, 2011; Rocha et al., 2000; Sun et al., 2010). GVHD can be life threatening for some people as there is a chance for the patient's immune system will identify the infused donor stem cells as a foreign body and destroy it. In such cases,

the original bone marrow cannot regenerate as it is destroyed completely by chemotherapy before the transfusion and this constitutes a life threatening event for the patient (Atkinson, 1997, 2004; Czechowicz, Kraft, Weissman, & Bhattacharya, 2007; Varricchio, 2004).

The second type of cancer treatment are complementary treatments which include the: 1) insertion of a central venous catheter (CVP) to provide a painless way of drawing blood or delivering drugs and nutrients into a patient's bloodstream over a period of weeks, months or even years; 2) administration of blood products because chemotherapy can kill some of the fast dividing normal body cells like some cells in the bone marrow that maintain the supply of white cells in the blood and hence human body needs some blood; 3) intravenous fluids support as the side effects of chemotherapy such as vomiting or diarrhoea can lead to dehydration and hence human body needs some intravenous fluids, and 4) prophylactic antibiotics because patients immunity became low following the chemotherapy treatment which increase the chance of infections (Estey, Faderl, & Kantarjian, 2008; Pizzo & Poplack, 2006; Whelan, 2003).

The last type of cancer treatment is called adjunct therapies and they are based on supporting the mental and psychosocial well-being of cancer patients. Adjunct therapies stand on the premise that there is no physical health without mental health (Wynaden, 2010). The aim of these treatments is to prepare and provide patients and their families with proper knowledge that enable them to cope and adjust to a cancer diagnosis.

In summary, haematological malignancies are compromised of three sub types: leukaemias, myelomas and lymphomas. Each disease has its own subcategories based on the type of cell involved. The treatment of cancer varies across the world, but generally it encompasses three types of care: advanced specialised treatments, complimentary treatment and adjunct treatments.

### **1.3: Epidemiology of haematological malignancies**

On a global perspective, cancers are considered one of the leading cause of death among adolescents (Bleyer, O'Leary, Barr & Ries, 2006; NCI, 2008; WHO, 2010c). Of these cancers, leukaemia is the most common followed by cancer of the brain and nervous system, thyroid carcinoma, non-Hodgkin lymphoma, Hodgkin lymphoma and

lymphoma (American Cancer Society, 2010; Bleyer et al., 2006). Leukaemias, Hodgkin lymphoma and non-Hodgkin lymphoma comprise more than one-third of all cancers (Bleyer et al., 2006; NCI, 2008). The data displayed in Table 1.1 shows the incidence rate of leukaemias, Hodgkin lymphoma and non-Hodgkin lymphoma across the world (International Agency for Research on Cancer, 2010).

The highest rates of haematological malignancies per 100,000 people in descending order are found in Israel (31.01), the United States of America (25.97), New Zealand (25.96), Canada (24.75), Australia (24.39), Italy (22.52), United Kingdom (20.07), Lebanon (19.80), Iraq (15.88) and Jordan (15.78).

The incidence of these malignancies is consistent across developed and developing countries. However, when the incidence and mortality rates are compared adolescents affected with haematological malignancies living in developed countries have far better outcomes than those living in under developing countries (see table 1.1). The mortality rates per 100,000 people is in Israel (9.2); the United States of America (7.7); New Zealand (8.03); Canada (8.5); Australia (8.0); Italy (7.9); United Kingdom (7.1); Lebanon (15.94); Iraq (14.18); and, Jordan (13.34). These rates highlight the difference that treatment makes to patient outcomes (see table 1.1).

**Table 1.1:**

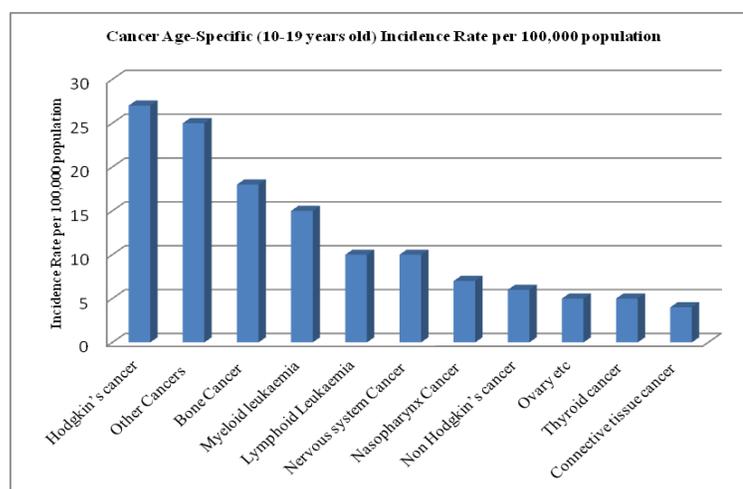
The incidence and mortality rate of Hodgkin lymphoma, Non-Hodgkin lymphoma and leukaemia per 100,000 people (WHO, 2010b).

	Incidence Rate	Mortality Rate
Israel	31.01	9.2
United States of America	25.97	7.7
New Zealand	25.96	8.03
Canada	24.75	8.5
Australia	24.39	8.0
Italy	22.52	7.9
United Kingdom	20.07	7.1
Lebanon	19.80	15.94
Iraq	15.88	14.18
Jordan	15.78	13.34

### 1.3.1: The incidence of cancer in Jordan

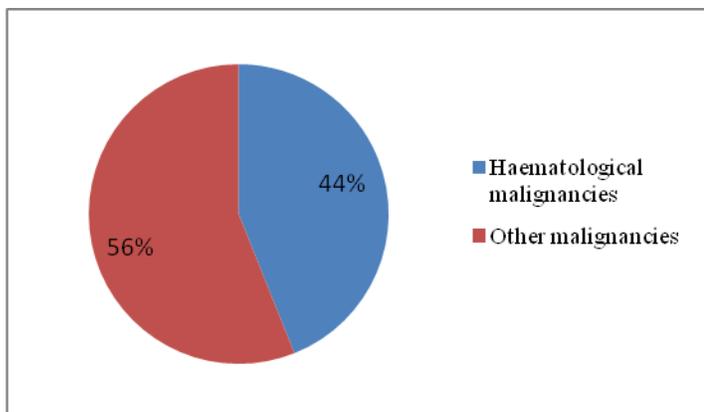
Jordan is a developing country and has a strong commitment to improve health outcomes for its population. In Jordan, the incidence of haematological malignancies is almost equal to the mortality rates for adolescents with haematological malignancies (WHO, 2010b). Although the mortality rate of adolescents with a haematological malignancy is high, their health problems were not always addressed in health care agendas and this may compromise the delivery of quality health care.

The most recent information regarding incidence rate of cancer for patients aged between 10 and 19 years was in 2007. In this particular year itself, 132 new cases per 100,000 populations of cancer were documented comprising both males and females aged between 10 and 19 years (see figure 1.2).



**Figure 1.2:** Incidence rate of cancers among Jordanians aged between 10 and 19 years for each 100,000 of the populations (Tarawneh & Tarawneh, 2007).

Among these cancers, haematological malignancies comprised almost 45% of all cancers (Tarawneh & Tarawneh, 2007; Whelan, 2003) (see figure 1.3) and the survival rate when compared to the incidence rate is in the 10<sup>th</sup> highest in the world (WHO, 2010d).



**Figure 1.3:** Incidence of haematological malignancies among Jordanians aged between 10 and 19 years old when compared to other malignancies or cancers (Tarawneh & Tarawneh, 2007).

Although, Jordan has registered all new cancer cases since 1996, there is still no reporting mechanism for the survival rates of affected people (Tarawneh & Tarawneh, 2007; Whelan, 2003). In conclusion, it is clear from the above statistics that Jordan and its other neighbouring countries, particularly Lebanon and Iraq face a serious problem regarding the outcomes of adolescents affected with haematological malignancies. Although standard treatments for cancer are constant all over the world, the outcomes or survival rates are different. The possible explanation is that access to health care system and adjunct therapy is not similar and varies from country to country.

#### **1.4: Adolescence**

Adolescence represents the developmental stage between childhood and early adulthood (Berk, 2008). During adolescence, the body is growing rapidly and bio-psychosocial changes are occurring at a more rapid rate than any other developmental stage since infancy (Johnson, 1997; Shaffer & Kipp, 2010). However, the adolescent's level of development depends on the inherited traits from their parents and the influence of the environment that they are brought up in (Adams & Berzonsky, 2003; Crosnoe & Trinitapoli, 2008; Hair, Moore, Garrett, Ling, & Cleveland, 2008; Karriker-Jaffe, Foshee, Ennett, & Suchindran, 2008). The changes occurring in adolescents will now be discussed under the headings of physical and psychosocial changes.

### **1.4.1: Physical changes**

Accelerated physical growth is the first marker that a child is entering into the stage of adolescence (Sigelman & Rider, 2009). These physical changes include accelerated growth in height and weight for both males and females (Christie & Viner, 2005). Both males and females begin to develop secondary sexual characteristics as they enter the stage of puberty and these include changes in facial characteristics, voice, increased body hair, increased strength and coordination (Berger, 1998; Christie & Viner, 2005; Shaffer & Kipp, 2010). Adolescence is also accompanied by excessive hormonal transformations and physical changes which have a strong impact on the self-image, mood, and social relationships (Johnson, 1997; Steinberg, 2005; Yurgelun-Todd, 2007).

### **1.4.2: Psychological and cognitive changes**

The mental, intellectual and comprehension abilities of adolescents develop more rapidly during adolescence (Shaffer & Kipp, 2010). Children use inductive reasoning abilities based on direct observation and concrete. However, as they enter adolescence, formal or abstract thought as described by Piaget develops (Johnson, 1997). As a result, the adolescent's thinking shifts to logical hypothetical and deductive reasoning (Laird, 2010; Steinberg, 2005). Furthermore, the adolescent's moral reasoning and thinking changes and shifts to a more complex process focused on both self-reflection and reflection of the external environment (Christie & Viner, 2005; Luna, Garver, Urban, Lazar, & Sweeney, 2004).

During adolescence the attention span increases and as a result adolescents are able to solve more complex problems; their awareness and ability to think is also surpassed and this enables them to think realistically about the present as well as the future (Kuhn, 2009; Luna et al., 2004; Watson, 2010). At the end of the adolescent period the person has developed an intellectual independent identity. However, research also showed that adolescents can still be poor decision makers and they adopt more risk behaviours decisions compared to other age groups (Gardner & Steinberg, 2005; Kuhn, 2009; Pillow, Pearson, Hecht, & Bremer, 2010; Spear, 2000; Steinberg, 2005, 2007; U.S. Department of Education, 2005).

### **1.4.3: Social changes**

The social dimension is the last indicator and covers four categories: interpersonal (relationships with family and friends), political (older adolescents can participate in elections), economic (older adolescent can earn money and work) and legal (older adolescents are responsible for their own actions) (Adams & Berzonsky, 2003; Johnson, 1997; Rotenberg, 2010).

Adolescents' relationships with their parents may become strained at this time and for the first time they begin to be more directly influenced by their peers than by their parents (Johnson, 1997). Parents often underestimate the influence of peers on their child as they share their inner feelings, and dreams with each other (Shaffer & Kipp, 2010). This mutual understanding between them drives the adolescents to give their friends complete loyalty which may lead to increased conflict with their parents (Adams & Berzonsky, 2003; Christie & Viner, 2005; Knecht, Snijders, Baerveldt, Steglich, & Raub, 2010; Spear, 2000).

### **1.4.4: Challenges during adolescence**

Adolescents face many challenges during this transitional and turbulent period. To begin with, they experience different internal conflicts including: the conflict between the desire to be independent from their families and the fact that they still need to rely upon them; the conflict between childhood behaviours and the challenges of their developing gender identity; the conflict between their ambitions and the reality of their daily lives (Kjønniksen, Torsheim, & Wold, 2008). Moreover, the conflicts are between their desires and their social traditions; the conflict between what they had learned while growing up with the new thought processes and the development of a new philosophy of life (Shaffer & Kipp, 2010). In conclusion, the developmental stage of adolescence is often referred to as one of the most stressful developmental stages (Shaffer & Kipp, 2010). The different bio-psychosocial experiences adolescents go at this time shape their beliefs, attitudes and values into the future (Adams & Berzonsky, 2003; Berger, 1998; Spear, 2000; U.S. Department of Education, 2005). Unwanted influences during this time such as the development of cancer can have a negative impact on them affecting

the natural development of this stage as well as the next developmental stage of adulthood.

### **1.5: The gap in caring for adolescents who have haematological malignancies**

While mortality rates from cancer for paediatric and adult patients over 50 years of age have decreased in the last 25 years, adolescents survival rate have not improved at the same rate (Bleyer, 2002; Watson, 2001; Wood & Lee, 2011). This can be related to several factors one of which is the access to health insurance. In Jordan, adolescents and in particular those whose age falls between 18 and 21 years often comprise the highest proportion of uninsured persons (Banks, Milburn, & Sabri, 1999). Although Jordanian adolescents are eligible for governmental insurance after being diagnosed with cancer, the coverage does not offer a choice of doctor or hospital, and the adolescent needs to queue for a long period of time before having access to the treatment at governmental hospitals (Jordanian Ministry of Health, 2004). Consequently, this makes access to health care services more difficult for this age group. In accordance with this, Parsons, Harlan, Seibel, Stevens, and Keegan (2011) found that uninsured adolescents and those who were treated by physicians specialised in adult patients are less likely to engage immediately with active treatment plans, which compromise their health and may affect their survival rates.

Another contributing factor affecting the survival rate of adolescents with cancer in Jordan is the lack of adolescent oncological medical specialists (Geehan, 2003; Zebrack, Mathews-Bradshaw, & Siegel, 2010). Due to the lack of evidence-based guidelines and standards of care specific to adolescents with cancer, the treatment provided for this age group is often lacking. Adolescents admitted to a paediatric or adult ward depending on the availability of beds and specialised doctors, hence they were treated by either paediatric or adult oncologists (Herbertson & Hancock, 2005; Pentheroudakis & Pavlidis, 2005; Stock, 2010). The treating physician may view these patients either as an older child or as a younger adult (Stock, 2010). Therefore, health team member are often not sure how they should care for these patients as adults or children as they belong to neither of these groups. Furthermore, the oncologists who do not specialise in this age group may be unsure whether paediatric or adult dosages of chemotherapeutic agents are most appropriate for adolescents with cancer (U.S.

Department of Health and Human Services, National Institutes of Health, National Cancer Institute, & Livestrong™ Young Adult Alliance, 2006; Zebrack, Mathews-Bradshaw, & Siegel, 2010). Failing to determine which doses are most appropriate was found to have a detrimental effect on the adolescent's prognosis as this age group has unique characteristics when compared to adults and children (Tricoli, Seibel, Blair, Albritton, & Hayes-Lattin, 2011). Recent research has shown that adolescents with acute lymphoblastic leukaemia who were treated on paediatric protocols have better outcomes compared with those treated on adult protocols (Bleyer et al., 2008; Boissel et al., 2003; Stock et al., 2008).

The United States Department of Health and Human Services, et al. (2006) reported that general physicians (GPs) often ruled out the possibility of cancer in adolescents because the cancer presents in the early stages as mimicking other minor illness such as colds and sore throats. Therefore, there is often a delay in diagnosing cancer for this age group which may worsen their situation and as a result may reduce their survival rate (U.S. Department of Health and Human Services et al., 2006). This is supported by previous research which reported a diagnosis time of between one to 17 weeks with an average of more than 10 weeks (Dixon-Woods, Findlay, Young, Cox, & Heney, 2001; Eiser, Parkyn, Havermans, & McNinch, 1994; Pinkerton, Cushing, & Sepion, 1994; Sloper, 1996).

Adolescents also perceive themselves as not being vulnerable to any serious illnesses and this leads to negligence of their symptoms and as a result, delay seeking medical advice (Berger, 1998). Culture plays a crucial role as in some countries cancer patients are stigmatised and adolescents are very sensitive to these experiences. As a result they are scared of the associated stigma and they prefer not to visit the doctors (U.S. Department of Health and Human Services et al., 2006). In addition, medical tests for cancer may involve exposing sensitive parts of the body including breast and genitalia for examination. This may pose an embarrassment for an adolescent, particularly those from more conservative countries like Jordan (Berger, 1998; Else-Quest, LoConte, Schiller, & Hyde, 2009).

Finally, it is acknowledged that, there is still limited understanding of the cancer biology in this group and adverse cancer outcomes are often under-estimated in this

population (U.S. Department of Health and Human Services et al., 2006), which may give another explanation for the adolescents' poor survival rate. Bleyer et al. (2008) reported that the aetiology of cancers in adolescents is different than that in children and older adults, not only in the spectrum of cancers but also within individual cancer types and within the patients. Therefore, health team members should not treat adolescents with cancer in the same methods as other age groups.

### **1.6: The adolescent's haematological malignancy journey**

Although there has been advancements in cancer treatments which has increased the survival rate for affected adolescents (Jordanian Department of Statistics, 2008; Horner et al., 2008), it does not reduce the adverse outcomes of the individual's spiritual and bio-psychosocial dimensions of their experiences (WHO, 2009). The literature review presented here will explore the physical, psychosocial and spiritual lived experiences of children, adolescents and young adults (CAYA) who have cancer. The review has covered these age groups because there is a dearth of literature related specifically to adolescents and haematological malignancies.

Usually parents are one of the first people to notice any health problems occurring in their child (Kreitler & Arush, 2004). They then take their child for a comprehensive check-up from their family doctor. Once a diagnosis of cancer is declared, the lives of the affected adolescent and their family is never the same again. For most people, the word cancer is synonymous with death (Abrams, Hazen, & Penson, 2007) and the news that a family member has cancer creates a time of crisis and extreme stress for all members of the family (Alderfer et al., 2010; Janes-Hodder & Keene, 2002; Kreitler & Arush, 2004; Martinson & Cohen, 1989; Pai et al., 2007; Vrijmoet-Wiersma et al., 2008).

As soon as the adolescent is diagnosed, treatment starts because any delay in treatment decreases the possibility of remission, worsens the condition and increases the possibility of complications and death. The cancer treatments usually take a long time and require the patient to undergo several periods of hospitalisation. As a result of their illness, treatments and hospitalisations the adolescent is exposed to different physical, psychological, social and/ or spiritual experiences.

### 1.6.1: The physical impact of cancer on adolescents

The physical impacts of cancer on adolescents are numerous and include the side effects of chemotherapy, surgical interventions and radiation to reduce the size of the cancer (Baird, McCorkle, & Grant, 1991; Carelle et al., 2002; Coates, Abraham, & Kaye, 1983; Davies, Noll, Hobart Davies, & Bukowski, 1993; Finley, Forgeron, & Arnaout, 2008; Forgeron, Finley, & Arnaout, 2006; Griffin et al., 1996; Groenwald, Frogge, Goodman, & Yarbrow, 1991; Herbertson & Hancock, 2005; Nadège et al., 2002; Ruth, 2002; Veronica, Wilson-Barnett, & Goodhart, 1998). The types of physical side effects differ according to the causes of cancer and their related treatments. For example, while the physical side effects of surgery include the possibility of infection and bleeding, the side effects of radiation are most commonly feelings of weakness and fatigue. Similarly, chemotherapy side effects are dependent on the strength and of the drugs being utilised and include side effects such as those detail in table 1.2 below.

**Table 1.2:**

The common physical side effects experienced by patients following the cancer treatment.

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Pain, constipation, diarrhoea, tingling or numbness, weight loss, weight gain, increased hair growth on legs, constant fatigue, giddiness on standing, loss of appetite, mouth soreness, shortness of breath, redness, rashes, urticaria, bruising, difficulty in sleeping, increased urination, painful urination, tinnitus, deafness, general aches, abdominal pain and swelling, amenorrhea, dysmenorrhoea, change in skin colour, hot flushes, palpitations, headaches, migraines, loss of hair, increased thirst, dry skin, acne (pimples.), increased appetite, dysphagia, nosebleeds, bleeding in general, discoloured fingernails, haematemesis.

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The physical side effects of cancer treatments are described by adolescents to be one of the most unpleasant parts of the cancer journey (Enskär, Carlsson, Golsäter, & Hamrin, 1997). In all the studies previously mentioned the researchers assumed that the side effects would be consistent across all of the age groups and hence did not target specific age groups or cancer types in their studies. Therefore, there is a need to describe

the side effects of chemotherapy according to the participants' age, types of cancers and the treatments being provided.

Patients tend to have different ideas about which types of physical side effects are the most distressing for them. However, according to previous research, the three most distressing side effects are nausea, vomiting and hair loss (Coates et al., 1983; de Boer-Dennert et al., 1997; Griffin et al., 1996). These side effects have a significant impact on CAYA experiences' with cancer and are found to be the main cause of this age group of patients withdrawing from their daily activities (Berger, 2003; Chao-Hsing, 2002; Enskar, Carlsson, Golsater, & Hamrin, 1997; Hokkanen, Eriksson, Ahonen, & Salanterä, 2004; Novakovic et al., 1996; Ramini, Brown, & Buckner, 2008; Woodgate, 2005). The perception of the impact of the physical side effects of chemotherapy varied according to the patients' perceived level of support, the type of cancer, the type and dose of chemotherapy, and their developmental age (Carelle et al., 2002).

Woodgate and Degner (2004) described the perception of CAYA and their families toward the signs and symptoms of cancer and the side effects of chemotherapy over an extended period of time using a qualitative research approach (n= 28, age 4.5-18 years old). Six themes emerged from this study which described participants' progressively worsening side effects over this period of time as: "it is just the flu", "it is more than flu" "it hits home" "it is nasty" "it is not so bad" and "it is dragsville" (Woodgate & Degner, 2004). Woodgate and Danger is one of the few longitudinal qualitative studies that provided an integrated view of the experiences of cancer patients and their families. However, even these authors continued to assume that children, regardless of their developmental stage or cancer type shared a common understanding with their parents, of the cancer experience. Therefore, there is a need for a qualitative study that considers the uniqueness of cancer during each of the developmental stages from the patient's perspective.

In summary, there was a plethora of literature conducted in western countries that focused on the physical impacts resulting from the side effects of chemotherapy and diagnostic tests (Baird et al., 1991; Coates et al., 1983; Davies et al., 1993; Finley et al., 2008; Forgeron et al., 2006; Griffin et al., 1996; Groenwald et al., 1991; Herbertson & Hancock, 2005; Nadège et al., 2002; Ruth, 2002; Veronica et al., 1998; Woodgate &

Degner, 2004). However, after a comprehensive literature search using Medline, ProQuest, Science Direct, Wiley InterScience, PsycInfo, CINAHL and Google Scholar database, I was unable to find any study conducted in Jordan or in other Arab countries that investigated this issue from Jordanian or Arab perspectives. There is also the need to further investigate which side effects are most distressing for the Jordanian adolescents and how these side effects are best managed within this cultural context.

### **1.6.2: Psychosocial experiences of cancer**

In order to understand the psychosocial experiences of adolescents with cancer, it is necessary to define the term psychosocial. The word “psycho” means relating to the mind or the psyche and “social” relates to relationships that people have with their family and other people in society. In other words, in the context of this study “psychosocial” means the impact of the illness on the individual’s level of emotional wellbeing, their relationships with others as well as the emotional aspects of the cancer experience (Canadian Association of Psychosocial Oncology, 2009).

There are many reasons for adverse psychosocial effects to occur during the cancer journey and one is due to the stigma associated with cancer in certain communities such as Jordan where some people still believe the cancer is contagious and a life threatening disease (KHCC, 2011d). Another cause of adverse psychosocial effects of cancer on adolescents is the impact of the side effects of chemotherapy on the patient’s body image (Hedström, Haglund, Skolin, & von Essen, 2003; Lansky, List, Ritter-Sterr, & Hart, 1993; Larouche & Chin-Peuckert, 2006; Palmer et al., 2000; Price, 2009; Wasserman, Thompson, Wilimas, & Fairclough, 1987). These side effects change the adolescent’s appearance and these changes affect them both psychologically and socially. As a result they may begin to isolate themselves from their friends and families (Frank, Blount, & Brown, 1997; Kreitler & Arush, 2004; Mulhern, Fairclough, Smith, & Douglas, 1992; Sanger, Copeland, & Davidson, 1991; Vannatta, Gartstein, Short, & Noll, 1998; Vannatta, Zeller, Noll, & Koontz, 1998). In fact, Wallace, Harcourt, Rumsey, and Foot (2007) identified altering one’s physical appearance as one of the most stressful experiences that adolescents face while living with cancer. Adolescents in the aforementioned study did not elaborate in detail as to why their altered body images caused them such high levels of stress, hence conducting further research into this issue

is crucial. Later, Williamson, Harcourt, Halliwell, Frith, & Wallace (2010) tried to elaborate more on this issue and investigated the impact of changes in body image and appearance in 22 adolescents receiving cancer treatments. The results showed that the adolescents were teased and stigmatised due to their appearance, which may explain why the adolescents in Wallace et al.'s (2007) study identified the altered appearance as the most stressful events they were exposed to during their cancer journey. The findings of Williamson et al.'s (2010) study further illustrated the need for more research in this area to assist in finding effective coping methods to manage these stresses caused by alterations in body image.

Having psychosocial problems prior to being diagnosed with cancer was also found to be a significant predictive factor that a patient was likely to develop further psychological problems after diagnosis (Frank et al., 1997; Sanger et al., 1991). Furthermore, the type of cancer played an important role in the development of psychological problems. For example, adolescents with cancers of the central nervous system were found to experience the greatest levels of psychological distress. In addition, being diagnosed with cancer during adolescence may delay the successful achievement of age appropriate developmental milestones like intimacy, identity and independence. This delay may cause additional stress when the adolescent compares him/herself against their healthy peers (Heiney, Wells, Coleman, Swygert, & Ruffin, 1990; Hokkanen et al., 2004; Price, 1992; Ritchie, 1992).

Lastly adolescents were exposed to different sources of stress, for example, during hospitalisation, surgery, radiotherapy and chemotherapy as well as stress from witnessing the death of other adolescents who had similar illnesses to themselves (Enskär & von Essen, 2007; Enskar et al., 1997; Novakovic et al., 1996). In particular, the frequent exposure to unfamiliar medical procedures was found to be an important factor in increasing participants' levels of psychological stress (Patenaude, Farkas, Kupst, & Mary Jo, 2005). Enskär and von Essen (2007) found the greatest fear and stress during hospitalisation came from the lack of knowledge of what was happening to them along with the lack of information provided to them by health team members.

The main adverse effect of cancer on the psychosocial well-being of adolescents were problems associated with low self-esteem, poor social relationships, poor peer

acceptance, depression, and stress (Hesketh et al., 2004; Larouche & Chin-Peuckert, 2006; Münstedt, Manthey, Sachsse, & Vahrson, 1997; Roberts, Turney, & Knowles, 1998; Rosman, 2004; Seitz, Besier, & Goldbeck, 2009). After being diagnosed with cancer, adolescents feared rejection from their friends and they felt inferior to them in term of their physical abilities and capabilities. They also had poor school attendance when compared with their non-cancer peers (Hokkanen et al., 2004; Stegenga & Ward-Smith, 2009).

A quantitative study conducted by Noll, Bukowski, Rogosch, LeRoy, and Kulkarni (1990) found that, CAYA between eight and 18 years of age with cancer were perceived by their teachers as less sociable and likely to assume leadership roles and were more socially isolated and withdrawn. The mothers of these CAYA also confirmed the views of these teachers in a different study. A study by Earle and Eiser (2007) investigated the mothers' perceptions of newly diagnosed children and these mothers reported that their children complained of loneliness, social isolation and did not want to go to school any more. Most of the studies above which investigated the psychosocial well-being of CAYA with cancer have focused on developmentally heterogeneous samples without reference to their current developmental stage and respect to their cancer type. These studies highlight the need for further research to explore each developmental stage of patients independently as their needs will differ according to their age and diagnosis (Roberts et al., 1998; Seitz et al., 2009; Whyte & Smith, 1997). This view is further supported by Dashiff (2001), who claimed that disregarding the developmental stage of the participant may significantly affect the trustworthiness of any research.

Eiser (1996) argued adolescents' experiences and reactions to illness differed to those of younger children or adults and recommended that they should be explored and investigated independently to fully grasp their whole journey. Dashiff (2001) recommended that further research should take into account the different developmental stages within this population as their experiences vary. Given these deleterious effects of cancer and a paucity of research that focuses on the psychosocial experiences of adolescents with haematological malignancies, further international studies are recommended.

From an Arab perspective, there is a paucity of studies exploring the psychosocial experiences of Arab patients with cancer. Some literature was found in relation to cancer patients in Middle Eastern countries but most of these were epidemiological studies which focused on the incidence and prevalence of cancer (Al-Sheyyab, Bateiha, El-Kayed, & Hajjawi, 2003; Freedman et al., 2003; Freedman, Edwards, Ries, & Young, 2008; Qasem, 2001). There were some descriptive studies using a questionnaire to collect data (Abu-Alsundus, 2002; Abu-Obeid, 2004; Al-Shmyleh, 1994) but these studies used small sample sizes with different patient characteristics, for example, age, type of diagnosis and time since diagnosis.

A mixed method study conducted in Jordan that examined the psychosocial experience of CAYA with leukaemia examined the major characteristics of this group (n=50 families having patients aged between 5-14 years old). Children with cancer were more conscious of their changing bodies, were nervous and stressed due to frequent hospitalisation and they were scared of being left alone (Abu-Alsundus, 2002). The findings of this study are also support by other Jordanian studies (Al-Shmyleh, 1994; Milkawe, 1998). However, all of the above studies used questionnaires developed for use in Western countries and they may not have been sensitive to Jordanian CAYA.

Some of these studies focused on chronic illness in childhood and did not specifically focus on cancer and assumed that CAYA with various chronic illnesses would share similar experiences (Al-Shmyleh, 1994; Milkawe, 1998). The researchers interviewed each patient and their family in a single interview focusing on the parents, without interviewing the patients independently (Abu-Alsundus, 2002). This data collection method may have compromised the quality of the results of these studies in that one member may dominate the interview. There is a need for longitudinal studies to explore the lived experiences of cancer patients from their own perspective.

The psychosocial impact of the cancer experience extends to the patient's family. Parents of afflicted CAYA complain of depression, anxiety, tension, and disruption of work/home duties, and social activities (Boman, Lindahl, & Björk, 2003; Dahlquist et al., 1993; Griffin, et al., 1996; Kreitler & Arush, 2004; Langton, 2000; Nadége et al., 2002; Sawyer, Streiner, Antoniou, Toogood, & Rice, 1998; Sloper, 1996; Woodgate & Degner, 2004). In a Jordanian study conducted to develop a paediatric pain program at

King Hussein Cancer Centre in Jordan, parents reported the most terrible psychological pain they had ever faced was when their children was diagnosed with cancer (Forgeron, Finley, & Arnaout, 2005). Siblings of cancer patients were also affected by the cancer experience and they complained of loneliness, sadness, anxiety, depression, guilt, shame, jealousy, isolation from the family and portrayed attention-seeking behaviours (Alderfer, Labay, & Kazak, 2003; Fanos, Fahrner, Jelveh, & Tejada, 2005; Heffernan & Zanelli, 1997; Houtzager, Grootenhuis, Hoekstra-Weebers, & Last, 2005).

A study which examined family functioning and coping strategies was conducted in the United Arab Emirates on 38 children with cancer (Eapen & Revesz, 2003). The findings revealed all the above-mentioned psychosocial impacts and, in particular, poor family communication. The study also revealed a lack of sharing of emotional expression in the Emirati population, perhaps influenced by what was described as cultural social stigma associated with cancer. Similarly, the diagnosis of cancer carries a significant social stigma in Jordanian society (Jadalla & Sharaya, 1998). However, as the above two groups of researchers did not explain what they meant by social stigma, it represents a concept that requires further investigation.

Although these research findings in Arab regions appear to be similar to research outcomes in developed countries, there are major differences. In Arab countries cancer carries with it a greater degree of social stigma resulting in the hesitancy of families to share their grief with others and between themselves. Stigma occurs when a cohort of people are labelled by others as being different, inferior or blemished in some way so that others look at them less favourably and with prejudicial characteristics (Brunton, 1997; Dain, 1994). Stigma devalues the person as a human being (Brunton, 1997; Chapple, Ziebland, & McPherson, 2004) and as a result the affected person suffers from guilt, shame, feeling of discrimination, inferiority and self-blame (Else-Quest et al., 2009; Pescosolido & Martin, 2007). Stigma impacts on the person's ego, his/her social life and it may also extend to the family of the stigmatised person (Ablon, 2002; Fife & Wright, 2000).

Globally, stigma is attached to many issues such as the nature of the disease, cultural beliefs about the cause of illness, and negative media coverage on the topic (McKeon, 1998; Rosman, 2004). It is most commonly found to be associated with

people who are affected by certain illness such as mental illness, HIV/AIDS, tuberculosis, leprosy and cancer (Bloom & Kessler, 1994; Brunton, 1997; Corrigan & Wassel, 2008; Else-Quest et al., 2009; Kleinman & Ryan, 2010; Lebel & Devins, 2008; Macq, Solis, & Martinez, 2006; Whetten, Reif, Whetten, & Murphy-McMillan, 2008). However, in Jordan, culture plays an important role in sustaining the level of stigma directed towards people who have cancer. Jordanians believe that cancer is a lethal contagious disease and therefore are wary of having contact with people who have been diagnosed with the disorder (KHCC, 2011d). Therefore, the stigma directed towards cancer adds to an already complex and stressful experience. The stigma leads to affected people experiencing isolation, lack of support as well as unexpected reactions from people they know (Carlsson, Kihlgren, & Sorlie, 2008; Chao-Hsing, 2002; Williamson et al., 2010).

Another source of psychosocial problems for CAYA with cancer was that their parents tended to hide the information about their condition from them, which caused them additional stress. In a grounded theory study conducted to develop a conceptual framework of the experience of Taiwanese adolescents with cancer (n=16, age 13-18 years old) parents did not inform their child about their diagnosis and requested that health team members acted in the same manner. However, parents and health team members discussed the progress of the affected adolescent at the adolescent's bedside. This led to the adolescents becoming aware that something was wrong with them but due to the lack of communication they did not know what was wrong (Chao-Hsing, 2002). Most of Jordanian parents share the perception of their Taiwanese counterparts in regards to not disclosing information to their children (Arabiat, Alqaissi, & Hamdan-Mansour, 2011; Jadalla & Sharaya, 1998; Mahadeen, Arabiat, Abdelkader, & Hamdan-Mansour, 2011) because they want to protect their children and because they believe that providing their children with a modified version of this information will maintain their hope in the future (Farmer et al., 2010; Petro Nustas, Norton, & Al Masarweh, 2002). However, studies conducted in other countries showed that hiding the diagnosis increased the adolescents stress and make them worry about their health (Chao-Hsing, 2002; Together against cancer, 2010).

In summary, there were a limited number of studies which discussed the topic of disclosure of cancer to adolescents with haematological malignancies and the impact of silence on adolescents (Chao-Hsing, 2002). Most of the studies subsumed adolescents within childhood or adulthood (Al-Amri, 2009; Eapen & Revesz, 2003; El Ghazali, 1997; Harrison et al., 1997; Jenkins, Fallowfield, & Saul, 2001; Jiang et al., 2006; Jiang et al., 2007; Meredith et al., 1996; Seo et al., 2000; Younge, Moreau, Ezzat, & Gray, 1997; Yun et al., 2004) and were not specifically for people with a haematological malignancy (Al-Amri, 2009; Arabiat et al., 2011; Davison, Degner, & Morgan, 1995; Davison et al., 2002; Jenkins et al., 2001). Moreover, the Arab and Asian studies presented here (Al-Amri, 2009; El Ghazali, 1997; Harrison et al., 1997; Jiang et al., 2006; Jiang et al., 2007; Seo et al., 2000; Younge et al., 1997; Yun et al., 2004) did not provide evidence as to why they did not disclose information to cancer patients. To the best of the researcher's knowledge there are no Jordanian studies that investigated the parents and doctor's perceptions regarding disclosure of information to adolescent with cancer in one single study. There also a need to investigate adolescents' attitude toward disclosure of information as both of these issues can have significant adverse psychosocial effects on both the affected person and their family.

### **1.6.3: Spiritual experiences of cancer**

As time progresses, adolescents with cancer begin to accept their situation, and learn to live with their illness. In this process, patients often become more conscious about their spirituality (Taylor, 2003) which along with religion plays an important role in the coping strategies used by these adolescents (Gallup & Gallup, 2005; Jenkins & Pargament, 1995; Michael, Paige-Green, & Stephanie, 2005; Taylor, 2003). Some nursing literature describes spirituality as being religious, therefore using spirituality as a synonym for religion (Ellis, 1980; Emblen, 1992; Michael et al., 2005; Narayanasamy, 1993). However, spirituality is broader than religion; it includes other components such as searching for the meaning of life, and the harmony between the inner-self and the community (Dyson, Cobb, & Forman, 1997; Narayanasamy, 1993; Ruth, 2002). Therefore, spirituality could be applied to those who are atheists, as these individuals have values and relationships that provide similar meanings and grounding in life to those who are advocates of organised religions (Narayanasamy, 1993; Ruth, 2002).

The major spiritual needs of cancer patient are identified by Murray, Kendall, Boyd, Worth, and Benton (2004) and Taylor (2003, p.260) as “needs associated with relating to an ultimate other”, “the need for positivity, hope, and gratitude”, “the need to give and receive love”, “the need to review beliefs”, “the need to have meaning” , and “needs related to religiosity and preparation for death” (Murray et al., 2004; Taylor, 2003, p.260). There are a few studies in Muslims countries exploring this aspect with cancer patients but none have explored the spiritual needs of adolescents with haematological malignancies.

Some studies have investigated the Muslims’ spiritual experiences of cancer. Errihani et al. (2008), examined the impact of cancer on Moroccan Muslims, and found that practicing Muslim patients understood their malignancy to be a test from Allah (God) which determined their acceptance of fate. The researchers used religion as a basis to describe the spirituality of the cancer patient and its influence on the patient’s ability to cope with the disease. Another study conducted in Jordan investigated the knowledge and attitudes of 219 Jordanian students about cancer using the “Public knowledge and attitudes of cancer questionnaire” (Jadalla & Sharaya, 1998), where 64% of the students perceived cancer as a test from Allah, and 20% perceived cancer as a punishment from Allah (Jadalla & Sharaya, 1998). In another study to develop a paediatric pain program at King Hussan Cancer Centre in Jordan, parents described disease and pain as “God’s will”. Furthermore, they believed that reading from the holy Qur’an helped them and their children to reduce pain (Forgeron et al., 2006). Patients from other religions, such as Christianity hold similar beliefs (Alferi, Culver, Carver, Arena, & Antoni, 1999).

In all the previous studies the researchers continued to view spirituality from a religious perspective. Therefore, they believed that religion helped people to cope with cancer, as a chronic disease; helps patients accept their illness; and is considered a coping mechanism for many religious groups (Alferi et al., 1999). No studies have been conducted in Jordan to assess the spiritual needs of adolescents with haematological malignancies but there is a need to explore the spiritual dimension of adolescents with cancer journey as most of the Jordanians are Muslims and Islam dominates their life.

In conclusion, the physical, psychosocial and spiritual impact of cancer is documented in western literature. However, most of the previous research focuses on the psychosocial experiences of the cancer patient cross-sectionally rather than following the trajectory of the disease and depend on questionnaires to collect participants' responses. The current literature in the area explains the psychosocial and spiritual experiences of CAYA with cancer, but not specifically during the stage of adolescence and the research was not limited to one cancer type. Some research, especially research conducted in Muslim countries; relates spirituality to religion without trying to understand the meaning of spirituality from the patient's perspective.

A comprehensive review of electronic data bases; such as, Medline, ProQuest, Science Direct, Wiley InterScience, PsycInfo, CINAHL and Google Scholar did not reveal any studies that discussed the bio-psychosocial and spiritual experiences of adolescents with haematological malignancies from the Jordanian perspective. In addition, I was unable to find literature discussing the coping strategies that adolescents utilised to manage their illness trajectory. There is a need to conduct a study that addresses these gaps in previous research by exploring the experiences of adolescents with cancers, as a particular group, during the illness journey and how they describe the situation from a Jordanian and qualitative perspective as the awareness of their need would establish a more cultural sensitive care (see table 1.3)

### **1.7: Need for the study**

The area of adolescent health care is not well addressed in developing countries because this developmental stage of the life cycle is not well defined and as a result adolescents may be subsumed under the areas of childhood or adulthood health. In addition, when care of this group is documented, it usually has a physical focus while the psychosocial dimensions are often neglected or deemed to be less importance to patient outcomes.

Given the high percentage of young people in the Jordanian population and the rate of haematological malignancies in this age group (Tarawneh & Tarawneh, 2007; Jordanian Department of Statistics, 2008) there is an important need for an in- depth study in this area of health care. As many of these adolescents have poor survival rates when compared to adolescents in developed countries (WHO, 2010b) it is also important to fully understand and document the lived experience of Jordanian

adolescents in a culturally safe manner. This insight will provide avenues for new interventions that will promote quality cancer care to the population and increase the health and well-being of affected patients and their families.

The family, as well as the affected adolescent are impacted by the cancer experience and it is important to identify family focused strategies that provide increased support during this time thus ensuring the family is fully engaged in all stages of the patient's care trajectory. In addition, this study documents the longitudinal lived experience of adolescents and this is important as both the affected individual and their family has different needs during this time. The finding of this study will assist the patient, their family, health team members and policy makers to plan and deliver quality culturally safe care to the individual and their family.

### **1.8: Significance of the study**

Given the importance of this stage of the life cycle in shaping the future identity of the individuals it is important to understand the impact of cancer and the current treatment interventions on the individuals and their families. Failure to identify and address the needs of adolescents will adversely affect their level of well-being and quality of life at this critical time in their lives. It may also predispose them to the development of co-morbidities such as anxiety and depression which will impact significantly on their primary cancer illness and their future.

The findings of this study will generate new knowledge and understanding in this area of health care that will facilitate the development of improved nursing care for this patient group. The findings will facilitate engagement with families and their significant others and assist them to better support both themselves and their family member during this critical life event.

Integrating bio-psychosocial and spiritual interventions to patients with cancer will give adolescents support and knowledge to cope with and to overcome their illness and to support their families at this time. This highlights the improvements that may need to be made in cancer care in Jordan in order for adolescents to normalise and manage their cancer experience and to live productive lives within their local communities.

Insight into and awareness of the adolescent's journey will enable health planners and decision makers in Jordan to develop new policies and educational programs to increase their level of competency of health team members to work with this patient group and to ensure high quality care is provided to the adolescents. Health team members need to decrease adolescents' feeling of stigma and improve their communication with the affected person and their family. Finally, the findings of this study will add to trans-cultural research in the area of adolescent health and cancer and will assist health professionals to develop a culturally sensitive approach to care. It will also facilitate further research in this area in Jordan.

### **1.9: Purpose of the study**

The purpose of this study was to explore, understand and describe the lived experiences' of Jordanian adolescents with haematological malignancies and to identify factors that facilitate or inhibit those experiences. This will facilitate the development of culturally sensitive care plans and make a significant contribution to existing knowledge and understanding within the Arab world in particular and trans-cultural literature from a global perspective.

### **1.10: Objectives of this study**

In order to achieve the above purpose the objectives of this study were to:

1. Explore and describe the experiences of Jordanian adolescents living with haematological malignancies during the first six months following diagnosis.
2. Identify factors that facilitate or inhibit that experience.
3. Set the findings within the context of Jordanian and other international literature in the area.
4. Provide recommendations for the delivery of culturally sensitive quality care in Jordan to this group of patients.

### **1.11: Assumptions underlying the study**

There were several assumptions made by myself before commencing this study. These were:

1. Adolescents are subjected to considerable, even severe, psychological and emotional suffering as a result of their diagnosis of cancer.
2. Jordanian culture shapes the cancer experience for adolescents.
3. The side effects of cancer treatments given to Jordanian adolescents are similar to those experienced by patient in other countries.
4. Jordanian adolescents with haematological malignancies have common and different psychosocial experiences to adolescents in other countries.
5. A better understanding to the lived experiences' of adolescents with haematological malignancies can lead to improvements in health care delivery which may improve survival rates.
6. A better understanding to the lived experiences of adolescents with haematological malignancies will promote more culturally appropriate and effective models of family centred care.
7. Families are an important support to adolescents with haematological malignancies.
8. That in response to cultural norms in Jordanian society parents will be present when I interview participants for this study.
9. That the developmental age of participants will increase the difficulty of this interview process.
10. Jordanian nurses provide good care to adolescents with cancer but this care does not routinely address the psychosocial needs of adolescents.

### **1.12: Definition of terms used in this study**

Throughout this study, the term “haematological malignancy” rather than “cancer” or “childhood cancers” and the term “adolescents” rather than “youth”, has been predominately used. When conducting research it is important to be precise and consistent in terminology so that others can accurately understand what has been examined.

To avoid ambiguity and enhance the understanding, definitions are provided for the terms ”adolescence”, “haematological malignancies”, “health team members”, “participant”, “family”, “lived experience”, “lifeworld” and “culture”.

<b>Adolescence</b>	The period in development from the onset of puberty until adulthood. It usually begins between 11 and 13 years of age with the appearance of secondary sex characteristics, and spans the teenage years, terminating at 18-20 years of age with the completion of the development of the adult form (Harries, Nagy, & Vardaxis, 2006 ). From a Jordanian perspective, 18 years of age is considered a time when a man or woman is responsible for their behaviour and actions. Therefore, in this study the term adolescence will refer to people whose age falls between 13 and 17 years of age.
<b>Haematological malignancies</b>	“Proliferation of malignant cells that derive originally from bone marrow...” (Baird et al., 1991, p.536). In this study the term haematological malignancies (HMs) will refer specifically to Hodgkin lymphoma, non Hodgkin lymphoma or leukaemia. In some areas of the thesis the researcher will use the word “cancer” and “illness” interchangeably with haematological malignancies
<b>Health team members</b>	Any member of the multi-disciplinary health professionals/ personnel. However, the majority of health team members in this study were doctors, and nurses. The generic term “health team members” is used except when the participant has specifically used a term to denote a specific discipline, such as “doctor” or “nurse”.
<b>Participant</b>	It refers to all of the patients in KHCC and Al-Basher hospital who agreed to help the researcher by sharing their experiences as adolescents living with haematological malignancies.
<b>Family</b>	The concept of family could be defined in many ways. It could be defined as “a filter, or mediating structure that functions as a gatekeeper between us as individuals, our culture and the society in which we live. It is a conduit through which society transmits to

	<p>individuals its social and cultural norms, roles and responsibilities” (McMurray, 2007, p.108), or the family can be defined according to its structures and relationships as “two or more people who share goals and values, have long-term commitments to one another, and reside usually in the same dwelling place.”(The Free Dictionary By Farlex, 2009). However, for the purpose of this study the researcher defined family as a group of people living together and having a blood relationship to each other.</p>
<b>Lived experience</b>	<p>Is the “experience as we live through it and recognise it as a particular type of experience”... The notion of lived experience, as used in the works of Husserl, Merleau-Ponty, and like-minded phenomenologists, announces the intent to explore directly the original or pre-reflective dimensions of human existence (Given, 2008, p.616).</p> <p>Phenomenology is interested in recovering the living moment of the here and now- even before we put language to it or describes it in words. Or to say this differently, phenomenology tries to show how our words, concepts, and theories always shape (distort) and give structure to our experiences as we live them (Given, 2008, p.617).</p>
<b>Lifeworld</b>	<p>Lifeworld refers to an individual’s environment that is based on his/her current intentions and goals. It is the pre-given world, the existent world that we find ourselves in it. Husserl described the lifeworld as the “world of immediate experience,”... Each lifeworld shows certain pervading structures or styles that can be explored phenomenologically... Each of us may be seen to inhabit different lifeworlds at different times of the day, such as the lived world of work and the lived world of home (Given, 2008, p.617).</p>
<b>Culture</b>	<p>Is an inherited “lens” through which individuals perceive and understand the world that they inhabit and learn how to live within it. Growing up within any society is a form of enculturation</p>

	<p>whereby the individual slowly acquires the cultural “lens” of that society. Without such a shared perception of the world, both the cohesion and the continuity of any human group would be impossible (Helman, 1990).</p>
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### **1.13: Summary**

In this chapter, I have presented the major haematological malignancies that affect adolescents in Jordan, and discussed adolescence as a critical developmental stage of the life cycle. I have also highlighted the impact of a major illness such as cancer on the adolescent and their family. When the adolescent is first diagnosed with cancer they are exposed to physical, psychosocial, and spiritual risk factors as a result of chemotherapy and prolonged hospitalisation which may compromise the quality of their care.

The findings of this study will contribute significantly to existing knowledge in the area and towards improving the care for adolescents with haematological malignancies in the Jordanian community. In addition, it will contribute to the global body of knowledge that is set within the context of the current scientific literature on caring. In the context of adolescent health care reforms locally, nationally, and internationally, the findings will provide valuable insight into the experience of being adolescent with a haematological malignancy.

### **1.14: Organisation of the thesis**

Chapter one has provided an introduction and background to the study and the research purpose, objectives, and justification for the research. The chapter also includes a review of the physical and psychosocial research completed in the area of CAYA with cancer. Chapter two presents a contextual description for the setting for this study and provides information about the Jordanian health system and common disorders. It also provides the reader with some important information about each participant and an insight into their beliefs and values which shaped their experiences. The chapter also contextualised and introduced myself as a researcher and showed the context from which I approached data collection and analysis.

Chapter three covers the methodology along with the ontological and epistemological reasons behind choosing this study. It also details the historical development and the underlying philosophy for the interpretative phenomenology. This chapter concludes with a description of the application of the Interpretative phenomenological research method as used in this study.

Chapter four details the fourteen adolescents' experiences with cancer in the first three months of the diagnosis, and three months after the initial meeting. This chapter consists of three main themes. In chapter five, a summary of the major findings in chapter four are provided and comparisons of findings with previous literature in the area. Chapter six, the final chapter of this thesis presents the implications of the research findings and the concluding statement of the thesis.

## CHAPTER 2

### CONTEXT OF THE STUDY

#### 2.1: Introduction

The ultimate objective for using interpretative phenomenological analysis (IPA) methodology is to understand and interpret the research participants' stories allowing the reader to make sense of their lived experiences. In order to do so, I had to actively engage with the participants' account and to try to access their world. However, access to the participants' world is "dependent on and complicated by the researcher's own preconceptions which are required to make sense of that world through interpretative activity" (Smith, 2003, p. 264). By adopting such a notion, I acknowledged and accepted the inevitability of bringing my personal and a cultural perspective to bear on the analysis. In an epistemological sense, I consider myself as a "contextual constructionist" (Madill, Jordan, & Shirley, 2000). That is, as the researcher I must recognise that the ways in which I constructed meaning, was contextually different to that of the participants (Pidgeon & Henwood, 1997). Therefore, the results may vary according to the context in which the data was collected and analysed (Jaeger & Rosnow, 1988).

Data for this study was collected in Jordan where people have a different set of cultural and religious beliefs to most Australians, the country where I completed this PhD study. Therefore, it is important that I detail the contextual information related to this study including the cultural backgrounds of the participants and the researcher. Providing this context assists the reader to better understand how data has been collected, analysed and interpreted within this cultural context.

In this chapter, I present information about Jordanian society and the Jordanian health care sector. In addition, information will be presented regarding relevant Jordanian traditions and customs which may have impacted on the experiences of adolescents with cancer. I will also articulate the stance from which I approached the participants and the context of each participant in this study.

Since there was a paucity of literature regarding descriptions of health care services in Jordan (Mawajdeh, Hayajneh, & Al-Qutob, 1997), I obtained a large amount

of information from international and Jordanian government websites to reference the information presented in this section.

## **2.2: Introduction to Jordan**

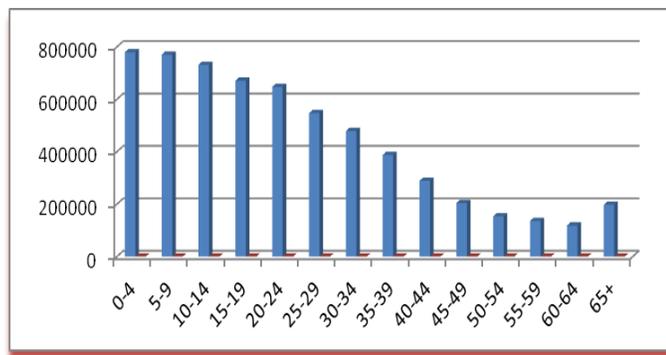
The Hashemite Kingdom of Jordan commonly known as “Jordan” is a developing country in the Middle East, bordering Israel (Palestine) to the West, Saudi Arabia to the south and west, and Syria to the north. Jordan is a small country around the size of the state of Tasmania in Australia or the State of Indiana in the United States of America (91, 000 km<sup>2</sup>). Arabs are the main ethnic group of Jordan and account for 98% of the population with the remaining two percent comprised of Circician and Armenian ethnic groups (Geography IQ, 2007; Jordanian Department of Statistics, 2010).

Jordan has a population of approximately six million people. Young people make up 49% of the total Jordanian population, and most of these are under 19 years of age (Jordanian Department of Statistics, 2008). Around 92% of Jordanians’ are Muslims and the majority of people speak Arabic (Index Mundi, 2011; Jordanian Department of Statistics, 2008).

Jordan’s education system is considered to be the best in the Arab World and is one of the highest ranked among developing countries (The U.S Agency for International Development [USAD], 2006, 2010). However, postgraduate research education, such as PhD programs, are very limited in Jordanian medical schools even though Jordan has the most researchers, per capita, among the 57 countries in the Organisation of Islamic Conference (OIC), (Declan, 2006; World Development Indicators database, 2006).

## **2.3: Demographic profile of the Jordanian population**

According to the Jordanian Department of Statistics (2008) the population of Jordan in 2004 was approximately six million people and growing at 2.2% per year. Of that 49% were aged less than 19 year of age; 47.7% for people were aged between (15-64) years old and only 3.3% more than 65 years old (see figure 2.1).



**Figure 2.1:** Number of Jordanian according to their age group (Jordanian Department of Statistics, 2008).

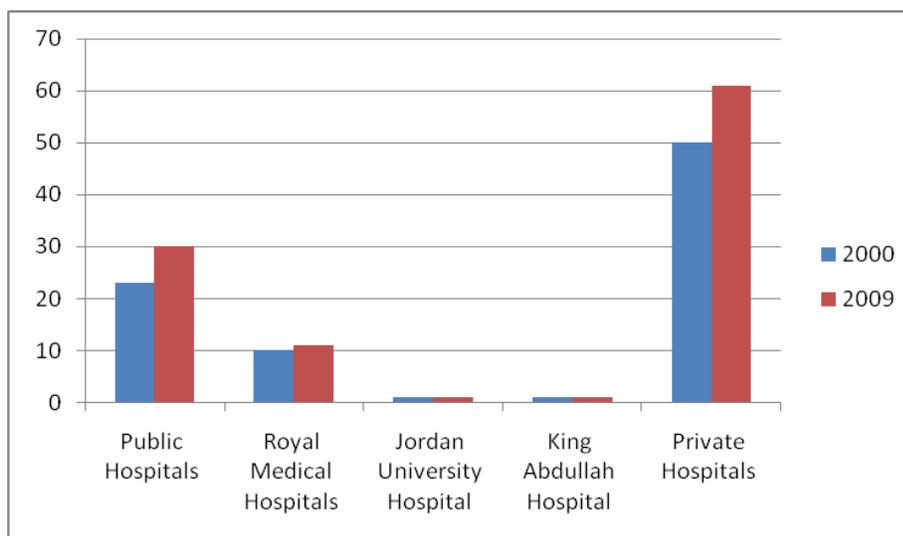
The population growth rate is 2.2% with 30.6 new births and 7.0 deaths per 1000 capita (WHO, 2010e). The sex ratio between males and females is 1.04 males to females. The average life expectancy for Jordanians is 80.05 years. The total fertility rate is 3.39 children born to each woman (Index Mundi, 2011; WHO,2010e). The main population centre is Amman where 55% of the total Jordanian population is located (Jordanian Department of Statistics, 2008). In general 79% of the total population lives in urban areas. Most cities have hospitals, banks, governmental and private schools, churches, mosques, shopping and entertainment facilities (Jordanian Department of Statistics, 2008).

#### **2.4: Health care sectors in Jordan**

Despite the limited natural resources and continued conflicts in the area, Jordan has one of the most advanced health care services in the Middle East and many patients come from other Arab countries to receive care for illnesses such as heart disease and cancer (Jordanian Ministry of Health, 2010a). The World Bank has ranked Jordan as the top medical tourism destination in the Middle East and North Africa, followed by Dubai, Abu-Dhabi and Israel (Hazaimah, 2008). Jordan was also, ranked first in the Arab region and fifth in the world by World Bank medical tourism experts as a top medical tourism destination (United States Agency for International Development [USAID], 2010). However, a significant number of the Jordanian population have a chronic illness, with heart disease and cancer having the highest prevalence and mortality rates

(KHCC, 2000). The incidence of cancer in Jordan is 67 cases per 100,000 capita with the number of new cases estimated at 3470 per year (KHCC, 2000). Furthermore, 32% of all Jordanians, which is equal to around 1.5 million people, are not covered by any form of health insurance (Banks et al., 1999).

The total ministry of health budget in 2008 was 7.015 % of the total gross domestic product of the country (Jordanian Department of Statistics, 2008) and the total cost of health care in 1990 composed four point eight percent of the governmental budget, increasing to five point nine percent in 2000, and seven percent in 2008 (Jordanian Department of Statistics, 2008). This increase in the health budget reflects the increase in population size. Over the past nine years, the total number of hospitals has increased from 95 to 108 (Jordanian Ministry of Health, 2010b) (see figure 2.2). Consequently, the number of beds has also increased. Jordan has a high percentage of physicians when compared with other countries in the region and the population per physician is currently about 25 doctors and 33 nurses for every 10,000 (Jordanian Ministry of Health, 2010b). One possible explanation for the large number of health team members is that culturally medical professions are highly prestigious and respected in Jordan.



**Figure 2.2:** Total number of Jordanian hospitals (Jordanian Ministry of Health, 2010b).

The Jordanian Ministry of Health is the primary authority responsible for the delivery of health care in Jordan. It has four different types of health care providers: public or governmental sector, military sector, private sector and United Nations Relief and Works Agency (UNRWA).

The governmental sector provides health services to all people who work in government positions and their families. It also provides free or nominal payments for health services to all Jordanians under the age of five and to all Jordanians suffering from chronic illness such as hypertension, diabetes mellitus and cancer (Jordanian Ministry of Health, 2004). People who do not work for the government may still elect to utilise governmental hospitals which are still significantly cheaper than seeking treatment from a private hospital. Although governmental hospitals are willing to provide health services to the general Jordanian population, governmental hospitals are always busy and patients are often placed on a waiting list to receive treatment. In special circumstances, the general public not covered by any health care system may still receive free treatment according to illness type and financial circumstances. For example, patients diagnosed with cancer regardless of age and job type are eligible to receive this benefit from the governmental health care system but they must follow certain protocols to obtain this privilege which may take a long time to complete.

The military health care sector also provides health care services to its employees and their families. Military hospitals have the most skilled Jordanian health team members and the most advanced medical equipment and they provide a high quality of care. Sometimes with complicated medical cases, public hospital doctors can refer their patients to the military hospitals. However, access to this treatment will still require queuing, but will still provide faster access to medical treatment when compared to governmental hospitals.

The third sector is the private health sector which allows for fast and high quality care to any person. However, utilising these services requires a lot of money, some people who have private insurance or those who hold prestigious positions in governmental sectors are covered by their respective organisations. The quality of care is comparable to the other sectors services but they are more expensive and private hospitals are mostly only available in the capital cities. The last type of health care

service, which is considered to be independent of the government called United Nations Relief and Works Agency (UNWRA). It provides primary health care, including medical services and nutritional relief, to the Palestinian and Iraqi refugee population (United Nations Relief and Works Agency [UNRWA], 2010). Finally, to the best of researcher's knowledge, only King Hussein Military Hospital-Medical City, King Abdullah University Hospital, King Hussein Cancer Center and Al-Bashir Government Hospital provide holistic cancer care for adolescents with haematological malignancies as a part of many other health care services, while King Hussein Cancer Center is the only hospital in Jordan that provides highly specialised cancer treatment. The shortage of such specialised health care facilities could impact on the quality of care provided to adolescents with haematological malignancies as the occupancy rate is very high for these facilities to cope with increase demand of the admitted patients.

## **2.5: Traditions and beliefs of Jordanians**

### **2.5.1: Introduction**

The majority of people in Jordan are Arabs, and around 92% of them are Sunni Muslims (Jordanian Department of Statistics, 2008). Jordanians are proud of their Arabic origin as they believe Mohammad was the final messenger and belonged to the Arabs. The word "Arab" is given to anyone whose mother tongue is Arabic and whose parents belong to an Arab ethnic group. In this context, not all the Arabs are Muslims and not all the Muslims are Arabs as there are also Christian Arabs. The importance of this notion is that Islam set broad guidelines for people to show them their way in life. Therefore, although it is expected to find common customs across all the Muslims, there are minor discrepancies between them based on their different ethnic and cultural backgrounds.

### **2.5.2: Islam**

According to the Jordanian constitution, Islam is the state religion. Islam and the law prevent discrimination towards any other religion and this is demonstrated in the fact that the population includes 92% Muslim, six percent Christian (mainly Greek Orthodox, but some Greek Catholics, Roman Catholics, Syrian Orthodox, Coptic Orthodox, Armenian Orthodox and Protestant denominations), and two percent other several small Shia Muslim and Druze populations (Geography IQ, 2007).

Islam has a major impact on all aspects of Jordanian life. Islam means “Surrender to the wishes of Allah”. Mohammad, the prophet of Muslims, explains to followers how to live according to the Qur’an which is the word of Allah (Allah is the Arabic word for God). The Qur’an besides the behaviours and instructions of Mohammad gives Muslims the code by which they live (Khan & Al-Hilali, 1996). Muslims believe that the major reason behind their creation is to worship Allah. Islam stands on five principles “pillars of Islam”. These consist of (1) oral testimony that there is only one God and that Mohammad is his final prophet; (2) ritual prayer practiced five times a day; (3) concern for and alms-giving (the practice of charitable giving by Muslims based on accumulated wealth and is obligatory for all who are able to do so) to the needy; (4) fasting one month per year in Ramadan; and, (5) the pilgrimage to Makkah for those who are able.

Muslims believe that there is another life after death (Khan & Al-Hilali, 1996). Consequently, Muslims prepare themselves for that life by praying, fasting, almsgiving and pilgrimage. Furthermore, Muslims generally believe on many occasions Allah will test their beliefs according to the strength of the faith that that person carries. Those who have stronger faith will be tested more by Allah than those who do not have the same level of belief. Most of the Muslims believe that their age is considered by Allah before they are created. Islam allows relatives and friends to express the feeling of sadness at death events. Of course, if the family shows more control on their feelings and displays patience for the lost one, Allah will reward them in different ways (Khan & Al-Hilali, 1996).

The role of mosques for Muslims, beside its role as a worship place, is a place for socialising and they are found in most populated areas. Muslims are encouraged to pray in the Mosque five times per day and have special prayers every Friday. This Friday sermon is podcasted through the television and is an important way of educating the public about community issues (Hathout, 1995).

### **2.5.3: Islam and health**

The main purpose of Islam is to keep and maintain what is called the five necessities which are keeping religion, life, property, the mind and the propagation of human beings (Bukhari, 1979). Therefore, the maintenance of health and the prevention of disease are

considered a kind of worship to Allah. Health is also given considerable attention in Islam:

- The first chapter in The Sharia books is “purification”. In this chapter, Allah [God] asks his followers to perform Ablution five times a day before praying the formal five prayers in order to maintain their cleanliness and Islamic instructions urge Muslims to wash their hands before and after visiting the patients to minimize the risk of infection (Bukhari, 1979).
- Islam encourages Muslims’ to perform physical exercises, specifically: Swimming, archery and horse riding in order to preserve their physical and mental health.
- Islam forbids the consumption of substances such as (cigarettes, alcohol and drugs) that are believed to have a negative effect on the human body and minds.
- Islam also tries to promote health spiritual by instructing Muslims to pray to Allah for good health (al-Jawziyyah, 1985).

Islamic instruction tries to integrate the physical and spiritual methods of promoting health and praying to Allah constitutes a major part of Islamic life as many Muslims believe that only Allah is capable of curing them. This belief does not contradict the importance of seeking medical treatment. In fact, Islam encourages Muslims’ to seek medical treatment for any disease; and not rely upon God’s power and mercy (Ibn Hajar, 1989). Islam gives priority for good health over Ibadat (worship) because it cannot be performed without good health and well-being. For example, although it is compulsory for Muslims to fast during Ramadan, Allah gave special permission for patients not to fast during this time. In Islam, care for those who have health problems and are unable to take care of themselves is the responsibility of the immediate family and considered a religious duty. Care presented by another person from outside the family such as health team members is also welcomed as long as it does not contradict with Islamic belief and Arab culture (Miles, 1995).

In conclusion, this overview regarding how Muslims’ perceive health and illness is important as religious beliefs directly affected the adolescents’ who participated in this study experiences with cancer.

## **2.6: Introducing myself as a Jordanian researcher**

I am a Jordanian male in my late twenties and I speak fluent Arabic and follow the Islamic religion. I am married with three children. English is my second language and I belong to a very well educated family. Due to the nature of my father's work, I travelled across several Arab countries when I was a child. I was nurtured within a family proud of its Arab and Islamic heritage. I harbour this heritage, beliefs, customs and habits within my heart and I view the world around me according to these beliefs.

I had worked with cancer patients (adults and children) in different units and in different hospital settings in Jordan since qualifying as a registered nurse eight years ago. I have worked in medical wards, ICU and haematological units. I completed a master's degree and I then went to Saudi Arabia and worked there as a lecturer in School of Nursing and Midwifery for three years. Now, I am doing my PhD in Australia which has a different context, culture and beliefs compared to my home country. In Australia, I was introduced to qualitative research methodologies which I have not been exposed to previously. In my discussion with my supervisors and reading through qualitative literature, I decided to use this paradigm in my thesis.

As a registered nurse I have encountered many cancer patients and I have witnessed significant physical, social and psychosocial and emotional distress in these patients. This distress is further exacerbated by the restrictions imposed upon them by their poor health, hospital rules, and lack of support and contact with their friends. I had also observed differences within patients in terms of their capacity to express and cope with these hardships. During my work as a registered nurse (RN), with cancer patients I noticed that the health team member gave more attention to the patient's physical dimension and that they judge the patient's improvement through physical parameters while often neglecting the psychosocial dimension of care. Acknowledging this care deficit I began to give equal attention to both the physical and psychosocial dimensions of the patient and tried to ensure a balance between the patient's physical and psychosocial well-being. As a result, I noticed a great improvement in my patients' level of well-being and in the satisfaction with the care I provided as a nurse. Other health team members also commented on my care of the patients and the esteem in which I was held by the patients on the ward. I then became more concerned to maintain their

optimal level of health and well-being during hospitalisation. My belief about the importance of holistic care grew even stronger after reading the literature that demonstrated the importance of this care in all health care settings as well as the need for this current study.

I became very interested in caring for adolescent patients with cancer following an interaction with a young sick patient where it was clearly demonstrated to me the importance of delivering holistic care. I also noticed that adolescents were usually admitted to adult or children's wards within the hospital but they did not fit developmentally in either category. As a result they struggled to find friends while hospitalised and this impacted on their ongoing level of health and wellbeing.

While I was aware of the global literature that highlighted the physical and psychological impacts of cancer on adolescents, I believed that adolescents in Jordan had a set of unique additional factors as Arab Muslims when compared to adolescents from other countries. I believed that Jordanian adolescents with cancer had their own story to tell and that this should be done in a manner that allowed health team members to fully understand these factors hence allowing the affected people to employ constructive way to maximise their coping mechanisms. Therefore, I chose to complete my PhD studies in this area and to report these experiences in detail to facilitate the delivery of quality cancer care to Jordanian adolescents with haematological malignancies.

## **2.7: Context of the interviews**

Data was collected for this study from semi-structured interviews conducted with hospitalised Jordanian adolescents who have haematological malignancies. Due to the sensitive nature of the illness, I was expecting some difficulty in interviewing the adolescents who agreed to participate in this study. Religion posed other challenges for me as a researcher. Islam forbids any physical contact between men and women unless they are closely related. Therefore, caring by a person of the opposite sex is only allowed under certain circumstances (Leavitt, 1999). For example, if no one of the same sex is available and the care and intervention is considered necessary patients can consult health team professionals of the opposite sex. One rule of Islam state that "necessity overrides the prohibition". Therefore, as a male researcher I was expecting to

have some resistance when requesting to interview female adolescents to participate in this study as the findings would have direct benefits for them.

Due to the developmental age of the participants I expected to have some challenges during the interview process. However, I overcome these issues by using the following strategies. I collaborated with a female psychologist and she agreed to be present during each interview which gave the adolescents, particularly female adolescents, comfort and feelings of security. I also welcomed the parents to be present during the interview as well. Lastly, I met with the participants and their families before the interview and explained the objectives of my study and the interview and during this time I established a rapport with them. These strategies allowed me to access the participants' world to obtain the detailed experiences to emerge through the interviews.

### 2.7.1: Characteristics of the participants

Fifteen adolescents, diagnosed with a range of haematological malignancies, participated in this study; their demographic characteristics are shown in the table 4.2. The youngest participants in this study were 13 years old. Only two participants did not attend school and three lived outside of the metropolitan area in the country (see table 2.1).

**Table 2.1:**

Profile of participants

Item	N	%	Item	N	%
<b>Participants' Age</b>			<b>Participants' Diagnosis</b>		
13.00	6	40.0	Hodgkin lymphoma	5	33.3
14.00	2	13.3	Non Hodgkin lymphoma	3	20.0
16.00	3	20.0	Leukaemia	7	46.7
17.00	4	26.7	<b>Participants work</b>		
<b>Gender</b>			Student	13	86.7
Male	9	60.0	Farmer	1	6.7
Female	6	40.0	Electrician	1	6.7

<b>Item</b>	<b>N</b>	<b>%</b>	<b>Item</b>	<b>N</b>	<b>%</b>
<b>Type of Treatments</b>			<b>Parents' Income/ year</b>		
Chemotherapy	15	100	Less than 3000JD	11	73.3
Radiotherapy	0	0	4000-6000 JD	3	20.0
Bone Marrow	0	0	7000-9000 JD	1	6.7
Transplant					

### **2.7.2: Information provided to participants at the first meeting**

During the first meeting I set the scene for each participant in order to illustrate their personal lifeworld. From an interpretative phenomenological analysis point of view, experience means nothing without context, which meant that in order to understand the participants' lived experiences in the analysis process it was necessary for me as a researcher to have access to the participants' lifeworld. By accessing the participants' lifeworld, I was able to reconstruct their experiences in its original terms and was able to go beyond the text and interpret their lived experiences. This occurred because the participants and I were both from Jordan, we speak Arabic, we are Muslims and we belong to the same culture. These basic elements that I shared with them allowed me to build trust and to have access to their lifeworld. I will now provide an overview of each participant to allow readers to share with me the position from which I analysed and interpreted the participants' lived experiences. It is important to mention here that confidentiality was maintained throughout the thesis by using false names or pseudonyms.

#### **2.7.2.1: Nancy**

Nancy was a 17 year old female from a village far away from the capital city of Amman. She was happy with her village life and missed being among her family and friends. Nancy had a happy strong relationship with her family especially her mother. During her hospitalisation she was complaining from homesickness and that she missed her sisters, school, and her friends a lot. When I first met Nancy, she refused to accept that she had cancer and she insisted that it was only blood infection and not leukaemia. Nancy tried to hide her disease from her friends as well. At the time of her second interview, Nancy

had accepted her illness and hoped to return back to her village to see her family and go back to her school (Field note 13, 1<sup>st</sup> December 2009).

#### **2.7.2.2: Abkr**

Abkr was a 16 year old male and he presented as an unhappy and lonely boy who had been diagnosed with leukaemia. He used to live with his family in the gulf area, but after being diagnosed with his illness he had been left in the care of his relatives who lived closer to the hospital. He was not happy with his family decision and wanted their support during this time. He kept refusing the medication and tried to leave hospital twice. At the end he refused treatment as he decided to return back to his family in the gulf area and refused any help from other family members. He did not participate in the second round of interviews as he had already returned to his family when data collection commenced (Field note 25, 1<sup>st</sup> December 2009).

#### **2.7.2.3: Tariq**

Tariq was a 17 year old male who was very independent and had a good sense of humour. All the nurses on the ward were very fond of him and he has many friends of both genders. However, he was not comfortable with his family as he believed that his father did not take care of him as he should have. He believed that his father favoured his siblings over him. However, while he was able to make superficial friendships quickly with new people, he did not trust anyone. Tariq expected that something good will eventually happen with him and finally he fell in love with a girl and he appreciated her support and he wanted to marry her one day (Field note 4, 13<sup>th</sup> December 2009).

#### **2.7.2.4: Shahed**

Shahed is a 16 year old female who was happy and full of energy. Her diagnosis of cancer took a long time when compared to other participants. However, after being diagnosed with cancer she developed new thoughts and new insights to life. She reported that she needed more and more support from her family. She came from a conservative family and her father did not allow her to visit her friends or go outside the home without her little sister (Field note5, 16<sup>th</sup> December 2009).

**2.7.2.5: Haneen**

Haneen a 16 year old female, was a very quiet girl who did not talk much. She was shy of foreigners and she came from a strict conservative family. She did not feel comfortable with her father as she believed that he deprived her of everything that other girls in her age were doing like visiting friends and going out shopping by herself. While Haneen did not like her father's attitude towards her she respected him and did not mention anything that could hurt his feelings (Field note 8, 28<sup>th</sup> December 2009).

**2.7.2.6: Adam**

Adam was a 17 year old male and worked on a farm far away from the city. He was a hard worker before he was diagnosed with Non Hodgkin lymphoma working up to 12 hours per day. He described himself as an easy going person and followed his boss' orders without arguing or questioning him. He was very popular and all of his work mates liked him. Adam fell in love with a girl and he believed his problems resulted from this attraction to this girl. However, after being diagnosed with Non Hodgkin lymphoma, Adam was transferred to a distant hospital outside of his hometown, which made visiting him a difficult task for his family (Field note 10, 4<sup>th</sup> January 2010).

**2.7.2.7: Joseph**

Joseph was a 14 year old male and wanted to enjoy his school days. He liked to play soccer with his friends and was from a well-educated family. Joseph was obsessed with the internet and spent many hours each day surfing the internet enjoying chatting and playing online games. After he was diagnosed with a haematological malignancy, and disclosed his real diagnosis to his friends on the internet, they simply stopped communicating with him. However, he continued to play on his computer. Joseph was also in a state of conflict with his family as they wanted him to be a doctor and he wanted to pursue computer programming as his career. When diagnosed with cancer Joseph stopped going to the school even when his condition became better. He lost trust in his ability and capability to pass the exams and feared about his health (Field note 13, 8<sup>th</sup> January 2010).

**2.7.2.8: Nehal**

Nehal was a 13 year old female and she was diagnosed with leukaemia. She enjoyed school immensely as she had lots of friends and school was very entertaining for her. She came from a very committed religious family. She would wake up every day at early morning to pray with her family “Soubh”. Nehal likes her family very much and played with her siblings and she missed those moments after she was diagnosed with cancer. She particularly enjoyed going on family picnics with her family but now because of her illness she was no longer able to do these enjoyable activities (Field note 25, 8<sup>th</sup> January 2010).

**2.7.2.9: Muhannad**

Muhannad was a 17 year old male diagnosed with leukaemia. He worked as an electrician prior to his illness. His colleague and boss liked him as he worked very hard. His colleague used to call him a devil (that’s means that he used to work very fast and very hard). He also used to smoke heavily and drink a lot of coffee. He came from a loving family and tried to financially support them but his cancer stopped him from doing that. After cancer, he lost his confidence and stopped working or going out because he was scared that his health would deteriorate further (Field note 16, 10<sup>th</sup> January 2010).

**2.7.2.10: Sale**

Sale was a 14 year old female diagnosed with Hodgkin lymphoma. Prior to her illness she used to go to school each day and play with her friends. She also took on the extra task of caring for her younger siblings. Sale and her grandmother thought that she was more beautiful and matured than her friends which made her vulnerable to be envied. Sale lived with her father and her grandmother. Her father and mother separated when she was young. She considers her grandmother as her real mother. After cancer, her mother started to visit her often and she was very happy with this improvement in their relationship (Field note 20, 14<sup>th</sup> January 2010).

**2.7.2.11: Fatima**

Fatima was a 13 year old female diagnosed with leukaemia. She was very happy prior to her illness and went to school each day with her brother. Fatima was fond of camping which she said had a special feeling attached to it. She used to go camping with her family especially the extended family of aunts and uncles (Memo 30, 14<sup>th</sup> January 2010).

**2.7.2.12: Leith**

Leith was a 13 year old female diagnosed with Non Hodgkin lymphoma. Prior to his illness he would go to school every day and after that he used to have lunch and finish his homework. He played soccer in the evening with friends and relatives and this was very important to his life. He had memorised all the names of internationally famous soccer players. However, after he was diagnosed with cancer, he was unable to play sport anymore (Memo 24, 16<sup>th</sup> January 2010).

**2.7.2.13: Hadeel**

Hadeel was a 13 year old female diagnosed with leukaemia. She used to go to school every day and she liked to play with her friends and her sister. She missed this part of her life after she was diagnosed with cancer. Hadeel did not talk too much and following her diagnosis she chose to be even more silent (Memo 27, 21<sup>th</sup> January 2010).

**2.7.2.14: Younis**

Younis was a 13 year old male diagnosed with leukaemia. He lived far away from the hospital in rural area. He went to school every day and enjoyed reading the stories. He wanted to be a doctor like his father when he grew up. During holidays he used to spend a lot of time with his cousins in their house in another city and play soccer with them. However, after cancer he was not sure that he could finish school or study medicine. He was also concerned about his maturation i.e. not having a beard or moustache compared to his friend and this made him unhappy. Younis was looking for more support from his extended family as he used to spend a lot of time with them before he was diagnosed with cancer (Memo 31, 24<sup>th</sup> January 2010).

## **2.8: Summary**

Although Jordanians and non-Jordanian have common experiences regarding health and illness, there is always potential for differences in experiences among people from different cultural backgrounds. This study conducted in Jordan which had different financial, customs, and traditions than Australia. For example, the dominant religion in Jordan is Islam and people in Jordan are proud of their Arabic race. These differences shaped the experiences of Jordanian adolescents and their families along with their responses to illness. In this chapter I provided the reader with a general description of Jordanian demographics and the health care system in Jordan. I also described some aspects of Jordanian religion (Islam) and their customs that may play a role in shaping the adolescent's experiences towards cancer and simultaneously may have affected me as researcher in analysing the data. I provided a brief summary of myself and the participants in this study in order establish the position from which I approached the data. This assists the reader to better understand how data were collected, analysed and interpreted within this study context.

## **CHAPTER 3**

### **RESEARCH METHODOLOGY**

#### **3.1: Introduction**

This chapter describes the methodology used to explore, interpret and document the lived experiences of Jordanian adolescents who have a haematological malignancy. The rationale for using qualitative methodology and specifically for using interpretive phenomenological analysis (IPA), the philosophical assumptions of IPA, a description of IPA and the characteristics of IPA will be detailed in this chapter. Discussion on the continuing critique regarding the use of IPA is also provided. The chapter includes a discussion on ethical considerations, the recruitment of participants and other research issues such as the storage of data and the procedures undertaken to ensure the trustworthiness and rigour of the research process.

#### **3.2: Qualitative research**

The ultimate aim of research is to produce good quality findings that extend knowledge in certain areas irrespective of which research approach is utilised (Chamberlain, 2009; Creswell, 2003; Steckler, 1992). Qualitative researchers aim to explore and document the detailed in-depth experiences of people most commonly elicited from semi-structured interviews conducted with the researcher (Creswell, 1998, 2003; Holloway & Wheeler, 2009; Seale, 1999; Strauss & Corbin, 1998; Stubert-Speziale & Carpenter, 2007). In describing these experiences researchers aim to identify patterns, uncover meanings, and expand knowledge and insight (Given, 2008). Creswell (1998) defined qualitative research as:

An inquiry process of understanding based on distinct methodological traditions of inquiry that explore a social or human problem. The researcher builds a complex, holistic picture, analyses words, reports detailed views of informants, and conducts the study in a natural settings (p.15).

Qualitative research was chosen for this study as it was deemed the most suitable to explore the phenomena under study. In general, this area of research is dominated by quantitative studies and hence there is a need for a qualitative study to explore participants' experiences in this area (Griffiths, 2009). More importantly,

qualitative research has not previously been used within the Jordanian context to describe and explore the experiences of adolescents living with haematological malignancies. Most qualitative research in this area of health was conducted in western countries which have different cultures and health care systems to Jordan. Therefore, a need exists to explore this phenomenon from a Jordanian perspective and to compare the findings with existing knowledge in the area. In this regard, qualitative research was deemed appropriate and useful in adding knowledge and understanding when there is a paucity of information in a particular area (Stubert-Speziale & Carpenter, 2007).

Qualitative research is suitable for use with adolescents as questions which form the basis of the interview can be directed at the developmental level of the participant so that they are able to interpret and understand what is being asked of them (Eiser & Morse, 2001). Eiser and Morse (2001) found that questionnaires used as an instrument to collect data with adolescents are associated with many problems in terms of the adolescent's understanding of the questions and in generating their exact responses. Qualitative methodologies and the interview process enabled me to ask and respond to the participants in a language that was more appropriate to their level of understanding which facilitated the quality of data collected.

In the context of using qualitative research, there is a need for data to be underpinned by a specific framework, in order to provide the study with shape and direction. For ontological and epistemological reasons, the IPA was chosen as the methodology for this study. Interpretive phenomenological analysis is a rigorous, and systematic investigative method used to study human lived experiences within their natural context (Cohen, Kahn, & Steeves, 2000; Mackey, 2005; Morse & Field, 1995; Parse, 2001; Rennie, Watson, & Monteiro, 2002; Stubert-Speziale & Carpenter, 2007; Woodgate, 2001). This methodology will now be discussed in detail.

### **3.3: Phenomenology and nurses**

Historically, many phenomenological research conducted by nurses to address areas of interest. For example, Benner (1994) in his work "Interpretative phenomenology: Embodiment, caring, and Ethics in Health and Illness" mentioned 21 doctoral dissertations that all employed hermeneutic phenomenology to address their areas of interest. In addition, Crotty (1996) critiqued 30 other phenomenological studies

conducted by nurses and not discussed in Benner work. Koch (1995) referred to an additional seven phenomenological research not stated by Crotty and Benner. Carpenter (1995) referred to another 19 studies not mentioned elsewhere. An examples of topics that explored by using phenomenology paradigm are Benner (1985) used a Heideggerian phenomenology to explore the phenomenon of quality of life. Taylor (1991) in his work "The phenomenon of ordinariness in nursing "used"interpretive phenomenology" as described by Heidegger and Gadamer. She described the effects of various aspects of ordinary nursing encounters that enhance nursing and thus make accessible to nurses a deeper understanding of nursing. Osborn (1993) examined the impact of stroke on participant's life by using "Parse's theory" to enhance nurses' understanding of the experiences of patients who suffer from stroke. Contemporary, Hayes (2008) explored the experience of mothering after prison using Interpretative phenomenology and interviewing two participants and follow them for four months. Four themes emerged from this study "always the mother," "separation anxiety," "new demands: divided loyalties," and "the honeymoon is over". Another recent and relevant study is an interpretive phenomenological study used in Australia to explore the lived experiences of adolescents recently diagnosed with cancer, as the authors attempted to make sense of the vulnerabilities and life-threatening component of their illness. Nine families were interviewed twice over a period of 12 month. Five theme were emerged the experience of illness, the upside of being sick, refocusing on what is important, acquiring a new perspective, and the experience of returning to wellbeing (Griffith, 2010). The later research put special emphasise and value to the personal experiences of individuals. In this regard, nursing research pay special attention to phenomenological research for many reasons. In general sense, phenomenological research is important for nurses because nurses are interested in human experiences and IPA is a rigorous, systematic investigative method to study human lived experiences (Speziale & Carpenter, 2007). Phenomenology gives special attention to understand the individual and group of human experiences within it natural settings, which in turn is important to nurses who focus on caring communication and interaction (Cohen, Kahn, & Steeves, 2000). Phenomenological research cares about developing relationship with the participants in the study and nurses-patients relationship is important for nurses (Parse,

2001). This mode of investigation enables nurses to obtain knowledge and better understanding of the human being which may trigger changes in the nurse-patient relationship (Parse, 2001). Nurses and phenomenological research gives special attention to the human beings within their social and cultural context which means more emphasis is placed on the emotions, perceptions and actions of people rather than physiological variables (Parse, 2001). Lastly, phenomenological research and nurses share the elements of commitment, trust, openness and understanding of the human being experiences. Given the researcher interest to study adolescents with haematological malignancies experiences within their social and cultural context interpretive phenomenological analysis deemed to be the most appropriate methodology for this study.

### **3.4: Interpretive phenomenological analysis ontology**

Ontology as a branch of philosophy is devoted to the study of existence and “being” in the lifeworld. The general aim of ontology is to provide a rational, deductive account of the basic essence of the person’s existence (what is being?). Therefore, the ontological question regarding scientific inquiry is to ask about nature and different forms of reality. However, from Heidegger’s perspective (one of the founders of the phenomenological approach), “what is being?” varies according to the frame of meaning within which the query is being held. This means, “being” has no meaning apart from the context that contains it (Given, 2008).

Ontologically, IPA broadly adopts a realist position that assumes a pre-given lifeworld of the individual, group or culture. Therefore, each individual’s lifeworld has distinct characteristics that are rendered unique by its particular context. For example, the lifeworld of adults, is different to that of children (Cohen et al., 2000; Larkin, Watts, & Clifton, 2006; Smith et al., 2009). This current study recognises that each adolescent has, and is contained by, their own lived-experiences resulting from their illness, respective culture and upbringing.

### **3.5: Interpretive phenomenological analysis epistemology**

Epistemology, according to the online Oxford English Dictionary (2011a), is the theory of knowledge. It is concerned with what we know, how we know it and what we regard

as knowledge. In the context of IPA the epistemological question is constrained by the ontological position that researchers adopt (Guba & Lincoln, 1994).

Epistemologically, IPA takes up the phenomenological position that the meaning and nature of reality are dependent upon the human's view of it and their involvement and engagement with it. That is, IPA claims that each person operates from their own reality depending on their context, allowing them to make sense of lived-experiences that shape their lifeworld (Chesla, 1995; Dahlberg, Dahlberg, & Nyström, 2008; Smith et al., 2009). To understand "how people make sense of what happens", researchers try to access the participant's lifeworld. However, it is not possible to do this directly or completely. So, getting closer to the lifeworld relies on, and is complicated by, the researcher's own preconceptions. This suggests that to access and make sense of the lifeworld of others, the researcher must utilise a process of interpretation. Thus, a two-stage interpretation process otherwise known in phenomenology as a double hermeneutic, is involved. These ideas will be further referred to and discussed in a later section of this chapter.

### **3.6: Interpretive phenomenological analysis methodology**

#### **3.6.1: Introduction**

Interpretative phenomenological analysis has as its focus the lived-experiences that are momentous enough to cause the individual to reflect-on-those experiences. That is, the lived-experiences confronted by the individual are difficult, problematic, or perplexing for them (Eatough & Smith, 2008; Smith, 2004; Smith et al., 2009). Interpretative phenomenological analysis as a distinctive step-wise method was first described in 1996 by Jonathan Smith (Smith, 1996; Smith et al., 2009). However, IPA has its foundations within the schools of phenomenology (descriptive and interpretative) and idiography (Cronin-Davis, Bulter, & Mayers, 2009; Eatough & Smith, 2008; Smith, 1996; Smith et al., 2009; Willig & Rogers, 2008).

#### **3.6.2: Descriptive phenomenology**

Phenomenology is a qualitative research method that has its roots in both philosophy and psychology. The aim of phenomenology is to describe the lived experiences of individuals (Koch, 1995; Polit & Beck, 2004; Stubert-Speziale & Carpenter, 2007). The

philosophy behind phenomenology has its origins in the work of Kant, Hegel and René Descartes in the 15th Century (Dahlberg et al., 2008; Mohammadi, 2008). Husserl (1859-1938) first developed phenomenology as an approach to enquiry (Dahlberg et al., 2008; Dowling, 2004; Mohammadi, 2008). His main intention was to find the absolute foundation of all knowledge; in a philosophical sense something called “necessarily true” (Smith, 2007).

Husserl went on to highlight that “nature” and “knowledge of nature” if it is to be understood, requires a notion of certainty, a notion of foundation, a basis on which to develop our sense of causality and understanding of the objects (experiences) around us (Smith, 2007). Husserl was not the first to be concerned about certainty (Smith & Smith, 1995) as Descartes’ philosophy also stood on certainty. He attempted to find certainty through the method of doubt (we should doubt everything until we prove it beyond doubt). Kant also used human scepticism as a way to demonstrate the role of minds and reveal what is necessary for any possible belief to be a true. The latter point is what Husserl was looking for, the basis for his thesis and the basis for all experience. He was looking to establish something that people know with certainty from which they might then prove other knowledge (Smith & Smith, 1995). Later in his philosophy he called the aforementioned point “transcendental ego” (Moran, 2000).

The transcendental ego was an approach that started from what was in consciousness, and then used it as the basis for understanding (Lopez & Willis, 2004; Moran, 2000). Through transcendental ego, Husserl explored the basics in which human consciousness grasps reality by attempting to isolate the process of cognitive functions from empirical data (Moran, 2000). That is, Husserl maintains that what people hold as truth can only be the truth according to what is evident to them. For Husserl truth was derived from intuition and in this way he attempted to explain experiences as they were, without interpretation (Husserl, 1999). Husserl believed that when a person describes phenomena, they not only describes the surface part of the phenomena which could be called a snapshot; they also describes a very complex and interrelated set of concepts. That is, the description of these experiences was built on the experience itself, which renders the experience richer (Husserl, 1999).

To reach such rich description, a person will need to clear their mind, ego and self to achieve understanding, but how? (Dowling, 2004, 2007; Fleming, Gaidys, & Robb, 2003). The solution existed in Husserl's work on "phenomenological reduction" of which he provided two methods. The first method, exhibited in his early work was called "suspension" or "bracketing". He strived to bracket out our common sense in order to achieve understanding of the object (experience) (Husserl, 1999). A common sense of understanding occurs through a process of perception and cognition. As such, the person is able to confirm the reality of their sense. Husserl wants to get rid of such an idea. The point is, whether humans experience through direct observation or by hallucination, is not important and should not affect the experience itself. From Husserl's perspective, when investigators perceive the experience, they should not pay attention to the reality (material existence) of the experience but rather pay attention to the experience itself (Husserl, 1999). Husserl in his subsequent work gave consciousness less attention and moved to more complicated second method of reduction based on transcendental ego which was called eidetic reduction (essence of things) (LeVasseur, 2003; Lopez & Willis, 2004; Mohammadi, 2008; Polit & Beck, 2006).

The idea of eidetic reduction depends on the ability of the individual to evoke their experiences so as to determine the essential characteristics of an object (experience). The essential characteristics are shared between individuals and provide a common understanding of an object (experience). It is these shared understandings that Husserl referred to as "universal essences". What phenomenology attempts to do is to isolate those universal essences (Kearney, 1994; Lopez & Willis, 2004). Therefore, Husserl opens up the possibility of describing and understanding the essences of the lived experiences of humans, without interfering with or being distracted by prior knowledge, culture, religion, society, environment and time. Husserl referred to this as "radical autonomy" (Koch, 1995; LeVasseur, 2003; Omery, 1983; Polit & Beck, 2004; Stubert-Speziale & Carpenter, 2007). By imposing the concept of bracketing and radical autonomy, Husserl was attempting to expose the world of objects (including experience) to a value free and neutral examination (Kearney, 1994; LeVasseur, 2003; Lopez, Sek Ying, Poon, & Wai, 2007).

Husserl's work established for IPA the significance of a focus on the process of reflection through the use of phenomenological principles of reduction (Smith et al., 2009). He established the basic practice principle for the detailed, thoughtful and systematic examination of the content of consciousness'. Reduction, or the attempt at reduction, is considered an integral part of the IPA research process (Smith et al., 2009, p.16). It is important to clarify that IPA did not seek to bracket the researcher's context through the process of understanding lived experiences. Rather, the IPA used the context of the phenomena (object) to reflect on current experiences to make sense of these experiences (Clarke, 2009; Smith et al., 2009).

### **3.6.3. Interpretative phenomenology**

The second influence on IPA came from interpretative phenomenology or hermeneutic. Heidegger (1927/1962), a pupil of Husserl built on and adjusted the work of Husserl by developing a different emphasis in studying life experience. Heidegger aimed to reveal what is conscious and hidden with regards to the lived experiences of people and the relationship between these experiences and their lifeworld (Dowling, 2004). He endeavoured to establish an understanding of the essence of being through shifting the philosophical argument from epistemology to ontology (Dowling, 2007; Kearney, 1994). He attempted to detail how phenomena stand out in lived experience, in the human lifeworld (Van Manen, 1990). Unlike Husserl, Heidegger argued that an understanding of the individual cannot emerge in isolation from the person's context (For a comparison between Husserl and Heidegger phenomenology, see table 3.1 below) (Alasad, 2002; Alasad & Ahmad, 2005; Lopez & Willis, 2004; Packer, 1985; Rice & Ezzy, 1999; Walters, 1995). That is, the lifeworld of people is made up of their background, their pre-understanding, co-constitutions, and interpretations (Koch, 1995). The only way to understand human experiences, is to understand the influence of the lifeworld on people and by surfacing those experiences that generally remain hidden (Lopez & Willis, 2004; Polit & Beck, 2006).

Many other existential phenomenologists shared and supported some of Heidegger's notions. Regarding "being", Sartre agrees with Heidegger that "being" comes before essence (experiences) (Sartre & Elkaim-Sartre, 2007). Regarding "context", Merleau-Ponty, another French existential phenomenological philosopher,

believed in contextualising and situating the phenomena within a certain context and the importance of considering the participant's and the researcher context in order to reach an understanding of the phenomena under study (Smith et al., 2009, p. 18).

Heidegger relied on hermeneutic, which was a theory of interpretation, to explicate the meaning of "being" and described the essences of the human being (Mohammadi, 2008; Smythe, Ironside, Sims, Swenson, & Spence, 2008; Witt & Ploeg, 2006). Hermeneutic, derived from the Greek word Hermes, the Greek God who conveyed messages between Gods and made their messages clear (Lopez & Willis, 2004). Heidegger's hermeneutic stands on two ideas, the hermeneutic circle and "historicality" of understanding (Heidegger, 1962). The hermeneutic circle is a fundamental concept in Heidegger's phenomenology in which he claimed that all persons' understanding is iterative, in the sense that "any interpretation which contributes to the understanding must already understand what is to be interpreted" (Heidegger, 1962, p.194). This means peoples' interpretations must themselves come from prior understanding and interpretation, which Heidegger refer to as "historicality" of the person, in order to generate understanding and knowledge in a reiterative manner. Hermeneutic considered the person's background and language to be key variables in interpreting the phenomena, which meant that a variety of realities could emerge (Alasad, 2002). So, the reality is always subjected to its context and in this regard must be accepted (Lopez & Willis, 2004).

**Table 3.1:**

Comparing and contrasting Husserlian phenomenology and Heideggerian phenomenology (Koch, 1995, p.832).

<b>Husserlian phenomenology</b>	<b>Heideggerian phenomenology</b>
<ul style="list-style-type: none"> <li>• Transcendental phenomenology</li> <li>• Epistemological</li> <li>• Epistemological questions of knowing</li> <li>• How do we know what we know'?</li> <li>• Cartesian duality mind-body split</li> <li>• A mechanistic view of the person</li> </ul>	<ul style="list-style-type: none"> <li>• Philosophical hermeneutics</li> <li>• Hermeneutic phenomenology</li> <li>• Existential-ontological</li> <li>• Questions of experiencing and understanding</li> <li>• What does it mean to be a person?</li> <li>• Dasein</li> <li>• Person as self-interpreting being</li> </ul>

<b>Husserlian phenomenology</b>	<b>Heideggerian phenomenology</b>
<ul style="list-style-type: none"> <li>• Mind-body person lives in a world of objects</li> <li>• Unit of analysis is the meaning giving subject</li> <li>• What is shared is the essence of the conscious mind</li> <li>• Starts with a reflection of mental states</li>   <li>• Meaning is unsullied by the interpreter's own normative goals or view of the world.</li> <li>• Participants' meanings can be reconstituted in interpretive work by insisting that data speak for themselves.</li> <li>• Claim that adequate techniques and procedures</li> <li>• Guarantee validity of interpretation.</li> <li>• Bracketing defends the validity or objectivity of the interpretation against self-interest.</li> </ul>	<ul style="list-style-type: none"> <li>• Person exists as a "being" in and of the world</li> <li>• Unit of analysis is the transaction between the situation and the person.</li> <li>• What is shared is culture, history, practice, language.</li> <li>• We are already in the world in our pre-reflective selves.</li> <li>• Interpreters participate in making data.</li>   <li>• Within the fore-structure of understanding interpretation can only make explicit what is already understood</li> <li>• Establish own criteria for trustworthiness of research</li>   <li>• The hermeneutic circle (background, co- constitution pre-understanding).</li> </ul>

Gadamer, (1960/1990) a student of Heidegger, in his classical work "truth and method" identified the idea of "historicality" and moved Heidegger's work forward (Gadamer, Weinsheimer, & Marshall, 2004). Gadamer gave special attention to the individual's history so as to interpret their current experiences. He used the concept of "pre-judgments" which result from one's past history. Pre-judgments mean the preliminary concepts and prejudices that people hold within themselves. These prejudices and preliminary concepts make understanding possible (Dowling, 2007; Gadamer et al., 2004). Furthermore, Gadamer emphasised that the common human consciousness existing between individuals who communicate, and individuals who understand, play an important role in making understanding relatively possible. He called this common human consciousness "universality" (Dowling, 2004, 2007; Gadamer et al., 2004). Therefore, following in Heidegger's footsteps, Gadamer, refuted Husserl's notion of bracketing as he based his way of understanding on "pre-judgments" and "universality" (Gadamer, 2004).

Gadamer modified and developed Heidegger's concept of the hermeneutic. Heidegger's notion of understanding was based on assuming a direct relationship between the reader and the author without giving the text considerable attention. However, Gadamer claimed that the relationship should be between the reader and the text, as the text would reflect the author's view. In this sense, the hermeneutic circle consisted of a dialogue between the reader and parts of the text to reach an understanding (Stubert-Speziale & Carpenter, 2007). The basic premise underlying the hermeneutic cycle is that the whole depends on the part and the parts depend on the whole (Smith et al., 2009). For example, when someone approaches any text, they bring with them their prejudice or preliminary knowledge that they already have gained through their past and present experiences. As soon as they start reading the first sentence of the paragraph in the text, they start forming a general opinion regarding the whole text based on their preliminary concept. As they continue reading through the text, they keep referring to the preliminary ideas held in consciousness. This means, the reader moves back and forth between the text and the prejudices they have with regard to the general opinion they formed at the beginning of reading the text. Therefore, a process of actions and interactions occur during this active process which amplifies understanding. Hence, and in the phenomenological sense, the hermeneutics cycle represented a process of data analysis that progressed from a position of unsophisticated understanding towards one of increasing sophistication in an iterative manner (Stubert-Speziale & Carpenter, 2007).

Hermeneutic phenomenology describes not only the apparent experiences, but also describes the interactions and reactions of humans, and the possible explanations of their behaviours in response to their lifeworld. Therefore, Heidegger's and Gadamer's hermeneutic adds the possibility of both describing and understanding the human experience (Polit & Beck, 2006; Stubert-Speziale & Carpenter, 2007). Hermeneutic phenomenology as a tool aims to "bridge the gap between what is familiar in our worlds and what is unfamiliar" (Stubert-Speziale & Carpenter, 2007, p.88).

Hermeneutics influenced IPA and it took the methodology to the next level of interpretation and provided it with a systematic approach and a rational way of thinking (Finlay & Gough, 2003; Smith et al., 2009). The notion in hermeneutic, of moving

between the part and the whole in an iterative manner in order to achieve a sophisticated understanding allows for the IPA researcher to analyse the data in an iterative way. The researchers interpret the data in a variety of ways each time they revisit the transcription. This means an evolution of new ideas by frequently moving backward and forwards within subsequent texts.

#### **3.6.4. Idiography**

The third approach influencing IPA is the Idiographic approach. The term “idiographic” comes from the Greek word “idios” meaning “own” or “private”. “It is concerned with the particular” (Smith et al., 2009, p. 29). It focuses on the unique characteristic of people, rather than on broad generalisations about people’s behaviour. This way of investigation opposes the nomothetic method which has been widely adopted by psychology. However, psychologists are concerned with the particular aspect of experience to figure out what makes each individual distinct from the other (Lyons & Coyle, 2007).

In the nomothetic approach, researchers recruit a sample and perform the analysis at the level of the group to reach to a conclusion and then generalise their findings to the population. However, this is not the case in idiography. The researchers investigate the individual case and provide detailed findings regarding this case in order to obtain valid explanatory knowledge (Lyons & Coyle, 2007; Smith et al., 2009; Tsoukas, 1989).

In this context, idiography, as an approach, influenced IPA in two ways. Interpretive phenomenological analysis researchers pledged to detail the particular experiences of single individuals, which enriched and add meaning to the analysis. Interpretive phenomenological analysis also pledges to understand particular people’s experiences within their particular cultural context (Smith et al., 2009; Willig & Rogers, 2008).

### **3.7: A description of interpretive phenomenological analysis**

In general, IPA can be described in three parts: idiographic, inductive and interrogative (Smith, 2004). Interpretative phenomenological analysis agrees with idiography in “situating the participant in their particular contexts, exploring their personal

perspectives, and start with a detailed examination of each case before moving to more general claims” (Smith et al., 2009, p. 32). In his original work Smith et al. (2009) referred to participants as “cases” and as such I have followed this term and used “cases” as a synonym to “participant’s interviews” in this chapter. The essence of IPA, as a methodology, is to allow participants to tell their own story, in their own words, about the topic under study rather than following a predefined structure system. In order to understand the lived experiences of individuals, researchers should analyse and operate a cautious examination of the individual’s cases, one by one. Following this, the researcher then carefully carries out an analysis across all cases of those lived experiences. By following the previous steps, the researchers preserve the particular participant’s experiences and at the same time allow for new themes to emerge from all the shared individual experiences of the participants (Smith, 2004). According to Schleiermacher and Bowie (Schleiermacher & Bowie, 1998) “everyone carries a minimum of everyone else within himself” (p. 92-93). In this regard, it is important to stress here that the main concern of IPA is to take the interpretation as far as possible but not to create a generalised objective description (Lyons & Coyle, 2007; Smith et al., 2009).

Secondly, IPA is inductive as are all other qualitative research methodologies and researchers utilise methods that are flexible to allow for unexpected experiences to emerge during analysis (Willig, 2001). The researchers do not try to ask specific questions or details about the participants’ experiences on the basis of the current literature but build broader research questions which lead to the collection of detailed data. Therefore, unexpected phenomena are able to emerge during this analysis. For example, I was not aware of, and current literature did not address, the impact of chemotherapy on adolescents “developing gender identity” and how it affected their life after being diagnosed with a haematological malignancy. Participants talked about it with me during their interviews and attributed the threat to their developing gender identity as a significant impact that their chemotherapy treatment had on them. However, this experience emerged because I used broad questions and hermeneutics (see Appendix III) (Smith, 2004).

Interpretative phenomenological analysis school agrees with Heidegger and his followers, regarding the use “hermeneutic” as a method of interpretation. From Heidegger’s perspective, there is always an experience ready to represent itself but it needs deductive skills to extrapolate the experience and enable it to make sense. Therefore, the researcher plays an important and active role in IPA by interpreting participants’ experiences. Likewise participants need to detail their experiences to facilitate the role and the ability of the researcher to make these interpretations. In this context, the relationship between the researcher and participant are dynamic. In a phenomenological sense, individuals are attempting to make sense of their personal and social experiences. Similarly, the researcher, attempts to make sense of the individuals attempting to make sense of their personal and social worlds, which is called in IPA a double hermeneutic (Smith, 2004; Smith et al., 2009). As such, the researcher has two paradoxical duties. The researcher tries to engage in the participants’ lifeworld in order to make sense of their lived experiences. However, the researcher is not a participant and can only experience the phenomena through the participants’ descriptions which filtered and understood through the researcher’s preliminary notions that are already held in their consciousness. Therefore, for the researcher the participants’ understanding comes first followed by their interpretation to make sense of the lived experiences (Lyons & Coyle, 2007; Smith et al., 2009). Another application of double hermeneutic relates to the researcher’s need to adopt “hermeneutic of empathy” and “hermeneutic of suspicion” at the same time. This means that the researcher needs to be empathetic with participants to obtain their experiences in their own language and terms and finally to adopt their positions in interpretations of data. At the same time, the researcher needs to be suspicious in order to view the phenomena from outside and therefore, understand it from a different angle by challenging and questioning participants’ experiences. In this way, the researcher moves from the surface experiences to a deeper analysis in terms of understanding (Smith et al., 2009).

Lastly, IPA is interrogative in nature as it aims to expand and build on the current body of knowledge. Although IPA provides in-depth analysis of the experiences of a small number of individuals, the result can be discussed in relation to the global literature in the area of research (Smith, 2004).

### **3.8: Data collection**

The data collection methods for this study used in-depth semi structured interviews, field notes and a demographic questionnaire.

#### **3.8.1: Demographic questionnaire**

One demographic questionnaire was given to each participant before the interview commenced. The information collected about the participant included, for example, gender, age, modes of treatment being used, patient diagnosis, and the parent's income (see Appendix II).

#### **3.8.2: Semi structure interviews**

As the most popular data collection method in IPA is in-depth semi-structured interviews (Clarke, 2009; Cronin-Davis et al., 2009; Reid, Flowers, & Larkin, 2005), audio-taped, in-depth, semi-structured interviews were recorded using a USB recorder with each of the study participants. The aim of the interviews was to explore the complex phenomenon that cannot be elicited and studied using positivist methodologies (Rice & Ezzy, 1999; Stubert-Speziale & Carpenter, 2007). Furthermore, according to Smith et al. (2009) the use of "semi-structured interviews facilitates rapport, empathy and permits great flexibility of coverage" ( p. 66).

The interviews were completed in Jordan between November 2009 and April 2010. The time taken for each interview was, on average, 75 minutes. A total of 27 interviews were conducted and, except on two occasions, each participant was interviewed twice. One participant withdrew from the second interview and another asked to withdraw from the study completely, and to omit his first interview, which the researcher did (see table 3.1). All interviews were conducted in a private, mutually agreed upon location with adequate lighting and acoustics distance at KHCC and Al-Basher Hospital. In KHCC, interviews took place in the family planning room on the 5<sup>th</sup> floor, which was allocated for the purpose of this research. In Al-Basher hospital, the researcher interviewed the participants in their own rooms.

The interview process was clearly explained to the participants, as previously stated, prior to starting the interview. I sat with each participant for 30 minutes or so

prior to commencing the interview to establish rapport, to answer questions about the study, and to allow the participant time to complete the demographic questionnaire.

During the interview, I portrayed a professional, engaging communication style, which Smith, et al. (2009) identified as an important part of the data collection process. Furthermore, these authors advised the researcher to actively listen to the participants and give them enough time to respond completely to each of the questions during the interview. Smith et al (2009) reinforced that participants should be allowed to answer one question at a time to eliminate confusion and to allow the participant to relax in telling their story. Allowing the participant to answer one question at a time gave them time to assimilate the entire question at a single point of time. To ensure a smooth flow of the interview, I provided each participant with a notebook to write down their own thoughts and ideas that arose during the interview, which they could refer to later in their conversation with me as the researcher.

Prior to commencing the interviews I received some training in conducting interviews from my supervisor who is a counsellor and expert nurse. I started each interview by asking a broad general open-ended question to keep with the inductive nature of IPA and to create an environment where participants were able to talk about their important lived-experience; for example, “Can you start by telling me a little about yourself after being diagnosed with cancer” in order to encourage participants to speak, which is congruent with the inductive nature of the IPA. When the participants reached a certain level of comfort in speaking with me I was able to relax more and sit back and listen to the story they were telling. I utilised a set of pre-set topics as a guiding tool throughout the interview (see Appendix III).

Participants were interviewed on two occasions for this study 1) within three months of the diagnosis and 2) three months following the first interview. I chose these two points as the first point in time (first three months of diagnosis) captured the immediate experiences of the participants with haematological malignancies and the early part of the adaptation of the participants after they were diagnosed with a haematological malignancy. The second point in time (three months post the first meeting) captured later experiences and adaptation, during which adolescents attempted to carry out self-care strategies related to their illness (Hinds et al., 1999; Williamson et

al., 2010). The researcher who is fluent in Arabic conducted all the interviews in this language format as all participants spoke this language.

**Table 3.2:**

Interviewees

Pseudonym	Interview 1	Interview 2
Nancy	√	√
Abkr	√	.....
Tariq	√	√
Shahed	√	√
Haneen	√	√
Adam	√	√
Joseph	√	√
Nehal	√	√
Muhannad	√	√
Sale	√	√
*Osama	.....	.....
Hadeel	√	√
Younis	√	√
Nancy	√	√
Abkr	√	.....

\* Osama withdraw from the study completely and ask to delete his first interview

### 3.8.3: Field notes:

Field notes are an important data source in qualitative studies and are similar to a personal journal for the researcher that includes all the information obtained during the interviews that an audiotape recorder is unable to capture (Given, 2008; Groenewald, 2004; Mulhall, 2003; Stubert-Speziale & Carpenter, 2007). For example, field notes may capture the interview atmosphere, participants' dress, demeanour and facial gestures or expression. They also capture the researcher's impressions, assumptions, and feelings during and following the interview (Groenewald, 2004; Mack, Woodson, MacQueen, Guest, & Namy, 2005; Polit & Beck, 2006). Glaser and Strauss (1967, p.226) noted the importance of fieldwork and the resulting documentation, claiming it provided "real life character". Field notes were used to augment and enhance the

understanding of the interview data (Rice & Ezzy, 1999; Stubert-Speziale & Carpenter, 2007). During the interview, I also documented participants' paralinguistics resulting from the questions asked. For example, I documented their emotions and body reactions to certain questions since USB recorder was unable to depict these reactions.

Furthermore, after the interview, I documented my observations and feelings about each interview process and outcome. The following is an example of a memo made after an interview with one participant:

The interview with this participant is different from all other interviews I have conducted as the participant did not appear to feel the direct impact and the reality of having cancer to the same extent as other participants. This may have occurred because he was enjoying the sudden change of his family attitude towards him. He had now become a source of his family's attention which he had not previously experienced. Of course this does not mean that this adolescent was not aware of the true diagnosis of his illness or was not suffering from the symptoms. What is interesting here is how the illness can strengthen family bonds and relationships even during times of stress such as experience when a family member is diagnosed with cancer (Field note 20, 8<sup>th</sup> January, 2010).

### **3.9: Selection of participants**

#### **3.9.1: Sampling**

With IPA roots in idiography the aim of the methodology is to generate detailed in-depth descriptions of individual experiences to facilitate understanding of the lived-experiences of participants under study. Hence, as suggested in this chapter, the focus of IPA is theoretical transferability rather than empirical generalisability (Smith et al., 2009). Therefore, IPA advocates small sample sizes that are homogeneous and purposeful as a small sample size can provide a sufficient perspective given adequate contextualisation and hence IPA does not require data saturation (Clarke, 2009; Coyne, 1997; Miles & Huberman, 1994; Reid et al., 2005; Smith & Osborn, 2003). Smith (1999) argues that "from an idiographic perspective, it is important to find levels of analysis which enable us to see patterns across case studies while still recognising the particularities of the individual lives from which those patterns emerge" (p. 424). Congruent with this goal, a homogeneous purposive sample (Clarke, 2009; Coyne, 1997; Miles & Huberman, 1994) was used to explore and describe the experiences of Jordanian adolescents living with haematological malignancies. The final sample size

was of 14 participants, which is considered sufficient to conduct an IPA study (Beanland, Schneider, LoBiondo-wood, & Harber, 2000; Clarke, 2009; Polit & Beck, 2006; Reid et al., 2005; Smith et al., 2009).

The following inclusion criteria were applied to the participants who were:

- Diagnosed with leukaemia, Hodgkin’s lymphoma, or non Hodgkin’s lymphoma.
- Received the diagnosis within three months prior to the day of the first interview.
- Aware of their diagnosis before the interview.
- Aged between 13 and 17 years of age.
- Able to communicate in the Arabic language because as the “interpreter” of their stories I need to share culture understanding with the adolescents in order to enter to their lifeworld.
- From Jordan.
- Did not have a mental or physical condition that affected their ability to understand the researcher’s questions or to express their experiences of living with a haematological malignancy.
- Gave informed consent and were accepting of being interviewed by a male researcher.
- Received their formal treatment for their illness at either in KHCC or Al-Basher hospital.

### **3.9.2: Setting**

The participants were recruited from the following hospitals in Jordan: (1) King Hussein Cancer Center, the largest cancer institute in Jordan and, (2) Al Bashir Hospital, which is one of the largest governmental hospitals in Jordan. These hospitals were located within a radius of 12 Km from each other in Amman, the capital of Jordan.

King Hussein Cancer Center (KHCC) opened in 1997 and it is one of the most advanced specialised medical centers, that provides holistic cancer care. KHCC consists of 370 beds and is the first hospital in Jordan to obtain the Joint Commission Accreditation (JCIA) and the first Center outside the United States of America (USA) to have Disease Specific Accreditation which recognise the Center as specialised in

cancer care. KHCC health team members received direct support from the national cancer institute in the United States (NCI) and special training was provided for them in the USA and in Europe. Finally, Jordanians and Arabs from other Middle Eastern countries afflicted with cancer seek specialised treatment at KHCC.

Al-Bashir Hospital is considered one of the largest, busiest and oldest governmental hospitals in Jordan. It was established in 1954 and has approximately 950 beds. In 2009, around 76,000 people were admitted to the hospital. Al-Basher is considered as the primary referral hospital and accepts patients from all other governmental hospitals in Jordan.

### **3.10: Recruitment of participants**

In KHCC, as a part of their regulation and rules, hospital administrators assigned a paediatric psychologist as a research assistant to assist me in the data collection for this study. The main responsibility of the research assistant was to independently recruit participants to the study who met the inclusion criteria and agreed to participate. She also established communication with participants' parents either personally or via telephone to ask their permission for their son or daughter to take part in this study. The information provided during this initial stage was taken from the information sheet and covered the purpose of the study along with the perceived benefits to patients and their families (see Appendix IV, V, VI, and VII). When I met with potential participants and their parents, I again explained the objectives of the study and took time to answer any questions they had. Consent forms were also signed at this time if the adolescent and their family agreed to participate in the study (see Appendix VIII, IX, and XI).

In Al-Bashir hospital, I recruited participants by distributing flyers and attaching flyers to the patient's notice board at the hospital (see Appendix I). Another way of recruitment was with the help of staff. I conducted meetings with the staff and the nurse in-charge of the Haematological unit and explained the study and inclusion criteria for recruiting participants. The in-charge nurse and staff nurses in turn identified potential participants and their respective contact information after gaining permission to do so from the potential participants. I then contacted the potential participants and their parents and explained the research and its aim to them in more detail and provided them with an information sheet. I also gave them my contact details and asked them to

contact me if they were interested in participating. For participants who were already admitted in the hospital, I introduced myself to them and their parents. I handed them the information sheet and asked them to call me if they wished to join this research. The interested participants and their parents contacted me and agreed to further meetings to discuss the study and sign the consent form.

All potential participants were given detailed information sheets about the study which along with the consent form which were in Arabic. Prior to being used the Arabic version of the consent forms and information sheet was edited and approved by KHCC and Al-Basher ethics committee (see Appendix XIII and XIV).

### **3.11: Data analysis: Interpretive phenomenological analysis method**

The purpose of data analysis in the IPA is to conserve the uniqueness of each lived experience of the phenomenon, while permitting an understanding of the meaning of the phenomenon from the shared individual experiences (Banonis, 1989; Smith, 2004). When researchers using IPA access the data, they should keep in mind two main objectives. First, to gain access to the participant's lifeworld, in order to understand their individual experiences of a specific event, process and relationship. Secondly, the researcher should aim to achieve an interpretation of the data that places the original description in its wider social and cultural context (Larkin et al., 2006). In the context of interpretation, an IPA emerges to answer critical questions from participant's transcripts such as, "What is the person trying to achieve here?"; "Is some information leaking out here that was not intended?"; "Is there any reality for this participant beyond the bounds of the interview situation?" (Langdrige, 2007; Pringle, Drummond, McLafferty, & Hendry, 2011).

In this current study, data were transcribed verbatim in Arabic by the researcher soon after each of the interviews was conducted. These interviews were then reviewed for accuracy, by the researcher, against the original data recording. The data, questions, interviews and field notes were translated into English by an independent professional translator in order for the researcher to analyse them accurately and for supervisor check of analysis. Back translations (from English to Arabic) were also conducted to ensure that the data did not lose its richness and meaning (Beaton, Bombardier, Guillemin, & Ferraz, 2000; Chapman & Carter, 1979; Del Greco, Walop, & Eastridge,

1987; Sperber, 2004; Sperber, Devellis, & Boehlecke, 1994). The data were managed using ©QSR NVivo8 software. Data analysis was facilitated through the use of the method of IPA described by Smith et al. (2009). This included a six stage process:

**1. Reading and re-reading phase:** I read the transcripts several times while listening to the recorded interviews. This data was reviewed alongside field notes portraying the interviewee's reactions and emotions. This allowed access to an enriched understanding of the participant's experiences. These processes ensured that the participants became the focus of the analysis, and that I was able to immerse myself in the participant's story. At this stage I imported the transcripts into ©QSR NVivo 8 to analyse them. This program is designed to help users organise and analyse non-numerical or unstructured data such as audio and video. This program allowed me to manage, explore, and search documents; link ideas, and generate reports from the data.

**2. Initial noting phase:** I started reading through the text and recorded the initial notes as a memo in ©QSRNVivo 8 program. The notes were basically descriptive in nature, linguistic comments and conceptual comments. It also consisted of my documented thoughts, emotions, observations and questions about the text. The purpose of this step was to allow more engagement with the data in order to familiarise myself with the participant's thoughts and their reactions to the phenomena under study.

**3. Developing emergent themes:** When I finished the initial noting phase from the first case, I had to shift my focus from the transcript to the notes I had made about the transcript from the first case. Analysing these notes allowed me to begin surfacing the emerging sub-themes, while still preserving the complexity of the original notes. Again I used ©QSR NVivo 8 program, and coded the data as free nodes.

**4. Searching for connections across emergent themes:** During this stage, sub themes were further refined using strategies such as abstraction, subsumption, and polarization.

**Abstraction:** is a basic process of identifying patterns between evolving themes and grouping like data together in that theme. For example, table 3.3 shows how "The changing self" becomes a sub theme and brings together the emerging sub-themes.

**Table 3.3:**

Abstraction leading to the development of sub themes

---

**The changing self**

- Low physical activity after being diagnosed with cancer.
  - Their general shape began to change after chemotherapy.
  - Face began to change after chemotherapy.
  - Hair began to fall out after chemotherapy.
  - Acceleration in growth due to cortisone.
  - Low self-esteem after cancer.
  - Loss of future.
  - Losing my gender identity.
- 

**Subsumption:** This analytic procedure is similar to abstraction but it revolves where an emergent theme itself acquires a theme as it helps bring together a set of related sub themes. Table 3.4 shows how “Silence of HM” becomes a theme and brings together a set of clearly related sub themes.

**Table 3.4:**

Subsumption leading to the development of super ordinate theme

---

**Silence of HM**

- Surrounded by silence
  - Confusing the silence
  - Trying to make sense of what is happening in the presence of the silence
  - When communication resumed
- 

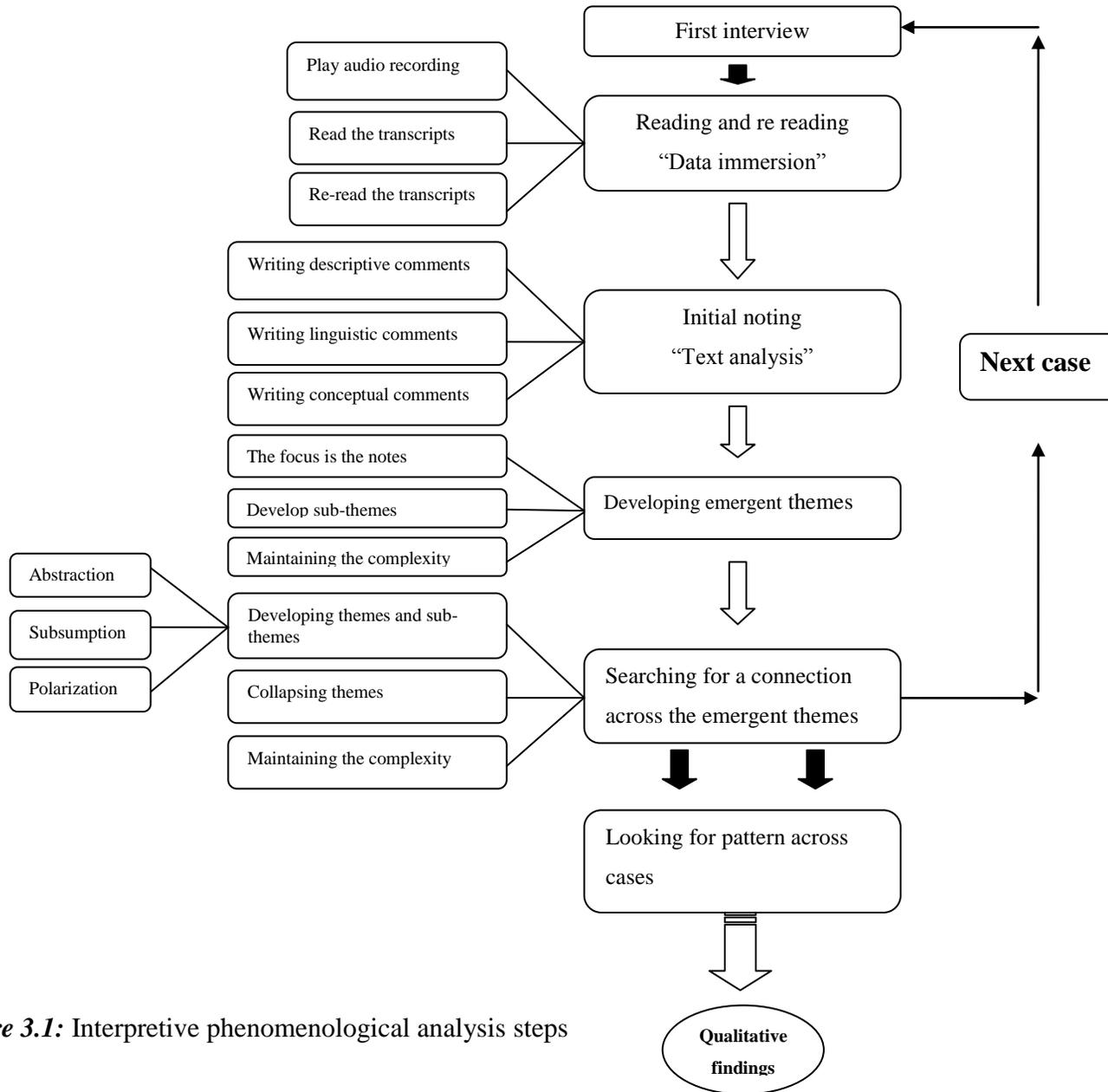
**Polarization:** It examines transcripts for the contrary relationships between emergent themes by focusing on differences instead of similarities. Although participants in this current study had negative experiences due to chemotherapy, there were other experiences elsewhere which articulated some new positive experiences that resulted from cancer. For example, because of the cancer journey and its associated difficulties, participant’s re-evaluated their current relationships and adopting new values to choose their friends based on quality rather than quantity.

In NVivo terminology, free nodes were also further refined. Practically, in this step, I searched for a connection across the emerging sub-themes (referred to as

clusters). The clusters were given labels which depicted their meaning and in NVivo terminology is referred to as the generation of “tree nodes”. Therefore, free nodes were collapsed into tree nodes, while maintaining the complexity of the relationships between the major themes.

**5. Moving to the next case:** The next step was to move to the next participant’s interview and repeat the previous process.

**6. Bringing the themes together:** The final phase entailed bringing all the themes that were formulated for each case in stage four together in order to determine patterns across cases. I identified the similarities and differences between the collected themes. The idiographic nature of the interpretative phenomenological analysis highlights the importance of ensuring the sub-themes are not subsumed without first ensuring that the experience being described is not lost. All the free node and tree nodes were printed out and further clustering of the data was conducted. The diagram in figure 3.1 summarises this process.



**Figure 3.1:** Interpretive phenomenological analysis steps

### **3.12: Writing the interpretive phenomenological analysis study**

When the researcher finished analysing each interview and then all interviews the process of describing and interpreting the lived experiences of adolescents with a haematological malignancy continued. In writing this study, a high percentage of direct quotes from interviewees have been incorporated to provide rich descriptions. Inclusion of these experiences assisted the researcher to descriptively clarify variations of the themes and sub-themes used in the study.

In documenting the experiences attained from the participants in this study the following procedure was followed:

1. For each quote by a participant documented in this study the participant's pseudonym, age, and number of interview is recorded, for example, Tariq 17 year old, Interview 1.
2. For each field note the number and date is recorded, for example, Field note 1, 20th January 2010.
3. Major conceptual terms used in the study were placed in italics.
4. Square brackets [ ] were used in direct quotes when additional information was added by the researcher to clarify or add meaning.
5. Two enclosing brackets ( ) were used to represent non-language responses, such as (chuckles).

### **3.13: Critique of interpretive phenomenological analysis**

Interpretive phenomenological analysis is increasingly being used by health researchers as an approach of inquiry due to its accessibility, flexibility and applicability. Due to the hermeneutic nature of the IPA it allows the researcher to interpret the data according to their backgrounds (i.e. their culture, language) (Cronin-Davis et al., 2009; Larkin et al., 2006; Smith et al., 2009). Within the flexibility, the hermeneutic and inductive nature of IPA there is a great chance for phenomena to emerge that might not be expected or presented in the existing literature. The idiographic nature of IPA has the ability to obtain particular experiences that are distinctive to individuals as well as to

procure the shared experiences across a sample of participants. Hence, IPA is capable of finding shared and unshared lived experiences (Griffiths, 2009; Smith et al., 2009).

Despite the small sample size advocated by the IPA methodology, it is capable of providing detailed and rich descriptions of phenomena, which cannot be achieved with larger sample sizes (Yardley, 2000). Collins and Nicolson (2002) stated that “IPA is not intended to analyse large data as potentially subtle inflections of meaning may be lost in the analytical process of coding large swathes of transcribed interview data” (p.226). Furthermore, due to the iterative nature of the IPA in analysing the phenomena, researchers, who analyse the data may find it difficult to reach a definite end point to their analysis. For example, I was always preoccupied with the idea about when stop the data analysis. For each interaction the possibility of interpreting the data from a slightly different perspective presented itself. This was compounded by my supervisors’ involvement in reviewing the data and my analysis. In my case, I first interpreted the data, and then both my supervisors reviewed the data to validate my interpretation. Each time the data was reviewed the possibility of a new interpretation arose, which is in keeping with the hermeneutic nature of the IPA. The end point of this study was when the story was rich and dense and all the themes are well described and the final report documented the individual and shared experiences of adolescents with HM. I discussed this end point with my supervisors and joint decision was made.

Moreover, the IPA argues that the researchers need to have access to the participant’s lifeworld and stand in their shoes to understand their experiences. That is, IPA advocates that the experiences emerging through IPA is a result of the double hermeneutic and a co-construction between the researcher and participants. In reality, this may not be attainable because the researchers and participants do not share the same lifeworld (Cronin-Davis et al., 2009). As such, even though particular lifeworld are not shared, there are common understandings about structures and experiences that allow the researcher to represent the lifeworld of the participants (Cronin-Davis et al., 2009). In this case, the role of the researcher is to seek these points of common understanding in order to make sense of and present the experiences that derive from the data of this study. In this regard, the researchers should adopt an empathic position as previously identified in this chapter. To achieve this end, the researcher must always

be aware of the content of their consciousness, which is not an easy task as it requires a lot of training and attention.

### **3.14: Trustworthiness of findings**

Many approaches have been developed to increase the trustworthiness of the data in qualitative research (Brocki & Wearden, 2006; Creswell & Miller, 2000; Defeng, 2004; Dorothy, 2003; Elliott, Fischer, & Rennie, 1999; Koch, 2006; Lietz, Langer, & Furman, 2006; Lincoln & Guba, 1985; Madill et al., 2000; Mathison, 1988; Sandelowski, 1986; Smith et al., 2009; Yardley, 2000), however, some of these approaches contradict the underlying epistemology of an IPA (Witt & Ploeg, 2006). Therefore, I used a number of approaches that did not generate this contradiction. In this study, the researcher used the guidelines recommended by Cronin-Davis et al. (2009) Elliott et al. (1999) Smith et al. (2009) and Yardley (2000) to ensure the trustworthiness and quality of findings.

The first approach utilised to enhance the trustworthiness of this study was by employing “triangulation”. Although there are many descriptions of triangulation within the literature, triangulation within this study means the use of multiple data sources, multiple methods, and different researchers to draw conclusions about what represents the truth (Elliott et al., 1999; Harman & Clare, 2006; Mathison, 1988; Robinson, Clare, & Evans, 2005). I triangulated on the different data collection sources; that is, demographic questionnaires, field notes, and interviews. Furthermore, I conducted the interviews in two different settings at two different points of time, with different participants, to further triangulate in place person and time. I also triangulate on the data analysis independently by using two different investigators (myself, and my supervisor) to analyse a random selection of transcripts. This analysis increased the trustworthiness of the findings and allowed me to discuss and identify the similarities and differences in the data.

The second approach to enhance trustworthiness was by “audit trails” or “thick description” or “the independent audit” of the research process and findings (Curtin & Fossey, 2007; Lincoln & Guba, 1985; Smith et al., 2009). The methodology section in this study was detailed so as to clearly articulate the reasons for using qualitative research, in general and IPA in particular. Furthermore, I explained the IPA methodology in detail as I did the process of data collection and analysis. I made

detailed descriptions in order to allow subsequent researchers to be able to follow the process that would lead to similar results. Particularly, my supervisors were able to follow and validate each step taken.

The third approach used to enhance trustworthiness was a combination of two approaches, which are “owning one’s perspective” and “situating the sample” (Elliott et al., 1999). It is important for researchers to demonstrate their own positioning regarding the research and data analysis because the outcomes of analysis result from a process of interaction between the researchers and the social and historical context and the text, which represent the participants’ experience. Therefore, in this study, I as the researcher, in chapter two of this thesis set the context of the study by describing myself and my stance, as well as my background, to inform the readers about the perspectives from which I interpreted the data. Furthermore, I gave a detailed demographic description (age, gender, level of education, the total income/year, diagnosis, and type of treatments) of the participants in the study and provided a general brief description about each participant. Providing this description assists the reader to better understand how data has been analysed and interpreted within this study.

The last approach that I followed, to enhance trustworthiness, was by “grounding in examples” (Elliott et al., 1999). That is, I supported each theme and sub-theme in this current study using exemplars. For example, in the sub-theme “The changing self” I provided the following exemplar to illustrate this sub-theme:

I used to not wear a Hijab before my sickness but now I wear it all the time. Sometimes I was wearing a pyjama, blouse and jeans while making my rounds to see my friends. The nurses were laughing at me and at my appearance as I looked funny, it was really funny. My hair was long and I was pretty, not like now. I do not have any hair and my shape has changed. I was beautiful [before I became ill]. ... Compared to what I looked like before I am not that beautiful [now]. (Shahed 16 year old, Interview 2)

Elliott et al., (1999) suggests that using this technique allows the reader to compare the exemplars (data) and the researcher’s understanding of them. All of the above methods contributed to the rigour of this research and, ultimately, enabled the results to be transferred to other Jordanian adolescent patients in similar contexts.

### **3.15: Ethical considerations**

Prior to the commencement of this study, permission was obtained after evidence was presented that the study met the research guidelines set down by the National Health and Medical Research Council (NH&MRC) (2007) of Australia from Curtin University Human Research Ethics Committee and the hospitals' ethics committees and executive officers. The study was approved by Curtin University Human Research Ethics Committee on 7<sup>th</sup> of October, 2009 (No. HR109/2009) (see Appendix XII ). Prior to submitting the proposal to the ethics committee in Al Basher hospital, I met with the members of Al Basher Ethical Committee and they requested that I contact the central human resources unit in Amman, as it was the responsible authoritative body that provided the ethical approvals for all governmental hospitals in Jordan. The study was approved on 15<sup>th</sup> December, 2009 from Al Basher Hospital Ethics Committee (No. 17434) (see appendix XIII).

A similar process ensured for KHCC. The researcher met with the chairman of the institutional board. As a part of the ethical approval, the institutional board asked me to complete an online course in ethics to demonstrate my ability to preserve human rights. I attended this course and successfully completed it (certificate No. 267109) (see Appendix X). Furthermore, the institutional board assigned a psychologist, working in KHCC with children, to be a research assistant as previously mentioned in this chapter. The psychologist also worked with me to ensure participants psychological well-being during the interview, and to monitor my activity during the data collection. I obtained the final ethical approval from the institutional board in KHCC on 21<sup>st</sup> of November, 2009 (No. 09 KHCC 56). Data collection took place between 1<sup>st</sup> December, 2009 and 29<sup>th</sup> April 2010. The major aspects of the ethical considerations that influenced the research process follows.

### **3.15.1: Informed consent**

One voluntary consent form was given to the adolescent and their parents to sign when they agreed to participate in this study (NH&MRC, 2007) (see Appendix VIII, IX and XI). The adolescents and their parents were reassured that even if they declined to participate in the study, their care in the hospital would not be affected in any way and that this research was being done independently of the hospital. In compliance with Jordanian law, the father is regarded as the guardian and must sign the consent forms

(Jordanian Ministry of Health, 2004; NH&MRC, 2007). In this regard, I acknowledge that few issues arose regarding the consent form. One issue related to who should sign the consent form as I sought consent from both the parents as well as the participants. Although it was not compulsory to obtain consent from the participants and their mothers, I asked for their consent as a way of meeting both NH&MRC and Jordanian Ministry of Health ethical requirements. As a secondary outcome, this helped to establish rapport and support for the participants and their mothers.

### **3.15.2: Withdrawal from the study**

Participants were informed that the interviews conducted could be terminated at any point of time if they requested this or because they demonstrated distress. Furthermore, the participants possessed the right to delete any dialogue or other related information, such as audio tape recordings, written material, and field notes. The participants were assured that they would not have to provide any reasons as to why wished to withdraw from the study or delete information, and that any such action would not compromise to their care. Two participants withdrew from the study simultaneously after attending the first interview. The first participant asked to have all of his available information erased while the second participant withdrew after the second interview, but allowed the researcher to use the information provided in the first interview.

### **3.15.3: Privacy and confidentiality**

The information that the participants provided was managed in a private and confidential way. Participant's identities were known only to me as the researcher in order to follow and maintain continuity between the first and second interviews. A code was given to each participant and the coding key was stored in a separate locked cupboard away from the data. After completing data collection, all data emerging from the study was de-identified by destroying the coding key (paper shredded).

The researcher provided the participants pseudonyms and omitted any information that could reveal the participant's identity. For example, significant data about the individuals such as doctor's name, or names of family members mentioned by the participants.

#### **3.15.4: Attending the interview**

The participants and their parents were given the choice as to whether the parents wanted to be present or not during the interview with their child. I interviewed three participants alone, the rest being interviewed in the presence of their parents.

#### **3.15.5: Cultural barriers**

As the majority of Jordanians are Muslims, and participants were adolescents and I am a male researcher, I expected to face some cultural and religious barriers during the interviews, especially with female participants. I should acknowledge the importance of the research assistant's role during interviews as she had a very good relationship with the participants and their parents, which facilitated my role and ability to conduct the research. Furthermore, as the psychologist is female, this gave the participants more confidence and trust during the interview to express their experiences, and enabled me to establish rapport more readily with them. Although I did not experience any major difficulties during the interviews, I did experience some hesitance from one father, but not from the participant. In this incident, although the father signed the consent form for his daughter, he asked to attend the interview to check my identity and what I was doing. However, after 30 minutes into the interview he left the room leaving me with his daughter and her mother.

Another important cultural issue related to my inability to discuss sexual matters with participants and the impact of their illness on their sexual development. It is a sensitive issue for Jordanians and for adolescents in particular. The participants, as well, did not try to discuss this issue with me. Therefore, this topic remained closed during the study and I was unable to explore the effect of haematological malignancies and its treatment on these adolescent's emerging sexuality.

#### **3.15.6: Minimising risk of harm to participants**

Due to the nature of the topic being researched, it was anticipated that some participants might experience some temporary stress while recalling their experiences with haematological malignancies. I as a registered nurse, and the psychologist attending the interview with me, were able to identify the initial signs of distress in the participants. Preparations were made with a different psychologist and physician to refer participants

for counselling and support if needed. At the end of the interview, I made sure that the participants and their parents were not experiencing any distress from the interview.

Approximately three days following the interview, participants were contacted again to enquire about their well-being and were thanked for their participation in this study. This action facilitated my assessment of any distress being experienced by participant. In addition, the information sheet given to the participant contained my name, as well as that of the principal supervisor and contact in Jordan in case the participant required any assistance following the interview. All participants were reminded of this resource at the end of each interview.

Stress was demonstrated by one of the participants during the interview. To combat this, the psychologist assessed her stress level and I provided the participant with a short breaks. I also reminded the participant of their right to withdraw from the study and supported their decision. The participant wanted to continue with the interview and after a short break, was able to proceed. At the end of the interview, every endeavour was made by the researcher and the psychologist to ensure that the participant in question did not suffer from any adverse signs of stress.

### **3.15.7: Minimising risk of harm to the researcher**

My main role as the researcher in this study was to explore and interpret the lived experiences of adolescents with haematological malignancies. In order to do this, I spent a lot of time in the hospital with the adolescents during the process of collecting data.

A trusting relationship developed between the participants and myself which reflected on the quality of information that was provided. Patton (2002) proposed that the researchers needed to implement a technique of empathic neutrality, whereby they engaged empathically with the participants' experiences but maintains their neutral position towards the content of the material that was generated. Although the relationship between the participants and I did not operate on the basis of a therapeutic relationship, there were times when I provided information, reassurance and emotional support to participants. During the collection phase of data I was also aware that I might also be subjected to stress and to highlight this, one of my experiences with a participant is provided below.

At the end of the interview with one of the participants, she said:

Thank you so much. Before I met you, I was reassured by everyone that I would be fine. Although initially I was stressed at the start and challenged myself during the interview, I did find this interview very helpful. The first interview made me feel comfortable and express my inner withheld feelings. I felt as if a heavy burden in my heart was released suddenly. I was able to stand in front of the mirror and see myself more clearly as I was within a reach of the reality in terms of coping with my ailment which otherwise no one was able to comprehend. (Nancy 17 year old, interview 2)

In response to Nancy's comments I found myself being very emotional and I wrote the following as a field note:

I was deeply affected by the sentiments expressed by the patient. I questioned myself and pondered as to how can a person withhold so many emotions? Is it possible to find someone whom the patient can trust and share thoughts with.... The health team members are constantly busy with other patients in order to maintain their physical health. Family did not have enough experience to support their son/daughter. It made me realise that even after leaving clinical practice for six years, nothing changed. Nurses still emphasise giving medications and documenting their notes in a proper way in order to avoid getting into trouble. Doctors were so busy that they examined 30 patients or more / day and gave the patients one or two minutes during the round and most of the time they asked the nurse who responsible for the patient and not the patient themselves. I thought that this patient was lucky to be able to participate in such a study but what about other patients who go through the same process and have to carry all of these emotions in their heart forever because no one gave them the chance to talk or to share their experiences (Field note 22, 14<sup>th</sup> January 2010).

After the interview I took some time off from interviewing participants for two days so as to balance myself again. However, when I started transcribing this study, I felt so proud because this research seeks to address and solve such problems to give participants and their families a voice as well as hope and a way of dealing with their illness.

Due to my level of engagement with the participants, a sense of comfort and friendship developed mutually between us. Thereafter, if an issue arose in the hospital, some of the participants would notify me and seek my advice. I was aware that I would soon leave the field of study and that it may pose difficulties for both the participant and me. However, we all had known from the beginning of the study that the end of data collection would mark the end of our time together. Therefore, I staggered my exit from the field and attempted to correlate it with data collection with each participant

and hence leaving the field progressed naturally into the next stage of the study, and did not result of any traumatic consequences for any of us.

As I left Jordan following data collection I hoped that I would be able to understand the adolescent's lived experiences with haematological malignancies and would be able to portray these experiences to them, their families, and to health care decision makers in order to assist them to live more positively with this potentially life limiting experience.

### **3.15.8: Data storage, access, and disposal**

All data was stored in a secure locked cupboard and soft data were stored in a computer protected by a password in my office. All data will be kept for a period of five years from the date of publication (NH&MRC, 2007), following which the data will be destroyed. All USB-recorded interviews and data contained on the USB drive will be erased; files on the computer will be deleted. Furthermore, transcripts and notes contained on paper material will be shredded (NH&MRC, 2007).

### **3.16: Summary**

This chapter detailed the ontological and epistemological reasons behind choosing an interpretative phenomenological analysis as methodology for this current study. It also outlined the development, philosophy and the characteristics of the IPA. I described the data collection methods. At the end, I handled all ethical issues concerning the participants.

This chapter analysed the use of interpretative phenomenological analysis as outlined by Smith et al. (2009). The recommended steps led to the emergence of themes and sub-themes described the adolescents lived experiences with haematological malignancies. The lived experiences of adolescents and their response to cancer will now be presented in chapter four of this thesis.

## CHAPTER 4

### PRESENTATION OF RESULTS

#### 4.1: Introduction

Haematological malignancies hereafter, due to the repeated use of these words in this chapter, will be referred to as HMs are severe illnesses affecting adolescents worldwide. During this stage of the life cycle, adolescents begin the process of becoming more independent from their families. In addition, most do not contemplate the possibility of negative life events such as developing an HM. During this stage of development the adolescent believes they will live forever, that they know many things and that they can solve most of the problems they are confronted with. Generally, when adolescents in Jordan are asked about the future it is usual for them to speak with optimism and a great deal of hope and enthusiasm. As occurs commonly in other countries, Jordanian adolescents do not spend time talking or thinking about their own death. Therefore, when participants in this study were told they had a HM most were unprepared for such a diagnosis or the impact this would have on their lives. The diagnosis was not only unexpected but, for the first time, participants found themselves in an unstable, uncertain and unfamiliar lifeworld. It is this environment of instability that forms the context of this study. I (the researcher) have reported the lived experiences of adolescents living with HM.

This chapter reports on the results of two semi-structured interview sessions conducted with each of the 14 participants who agreed to participate in this study. The first set of interviews (n=14) depicted *the experience of the adolescents before, and three months following their diagnosis* of cancer. This period is best described as a time when they attempted to seek, know about and begin to accept and understand their diagnosis. During this time participants also began to experience some adverse effects from their treatment, which affected their health, relationships and well-being.

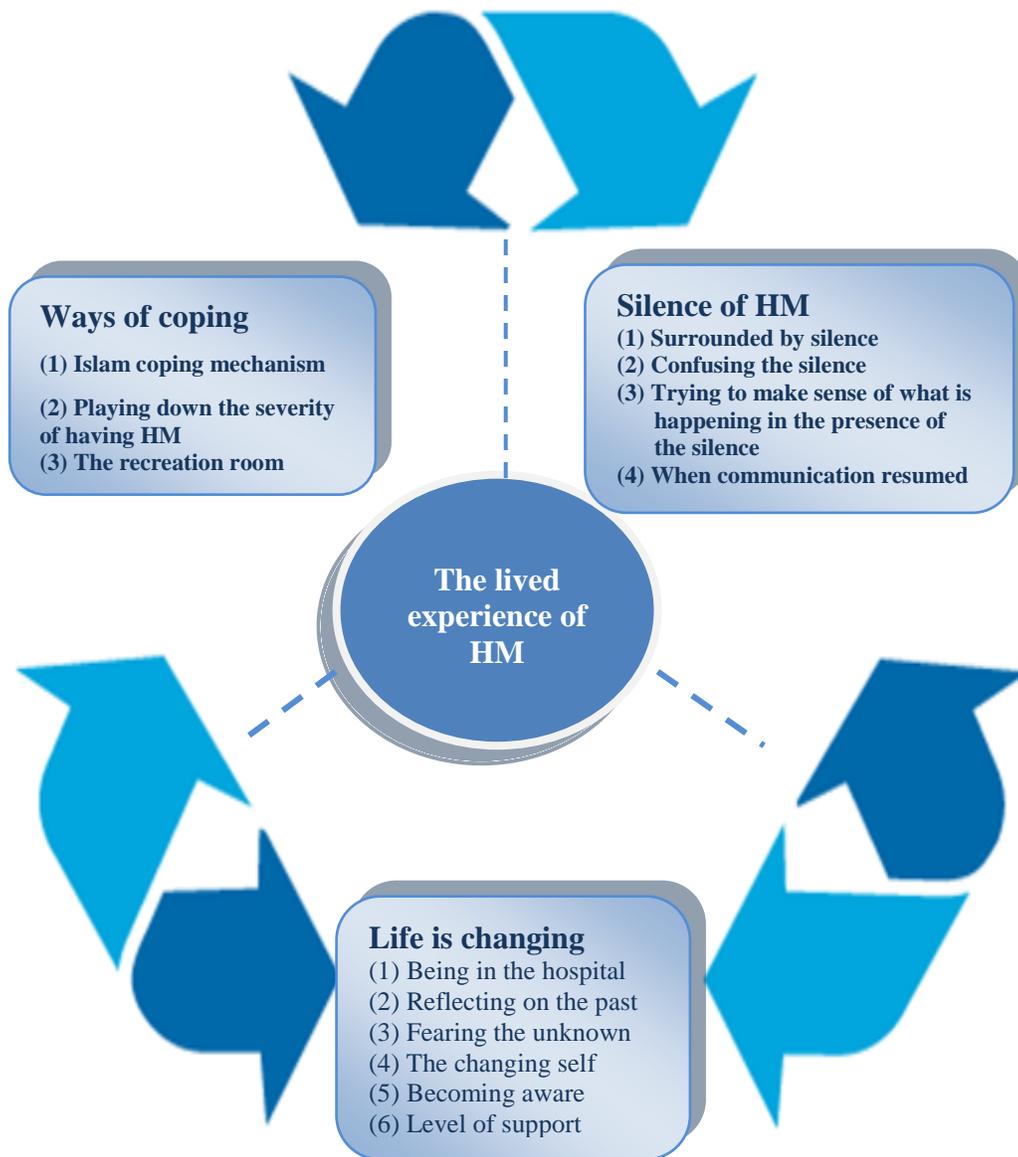
The second set of interviews (n=12) continued to explore participants' experiences beyond the first three months post diagnosis. During this stage of their journey they were fully aware of their diagnosis but not all of the difficulties that would face them during their treatment trajectory. In this way these adolescents came to

appreciate that the negative effects and impact of their diagnosis extended to their families, and they became more conscious of the changes occurring in their lives because of their HM diagnosis. In so doing, they moved hesitantly towards learning to cope and live with their illness.

Interviews conducted with all participants were analysed using an IPA that elicited the emergence of three major themes: “*Silence of HM*”; “*Life is changing*”, and “*Ways of coping*” (See figure 4.1). Each one of these three themes will now be presented in detail. As the findings presented in this chapter were generated from two sets of interviews, when data is presented in the results chapter it will be identified as having been collected during interview one or two after each quote.

#### **4.2: Silence of HM**

The “Silence of HM” was identified during data analysis as the first theme. For adolescents and parents, a diagnosis of HM was a unexpected experience. For all of the adolescents in this study, their initial consultation with their general practitioner (GP) occurred for reasons. At the time the reasons for visiting the GP appeared seemingly unrelated to those defining a HM as these disorders are often silent in nature and their initial signs and symptoms can be confused with many other illnesses. Many GPs preferred to disclose the diagnosis of a HM, when it was eventually confirmed, to participants’ parents and so deferred for some time from telling the adolescent of their diagnoses. However, while parents were told of their child’s diagnosis, the emotional impact caused them to remain silent and again the information was not shared with their child. As a result, participants were left to interpret events on their own, often using their imagination to understand their frequent trips to hospital. Their interpretations made were based on their knowledge level, past experiences, culture and customs.



*Figure 4.1:* The lived experience for adolescents with a haematological malignancy

During the participants' journey to diagnosis and treatment, their parents, particularly mothers were unable to maintain their silence anymore and realised that they had to be strong so that they could assist their son/daughter to manage what was happening to them and to come to terms with the fact that they had a HM. Each parent reacted in their own way with some being very emotional to the diagnosis of their child's HM. Some parents felt guilty, they blamed themselves and considered that they were responsible for what was now happening to their child. Other parents when told by the doctor that their child had a cancer experienced shock, while others simply denied the diagnosis and refused to come to terms with the reality that their child was ill. During this time many parents displayed a range of labile emotions which included uncontrolled crying and feelings of being overwhelmed by what was happening and which they had little control over.

In some instances, the parent's reactions were initially more obvious than their child's to receiving the news of a HM diagnosis. This was because many of the adolescents were not aware of the meaning of HM and therefore failed, at least to initially, understand what these words meant and hence had limited understanding of the impact of the illness on their lives.

Given this situation, participants' parents tried to support them using all the means they had. They spent more time with their child and openly expressed their emotions and love towards them in a more intense manner. The change in the way parents related to their son or daughter after being diagnosed with HM was significant. Participants acknowledged that often their family treated them better after the diagnosis and that, subsequently from the participant's perspective the relationships within the family improved.

While at the beginning of the journey participants were unaware of their diagnosis, they later came to suspect that something was wrong with their health and finally their suspicions were confirmed. Many found out that they had HM through indirect methods, for example, they recognised the tests they were having as being linked to disorders such as cancer or they overheard communication between health team members and their parents regarding their illness. Furthermore, some participants

realised they were ill when they were admitted to a hospital that specialised in cancer care.

The inability of parents to break the silence and tell participants about their diagnosis, in the early stage of the journey, impacted on the participants' level of well-being and left them unable to discuss their concerns with their parents. Furthermore, although at some stage doctors eventually informed them of their illness it was not discussed clearly with them and follow-up information was not always provided. Doctors directed their communication to participants' parents leaving the adolescents excluded from such discussions which furthered their concerns. Therefore, participants in this study were cast into a realm of silence in which they found it difficult to understand the events that were rapidly unfolding in their lives.

I will now outline the participants' lived experiences of the impact of the silence on them. At a certain stage participants came to suspect the true nature of their diagnosis but were unable to comprehend, at the time, the magnitude of their illness or how it would come to impact their lives. Eventually, they did begin to comprehend what their diagnosis meant and this often occurred as a result of the varied observations they made on those around them such as: 1) the closed door conversations between their parents and doctors; 2) the visible shock of their parents following a conversation with doctors; 3) through the unexpected attention they began to receive from their families; and meeting other patients in the hospital who had similar experiences.

I, in keeping with this theme, captured participants' experiences from the onset of the signs and symptoms and from the time when participants were *surrounded by silence* until they were provided with a diagnosis, and their communication with their family resumed.

The theme *Silence of having HM* consisted of four sub-themes: (1) *Surrounded by silence*, (2) *Confusing the silence*, (3) *Try to make sense of the silence*, and (4) *When communication resumed*. Each of these sub-themes will now be presented and supported by participant quotes and researcher interpretations.

#### **4.2.1: Surrounded by silence**

The first sub-theme of *the silence of HM* was called "*Surrounded by silence*". Of the fourteen participants interviewed for this study, only four were diagnosed during their

first appointment with their doctor based on their presenting signs and symptoms. The remaining participants were diagnosed after several consultations with one or more doctors and, as a result, their journey to diagnosis was an onerous one. Their illness was not always clear to the doctors as cancer often passes through a silent phase and the symptoms in the early stages may mask many common health problems. For example, some participants presented with minor signs and symptoms like cough and fever, which could be interpreted by the GP as a minor illness such as influenza or be related to other multiple causes. From the participants' perspective, the silent signs and symptoms of their illness meant that it took time for their disorder to be diagnosed and as a result their illness became more advanced and the treatment more complicated.

During the journey to diagnosis most participants noticed that the signs and symptoms of the HM were silent and that their parents, family and health team members were also silent about the outcomes of the numerous investigations that were being conducted on them.

Participants' parents were silent at this time because when they were informed of what was wrong with their child they were shocked and in denial about the seriousness of the diagnosis. They themselves were struggling to comprehend what the diagnosis meant for their child and their future and were trying hard to learn and understand more about the disease. Parents were struggling with the reality that their son or daughter was very ill and they were coming to terms with what this meant to their child and their family. Therefore, during this time they tried to protect their son or daughter by hiding information about their illness from them and remaining silent about the course and cause of their illness.

Although both parents and doctors remained silent regarding the information they had about the illness, participants older than 13 years of age were aware that something was wrong because of the activity and the behaviour of people around them. This activity and behaviour conveyed a message to them that something bad was happening to them. However, as none of the participants were informed of their diagnosis at this time they continued to manage their feelings of uncertainty alone.

Eventually all adolescents came to know about their diagnosis from members of the health care team. However, even when they were informed of this their parents

remained silent about their illness in their interactions with their children. In addition, health team members, although telling participants that they had a HM, they did not provide them with the opportunity to discuss what this illness was or what this meant to their future opportunities and life goals. Shahed provided a good example of this. She was treated for two years by GPs, and told that she had a disease which was affecting her salivary glands as well as her thymus gland. The diagnosis was revealed to her only after finally being referred to a specialist, just three months prior to being interviewed for this study. Her journey to diagnosis was difficult and long and she suffered physically and emotionally as a result of this. When Shahed was narrating this experience to me she began to laugh:

I was diagnosed [with HM] three months ago; I was having treatment two years beforehand on the grounds that I had an infected salivary gland. Then they told me that I had [an infected] thymus gland! After the thymus gland, they told me it [a tumour] was in the neck [laughter! (Field note 7, 16<sup>th</sup> December 2009)]. (Shahed 16 years old, Interview 1)

I developed the feeling from Shahed's body language that her laughter was hiding undisclosed emotions, almost as if she believed that if the doctors had discovered her illness earlier, the possibility of complete remission may have been much higher and saved her from the some of the stress and uncertainty she was now facing:

... The hospital took a lot of time to do the surgery for me and the doctors took a lot of time to diagnose me. I was not convinced of what they did and I was not happy [My observations noted Shahed's face was flushed as if she was astounded that her diagnosis had taken so long and that now the treatment was more complex (Field note 9, 16<sup>th</sup> December 2009)]. (Shahed 16 years old, Interview 1)

Shahed first became aware that something was wrong with her due to the way her doctor interacted with her. Doctors when working in a public hospital are very busy but Shahed noticed that her doctor offered to accompany her when she went to get her blood test results. She also became aware of the doctor's reaction to the test results when he read them even though he tried to hide his response from her. Although he remained silent, his body language changed indicating to her that something was wrong and what he had read was not good news. Therefore, for Shahed there was a contradiction between the silence of the doctor and his body language, confirming for her that something was wrong:

After that, the results of the biopsy were ready, and they [doctors in hospital] told me to go and get them. One doctor accompanied me, and I did not know why, because it is usually me who goes and gets the results by myself without a doctor. When I asked him [doctor] about that, he said that he was coming with me because he liked having fun with me. He asked if I wanted him to go back [to the ward]. When the doctor read the results, he was shocked and he said to me “don’t worry, everything is OK”. I felt that there was something wrong, but he didn’t say anything at all. (Shahed 16year old, Interview 1)

Similarly, Tariq’s journey to diagnosis was also lengthy. He visited many doctors and dentists but none of them were able to provide a diagnosis. As he had a strong physique and was full of energy his dentist did not make the connection that Tariq could have a HM. Tariq consulted one doctor after another and he became increasingly frustrated that they were unable to identify what was wrong with him. However, he knew that something was wrong because his body was changing due to his illness:

I visited many dentists because my teeth are not firm; no dentist could know the diagnosis [of cancer]. ...Finally they [my parents] took me to a doctor in a private hospital. She didn’t know my diagnosis. I then went to a neurologist, because I thought that the matter [was] neurology, but [the] result [did not] show anything abnormal. Then I visited another neurologist and [again] no result. [Then] I went to another doctor. I visited different private hospitals and doctors there who prescribed for me [different] types of medicine but [with] no improvements. [Then] everything changed, I couldn’t talk, I began to miss many sounds of letters. [In] the end the [doctors] diagnosed me [with cancer] but they did not tell me anything regarding my diagnosis [Tariq attended the interview alone as he preferred to work independently without his parents (Field note 3, 13th December 2009)]. (Tariq 17 year old, Interview 1)

For Tariq, the silence also followed him as he attempted to find a diagnosis for his presenting problems. Like Shahed, his family was also silent regarding his diagnosis as they were in shock and unable to come to terms with what was happening to their son. As a result, they could not talk to him about it during the early stages following his diagnosis. Although Tariq noticed the changes in his family’s behaviour, and that the name of the hospital to which he had been admitted contained the word cancer, he initially refused to believe that he had cancer. He denied this fact and did not acknowledge that he had a form of cancer so he did not have to undergo the associated stress. Denial is an important defence mechanism that assists individuals during times of

intense stress:

He [dentist] gave the result to my family [that I had HM]. I was going around with my friends; I did all of that without knowing that I had cancer. No one told me about that... All the family members knew about my situation except me. [Pause] One morning I found that my older brother had awakened early [to join Tariq to go to the hospital]. That was strange because he doesn't care for anything other than his work. I'm not one of the people he takes care of, so I was surprised he was accompanying me. Then my uncle arrived. They asked me to join them to visit [the] doctor. [Pause] they [Tariq's family] did not explain to me that they were going to take me to KHCC. When we arrived to [KHCC], doubts began to invade me. I pointed to my uncle that this was not the University hospital, so why were we here? He told me, "no", we are in the University hospital. [Tariq said] "You imagine that". I lied to myself, telling my uncle okay. [I told him] we are not in KHCC we are in the University hospital (Tariq 17 year old, Interview 1)

Although most of the people around Joseph remained silent regarding his diagnosis, like the other participants he suspected that something terrible was wrong with him. He too was able to sense and observe the change in the behaviour of those around him. Joseph chose to break the silence himself and to ask his physician directly what was wrong with him and his physician responded promptly. He was then able to discuss and express his concern with his physician but not with his parents who still refused to talk to him about his illness:

No-one told me [about HM] and no one want[ed] to tell me anything, but I suspected [something was wrong]. Finally, I asked my physician, and she told me of my sickness [pause]. I was unable to discuss this matter with my parents. I only discussed this [my diagnosis] one time when I was alone with my physician [Joseph's facial expression was calm (Field note 15, 8<sup>th</sup> January 2010)]. (Joseph 14 year old, Interview 1)

During the interview Joseph did not demonstrate overt emotions but there was a sense from the way that he used silence that he was denying the inevitable truth about his illness. Denial is a protective mechanism in times of stress and this shows that Joseph was not yet ready to confront his reality and his future living with a HM.

Muhannad, a 17 year old participant, was also *surrounded by silence* from both his family and health team members. However, he found himself in a cancer hospital and in a ward with other cancer patients. He was not informed of his diagnosis, nor was he provided with further explanation. Consequently, the surrounding silence left him vulnerable as he did not know what was happening to him. After experiencing the

silence for some time Muhannad asked the doctor about his illness only to have his fears confirmed:

They [parents] did not tell me anything about my diagnosis, but all the people who were here [on this ward] had cancer and that was strange to me. I asked myself why I was there [on the cancer ward]. I asked the nurses. Then my doctor came and told me that I have cancer (Muhannad 17 year old, Interview 1).

Muhannad and Joseph picked up on the cues in their environment and from other patients that they may have cancer. Due to their age they felt empowered to speak to their doctors about their health problems allowing the silence to be broken. However, this new knowledge left the boys with a new type of silence compared with other participants. That occurred because although they knew their diagnosis they were not provided with information about the disorder. In addition, from my interactions with parents I noticed that they were not educated about their child's illness so they were unable to support them and therefore remained silent. As a result the participants were left to "fumble in the dark", trying to understand what their diagnosis of HM meant and how it would impact on their life goals and dreams.

Hadeel came to know about her diagnosis from a conversation about her by doctors standing by her bed. However, her treating doctor and family continued to underestimate her capability to comprehend the real nature of her illness. Due to her age (13 years) she was able to deduce from the conversation that she had cancer, but she did not share this immediately with her family. She responded to the silence from them about what was happening to her by also being silent. This was probably due to the fact that while she was aware she had a form of cancer she had little understanding of what this actually meant as the conversation between the doctors occurred in English, which she may not have fully comprehended. For example, the doctors used the word "cancer" which, as an English word would not be fully understood and therefore would carry a little emotional currency for her. Had the doctor used the Arabic word for cancer, "Saratan", the meaning would have been clear to the Hadeel:

Nobody told me about my diagnosis, I found out myself. From the way that the physicians talked and from the medicines I took [Hadeel figure out she had HM]. [Pause] No one knew that I was aware of my diagnosis and I did not discuss my concerns with anybody. (Hadeel 13 year old, Interview 1)

Although silence was a common experience for all of the participants, they experienced different types of silence. Some participants were unaware of their diagnosis and consequently were completely surrounded by silence. Other participants knew about their diagnosis but had been provided with little or no further information from health team members about this diagnosis. Lastly, some participants knew about their diagnosis but decided to remain silent almost as a response to the silence surrounding them. However, the one common denominator in the experience of silence for these participants was the persistent silence from their parents as to what was happening to them. As a researcher I interpreted that this represented a continuous source of discomfort for these adolescents.

In summary, although silence was ever present in the participants' lives they were able to appreciate that something was physically wrong with them. Most were at a developmental level where they were able to recognise the meaning of non-verbal communication and cues demonstrated by people around them and, used this information to conclude that they were very ill.

#### **4.2.2: Confusing the silence**

*Confusing the silence* was the second sub-theme of the *silence of HM*. In most situations, even though parents did not communicate verbally with their son or daughter about their diagnosis their non-verbal communication added to their child's confusion about what was happening. Participants' parents knew, or became aware following their son or daughter's diagnosis that this type of illness could kill their child. Depending on their level of understanding about the illness and their educational level, they held a variety of beliefs about the causes of HMs. For example, some were misinformed and still believed that cancer was an infectious disease. Many parents felt helpless and did not know how they could assist and protect their child from what was happening to them. As a result they tried to shelter their son or daughter from the facts and remained silent during their visits and did not speak about the illness in front of them. However, although they remained verbally silent they often broke down and showed displays of grief, for example, crying because they felt overwhelmed by the events unfolding before them in their lives.

Nonverbal communication is considered to be one of the most important means

of communicating and is as important as verbal conversation in transferring messages and emotions from one person to another. Therefore, when one person is trying to withhold information from another, the person receiving the mixed message may become confused by the information they are receiving. This state of confusion became central to the sub-theme of *confusing the silence*; while participants' parents did not communicate their feelings verbally, their non-verbal communication told their child that there was a problem. This sub-theme portrayed a situation for the participants where their parents continued to be silent about the diagnosis, but demonstrated emotions of concern and fear both verbally and non-verbally which were picked up on by participants and added to their level of distress and uncertainty.

Shahed's mother demonstrated confusion in message transmission very well. Shahed received her first dose of chemotherapy while her parents remained at home, when they later telephoned her to enquire about her well-being Shahed felt confused and concerned about her mother's response to her laughter:

...After that [my chemotherapy session] my mother called me [to ask about my health] on the phone and I started laughing, so she told me "I am losing my nerves and you are laughing?" I asked her "are you worried about me?" she started crying without giving me any explanations. I was unable to explain this [my mother's response] (Shahed 16 years old, Interview 1).

While Shahed did not discuss her diagnosis with her mother she witnessed her crying without providing any explanation to Shahed for her behaviour. This made Shahed very confused but her mother continued to hide the diagnosis from her out of concern. However, this only increased Shahed's level of distress. While the confusion of silence contained a strong familial wish to protect Shahed, its in-fact introduced a paradox whereas the desire to protect actually caused further distress.

Traditionally, Jordanian men are expected to contain their emotions when confronted with difficult life events. This expectation played out in Younis' family through the relationship between Younis and his father. They did not show emotion in-front of each other and Younis' father had to appear as if he was always in control of family issues and problems. However, when he was hospitalised, Younis' mother displayed an outpouring of emotions; she cried in-front of her son but without explanation:

... I became sad and started crying with her [my mother] and told her “mum don’t cry, God will dispel my trouble” [HM], she stopped crying and went outside to cry so she would not be seen and did not upset me. ... I saw my father secretly crying but not in front of me. [Researcher: Did you ever cry in front of him?] No, I don’t cry in front of him. Because I am a man and man should always be strong [not cry]. (Younis 13 year old, Interview 1)

For Younis, the paradox contained in the silence became evident and while his parents demonstrated strong emotions to his diagnosis they did so in secret without his knowing. However, Younis became aware of their internal turmoil because of their non-verbal communication with him and their lack of explanation about what was happening. Moreover, because of the lack of communication Younis felt helpless to assist his parents, which signaled another stressor for him - observing his parents experiencing stress and abnormal emotions.

Hadeel’s parents also conveyed this contradictory communication in their interactions with her. They cried when they were told about their daughter’s diagnosis but they did not explain the reason for their behaviour to her thus keeping their silence regarding her diagnosis. It is reasonable to suggest that as they were uncertain about Hadeel’s future, this uncertainty generated emotion and anxiety for them. While Hadeel’s father reassured her that everything would be okay her mother cried which confused her more and conveyed a sense that there was something wrong:

While I was out of the room, they [doctors] talked to my father and mother, and once the doctor started talking to my mother [telling her that I had leukaemia] and I had to receive treatment [chemotherapy]. My mother started weeping [pause]. Mum cried and wept, my father wept also. [Pause] In the car I asked them about the situation? My mother just cried and my father told me there was nothing to worry about and then there was silence. I was confused between their contradictory responses (Hadeel 13 year old, Interview 1).

In this exemplar, Hadeel asked her parents about their differing and changing emotional states. Hadeel’s father told her not to worry. Her phrase “and then there was silence” is telling, because the silence acted as euphemism for we will not discuss this very difficult subject anymore.

In summary, participants were surrounded by a silence that confused them and created a paradox for them. This hindered their communication and increased both their own and their parent’s level of stress. Silence prevented the participants from being able

to talk to their parents and as a result the silence left participants to their own resources to make sense of what was happening to them.

#### **4.2.3: Trying to make sense of what is happening in the presence of the silence**

*Trying to make sense of what is happening in the presence of the silence* was the third sub-theme of *the Silence of HM*. Being surrounded by silence, and in the absence of formal information, the past experiences of participants acted to inform their interpretations of what was happening. That is, they came to understand and process their illness through the existing filter of their fears, past knowledge, and memories of the cancer experiences of other family and friends.

As there were variations in participants' beliefs regarding the causative factors of their HM, their process of understanding was different for each individual. Although some participants believed in the possible role of diet, smoking and/or psychological status in causing haematological malignancies, some participants imagined other causes such as religious beliefs and the use of magic. There was a sense in this study that participants were left with no alternative but to understand the cause of their HM in informal ways, such as religious beliefs and the use of magic. The lack of information participants received along with the breakdown in communication with their parents and health team members lead participants to make their own interpretation of what was happening to them. This interpretation was based on their previous life experiences and cultural beliefs. I was able to analyse and sort participants' interpretations into two groups. The first group made their interpretations based on some information they had received on HM and other forms of cancer and therefore, they were able explain their illness in more scientific terms than the second group. For example, Adam knew about some of the medical causes of his illness. He made a connection between the physical and the emotional causes of his HM. He also suffered from another personal loss and confusion due to his previous girlfriend's engagement to another man and as a result of her leaving he stopped eating and drinking. He linked his current physical condition to the previous trauma he had experienced as a result of the breakup of his relationship:

I had a relationship with a girl previously, and I did love her and I wanted to marry her, but we were not destined to be together. She married another man. You know, I was still young and I wished to get married, but her family forced her to marry another man. I feel that this is the reason for everything that is happening to me. I

had feelings for her. [Researcher: could you explain more?] When she got married I was shocked for a period of time [pause] I did not know what to do. I stopped eating. I spent my time drinking coffee and smoking. After sometime, I felt I was losing weight and I felt pain in the flanks. (Adam 17 years old, Interview 1)

It is evident from this exemplar that Adam received little formal information from health team members and was left to contemplate what was happening to him in silence. Consequently, Adam built his own explanation and tried to make sense of his illness and its causes. Abker provided a similar story to Adam. He was more confused and uncertain due to the absence of formal education and communication between him and his family. He was more hesitant, unsure and confused about describing what he thought had caused his HM. In processing the information he was receiving from those around him he tried to obtain different explanations about the cause of his HM as a way of minimising his feeling of anxiety and uncertainty:

No one told me anything [about the cause of his HM] but I think the reason [for my HM] was because I had seen a mass on my neck and I did not visit a doctor. I think this was the reason, um [pause] it might have been because I neglected the mass on my neck or I think it was due to a virus, [pause]. Sometimes I think there is no reason because it appeared suddenly, but when I reconsider the situation, I think it was a virus that affected my body. (Abkr 16 years old, Interview 1)

The second group of participants who did not receive any formal explanation regarding the cause of their illness linked its cause to such things as extraordinary powers, like God and magic. The Islamic faith played a role in shaping the beliefs participants held in regard to the causes of their HM. Many Muslims believe that on occasion Allah (God) will test their religious beliefs according to their strength of faith. For example, of the believers, those who have stronger faith will be tested more by Allah than those who do not have the same level of belief. Allah said: “2. Do people think that they will be left alone because they say: “We believe,” and will not be tested.” (Qur’an: Al-‘ankabut: 2)

For those participants who believed that Allah was testing them, it was easier for them to accept the diagnosis as part of their faith. Most Muslims believe that Allah controls their lives, and that Allah determines their future and therefore, they acquired a HM for a reason. Haneen thought her diagnosis of cancer was a test from Allah and her answer to the researcher’s question portrayed this belief: “My illness [HM] is from

Allah and we should remain patient”. From an Islamic perspective, when someone ascribes the cause of any illness by way of saying “this is Allah’s will”, it means such an event is beyond the ability of the person to control. Therefore, Muslims are expected to accept this and not question what is happening to them. Haneen’s answer to the question about the cause of her HM also implied that she wanted to stop the researcher from asking further questions because this may stress her. Haneen was young and she established a culturally convenient statement to stop people from asking more questions about her illness. My interpretation was that Haneen was trying to respond to her family’s silence using silence, and supported this in the following way:

My illness [HM] is from Allah and we should be patient. [The patient’s facial expression is calm (Field note 1, 28<sup>th</sup> December 2009)]. [Researcher: Why?] This is Allah’s will, and anyone could suffer from a haematological malignancy [pause] we cannot question Allah’s will. (Haneen 16 year old, Interview 1)

There is a sense that Haneen adopted this general explanation, as she believed that Allah controlled everything and that she accepted that the cause of her illness was derived from an extraordinary power (Allah) and, as such, she was obliged to accept her fate. Similarly, Nehal referred to the cause of her cancer as a test from Allah (God):

I do not think it [HM] is because of eating or drinking [bad food or drinking]. It suddenly happened to me [without any reason]. It means that the matter is from Allah [pause]. This is Allah’s will. (Nehal 13 year old, Interview 1)

Other participants believed, in the presence of silence, that the cause of their HM was “magic”, and in particular the process of “envy”. In Jordan some people traditionally believe that if they wear new clothes, and if they are recognised as being successful in their work, or have a beautiful body shape, and/or a healthy body, other people will view them with “envy”.

Two female participants in this study prior to being diagnosed with a HM were healthy, happy and beautiful. However, they believed that they had been subjected to envy because people were jealous of them and, as a result, they developed a HM. Although Shahed was aware of a biomedical cause of her illness, the process of “envy” still played an important role in how she conceptualised the cause of her HM. Therefore, because she received no further knowledge and understanding of her illness from health team members she was forced to make her own interpretations of what had caused her

HM:

... The reason may be that [pause], I do believe in envy. In the past, I used to wear beautiful clothes and do things that made people envy me, so maybe some people envied me (Shahed 16 years old, Interview 1).

In the presence of silence, Shahed linked her current condition to the extraordinary power, which in her case, was envy, a kind of magic that she unable to resist. Sale described a similar experience but the cause of envy was somewhat different. She believed that other women envied her because she was tall and beautiful. Here it is important to emphasise the words “tall” and “beautiful”. She visualised herself in the past as having both of these valuable assets which she missed them due to her illness:

... One day a woman visited us [Sale and her grandmother]. Her [the visitor] only concern was to look for brides for others [who are looking for brides]. When I entered there [guest room], she said to my grandmother “I am searching for brides and Sale is here, she is very beautiful and tall”. I used to be beautiful and tall. However, my grandmother told her, Sale is just a young girl; she is only 14 years old. She said “she is only 14 years and she is very tall compared to other girls her age” [that meant she envied Sale]. After she left my home, my grandmother noticed a mass in my neck (Sale 14 year old, Interview 1).

In summary, in the absence of the ability to openly discuss the cause of their illness, participants were left to process what information they could collect from a variety of sources in order to assist them to make sense of the situation they now found themselves in. As participants had different life experiences, levels of education and accurate information presented to them by health team members their beliefs regarding the cause of their illness differed. However, eventually, over time, the silence resolved and proper communication recommenced and their life progressed.

#### **4.2.4: When communication resumed**

*When communication resumed* was the last sub-theme for the *silence of HM*. There came a time following their child’s diagnosis when the parents were unable to remain silent any longer. Over a period of time communication was re-established with their child. For example, when I interviewed adolescents for the first time, they were *surrounded by silence* and they had little meaningful communication with their parents, but when I interviewed participants for the second time in this study, they were aware of what was wrong with them as well as their proposed treatment pathways. Their

communication with their families had also improved. The communication channels had resumed and new communication between the adolescents and their families, both nuclear and extended, led to a reconfiguration of family dynamics, which enhanced family relationships. It also provided the adolescents with stability and support during their illness journey.

For Tariq HM reunited him with his family. Prior to his diagnosis his rebellious behaviour had alienated him and caused disharmony within the family, particularly between Tariq and his brothers. However, following his diagnosis of HM his family gathered around him more often and there was an improvement in relations between family members. This helped Tariq to reconstruct new, more stable boundaries around his current life. I was left with the feeling following my second interview with Tariq that there was also a process of reconstruction occurring within his family. The differences between family members were now forgotten as they came together to support him. At the end of the following exemplar, Tariq hinted about the seriousness of his illness and his feelings of fear:

The cancer was the cause because he [my brother] sat with me for a long time [taking about cancer] and I became close to him. [Pause] I have an uncle, and he has no relationship with my father, but when I became sick, my cousins began to visit me and my uncle's wife prepared meals and brought them to the hospital for me. I felt that my sickness reunited the whole family again. They called me and asked about my health because I'm sick with cancer, a dangerous disease, and scared. (Tariq 17 year old, Interview 2)

Equally, although the relationship between Tariq and his father was difficult, after his diagnosis of HM their relationship began to improve and Tariq's father provided him with much needed support. With the re-emergence of positive relationships and family support Tariq experienced an increasing inner strength and stability, which was important to him at this time:

... Yes, [Tariq relationship with his father] changed to good. [As a result] sometimes, when I ask him [father] to give me money, he gives me, and tells me that he'll take me by car to school and pick me up as well. He is more interested in me, sometimes he doesn't have money [and as a result] he became ashamed ...He is a merchant, and sometimes circumstances are difficult [and money is scarce]. I also became embarrassed to ask him to give me money.... (Tariq, 17year old, interview 2)

In addition, to his nuclear family Adam's extended family also started to visit him, when they heard of his illness. They communicated frequently with him which provided him with definite and additional support. This support enabled Adam to recognise the importance of family, and his communication with them and gave him new hope for the future. On another level, it would be reasonable to suggest that, because of his HM experience Adam began to evaluate what was important in his life:

Before my sickness I did not visit my relatives at all, but now all of them visit me and even my brothers are closer to me because of my HM [pause]. If I become cured I will visit them all again [Pause]. Life contains many things more important than what I thought in the past. (Adam 17 year old, Interview 2)

For all of the other participants, their subsequent communications with their families regarding their diagnosis resulted in a further deepening of bonds between them. In addition, their parents began to relax and share their experiences and emotions in regard to what was happening with their child. Although the relationship between Nehal and her parents had always been good, she reported that she became even closer to them following her diagnosis. Her parents visited and communicated with her for long periods of time while she was in the hospital. As a result of this increased closeness she developed a new image of her parents and this added to her feelings of comfort when around them. She also expressed the important role of her extended family, for example, her grandmother took care of her siblings to allow her mother to spend time with Nehal in hospital without interruption. Nehal was aware of the importance of her parents to her other siblings. However, her HM experience appeared to increase the demands she placed upon them including seeking increasing amounts of their time and support:

My brothers and sisters are staying at my grandfather's house alone and at night they take care of them. I love my father and my mother, they love me also always. Now they are closer to me because we stay together for a long time. Before being sick, my father went to work, and my mother's time was divided between her house and the houses of my sisters. Now they [my parents] are for me only because I really need them more than anyone else. [Because of hospitalisation] they spend their time with me. (Nehal 13 year old, interview 2)

Shahed compared the relationship she shared with her father and her mother. She believed that her relationship with her mother did not change following her diagnosis,

but that with her father it improved significantly. Contextually, some Jordanian parents, and particularly fathers, try to portray a sense of firmness in front of their children. However, after the diagnosis of HM Shahed was given more freedom to communicate with her father. He also tried to be more emotionally present and more supportive to his daughter and spent more time with her than he would normally do. These increased hours of contact and communication, generated a close relationship between father and daughter:

After my sickness my father became closer to me. He was encouraging me a lot and he spent more time [supporting and communicating] with me than ever before. Of course I loved my mother before and after [cancer and] my relationship with her was and still is very good. (Shahed 16 year old, Interview 2)

Haneen had a similar experience to Shahed. Freed from the bonds of silence, Haneen's father became increasingly attentive and loving towards his daughter:

...My dad became better with me and his care increased [after diagnosis of HM]. He bought a lot of things for me, stayed [a] long time with me [in hospital] feeding me with his hands, forbidding any of my brothers to touch me or speak to me [to tease me as he wanted to spoil me]. He loved me more after my diagnosis. (Haneen 16 years old, Interview 2)

Fatima also noticed a change in the way her family responded to her. When the silence was broken her family bestowed gifts on her, such as a new television, and bedroom suite. There is a sense in which the family's love, concern and fears of Fatima were expressed in this material way:

They [my parents spoilt me] more than before, they bought a television for me and a new bedroom and dad brings gifts, like a baby bear. [Pause] when I ask my sister to do something for me she does it and so do my other brothers. (Fatima 13 year old, Interview 2)

The improvement in communication between participants and their families was perceived by them all to be a positive outcome and indicated a new phase in their family relationships. Some participants revealed that the communication strengthened the bonds between the family members, and was an important step in re-establishing their sense of personal stability and harmony as a family. Participants also viewed this improved "communication" within the family as a vehicle which provided them with hope for a better tomorrow.

In summary, the theme “*silence of HM*” portrayed participants’ experiences from the moment they started seeking medical advice up until they knew about their diagnoses and communication resumed between them and their families. During the process of diagnosis, participants were surrounded by silence, which included the silence of their parents, families and health team members. It would be incorrect for me as a researcher to believe that the silence was created deliberately by either parents or health team members. However, what I have come to understand as “the silence” incorporated a socially constructed process that left the adolescents in this study separated from an important source of support because of a breakdown in communication and an underestimation of participants’ cognitive abilities and development age. The resulting absence of support, mediated as it was by the health care system, generated a division between adolescents and their parents that would not have been consciously chosen by either group. In the process of division the participants came to understand that their lifeworld’s were changing. Moreover, in some tacit way, both participants and families understood that the future would hold further uncertainty, instability, distress and challenges as their experience of living with HM continued.

#### **4.3: Life is changing**

The second theme in this study derived from data was titled “*Life is changing*”. This theme consisted of six sub-themes: (1) *Being in the hospital*, (2) *Reflecting on the past*, (3) *Fearing the unknown* (4) *The changing self*, (5) *Becoming aware* and (6) *Level of support*.

From the moment the participants were diagnosed with a HM their life changed forever. They were subjected to a variety of diagnostic tests and treatment modalities such as bone marrow aspirations and chemotherapy. Although chemotherapy is considered one of the most important treatments for this type of cancer, it generates many side effects. As a result participants experienced physical and emotional changes, as well as changes to their self- image and self-efficacy. During the first round of interviews this was not in evidence as most of the participants had just commenced their chemotherapy regime. However, during the second interview all participants were experiencing side effects from the chemotherapy used to treat their HM. Participants’ experiences of the HM treatment could be divided into two parts, primary experiences

that occurred as a direct result of the chemotherapy (e.g. nausea, vomiting, and alopecia) and secondary experiences, which came about as a result of long term use of chemotherapy and the associated side effects. For example, many participants stopped attending school because of fatigue and alopecia rather than the direct effects of the chemotherapy on their bodies. Consequently, participants were responding to the impact of the secondary experiences, which affected their social world. For example, Leith, in finding that he was no longer able to match his friend's physical endurance during play withdrew asking his mother to make excuses to his friends when they came to call.

By the end of six months, many participants spoke about significant changes in their lives because of the treatment they were receiving. This was particularly true of the changes occurring within their body and in their relationships with friends and family. For example, most of the participants lost many of their friends following their diagnosis of HM and they did not visit them in hospital. In addition, some of the participants' extended families regarded their affected relative with pity because they were no longer physically fit and healthy. Moreover, participants witnessed other young patients die and, as a result, they became more aware of the possibility of their mortality. They began to interpret the behaviours of those around them through the eyes of a cancer sufferer. That is, their lifeworld and what it contained before diagnosis was altered by their diagnosis. Their assumptions and interpretations of relationships and the world changed.

This second theme depicted the participants' experiences from the time of bone marrow aspiration as an inpatient procedure until the time they experienced the full effect of chemotherapy (a period of about six months).

#### **4.3.1: Being in the hospital**

*Being in the hospital* was the first sub-theme of *life is changing* as this became the central experience for participants during the first three months following their diagnosis. These periods of hospitalisation ranged from one to six months, with one or two weeks at home between each admission. When hospitalised, participants were subjected to a number of strict rules that placed firm boundaries around their lives, and defined a period best described as their "new life". In their new life, they were often deprived of seeing members of their family due to hospital rules and regulations.

Most Jordanian hospitals follow strict rules, especially for cancer patients. Hospital rules included restricting the number of visitors allowed to visit at any one time and limiting visiting times to certain hours during the day. Furthermore, if participants' exhibited signs of low immunity it was even more difficult for the family to visit. Of note is that the interviews for this study were conducted during the time of the global "Avian influenza scare" and the hospital's rules were even more rigid with some participants not being allowed any visitors at all. Consequently, most participants felt isolated and detached from their families and hated their stay in hospital. The experience of hospitalisation became a very difficult experience for participants and created a sense that their social world was changed forever as a result of their illness.

As participants were hospitalised for extended periods of time they often became friends with their health team members, especially nurses. They considered these staff members to be their new family as they had been rejected by many of their friends and were away from their families. Therefore, even though participants disliked being hospitalised they came to view the health team members as their friends. This relationship was important as they trusted and shared information with their new friends. Through these relationships their levels of hospital induced stress experience decreased.

Tariq did not like hospital and he was stressed by his interactions with his physician who was concerned about him following his diagnosis and wanted him to see a psychologist to help him to work through his problems. From a Jordanian perspective, people only usually see a psychologist when they have a mental illness. However, each time Tariq became upset in front of his physician he was referred back to the psychologist. As a result Tariq sessions with the psychologist became a sort of punishment for him. Although he had a good relationship with the psychologist his problems with his physician cause him distress during his periods of hospitalisation:

I do not like hospital because of physicians. There are some physicians who don't care about the patient's circumstances. I can give you an example. Sometimes you feel down, or maybe you sleep more than expected. The physician comes and asks me "What happened to you, do you want me to bring you to see the psychologist?" What's that; do you think I'm mad? [Tariq whispered to himself] Another example, once, she [the doctor] gave me medicine to take at home, and I forgot to take it, so I got tired. When I reported this to the centre she began to yell at my face, asking me "Do you want me to bring you to the psychologist?" That disturbs me very much. (Tariq 17year old, Interview 1)

On the other hand, the nurses provided Tariq with a sense of security as they spoiled him and because of his age treated him more like a friend. When he was with them, he forgot about his illness and he felt normal and secure and their relationship added stability to his changing world:

They are very good people [nurses], always joking, they spoil me! For example, a nurse came to me saying he wanted a break for a smoke so he took me with him, but I didn't smoke. Another one came to my room. I feel that I'm not a patient with her, it is not a relationship between a nurse and patient, and it is more than a friendship. It is like a brother and sister [Tariq's facial expression very happy (Field note 2, 10<sup>th</sup> March 2010)]. (Tariq 17year old, Interview 2)

Nancy also viewed the health team members as her new family. She believed that their jokes and support assisted in relieving her pain and sorrow. When a person describes another person they are unrelated to as a part of their family, it signifies that they like and trust the person. Nancy claimed that: "They [Health team members] became like my family. [Pause] It makes my life easier" (Nancy 17year old, interview 2). Given the fact that Nancy relied heavily on her family's support before hospitalisation, she appeared to transfer this need onto the nurses and doctors during her lengthy periods of hospitalisation:

Being in hospital is not like the initial stage [during the first interview], now I know the doctors, and nurses; they joke with me, and I joke with them also. It's a little easier, they became like my family. [Pause] It makes my life easier... They talk with me, I talk with them and we understand each other more. (Nancy 17year old, interview 2)

Conversely, Younis believed that the hospital was a barrier between him and his friends and felt isolated because his friends did not come to visit him. This was also applied to some members of his extended family, although his immediate family did visit him. He felt constrained by the four walls of the hospital and found he was unable to carry out the activities that would have previously filled his day. This presented for him in a sense of loss and regret:

... Here [in the hospital] I feel bored because I'm isolated in the room. I cannot get out; there is nobody to visit me [extended family and friends]. A person should be able to go out, walk and have fun. (Younis 13 year old, Interview1)

As a result, Younis disliked being hospitalised and the day to day routine he had to follow made him feel restricted: “I do not like hospital ... I do not like the routine [in the hospital]... it is not good. [Pause] I am sick of it [hospital and the routine]”. (Younis 13 year old, Interview 1)

Haneen also felt alone in the hospital and compared her life before and after being diagnosed with HM *and* the changes it had produced. Her family was important to her and to her identity as a person. My sense is that Haneen felt complete when she was with her family. She was able to be herself and to feel the comfort generated by her supportive family relationships. However, hospitalisation deprived her of this source of comfort; she had to be dependent on herself instead of being dependent on her family. Therefore she felt loneliness and insecurity in the hospital:

I was with my family happy and relax all the time and suddenly I feel that I am alone. That means I am used to be[ing] with my family every day, but when I came here I am not with them anymore, I wish that they will come and visit me, all of them, all of them [Haneen was not happy (Field note 5, 1<sup>st</sup> April 2010)]. (Haneen 16 year old, Interview 2)

Fatima was also unhappy with the hospital routine which made the hospital an uncomfortable place for her to live. The established normal hospital routine disturbed her normal life routine leaving her feeling exposed and insecure:

I do not like hospital. The most annoying things are the doctors. Doctors came and woke me up for [my] weight measurements in the morning. After that they woke up me for my temperature then for medical rounds or in the evening for another temperature reading. (Fatima 13 year old, Interview 2)

Leith recounted the impact of hospital rules on his family’s ability to provide him with support during hospitalisation. It made his stay in hospital more challenging and placed extra stress on his family to meet the strict criteria set by the hospital around visiting hours. Leith felt an increasing sense of insecurity when separated from his family, and he came to recognise the importance of the support that they provided:

Here [in the hospital] they [doctors and nurses] don’t allow visits from many people; I would like to see all of my younger brothers. I really miss them a lot. [Pause] I need my family to support me. I need my mother to stay with me. I need my siblings’ support. I talk to them [siblings] by the telephone. I like talking to my little brother very much, because I love him. I talk to my other brothers, who always encourage me and tell me to be faithful in Allah, and read the Qur’an. [Pause] I really need their support. (Leith 13 year old, Interview 2)

Participants' lives began to change because of their hospitalisation. They had to take on new roles and live within a new set of rules that conflicted with those they lived within before their hospitalisation. Consequently, due to their limited freedom and autonomy within the hospital environment they were deprived of the continuous support of their friends and extended family. My interpretation from data collected during the first interview is that health care team members became the participants' "surrogate guardians" and their primary carer responsible for meeting their needs. That is, health team members became the central controlling and dominant force in participants' lives. As a result of feeling that their lives were now controlled by their "surrogate guardians", participants complained of feeling insecure, uncertain and experienced separation anxiety from their family. However, at the time of the second interview some participants were able to cope with their hospitalisation and had found that health team members were another source of vital support and guidance providing them with stability and predictability in their new social world.

#### **4.3.2: Reflecting on the past**

*Reflecting on the past* was the second sub-theme of *life is changing* that emerged during data analysis and referred to the process by which participants reflected on their experiences before being diagnosed with HM. In this regard, the process of reflection revealed certain methods that previously acted to provide predictability and their everyday lives. In particular, participants reflected on two major components of their previous lives; going to school and the rhythm of their life. Both of these will be described below.

For the majority of participants school constituted a large part of their daily life that helped to shape their identity as individuals and prepare them for the future. All but two participants in this study went to school at the time of being diagnosed with a HM. For those who were attending school it was considered to be a second home and a place where they spent a large amount of time each day. It was also a place where they could release their energy, express their feelings and gain emotional support from their friends. However, following a diagnosis of HM participants' lives changed and they now found it very difficult to attend school on a regular basis.

Hadeel spoke of previously attending school and how it was important in her life, a place where she used to study and play. However, after her diagnosis, she was unable to play or study as she did before and, during the interview with her, she reflected on her current situation and felt sad. She reflected on school because, after home, it constituted the most significant part of her life:

I like my school and considered it as my second home [researcher: second home?!] Yes, I used to spend seven to eight hours every day at school. In school, I played some games with my friends like hide [and] seek and the circle game. I used to play with them for hours and I used to study with my friends every day, but now I cannot do any of these things. (Hadeel 13 years old, Interview 1)

For Nancy, school represented a place where she could study, laugh and joke with her friends and it was a place in which to be sociable. She happily referred to going to school as being her favourite part of the day. Nancy attested to the importance of school in her life and she saw it as the place that contained her and which now had been taken away from her:

I go to my school, and this is my favourite part of the day. I used to do everything at school. We [Nancy and her friends] spend the first three hours laughing and joking, then it is time to be serious and it becomes time to study. As you can see, the first three hours have nothing to do with studying, and we consider them to be a time for relaxing. Then we take ordinary classes that mean it is time to get serious. (Nancy 17 year old, Interview 1)

In Jordan, if an individual wants to stress and confirm the importance of something to the listener, they use the phrase “of course”. Fatima stressed the importance of school, and her love of school, by using this phrase which emphasised how much she missed school as part of her life since being hospitalised. Even so, although she recalled her experience of school in a nostalgic way, she also felt unprepared to return to school because she did not feel normal anymore and she believed she would be stigmatised by her friends because of her illness (which will be detailed later in the thesis):

Of course, I like my school; I study, speak and play with my friends. We have so much fun. We talk about teachers and the girls and we play and tell jokes until the end of the day. [Researcher: Do you want to go to school?] No, I do not want to. ... I feel that if I went to school I would be tired. When I am very well I'll go back. (Fatima 13year old, Interview 1)

Given the fact that the participants were all in the adolescent stage of life they did not have extensive interaction within the community apart from with their friends at school or with relatives. Therefore, school was a place that enabled them to participate in all sorts of activities including extracurricular activities like playing and socialising. They valued the routine that school brought to their lives and identified this routine as a marker of normality.

Another marker of normality was the rhythm of life. The word “rhythm” means something which is done in a pattern, at regular intervals (Online Oxford English Dictionary, 2011d). In reflecting on life before HM, participants responded in similar ways about the rhythm of their lives and described this rhythm using examples such as going to school, studying, laughing, playing and sleeping at night. The rhythm of these behaviours represented the predictability, certainty and stability of their lives prior to diagnosis.

Nancy spoke of her rhythm of life as going to school, returning home to sleep, studying and helping her mother with housework. Due to a prolonged period of hospitalisation, she came to feel constrained within the four walls of the hospital. She underwent frequent medical procedures which interrupted her normal sleep pattern, and which resulted in an alteration to her normal rhythm of life. For Nancy, her sleeplessness was associated with pain but also with coming to terms with the diagnosis:

I do not like to move a lot [now]. It [my life prior to being diagnosed] was normal: [pause] I was [previously] a very energetic girl. I would like to move all the time. I woke up in the morning, ate my breakfast, did the laundry, went to school, came back home, studied, watched TV, visited my sisters or my sisters would visit me, and also my friends and my classmates would sometimes visit me. (Nancy 17 year old, Interview 1)

Tariq provided a similar description of his rhythm of life prior to his diagnosis: First of all [I] get up in the morning, go to school, return [to the] house to sleep, then [I] go out with my friends or [I] return [to] study my daily lessons and [I] go out. On Thursdays and Fridays I used to go out with my friends.... We were troublemakers; we cheated in the exams and smoked. In the break, we would go outside the school for breakfast and then escape from the school. (Tariq 17 year old, Interview 1)

When Tariq was hospitalised he was unable to undertake what he described as his normal rhythm of life due to his illness which challenged his ability to maintain his

emotional stability. However, over time Tariq was able to establish a new rhythm of life where hospital became the central experience. Tariq stressed this in the following exemplar:

I did not go to school or go out with my friends, because I've been here [in the hospital] the whole time to follow up my situation and do tests. Now, I suffer from low immunity and I have to stay in hospital. Sometimes I go to the hospital for routine test. After [doctors] do the medical check up, they find low immunity and then I have to be hospitalised. I came sometimes because I had a headache, and when I do blood tests they tell me I have a problem in my blood results so they admit me again to hospital. (Tariq, 17year old, Interview 1)

Joseph provided a further description about his rhythm of life being disrupted since his diagnosis of HM. Prior to his illness he played on his computer and used the Internet regularly. In Jordan many adolescents like Joseph use the Internet to play games or chat with friends and it is a part of their everyday life. When Joseph was hospitalised he experienced a disruption to his normal rhythm of life as the Internet was no longer available to him and was only used by hospital staff in their daily duties. Consequently, he felt cut off from his friends and his normal routine. When asked about his life before his illness Joseph said:

Normally I wake up at 7.30 [in the morning] and go to school. During recess I play with my mates, basketball or football, we prefer football. We play for 30 minutes then go back to classes. After studying, we sometimes play football again and then return to our homes, to have lunch. Then I do my homework. I used to study for three hours a day, and after that I surf the Internet. I spend a lot of time on the Internet. During the holidays, I spend about 12 hours [per day], maybe more, and that's because I like the Internet more than anything else. (Joseph 14 year old, Interview 1)

Two participants in this study had chosen the vocational education pathway and hence no longer attended school at the time of being diagnosed with HM. Therefore, the rhythm of their lives was centred on work and their financial commitments to their families. Following their diagnosis, these participants were unable to continue to work and conveyed their sense of loss to me regarding what was a very important and meaningful part of their lives. Adam, one of the participants used to work for long periods of time on a farm prior to his diagnosis but now was unable to continue to do so:

I left my school to work. Work is important to sustain my life, but now I am not working because I got sick. I was waking up in the morning, going to work and

returning [home] in the evening. I worked on a farm, so this means just going from work to home and nothing else. I went to the farm at seven in the morning and returned home at seven in the evening and sometimes at nine in the evening. (Adam 17 year old, Interview 1)

In general, each participant in this study had an intrinsic rhythm of life that played out in their external environment and gave shape to their internal worlds on a daily basis. Their diagnosis of HM and subsequent hospitalisation altered this rhythm and left them in situations that they were unfamiliar with.

#### **4.3.3: Fearing the unknown**

The next sub-theme of “*Life is changing*” was called *fearing the unknown*. All participants were expected to manage the immediate changes that they were experiencing due to their hospitalisation. Furthermore, the treatment for their illness and in particular the diagnostic tests they undertook continued to generate stress and uncertainty for them. Of particular note was the impact on participants of the bone marrow aspiration that they had to have completed on them. This procedure required special preparation and was conducted on participants using a local anaesthetic. The procedure was very frightening for them as it was painful and it had the potential for the patient to experience complications as a result of the procedure. I interpreted from my observations that the health team members did not take the time to explain what would happen during the procedure and therefore I suggest that this lack of explanation exacerbated the participants’ levels of fear and anxiety.

Participants were also frightened of the chemotherapy treatment they received as it caused nausea, vomiting, as well as other side effects. Although these side effects differed depending on the type of chemotherapy and the dose being given all participants commented on living with the side effects of chemotherapy. Similarly, I further observed that participants received little information from health team members about the potential side effects and the strategies that might be helpful in managing these adverse effects.

Experiencing the side effects of chemotherapy and diagnostic tests made adolescents aware of the significance and seriousness of their illness and its long term consequences on them. They began to understand that the illness may have a devastating

effect on their physical and emotional functioning as well as their future life goals and dreams. Haneen complained of headaches and an increased body temperature as side effects of the chemotherapy she was receiving: “Yesterday they gave me the first dose of chemotherapy. At first, I had a headache and then my body temperature increased”. (Haneen 16 year old, Interview 1)

At the time of the second interview Haneen was still not coping well with her chemotherapy but she was experiencing both physical and emotional side effects. She was so frightened of the chemotherapy that she often vomited as a response to the nurse entering the room to give her medication. Haneen had developed an automatic behavioural response caused by an association between the colours of her chemotherapy solutions and her response of vomiting: “[The] colours of [the] chemotherapy [solution] are disgusting I do not like it [chemotherapy]” [Haneen vomited too much before she was given the chemotherapy (Field note 8, 1<sup>st</sup> April 2010)]”. (Haneen 16 years old, Interview 2)

For Adam, being presented with the news that he had to undergo a bone marrow aspiration procedure filled him with fear. Prior to his bone marrow aspiration procedure he received no education or preparation and as a result he became disabled by the fear and the doctors were unable to complete the procedure. However, after talking with other patients that had experienced the procedure he was able to agree to undergo the procedure and his compliance demonstrated the power of the support he achieved through his communication with other patients:

... Then they [the doctor] told me that they wanted to take a bone marrow biopsy, but I told them that I would not let them take it, because I knew nothing about it and I was afraid. [Pause] I fear pain and fear of becoming paralysed, but at the end some other patients convinced me to do it. (Adam 17 year old, Interview 1)

Shahed added another dimension to the nature of her *fearing the unknown*. Her fear was precipitated by a lack of knowledge about the procedure that she had to undertake. As a result she thought she may become paralysed due to the bone marrow aspiration procedure. This fear was linked to her superstition about envy and magic, namely that she may become paralysed as a payback from the perceived wrongs she may have committed towards others in the past. This clearly demonstrates that Shahed was experiencing a consequence of her inadequate preparation by health team members

before she undertook the bone marrow biopsy procedure. Because of this lack of preparation Shahed's regressed to the use of magical thinking based on her beliefs about envy and magic to explain what could happen to her during the procedure. She also demonstrated the age appropriate behaviour of becoming self-focused. In combination, these two behaviours led Shahed to believe that she may become a victim of payback, resulting from her past "mean" behaviours directed toward her friends:

The doctor said that we need to take a biopsy from the bone marrow in my back. I told him that I can't let you do that because maybe I will become paralysed. The doctor did not comment at all, instead he laughed. [Pause] I used to mock all the people around me, especially my cousins. If I became paralysed some people will look at me with pity and sympathy and others who hate me would be happy for my situation. So I did not want that to happen. (Shahed 16 year old, Interview 1)

Although Adam and Shahed initially expressed their fear about having a bone marrow aspiration procedure, their fear was extrapolated due to their limited communication with and preparation by health team members.

Leith also experienced fear of the unknown due to a lack of information and preparation from the health team member regarding the bone marrow aspiration procedure:

No, no one told me that the bone marrow aspiration would be painful, but I became afraid of the bone marrow biopsies until the last one, when they told me that they would anaesthetise me so I would not feel any pain. They anaesthetised me, so I felt no pain. (Leith 13 year old, Interview 1)

As a result of that experience Leith became sensitive and fearful of all future procedures. He not only feared the bone marrow aspiration procedure but he was also scared to go through with any further surgery. He also believed that the bone marrow aspiration was the first of a series of more invasive procedures: "...it is because I think that a serious thing has happened [due to my bone marrow aspiration], and now I'm afraid that they will perform another operation on me". (Leith 13 year old, Interview 1)

In summary, fear of the unknown was experienced by most of the participants in the study and this fear was heightened by the lack of education and preparation by the members of the health care team. As a result participants were not prepared for the side effects of chemotherapy or the invasive procedures conducted on them.

#### 4.3.4: The changing self

*The changing self* was the next sub-theme of “*Life is changing*”. During the developmental stage of adolescence the person begins to formulate their goals, dreams and identity for the future. They also become sensitised to world and life events and thought more deeply about these issues than they have previously done. Adolescents also believe that they are very important to other people around them. During this stage of development self- image and the formation of their identity is very important to them (Berger, 1998; Berk, 2008; Shaffer & Kipp, 2010). Their descriptions of self-image are usually focused on two areas: body image and self-schema. Body image refers to the subjective perception of the one’s physical appearance based on self-observation and reactions from friends (Hayward, 2003). Self- schema on the other hand represents the beliefs and ideas that the person holds in regard to self. Most of the adolescents in this study were conscious about their physical appearance and they believed it was an important factor in how other people perceived and/or judged them as a person (Berger, 1998; Berk, 2008; Shaffer & Kipp, 2010).

Adolescence as a developmental stage of the life cycle is often a difficult and challenging experience for many adolescents and being diagnosed with HM adds to this challenging time. As participants’ illness progressed they reported negative experiences about their body image and self-schema as they experienced their *changing self* as a result of their HM. Many participants experienced a negative self-image due to things such as their loss of hair, weight loss and changes in skin texture and colour as a result of the chemotherapy they were receiving. The participants’ culture compounded these physical changes occurring to their self- image and self- schema. For example, most Jordanians consider long hair for females is an important determinant of beauty. Therefore, in Jordanian society it is uncommon to find girls with short hair. Similarly facial hair for males is considered as an early indicator of masculinity. Due to the chemotherapy they were receiving, participants’ experienced alopecia (hair loss) and this physical change due to their illness impacted negatively on their self-image and in some circumstances threatened their developing gender identity. Due to the physical changes they began to lack confidence and viewed themselves as being different and unattractive to other people.

The chemotherapy also caused participants to experience fatigue and a decrease in their level of physical stamina and endurance. Participants also felt that they would be rejected by those around them and this was reinforced because of the common myths regarding cancer, their absenteeism from school as well as their past experiences with other people who had this type of illness. Lastly, as a result of the negative changes occurring in their body- image and self- schema participants felt that their HM had changed them forever.

Shahed provided a good example of her assessment of her physical appearance following her diagnosis of HM. She did not believe that she was beautiful anymore. Before chemotherapy, she was very proud of her hair and she did not wear a Hijab (head scarf) very often. However, when she began to lose her hair from her chemotherapy she wore it all the time to cover her baldness. Before cancer, she used her beauty to gain attention from those around her. She described herself as a funny girl with a good sense of humour which she had now lost. In evaluating her life before and after the diagnosis of cancer she was now experiencing a lower level of self- esteem and a poorer self – schema:

I used to not wear a Hijab before my sickness but now I wear it all the time. Sometimes I was wearing a pyjama, blouse and jeans while making my rounds to see my friends. The nurses were laughing at me and at my appearance as I looked funny, it was really funny. My hair was long and I was pretty, not like now. I do not have any hair and my shape has changed. I was beautiful [before I became ill]. ... Compared to what I looked like before I am not that beautiful [now]. (Shahed 16 year old, Interview 2)

Although Shahed cried when her hair began to fall out, in reality her response to her hair loss was a symptom of the turmoil and confusion she was now experiencing since being diagnosed with HM. She was also beginning to face the possibility that she might die from the illness that she was fighting as became evident in the next sub-themes. She was afraid, scared and in pain, and she was beginning to demonstrate some of the behaviours associated with depression:

Every one of us as human beings would be affected psychologically from such a situation [having cancer and receiving chemotherapy], and, to be honest with you, I was crying because my hair was very, very long and suddenly it became short compared to how it was before. ... At the beginning I wanted to stay alone and I did not want to speak to anyone. I was scared of dying too early. (Shahed 16 year old,

## Interview 2)

Nehal also feared rejection making a comparison between her illness and a friend's experience with cancer some time ago. She did not want to tell anyone about her cancer because she knew from previous experience that she may lose friends if she confided in them that she had HM. At the time of the second interview, Nehal had communicated with her friends via the Internet but she was still not willing to confide in them that she had a HM:

I expect that the students will ask me why I have been absent from school. This is an expectation, so I don't care about the answer. [Pause] I will answer that I was sick without telling them my real diagnosis. I don't want to tell them; even on the internet when I connect with my friends, they ask me "What's wrong with you?" I just tell them that I'm tired. [Pause] We have a girl in school who had a brother who was sick with this disease. Just imagine, when her brother had this disease, the girls kept away from her, they were scared of the infection! [Pause] You feel that people will keep away from you, so why should I put myself in the same situation? (Nehal 13 year old, Interview 2)

Nehal also spoke of the loss of her hair due to chemotherapy as having an impact on her identity and self-esteem. She described her new look as being deformed. In using the word "deformed" she was referring to the fact that something had become distorted in her body appearance and her body had now changed for the worse. The word "deformed" was not only applied to her hair loss, but also to herself now that she was sick with a HM. Due to her illness her life had now changed and she had also changed forever. I developed the feeling that she was hiding and minimising her feelings about her illness during the interview with me as a way of hiding the stress that she was really feeling about the changes that were occurring within her:

After the ARA-C injection [type of chemotherapy] all of my hair fell out all at once. When my mum brushed my hair I noticed that the trash can was filled with my hair. It's normal, I didn't care, I didn't cry, but I felt a strange thing, I felt that my look was deformed, and I will not live the same life [as before being diagnosed with cancer] any more. I felt that there was no hair. [Pause] in the past, when my hair annoyed me, I wished it would disappear, but now I wish it would come back again. (Nehal 13 year old, Interview 2)

Younis also talked about the loss of his future identity as a man. He recognised what his hair loss meant to him and the loss of his emerging masculinity. Younis was scared that he might experience rejection from friends who had already reached puberty.

In Jordan most men are proud of their beards and moustaches and some men believe that without a beard or moustache they resembled females and are not real men. The male members of Younis' family may also have believed this as he came from a village where the people were more conservative than those in bigger cities. As a result, Younis was "sad", want to be "isolated" and not talk to others. By mentioning this, it seems he was demonstrating some early signs of depression and anxiety:

I became sad; I went to a chair alone, sat down on it and didn't talk to anybody. I was anxious that my hair would not grow again and my friends would laugh at me. Hair increases the beauty of the face and [you should] be proud of it. If somebody has a face that is beautiful [without a beard and moustache] the people around you will say it. (Younis 13 year old, Interview 2)

At the time of being diagnosed Nancy experienced a combination of complex feelings that encompassed a mixture of shock, pain, crying and fear about what the future held for her. Before she was diagnosed, Nancy was full of energy and expecting a prosperous future for herself. She never expected that having something like HM would ever happen to her and was severely affected when she received the news:

I can't describe or understand my feelings at that time [when I knew about my diagnosis]. It was a mixture of complex feelings. [Pause] initially I did not say anything, but later I cried a lot and I was scared. I was very anxious about the future. I did not expect this to happen to me, that I would be inflicted with cancer. (Nancy 17 year old, Interview 1)

In her second interview, Nancy was worried about her gender identity and she expressed concerns about her femininity. She reflected on herself prior to her sickness and how she had now changed. She now looked like a boy due to her hair loss and believed that her new self-image would frighten her friends and that they would chose to avoid her. When Nancy was asked what things were the hardest for her during her illness she stated:

The hair loss [pause] I am a girl and I liked my hair. Without hair, I feel that I am like a boy and I do not know how my friends will respond when they see me like this [without hair]. They [friends] will not like it [my new look] [She looked sad (Field note 10, 4<sup>th</sup> March 2010)]. (Nancy 17 year old, Interview 2)

Life was also changing for Joseph and he did not feel himself any more. He initially had more complaints about his prescribed cortisone medication than the chemotherapy he was also receiving. He became taller due to the cortisone and the rapid

changes in his body in such a short time caused him immense distress. I interpreted the situation as following, he could not cope with the changes in his body image and therefore he could not expect his friends to cope with his changed appearance. When asked how the changes had affected his life he stated:

Yes, my shape changed, not because of the hair, but my shape and features changed, my eyes changed, the matter took a lot of time. I suppose that as a result of the Cortisone I would become 10cm taller within one week. .... Yes, of course, [it bothers me] I look older than my friends now and I do not think they will be happy with this [my appearance]. (Joseph 14 year old, Interview 2)

Due to his illness Joseph experienced low self-esteem and he stopped studying because he believed that he would be unable to pass his exams and lost faith in his academic abilities. He believed that his illness had affected his memory and as a result his ability to solve mathematical problems. Hence, he chose to withdraw from school even though his parents anticipated that he would follow in their footsteps and finish his education:

My family wants me to study and go to school, and I didn't study anything from the beginning of the educational year because of my sickness, so I failed. Because of that I'll not study. I can't memorise easily and if I want to solve a mathematical equation I'll take a very long time, even if they tried to explain it 100 times. [Pause] they do not understand, I am not able to study any more. (Joseph 14 year old, Interview 2)

Muhannad also did not feel himself following his diagnosis of HM. As a result he stopped socialising with his friends as he was anxious about his physical capacity and was unable to compete at this level with them. Safety became a more important factor for him than socialising with his friends. His rationale for this was that he lived in a notorious area that was high in crime, and although he had previously been able to counter any trouble that might come his way he could no longer protect himself in the face of danger. Muhannad portrayed his neighbourhood's crime rate in an exaggerated way as there is no area in Jordan which fits the description he provided. There is a sense in which that Muhannad was trying to cope with his new situation through rationalisation:

I will be honest with you. The area which I live in is full of trouble that means if you cannot defend yourself then do not go out. When I felt that I am not the same as before I decided to stay at home and not get assaulted. (Muhannad 17 year old,

## Interview 2)

Most of the participants cried as a response to their diagnosis and because they were overwhelmed by what was happening to them and concerns about their future. Their HM threatened their sense of identity and they were forced to spend large amounts of time in hospital isolated from their families and friends. They had little contact with their friends and feared rejection from them following their diagnosis of HM. Therefore they were left to manage their emotions alone and in silence which amplified their stress and the sense of impending change in their lives. Their inability to share their emotion with friends was described as one of their hardest and most painful experiences.

Participants stigmatised themselves because they believed that others would reject them if they knew they had cancer. For example, Joseph tried to gauge what kind of response he might expect from his school friends if he told them about his diagnosis by revealing the information in an anonymous internet chat room. His resulting experience was catastrophic for him and he felt the stigma from people whom he had never even met. They called him the “cancer boy”. After this experience, Joseph decided to keep his diagnosis secret staying silent about his illness as he feared further rejection. I observed that Joseph was affected deeply by this incident:

I told them [people in the chat room] yes [I have cancer], so they would leave me and go far away from me. I don't know why, and they called me “cancer boy”. In particular, a girl who I knew before [I got sick] she disturbed me with this title. [Researcher: What did you do?] I went to her house [on the internet] and caused her trouble, shouting that all people have cancer, not just me. She is an English girl and she said to me “Don't talk to me”. At that time I thought very seriously about leaving everyone [to isolate myself]. But another girl sent me many presents, telling me “You must be strong, fight for life”, but then she distanced herself, and doesn't want to be friends with me. (Joseph 14 year old, Interview 2)

Leith also feared his friend's rejection because of his cancer and thought that they would leave him if they knew about his illness. Although, at the time of being interviewed, Leith had not experienced rejection from his friends, he was scared that it could and would happen. He was unsure about whether he was still capable of fulfilling his general responsibilities within his peer group. If he felt pressured in this relationship in the future he had decided that he would withdraw from his group of friends. Although he viewed boycotting his friends as one of the most difficult experiences that he might

be exposed to, the idea of rejection was more dominant for him:

I won't tell them [my friends] that I have cancer, because I don't want them to know that I'm sick, and they think that cancer is a very serious disease, and they'll be frightened of being infected. So they will distance themselves from me. [Pause] I'll apologise, not play with them, tell them that my mother won't allow me to go out and play. [Researcher: What is your feeling toward that?] I will not be happy and maybe it is a very difficult part of my life to not stay in touch with my friends, but it is better to take this decision by myself now before my friends decide to leave me. I am sure they will leave me if they knew about my cancer. (Leith 13 year old, interview 2)

Hadeel had a straight forward response and she did not return to school because she was sick and could not stand. She did not want her friends to see her in this state. Hadeel feared she would be seen as inferior compared with her friends in regard to her physical abilities and hence she was frightened of being stigmatised and rejected by her friends:

I don't go to school because I got sick and my mother took leave for me from school. You see, I couldn't stand on my legs, they became swollen, as well as my abdomen and hands, even my face was like that. [Researcher: Your family can pick you up from school?] I don't want my classmates to see me in this situation. (Hadeel 13 year old, Interview 2)

Fatima who was acutely aware of her frailty used the need to keep herself safe from injury as a reason to stop socialising with her friends. She believed that if she went to the playground she may be hurt or perhaps pushed by other students. Self- protection became very important for her:

No, I don't want to [go to school]. [Researcher: Why?] Because I feel that if I went to school I would be tired. I went to school twice. My uncle carried me because he was the principal at the school. I was afraid to play with my friends at the playground so I decided to stay in the class. [Researcher: Why?] Some students who did not know about my diagnosis could have caused me harm by accidentally pushing me. When I get well I'll go back". (Fatima 13 year old, interview 2)

In summary, having a HM and undergoing chemotherapy had a deep effect on all participants as they moved through the experience of a *changing self*. They could no longer trust their bodies or their physical capabilities and they were scared of losing their gender identity. They were frightened to disclose information regarding their illness because they may be rejected by their friends. Therefore, they decided to stop socialising altogether. While adolescence normally demonstrate increased risk taking

behaviours, participants in this study became increasingly aware of the impact that injury could have on their cancer journey and so tried to protect themselves from any situation where they could be exposed to physical injury.

#### **4.3.5: Becoming aware**

*Becoming aware* was the fifth sub-theme of “*life is changing*”. As previously stated adolescence is a time when young people begin to think more about being independent, autonomous and ultimately separating from their family of origin. In addition, the adolescents’ changing cognitive abilities include the use of formal or abstract thought. They start to plan their future and to focus on their own abilities and resourcefulness. Theoretically, their HM journey may have hindered their intellectual development, by stopping them from continuing with their formal education program. However, they believed that they had developed and grown as a person in other ways due to their cancer journey.

After being diagnosed with HM participants’ interests changed and their criteria for choosing friends also changed. They sought out friends who they knew would be supportive of them and who would not reject them because they were ill. They were also aware to that their health was now compromised; that their physical abilities were limited and that they were more dependent on their families. At this time, participants also became *aware* of the life limitations effects and of the possibility that they may die. While it is unusual for most adolescents to think about death, the reality of having cancer exposed them to this possibility.

Tariq spoke of losing interest in the friends he had previously had and began to concentrate more on his inner beliefs and Islamic values. He realised that one good friend was better than a dozen friends who were not prepared to support him at this time. I realised from Tariq’s narration that before his illness he had a very unstable life. He used to associate with friends who exerted a negative influence on him. After cancer, he interacted with his carers and spent more time with his family which provided him with stability and a sense of security. Due to this, Tariq’s self-esteem improved between the first and second interviews. Now, he did not need to go back to his old friends because he had the support of his family and health team members. Therefore, he *became aware* of the quality of his friends, rather than the number of his friends:

Maybe my friends are happy with me, but I'm not. Now [after being diagnosed with cancer] I can distinguish between valuable stuff and fake stuff. In the past, I went with my friends to see girls, but now that's not important to me. [Researcher: What is the real cause of changing your view towards them?] I am afraid of God now. (Tariq 17year old, Interview 2)

Tariq's awareness of the responses of other people toward him increased after his diagnosis, for example, he recognised how worried his parents were about his progress and diagnosis. This insight was a new experience for him and he realised that his parents were carrying unnecessary pain about what was happening to him. On occasions he spoke of calming his parents when they became anxious and upset about his illness. Tariq, like many of the other participants in this study, gained in wisdom and now held a different view of the world. This allowed him to reach out to his parents in their time of need and distress about what was happening to their son:

He [father] asks all the time [about my health]. I tell him, "that's enough", but he insists on talking to me. They [my parents] take care of me too much. They give the problem much more importance than I do. I feel sorry for them. I don't want them [parents] suffering because of me. (Tariq 17 year old, Interview 2)

A part of *life is changing*, was to be confronted by death and this made Tariq reflect on his own mortality. He saw the people around him die and he heard unpleasant stories about the outcomes for people who have cancer. He used the word "dominant" to describe the impact and size of his potential death on his life as it became an important, dominant and consuming focus of his life:

... Yes, everyone thinks about death. [Pause] One in my circumstances and my situation thinks about death. After I got cancer, in the early stages, I did not know what the nature of my sickness was, but when I saw people and they began to tell me unpleasant stories about cancer, and I saw people die, the idea of death became dominant in my life. [Pause] cancer is a killer. (Tariq 17year old, Interview2)

Similarly, Nancy *became more aware* of her family's sadness about her situation. Her parents became distressed by her illness and this impacted on their ability to care for other family members. This distressed Nancy as she realised that her illness was impacting on all members of her family. In responses both Nancy and her family tried to hide their feelings from each other. However, she was now the centre of her family's attention and the entire family routine changed in order to allow the family to be there during visiting times to take care of her. Her siblings felt sympathy and pity for

her and they tried to give up their own pleasures in order to make her happy. However, this response also had a negative effect on Nancy as she felt disturbed by this change in family dynamics:

I got very disturbed, particularly when I saw my mum and dad weeping. My brothers and sisters tried to hide the situation and their feelings, but when I talked to one of them the other tried to hide their crying in front of me. Their tears and feelings were imprisoned in their eyes, so they hid themselves far away from me and cried. I pretended not to see them, but I knew, and I didn't want them to see my feelings towards that because it would make them feel very disturbed and sad. (Nancy 17 year old, Interview 2)

Nancy faced uncertainty about her future since she was diagnosed with cancer. She had a fear of being alone; the fear became more pronounced as she became more unwell as a result of her illness. Death became a complex reality for her and she began to imagine what her life would be like when she died:

... I'm scared of not seeing my family, and stay in the grave alone. I thought about death when I was very tired, when I was admitted to the ICU. I even told my mum, if I died, to bury me near the house because I'm afraid to be alone. (Nancy 17 year old, Interview 2)

Similarly Shahed also started to review her life knowing that she too may not live as long as she had once expected. She now fully understood what her illness meant and she adopted a "truth technique" as a method of preventing any surprises that would exacerbate her potential for anxiety. Therefore, for Shahed, truth telling became for an integral component of a stable lifeworld:

Compared to what I looked like before cancer I am not that beautiful. Perhaps because I no longer joke, laugh, smile or act the same. I am not the same; I am sure because a lot of changes happened to me. Before, I just cared about standing in front of the mirror, doing my make-up, getting dressed and going out. But now I am sure I am not the same anymore. Now, I will tell you directly and to your face, even if it makes you mad, accept it or die; that is not a problem, I will tell you what I think about you. (Shahed 16 year old, Interview 2)

Adam was aware of experiencing mood swings and behaviour changes before his diagnosis but he now became more relaxed. Before his cancer, he took his home life for granted but he now realised what was important to him. He experienced a new and closer relationship with his immediate and extended family. He transformed from a self-centered adolescent to one that was more aware of the value and benefits of

relationships and socialising with his family. This explains why he twice placed emphasis, during the interview on visiting his extended family after being discharged. Adam's story held the hope of recovering from his illness and being able to visit his relatives in the future:

I was very angry [before being diagnosed with cancer] but now I'm not. I am not angry at all. In the past, when I got home and found that my mother had not cooked that day I would lose my mind and become very cross. Now I think if that happened I would not feel the same. Before my sickness I did not visit my relatives at all, but now all of them visit me and even my brothers are closer to me because of my sickness. If I am cured I will visit them [my extended family] all again, I will visit them all again. Life contains many things more important than what I thought in the past. (Adam 17 year old, Interview 2)

Participants in this sub-theme all experienced changes in their lives as a result of their illness. They had to continually adapt to their situation and the changes that were occurring. They developed an awareness of their illness and the fact that they may die sooner than they expected. With their fears and increasing awareness to the possibility of death they reported the need for increased support and contact with their parents, siblings, supportive friends and extended family members which will be covered in the next sub-theme.

#### **4.3.6: Level of support**

*Level of support* was the final sub-theme of *life is changing*. One of the main developmental tasks of adolescence is separation and individuation from their family of origin. However, after participants' lives were thrown into turmoil due to their HM many of them regressed to a previous level of functioning where they were more dependent on their families for support. They also wanted more contact with their siblings and encouraged their parents to bring them to visit. Most of the participants in this study expressed overt emotions towards their families and the support that they provided. However, participants particularly spoke about the importance of the support provided by their parents. This kind of emotional response is unusual in Jordanian culture, where most of children do not generally express feelings of love and gratitude toward their parents in their presence. In this sub-theme I depicted the participants need for support and their reactions to the support they received from their family and friends.

Fatima relied on support from her parents: “[I need my parents to] stay with me

and support me” (Fatima 13 year old, Interview 1). As she was young this support was important. Unlike some of the older participants, who were a little more reserved in telling the researcher they depended on their parents for support, Fatima expressed this need openly. By the second interview, Fatima’s need for support had increased to the extent that she wanted all her family to visit her. As treatment progressed, the side effects of treatment became prominent and, in turn, Fatima’s uncertainty about the future increased. This resulted in her feeling exposed, vulnerable, and insecure. The presence of her family constituted a safety valve for her and she felt an increased sense of security when they were present:

I need everyone to visit me, all of my relatives; my siblings, aunties and uncles. I need them beside me at this time, and they will relieve my suffering. (Fatima 13 year old, Interview 2)

Even Sale, who had experienced a difficult early relationship with her parents, came to recognise the importance of her mother’s support. Although Sale was not raised by her mother she still expressed her closeness to her. Even though she had a close relationship with her grandmother she still wanted the support of her mother too at this time:

My mother and my father have been separated from each other for a long time, more than 13 years, and at the beginning my mother would not visit us at all. I live with grandmother and she takes care of me. She [grandmother] helped me with everything I used to do. [Pause] in the last few years, she [my mother] would visit us and I love her despite what she did for us while we were still children.... After [I found out I had] cancer, my mother took care of me and she supported me. I really need that support. My father is a good man but he is busy all the time, either with his work or with his new wife, so we do not see him and I really need him beside me [Sad facial expression (Field note 9, 20<sup>th</sup> April 2010)]. (Sale 14 year old, Interview 2)

Adam lost his father when he was young and his mother was elderly. Although Adam recognised that his brothers were unable to visit as frequently as he wanted them to, he missed them and yearned for their company. While his brothers attempted to juggle hospital visits with their work, they found it difficult to achieve and were only able to visit on weekends. Adam found this perceived lack of family support an additional stress of lacking family hard to accept:

Yes, of course [I have visitors]. However, my father is dead and my mother is an

old woman so she only came [to visit] once. But my brothers visit me all the time because they have a car, so they can come and go whenever they want. [However] now they are not visiting me as often as before [Adam's facial expression indicates that he is not at all happy (Field note 11, 4<sup>th</sup> January 2010)]. I miss them. I need them beside me. I know that it is a very long distance and they all work, so Allah helps them. (Adam 17 year old, Interview 1)

While participants feared rejection from their friends as outlined in the previous theme they still reported they wanted contact with and support from them. However, most participants did not receive this support from friends following their diagnosis and this experience was stressful for them. They felt rejected and sad that their friends left them at this critical time in their lives. For example, Shahed:

... I have a lot of friends and all of them are good. I don't want to say anything bad about any one of them [my friends]. After being diagnosed with cancer, my closest friend is my sister Suzie. I feel that she is very close to me. [Pause] I really need my friends' help, but most of them [have] left me [after being diagnosed with HM]. (Shahed 16 year old, Interview 2)

Tariq was one of the oldest participants and was at a critical point in time of his life when he was preparing to finish his high school and enrol in university. Therefore, he needed a different type of support than the other participants and his girlfriend provided this. Their relationship was full of empathy; she encouraged him to continue with his study and her support helped him to look to the future and remain cognitively active:

That's right! I remember my first relationship with a girl when I was a student at a private school. The school is mixed until the fourth year. I was very young, just a child, but when I was in the seventh year, I talked to a girl in the fourth year. In the fifth and sixth years I spoke with her, but not very often. I talk to her nowadays; she is now in the twelfth year. She supports and helps me to study, because she is top of her school. (Tariq 17 year old, Interview 1)

After being diagnosed with HM many of the participants felt vulnerable, exposed, insecure and uncertain about their futures. Therefore, they reported their need for support from their parents, siblings, and friends in order to manage their stress. For them, family and friends became the container for all their anxiety and fear. When they found this support they were able to look forward to the future in a positive way.

In summary, at this stage of their cancer journey adolescents began to understand the complex nature of their illness. They had lost most of their normal life routine as

well as many of their friends. They faced the reality that they may die from their illness and they began to value things that had once been less important to them as adolescents, such as their parents.

#### **4.4: Ways of coping**

The final theme to emerge from the data analysis was called “*ways of coping*”. Participants developed a range of coping mechanisms to assist them to manage their experience of living with their illness. Some of their coping mechanisms were constructive and creative in nature, such as when participants focused their thoughts to relax them and empower their minds. For example, writing stories about their experiences. Other coping mechanisms were more in keeping with their age, for example, being in the playroom at the hospital that allowed distraction from thinking about their illness and their chemotherapy treatments.

This theme consisted of three sub-themes: (1) *Islam coping mechanism*; (2) *Playing down the severity of having cancer*; and, (3) *The recreation room*.

##### **4.4.1: Islam coping mechanism**

Islam was important to all of the adolescents in keeping with their socialisation as Jordanians. Given the ubiquitous presence of Allah [God] and Islam, adolescents in this study turned their attention towards their religion to help them understand and cope with the cancer experience. More importantly, Islam represented the fundamental mechanism for understanding the significance of allopathic medicine; for example, the importance of spirituality in the illness process and the context of treatment. For these adolescents, regardless of the human claims of the efficacy of chemotherapy, unless it was contained within the will of Allah, treatment could not be successful. That is, they believed that the will of Allah contained the absolute power to cure, just as Allah held all knowledge of human action and destiny. For these adolescents, this fundamental tenet presented an imperative to trust in the will of Allah and follow the precepts and laws of Islam.

Almost all the adolescents in the study used instructions of Islam to adapt to life with cancer, as all of them were Muslims. However, these adolescents followed the instructions of Islam in different ways according to their own understanding of the faith. Many believed that being “given” HM was a test from Allah which they responded to in

two ways. They received their medical treatment, prayed to Allah and read the Qur'an.

From the participants' perspectives, the capability of Allah to cure people was not in conflict with receiving medical treatment because Mohammed, the messenger of Muslims, said "Allah has not created any disease without also creating a medicine or a remedy for it" (Ibn Hajar, 1989). Therefore, people who are ill are expected to seek help from doctors and participants engaged in both the medical and spiritual aspects of treatment. Leith read the Qur'an when he was tired at night because it helped him to relax and sleep and had a calming effect on him:

My mother encourages me [to read the Qur'an] and I read the Qur'an. I read the Qur'an at night as well when I can't sleep, often for long periods until I slept. [The Qur'an helped me to overcome my sadness. (Leith 13 year old, Interview 2)

Nancy had a similar belief in the Qur'an's ability to help her to relax and sleep. She believed that the Qur'an calmed her soul and had a positive influence on her ability to cope with the illness journey:

I always read and listen to the Qur'an, when I go to sleep I listen to the Qur'an a lot in order to sleep well. Sometime I keep the Qur'an playing during my sleep in order to have a deep sleep. When we read the Qur'an, I feel relaxed and my soul calms down. (Nancy 17 year old, Interview 2)

Haneen saw no difference between the effect of reading the Qur'an or listening to music to relax her inner self. Haneen use of the word "or" meant that both methods had an equal effect for her and they were used interchangeably:

I watch TV, listen to music or the Qur'an, or wait for my friends. [Researcher: What is the effect of music or Qur'an on you?] I listen to both of them in order to relax. (Haneen 16 year old, Interview 2)

Tariq decided to use another Islamic coping mechanism. He decided to go on a minor pilgrimage and he drank Zamzam water (holy water for Muslims) in order for Allah to cure him. Most of the Muslims believe Zamzam water has therapeutic qualities and by drinking it Tariq was trying to draw on the will of Allah to cure him, as his chemotherapy was not as effective as the doctors had hoped it would be. Tariq believed that the Zamzam was helpful and as a result decided to take more notice of his prayers. His belief system gave him hope for the future:

I drink Zamzam water, read the holy Qur'an frequently and I'll go to a minor pilgrimage to Makkah. I believe deep down that the cure can happen, [Pause]

nothing can stand against Allah's will. [Pause] [Researcher: Do you strongly believe in Allah's will?] Yes of course. Due to what I did last time [drink Zamzam water and read Qur'an] the results were satisfactory, I became glad, thankful. I praise Allah more and more and pray at night always. (Tariq 17year old, Interview 2)

Shahed also turned to Allah to help her in her struggle against cancer. Her prayers gave her and her family hope that Allah would spare her and she would make a full recovery:

I am always asking my Allah to help me become better and my parents are always praying for me to get better. One day Allah will accept our prayers. [Researcher: Are you sure?] Off-course I am sure. (Shahed 16 year old, Interview 2)

Fatima felt that Allah had already responded to her call for help. She attributed her recent improvement in her health to Allah and her prayers rather than the medical treatment she was receiving:

I pray to Allah in order to cure me and my parents and siblings pray at night for me in order to cure me. [Researcher: Do you think these prayers will help?] Yes of course. I am alive more because of the prayers than the chemotherapy. (Fatima 13 year old, Interview 2)

Adolescents in this study strongly believed that their HM was a form of "Allah's will" and that they were being tested. Their faith was a form of fatalism that gave them the inner strength to accept their illness. Adolescents in this study use instruction of Islam as a method to empower themselves as a tool for "self-empowerment". For example, the more adolescents believed in Allah's capability to cure them in the future, the more positive they felt about overcoming their current fears.

#### **4.4.2: Playing down the severity of having HM**

*Playing down the severity of having HM* was the second sub-theme of the theme *ways of coping*. Most of the participants in this study played down the severity of their illness believing they would get better after their chemotherapy. This was supported by the fact that they had met many people with cancer who were still alive. Therefore, they believed they too would improve when their treatment was completed.

The participants also played down the severity of their illness by comparing themselves with other patients in the hospital who appeared to have more severe forms of cancer. By comparison, their HM was viewed as a simpler form of illness and their

chemotherapy regime less complicated. They also believed that they had a higher chance of recovery and this provided them with hope for the future.

Shahed stated that she was not afraid of her illness anymore and she trivialised her condition by comparing it to the “fashion of the year”. She jokingly advised all the newly diagnosed children at the hospital not to fear it because it was a popular disease and everyone can live with HM. She referred to the fact that many of her friends had lived and managed the illness for a long time without any problems:

I will tell them [other adolescents who have cancer] to not be afraid because this disease is the latest fashion trend of the year, so do not be afraid... I know many people who were able to live and cope with their illness. [Pause] at the beginning you may find it difficult and you will be afraid but after that [living with cancer normally] is expected. [Researcher: What do you mean by fashion? I mean all the people around me [in hospital] had a child diagnosed with cancer. (Shahed 16 year old, interview 2)

Muhannad also began to show no fear related to his HM. Based on his observations he believed that many people live with this type of disorder for many years without any complications and he would too and as such played down the severity of his HM. Muhannad demonstrated in the following exemplar the importance of having a support group of other cancer patient and their capabilities of helping newly diagnosed patient to cope with their illness:

No, I am not afraid of it [my HM]. I used to be afraid but now I can see other patients around me [in the ward] and they have told me that it is a normal thing, they live many years with their cancer without any complications. I have heard stories about people being completely cured from their cancer. Therefore, I'm not scared at all. (Muhannad 17 year old, Interview 2)

Sale believed that her illness was in the early stages and that her prognosis was good after receiving chemotherapy. She stated that her parents had also confirmed that her illness was uncomplicated. This resulted in an increase in her self esteem and level of hope:

I have cancer, but it is still in the first stages and they [the doctors] will cure it. [Pause] I should not be afraid because my father and my mother assured me that there is nothing serious and my cancer is a simple one. This means that the possibility of a cure will be very high. (Sale 14 year old, Interview 2)

Similarly, Leith thought he would be cured simply by taking his chemotherapy.

He also thanked Allah because he contracted Burkitt's lymphoma, and not leukaemia, as he was convinced that Burkitt's lymphoma was less severe than any other type of HM. Leith and his family were *playing down the severity of HM* by evaluating his illness in this manner:

He [doctor] took a sample [biopsy], sent it to the laboratory and after 15 days we knew that it was lymphoma, to be exact, Burkitt's lymphoma. They wrote in the medical report, either Burkitt's lymphoma or leukaemia, but thanks to Allah that was Burkitt's lymphoma. They [parents] told me that it's very easy, compared to leukaemia. My father told me that the chemotherapy that I will receive is nothing compared to other chemotherapies. (Joseph 14 year old, Interview 2)

In summary, participants played down the severity of their illness as a means of coping with what was happening. Some depended on their direct observations and the positive stories about other people who had survived the cancer journey. Others depended on the information from health team members and their parents that the possibility of treating their illness was higher than any other type of HM. Most of the participants compared their illness with others who had more serious type of cancer to play down the severity of their illness and to increase their hope that they would survive the illness. This was an important technique for the participants because by "playing down the severity of their illness", they were able to reinforce their hope in their future and in the possibility of their treatment.

#### **4.4.3: The recreation room**

*The recreation room*, as a coping mechanism, was the third sub-theme. The participants in this study who were in KHCC enjoyed different activities in *the recreation room* which was a specific room designed to allow adolescent patients to use the internet, paint and play outside of their hospital room. From observing the participants using this room it was most suited to those who were under 15 years of age. The room helped them to normalise their lives and forget about their illness for a time.

Fatima played with other young girls for many hours in *the recreation room*, and was able to forget about her HM. She mentioned this story in particular because playing with this girl reminded her that she was still valuable and still able to provide and help other people around her. Supporting other people who were also ill was beneficial because it assisted her to feel better about herself and to compare her outcomes with the

people she was now supporting:

I went to the playing room to play on the computer and take care of a one year old baby girl that I loved very much. I was playing with her and carrying her. I played with her for many hours [Fatima facial expression was happy and smile (Field note 3, 15<sup>th</sup> April 2010)]. (Fatima 13 year old, Interview 2)

Hadeel thought KHCC was better than her previous hospital because of *the recreation room*, and she spent time playing with the play station and computer. The distraction of the room, as well as the friendships established there with other patients made this room a significant place for participants while hospitalised. It was very helpful in assisting them to manage their level of pain:

The hospital here [KHCC] is better because there are games and I can have fun with other patients. [Pause] I play on the Play Station, the computer, and I like to play with singing toys. When I play [in recreation room], I do not think about my illness and pain. (Hadeel 13 year old, Interview 2)

Joseph chose to involve himself in activities in the room to relieve the frustration he was experiencing due to being hospitalised. He wrote some stories, one of which he entered in a KHCC competition. He also sent this story to the local radio station and they broadcast it live on air. In this way, Joseph expressed his feelings and tried to communicate to everyone around him that he was still valuable, even though HM had affected his body. He told everyone that he was still capable of using his mind and therefore was useful and still able to make a contribution to those around him:

Well, I don't know [what I will be in the future], I want to be a story writer. I participated in a competition [writing story] here in the KHCC and I won. I was very happy for winning, and even forgot about my illness. I sent it [the story] to the radio station and they broadcasted it live on air. I was very proud of myself. (Joseph 14 year old, Interview 2)

Participants identified strongly with *the recreation room* that it became like a companion or friend to them. It reminded them of the things they did with their school friends and family before being hospitalised. It provided them with stability and predictability. As programs completed in this room were goal directed, the capabilities of the participants were emphasised. More importantly, participants were more able to re-connect with their previous lives, and to offer each other support within a familiar context.

#### **4.5: Summary**

This chapter consisted of three main themes which are: “*silence of HM*”; “*life is changing*”; and “*ways of coping*” (See figure 4.1). I described the lived experiences of adolescents before and during the first six months of their diagnosis. I detailed and made sense of their lived experiences within their natural context which was Jordan. In the next chapter I will discuss and compare the current finding of the study against the current body of literature to obtain further interpretations to the lived experiences of adolescents with HM. The next chapter will also detail recommendations to practice changes within hospitals that care for adolescents with HM as well as educational improvements for health team members. Finally the chapter will outline future research ideas in this area of health care.

## CHAPTER 5

### DISCUSSION

#### 5.1: Introduction

This study used an interpretative phenomenological analysis methodology to explore and document the lived experiences of Jordanian adolescents who have HMs. The study also sought to identify factors that impacted on the illness journey. In line with the interpretative phenomenological analysis framework, this discussion chapter will begin with an overview of the study findings, which were described in detail in Chapter four. The findings are then compared to the existing knowledge in relation to children, adolescents and young adults (CAYA) who have cancer. The review has covered CAYA because of differences in definitions in the literature of the age range of adolescences and the dearth of literature which focuses specifically on HM in adolescents.

Interpretative phenomenological analysis pays special attention to the interaction between the researcher and the participants as the researcher plays an important and active role in detailing and interpreting the participant's experiences (Smith et al., 2009). Furthermore, I had pre-assumed that the Jordanian adolescents with haematological malignancies have different experiences from patients living in developed countries. Therefore, I did not extensively review the literature in this area prior to conducting these interviews and analysing the data as I did not want to contaminate my analysis of the data during this time. In following the IPA process I considered the participants as experts and therefore explored their lived experiences using the role of the naïve inquirer. Therefore, while a literature review on cancer was presented in chapter one of this thesis, this literature included at that time was to provide evidence for the need for this current study. The literature presented in this chapter will allow me to discuss the findings within the context of existing knowledge and understanding in the area. It will also allow me to further contextualise the lived experience of Jordanian adolescents who were the participants of this study.

The findings of this study add to the knowledge and understanding of trans-cultural care of adolescents with cancer and specifically to the care of Jordanian adolescents with HMs. The findings emphasise the importance of educating adolescents

who have these illnesses to assist them to overcome many of the difficulties that may arise during their illness journey. It also presents cultural differences that impact on the lived experience between Jordanian adolescents and those from other cultures. This is significant as it assists health team members to plan care to this group of patients in a culturally safe manner. While culture plays an important role in empowering patients and assists them to cope with their illness, health team members also need to be aware of how culture can impact negatively on the patients' level of health and wellbeing. For example, while participants in this study received high levels of support from their family members, they lost many of their important relationships outside of their family due to stigma at this critical time in their lives. Furthermore, while participants' Islamic faith was a powerful support for them, the same faith and associated cultural expectations created a clear distinction between gender roles. As a result, this increased their concerns about gender identity and impacted heavily on their level of well-being and self-esteem. As importantly, this study highlights the need for health team members to approach care from a holistic perspective to ensure cultural sensitivity and safety to this group of patients.

## **5.2: Overview of major findings**

The lived experience of Jordanian adolescents with cancer was articulated under three themes: 1) *Silence of HM*; 2) *Life is changing*; and, 3) *Ways of coping*. The theme "*Silence of HM*" described the period when participants started to experience the signs and symptoms of their illness and to seek medical advice about their concerns. During this time health team members or family members did not discuss with participants the possible causes of their illness and as a result they were left to flounder with their concerns that something was wrong with them. The second theme, "*Life is changing*" covered the period of time when participants were hospitalised and experienced the full impact of their treatment/chemotherapy on their lives. The third theme, "*Ways of coping*" portrayed the coping strategies that participants' utilised to assist them to live with cancer and to overcome the difficulties they were experiencing. Each theme had several sub-themes which are outlined in table 5.1.

The three themes that emerged from the data clearly articulated a journey where participants first became aware of their diagnosis and then learnt to accept, live and cope

with what was happening to both themselves and to their families. Specifically, this study depicted participants' experiences: 1) from the time of onset of the signs and symptoms of their illness; 2) when participants first became aware that something was wrong with them but did not know what was wrong because they were surrounded by silence; 3) when they began to experience the full impact of their illness and its treatment trajectory; and 4) the coping strategies that they employed to assist them to manage the changes that were occurring in their lives.

**Table 5.1:**

The main themes and sub-themes in this study.

<b>Themes</b>	<b>Sub-themes</b>
<i>Silence of HM</i>	<ol style="list-style-type: none"> <li>1. Surrounded by silence.</li> <li>2. Confusing the silence.</li> <li>3. Trying to make sense of what is happening in the presence of the silence.</li> </ol>
<i>Life is changing</i>	<ol style="list-style-type: none"> <li>4. When communication resumed.</li> <li>1. Being in the hospital.</li> <li>2. Reflecting on the past.</li> <li>3. Fearing the unknown.</li> <li>4. The changing self.</li> <li>5. Becoming aware.</li> <li>6. Level of support.</li> </ol>
<i>Ways of coping</i>	<ol style="list-style-type: none"> <li>1. Islam coping mechanism</li> <li>2. Playing down the severity of having HM</li> <li>3. The recreation room</li> </ol>

The major critical events identified through interpretative phenomenological analysis of this journey were: seeking medical advice, the silence of their parents and health team members, how the adolescents' responded to the silence, when communication resumed, the effects of treatment on participants, and the way they coped with the bio-psychosocial changes resulting from their illness and treatment. Other important events in the journey were: the experiences of hospitalisation,

participants' loss of daily life routine and the stigma directed towards them as a result of their illness.

As each participant's lived experience differed, there are no absolute cut-off points in movement from one stage to the next in the journey. Hence, their experiences were, and are, an iterative process; a process represented on a continuum, with some experiences achieving a greater presence during a certain period depending on each participant's context. In addition, participants responded to similar experiences in different ways as a result of their past cumulative experiences.

Overall, Jordanian Muslim adolescents regarded their journey as a challenge that highlighted both positive and negative experiences. However, they all expressed that their acceptance to God's will and their strong spiritual faith gave them the strength to actively participate in their journey with all its challenges. This study findings draw attention to the importance of participants' bio-psychosocial and spiritual experiences during the journey.

### **5.3: Placing the findings in the context of existing literature**

In this section, I will compare and discuss the major findings from the themes identified in this study with existing literature in the area. These findings are outlined in table 5.2. The significance that the findings make to current knowledge and understanding in the area will also be highlighted. As the literature on adolescents with HM is minimal, comparisons made in this section will be made with all forms of cancer occurring in CAYA.

#### **5.3.1: Disclosure of information to adolescents with HM and other forms of cancer**

A significant finding of this study was that all participants wanted knowledge to better understand their illness, prognosis and the outcomes of treatments they were completing. However, all participants articulated that they did not receive enough information about this from those caring for them and from their parents. This finding supports previous research on CAYAs with cancer that this group of patients did not receive sufficient information about their illness (Al-Amri, 2009; Davison et al., 1995; Davison et al., 2002; Jenkins et al., 2001; Meredith et al., 1996).

Generally, disclosing information about their illness to cancer patients is quite a common practice in the United States of America and in some parts of Europe since the late 1970s (Gordon & Daugherty, 2003; Novack et al., 1979). However, current research identifies that in the Middle East and Asia, there is more inconsistency in what and how much information is disclosed to this group of patients (Parsons et al., 2007).

**Table 5.2:**

Summary of the major study findings

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**Disclosure of information to adolescents with HM**

- In general, parents and their children were not prepared to handle the diagnosis of HM and they both lacked the preparation, knowledge and understanding to do so which lead them to use silence in the early stages following diagnosis as a coping mechanism.
- Both parents and participants did not communicate effectively during the early stages of their illness journey.
- Participants in this study were lacking in education, preparation and support from their health team members. They were left to make their own interpretations in regard to what was happening and what was the cause of their illness.

**Danger of Silence**

- Silence had several adverse effects on participants: Silence increased their level of stress and fear, their vulnerability and feelings of uncertainty and their fear of treatments and diagnostic tests. It also decreased participants' level of well-being.

**The negative impacts of hospitalisation**

- Hospitalisation was viewed as an unpleasant experience as it separated participants from their home, family and friends.
- Health team members were able to provide support and friendship to participants but they failed to use this friendship therapeutically to prepare, educate, empower and support the participants in this study.

**The bio psychosocial adverse effects of HM**

- Chemotherapy had an adverse effect on the adolescents' level of bio-psychosocial well-being. Medications altered their body image, which increased their level of stress, and decrease their confidence level. They were scared of changes to their gender identity as a result of the illness and hence they feared to be rejected by their friends.

**The need for support and lack of family centred care**

- Participants in this study reported their need for different levels of support from
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their parents, family and friends.

### **Positive impacts of the HM journey on participants**

- The experience of having HM increased participants' awareness and comprehension in several areas.

### **Using effective coping mechanisms**

- Participants in this study use Islam instruction, playing down the severity of their illness and creativity room as the main coping methods to overcome their difficulties with HM.
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A cross-cultural comparative study conducted in Japan and the United States of America (USA) to investigate the perception of oncologists towards telling children about their diagnosis (n=350 US and 362 Japanese respondents) found that 65% of USA doctors always disclosed the diagnosis to the children, 31% disclosed information most of the time and only one percent never disclosed information. However, only nine point five percent of the Japanese physicians disclosed information and 34.5% never disclosed to children about their diagnosis (Parsons et al., 2007). In Asian countries, disclosing information is usually left to the discretion of the doctor and the parents as to what and how much information is shared even if the patient is of the developmental age where they are aware that something is wrong with them (Arabiat et al., 2011; Baile, Lenzi, Parker, Buckman, & Cohen, 2002; El Ghazali, 1997; Harrison et al., 1997; Jadalla & Sharaya, 1998; Jiang et al., 2006; Mahadeen et al., 2011; Morasso et al., 1997; Seo et al., 2000; Veronesi et al., 1995; Younge et al., 1997; Yun et al., 2004). Congruently, in this current study doctors were conservative and protective regarding the amount of information that was disclosed to participants. In addition, parents due to a lack of knowledge in the area as well as the need to cope with their own reactions to their child's illness meant that they did not disclose information to their child. Currently, there appears to be no guidelines about the level of information to be disclosed to CAYA patients and therefore it is determined by a number of factors (El Ghazali, 1997; Jiang et al., 2006; Jiang et al., 2007; Novack et al., 1979; Seo et al., 2000; Smith & Swisher, 1998; Younge et al., 1997; Yun et al., 2004).

Culture and ethnicity appears to be one of the factors in determining the level of disclosure which occurs between health team members, families and CAYA patients. Baile, et al. (2002) investigated the practices of oncologists from all over the world in

regards to disclosure of unfavourable medical information to cancer patients. Oncologists from Western countries tended to disclose the entire diagnosis and subsequent information to patients even if the information was unfavourable to the patients or their family's requested to withhold this information. However oncologists from other countries in Asia, The Middle East and South America would withhold information from patients under the families' request. While Western cultures value the principle of autonomy and the patient's participation in the decisions made about their care, this appears to be less valued in more traditional, collective cultures where decisions are often made by family elders or fathers (Baile et al., 2002; Blackhall, Murphy, Frank, Michel, & Azen, 1995; Gostin, 1995; Parsons et al., 2007).

The decision to not reveal information to CAYA cancer patients is usually made to shield the adolescents from additional trauma and to maintain their mental well-being and hope in the future (Seo et al., 2000; Smith & Swisher, 1998; Surbone, 1992; Surbone, 2006; Younge et al., 1997). Moreover, in Middle Eastern countries a diagnosis of cancer has until recently been associated with poor survival rates (Awadallah, 2006; El Ghazali, 1997; Farmer et al., 2010; Petro Nustas et al., 2002; Surbone, Ritossa, & Spagnolo, 2004; Younge et al., 1997); and therefore Arab parents and doctors do not always inform their patients because they want to prevent them from losing hope that a cure will found (Levetown & the Committee on Bioethics, 2008).

The aforementioned factors may explain the reasons behind the attitude of non-disclosure of information by health team members and parents to adolescents in this current study. It is important that further research and exploration occur within the Jordanian culture to ensure that the needs of patients are being met during this time of personal crisis. The sharing of information in an age appropriate manner allows the patient, their family and members of the health care team to begin to work together in a constructive manner to support the adolescent during critical life events such as this.

Education of health team members regarding the benefits of family centred care and psychosocial support to cancer patients is needed to allow them to see the impact of withholding information from adolescents during the early stage of their illness. The findings of this current study demonstrate that the silence caused by the decision to withhold this vital information dramatically impacted on participants' lived experience

and on their resilience to overcome the challenges they face in the future as a result of their illness.

### **5.3.2: Danger of silence**

Another significant finding of this study was the danger of silence. Due to the developmental age of participants most of them became aware of their diagnosis before being officially told by their doctors or parents. To the best of my knowledge, this is the first study conducted in Jordan, which describes the impact of the doctors' as well as parents' silence on adolescents with HM during this critical time in their cancer journey. All previous Middle Eastern studies that have explored cancer in the CAYA age group have focused on the attitude of physicians, families and patients regarding disclosure of information (Al-Amri, 2009; Arabiat et al., 2011; El Ghazali, 1997; Harrison et al., 1997; Jadalla & Sharaya, 1998; Mahadeen et al., 2011). However, they have not previously explored the bio-psychosocial impact of withholding such information on adolescent patients and their treatment outcome.

In this study, the created silence was dangerous because effective communication between family members was damaged and the adolescent found themselves alienated from the sources that provided them with information during times of stress. This increased their vulnerability and altered their existing coping mechanisms. Another danger caused by the silence was that participants did not feel that they could interact with health team members who were caring for them or ask information from them because of the confusing message conveyed to them by the silence.

The silence also created fear and apprehension in participants who were asked to undergo painful diagnostic tests and treatments without any explanation of what the test or procedures were for or what would happen to the adolescent during the test. Other researchers have also documented similar findings of the lack of preparation and care given to cancer patients and the impact of this on their level of satisfaction with their treatment (Barrera, D'Agostino, Gammon, Spencer, & Baruchel, 2005; Chao-Hsing, 2002; Eapen & Revesz, 2003; Enskar et al., 1997; Smith & Swisher, 1998; Stegenga & Ward-Smith, 2009; Antonella. Surbone et al., 2004; Yun et al., 2004).

A danger associated with silence for patients with cancer is the risk of the development of disabling co-morbidities such as clinical depression and anxiety. Depression as a co-morbidity had a dramatic impact on all areas of care and can double the length of stay in hospital and impact significantly on the individual's health decision making processes and long term outcomes (Offer, Ostrov, & Howard, 1981; Parle, Jones, & Maguire, 1996; Shaffer & Kipp, 2006; Sigelman & Rider, 2009; Wynaden, 2010). Eapen and Revesz (2003) found that lack of communication between family members was found to be a significant factor which altered patients coping mechanisms and increased their level of stress. Health team members need further education to enable them to care for the patient holistically and to assess for and intervene to prevent or effectively manage co-morbidities such as anxiety and depression if they occur (Earle & Eiser, 2007; Enskär & von Essen, 2007; Hesketh et al., 2004; Hokkanen et al., 2004; Larouche & Chin-Peuckert, 2006; Münstedt et al., 1997; Novakovic et al., 1996; Price, 2009; Rosman, 2004; Stegenga & Ward-Smith, 2009; Wallace et al., 2007; Williams, Wood, & Cunningham-Warburton, 1999; Williamson et al., 2010; WHO, 2009).

It was evident from the findings of this current study that *when communication resumed* between parents, health team members and participants their level of satisfaction with care also increased. This more effective style of communication provided them with more support during their illness journey. In this regard, to the best of my knowledge this study was the first in Jordan to highlight the importance of communication to health care outcomes with this particular age group of hospitalised patients.

### **5.3.3: The negative impacts of hospitalisation**

Another significant finding of this study was the negative impact of hospitalisation on participants. This was a result of participating in painful procedures and having to comply with powerful chemotherapy treatment, being excluded from their normal established daily routine and being away from their families and friends.

To the best of my knowledge, this study was the first Jordanian study to identify the negative impact on the illness journey for participants of painful procedures such as bone marrow aspirations. Participants reported that the bone marrow aspiration was very

painful and that they were provided only with limited information before being asked to participate in the procedure. However, studies conducted with CAYA with cancer in western countries also reported patients' fears and anxieties in regard to painful medical procedures (Carlsson et al., 2008; Chao-Hsing, 2002; Griffiths, Schweitzer, & Yates, 2010; Williamson et al., 2010), particularly bone marrow aspiration. For example, the following researchers all documented unpleasant experiences such as having to lie down with the back bent in a special position for prolonged periods of time during the procedure, extreme pain after the procedure and having to undergo the same painful test on several occasions (Chao-Hsing, 2002; Griffiths et al., 2010; Wu, Chin, Haase, & Chen, 2009). Therefore, it is important that all patients undergoing painful procedures such as bone marrow aspirations are fully prepared both physically and psychologically for the medical procedures. They need to have the procedure fully explained to them and have time to ask questions from health team members. In addition, they need to be provided with aids and supports that will reduce the pain they experience during the procedures.

Another negative effect of hospitalisation was that participants were prevented from engaging in their normal daily routine in their established lifestyle. Being hospitalised meant that they were unable to do many of the activities that they used to do, for example, catching-up with their friends and going to school. These effects have also consistently been reported in the literature and along with the effects of chemotherapy were perceived to be the worst aspect of being ill (Barrera et al., 2005; Enskär & von Essen, 2007; Griffiths et al., 2010; Stegenga & Ward-Smith, 2009; Woodgate, 2005).

Hospitalisation severely affected participants' established relationships with their family and friends. They were no longer able to stay at home and therefore, did not have regular access to their normal support structures which added to their level of stress. Several other researchers have found that being away from these important support structures caused major difficulties for CAYA with cancer to cope while being hospitalised (Abu-Alsundus, 2002; Abu-Obeid, 2004; Al-Shmyleh, 1994; Enskär & von Essen, 2007; Kyngäs et al., 2001; Milkawe, 1998a). Therefore, these important psychosocial support factors need to be incorporated into care to keep adolescents in

touch with their families and friends. This can be achieved through more family centred care and family friendly hospital environments where visiting hours are flexible and provide families with strategies to provide a high level of support to their child.

#### **5.3.4: The bio-psychosocial adverse effects of cancer**

Another significant finding of this study was the bio-psychosocial adverse effects of cancer. Many of the participants experienced adverse bio-psychosocial effects as a result of their chemotherapy treatments and these effects had a significant impact on the cancer journey. This current study and previous research have identified that losing hair (alopecia) from the body was the most devastating effect of chemotherapy and hair loss impacted greatly on the patient's body image (Carlsson et al., 2008; Novakovic et al., 1996; Wallace et al., 2007).

It is well established that negative body image can have a detrimental effect on the mental wellbeing of the CAYA (Friedman, Reichmann, Costanzo, & Musante, 2002; Pesa, Syre, & Jones, 2000; Siegel, Yancey, Aneshensel, & Schuler, 1999). As a result of changes in their body image, participants in this current study reported low levels of self-esteem, and descriptions of feelings that are consistent with depression and stress. These findings are consistent with other research with CAYA patients (Price, 2009; Wallace et al., 2007; Williamson et al., 2010). This previous research has also found a significant positive relationship between alopecia and vulnerability and stress when compared with patients who did not experience an alteration in their body image. Similarly, alteration in adolescents' body image has also been linked to the development of depression and decreased levels of self-esteem (Novakovic et al., 1996) as the adolescents evaluated their behaviour, appearance, and performance negatively (Kyritsi et al., 2007; Vance & Eiser, 2002) and led to this group expressing that they felt less happy and less satisfied with their current life than their peers (Kyritsi et al., 2007; Vance & Eiser, 2002).

The alteration in body image due to alopecia was further compounded for participants in this study because it led to an additional threat to their developing gender identity. For women particularly, hair is a symbol of their identity, beauty and femininity (Rosman, 2004) and research has shown that female adolescents with cancer are more concerned about their appearance than males (Novakovic et al., 1996).

However, in this current study, males and females were equally concerned about their hair loss and its impact on their body image and gender identity. This is seen as particularly important as in Jordanian society, hair is linked to gender identity and the associated values and boundaries that separate male and female roles.

Uncertainty is another adverse effect of cancer on participants in this current study. Uncertainty is defined as “inability to determine the meaning of illness-related events and occurs in a situation in which the decision maker is unable to assign definite values to objects and events and is unable to accurately predict outcomes”(McCormick, 2002; Mishel & Braden, 1988, p.98). Based on the definition, three features to the concept of uncertainty can be identified: probability, temporality, and perception (McCormick, 2002). Probability can be defined as “the extent to which something is likely to happen” (Online Oxford English Dictionary, 2011c). Probability in the context of cancer is the uncertainty of recovery from their illness, the possibility of relapse and associated unfavourable experiences. Temporality is referred to duration, pace, and frequency in relation to illness symptoms, progress, treatment and the possibility of relapse (Wiener & Dodd, 1993). Unpredictability of such aspects influences an adolescent’s capacity to plan for the future. Perception is the way, in which something is regarded, understood, or interpreted based on a person’s prior knowledge and understanding (Online Oxford English Dictionary, 2011b). The perception of the cancer experience often lacks a frame of reference to a person’s existing experiences, which limits their ability to adapt to the situation, and make effective decisions (Decker, Haase, & Bell, 2007; Mishel, 1981, 1984).

Uncertainty was found to be a common shared experience between CAYA patients in the literature (Barrera et al., 2005; Carlsson et al., 2008; Chao-Hsing, 2002; Decker, Haase, & Bell, 2007; Enskar et al., 1997; Hokkanen et al., 2004; Jörngården, Mattsson, & von Essen, 2007; Neville, 1998; Novakovic et al., 1996; Wu et al., 2009). Participants in this current study described all of the components of uncertainty outlined in the above definition including whether they were going to recover from their illness. Participants in this current study were also concerned about dying and this concern was further exacerbated each time they experience severe pain. These bouts of pain further increased participants’ levels of anxiety and stress. This relationship between pain and

the possibility of death has also been previously described in the literature (Chao-Hsing, 2002; Enskar et al., 1997; Williams, Davis, Hancock, & Phipps, 2010).

The negative impacts of cancer and the related psychosocial changes in participants exposed them to the risk of developing co-morbidities which may prolong their length of stay in hospital, impact negatively on their treatment journey and test their resilience and coping skills during this critical time in their lives (McCormick, 2002; Offer et al., 1981; Parle et al., 1996; Shaffer & Kipp, 2006; Sigelman & Rider, 2009; Wynaden, 2010). Another reason that could place participants at increased risk of developing disorders such as depression is the mood swings and distress which are the side effects of chemotherapy (Wu et al., 2009). Participants in this current study who were hospitalised for long periods of time showed that they were at risk of developing the early signs of co-morbidities such as depression and anxiety. For example, they began to isolate themselves and to withdraw from those around them and refuse to talk to their friends and felt anxious and fearful about their future. This finding is significant for the participants in this current study as to the best of my knowledge previous research conducted in Jordan has not identified the significance of co-morbidities such as depression and anxiety and of early at risk behaviours such as isolation in this group of cancer patients.

Adolescents with cancer in previous studies expected support from their friends and were not afraid to inform their friends about their diagnosis (Stegenga & Ward-Smith, 2009). Furthermore, Wallace et al. (2007) reported CAYA cancer patients tried to hide the changes in their body due to the cancer by wearing caps, scarves and wigs when interacting with their peers and not going in public with their heads exposed. These important discrepancies between previous research and the findings of this current study are important and require further exploration. The differences may be based on the level of education and support that patients during their cancer journey received from health team members and these appear to have a significant influence on shaping their behaviours toward cancer.

Many other factors have also been identified in the literature as impacting on the psychological well-being of adolescents with cancer (Carlsson et al., 2008; Enskär & von Essen, 2007; Hokkanen et al., 2004; Novakovic et al., 1996) and these were also

spoken about by some participants in this study. These factors included expressions of loss of control over their current life, increasing loss of independence and of regression to a previous developmental stage where they again became more dependent on their families.

In conclusion, while participants articulated responses that are consistent with risk associated with the development of co-morbidities that could extend their stay in hospital and influence the illness journey, health team members did not provide any specific care to address these early signs. Participants were provided with physical care for their cancer, and support in the form of friendship from nurses, but the nursing models of care were not family centred and did not focus on addressing the psychosocial issues that were reported by participants. Therefore, this study provided important findings in relation to the delivery of holistic care to CAYA cancer patients in Jordan and particularly the role of nurses in promoting health and preventing the development of co-morbidities in patients with HM.

### **5.3.5: Positive impacts of the cancer journey on participants**

The next significant finding of this study was the positive impacts of the cancer journey on participants. As they progressed through the cancer journey, as evidenced in the second interview, all participants displayed maturation in all aspects of their lives and in their ability to respond to the changes occurring in their lives. These changes have also been supported by previous research ( Enskär & von Essen, 2007; Ramini et al., 2008; Ritchie, 2001a; Wallace et al., 2007; Wu et al., 2009). This current study demonstrated that participants moved from being self- centred adolescents to become more in tune with the world around them and to value the importance of relationships and family. They also became more aware of their inner beliefs and Islamic values.

Participants in this current study became much stronger as individuals as a result of the difficulties they had experienced and were more able to cope with the daily stresses imposed on them by their illness. Other researchers have added additional findings in this area, for example, adolescents with cancer realised the importance of positive thoughts to their health outcomes (Wallace et al., 2007); they became more mature as a result of their illness (Enskär & von Essen, 2007; Ramini et al., 2008; Ritchie, 2001a) and they began to set realistic goals about their future when compared to

their healthy peers (Wu et al., 2009). It was also noted that the participants in this current study developed an increased level of maturity as a result of their cancer journey. This allowed them to realise the importance of the support provided to them by their families.

### **5.3.6: The need for support and family centered care**

Another finding of this current study that adds to existing knowledge and understanding was the need of the adolescents with HM to have support from both family and friends. Adolescents both in this current study as well as in existing literature highlight the importance of and their need for support from their families and peers (Enskar et al., 1997; Griffiths et al., 2010; Hokkanen et al., 2004; Larouche & Chin-Peuckert, 2006; Ritchie, 2001b; Williamson, et al., 2010; Woodgate, 2008; Wu et al., 2009). These important influences provide CAYA patients with stability in their lives and to protect them from unpleasant experiences (Griffiths et al., 2010; Larouche & Chin-Peuckert, 2006; Williamson et al., 2010). Increased levels of support was also found to be an important factor in decreasing the side effects of chemotherapy, such as, insomnia, stress, and distress mood (Corey, Haase, Azzouz, & Monahan, 2008).

Although participants in this current study would have valued the support of their friends they did not seek this support due to the social stigma attached to cancer in Jordan. Stigma directed to cancer patients has been previously identified by other researchers (Chao-Hsing, 2002; Eapen & Revesz, 2003; Hokkanen et al., 2004; Jadalla & Sharaya, 1998; KHCC, 2011d; Williamson et al., 2010; Wu et al., 2009). For example, Williamson et al. (2010) on his article “Adolescents’ and parents’ experiences of managing the psychosocial impact of appearance change during cancer treatment”, reported that the peers of adolescents patients teased them, avoided them and asked questions of them that increased their level of stress (Williamson et al., 2010). They also believed that their friends gossiped around them, stigmatised and avoided them due to their belief that their illness was contagious and as a result there was a possibility that they could catch the infection (Chao-Hsing, 2002; Eapen & Revesz, 2003; Jadalla & Sharaya, 1998; KHCC, 2011d). In school, CAYA with cancer have experienced similar stigmatisation from their teachers (Hokkanen et al., 2004; Novakovic et al., 1996; Wu et al., 2009). As a reaction to the stigma, adolescents in this current study deepened their

relationship with their parents and their extended family to fill the gap in the support once provided by their peers.

Support remains a critical issue for CAYA patients and previous studies have shown the importance of sharing their experiences with other CAYA patients who have or had cancer. These supports are extremely beneficial as they allow the patient to discuss sensitive issues with others who have the same lived experience (Enskar et al., 1997; Griffiths et al., 2010; Hokkanen et al., 2004; Larouche & Chin-Peuckert, 2006; Ritchie, 2001b; Williamson et al., 2010; Woodgate, 2008; Wu et al., 2009). An important finding in this current study is the need to establish similar support groups for adolescents with cancer in Jordan. Another issue raised in previous studies and reported by only one participant in this current study was the need for CAYA patients to have friends of the opposite gender. These relationships provided patients with a range of supports that fostered empathy and encouragement (Chao-Hsing, 2002; Hokkanen et al., 2004; Wallace et al., 2007). Only one participant in this current study raised and discussed this issue. However, this finding was expected as establishing opposite gender relationships are forbidden in Islam and culturally talking about this issue was sensitive for most of the Jordanian adolescents. This issue requires further research and adolescents should be provided with security, confidentiality and privacy to answer these sensitive questions from their perspective, thus a quantitative approach would be more suitable.

Another finding of this study that adds to the existing knowledge and understanding was the lack of a family centred care model in Jordanian haematological units. The family-centered care model has evolved as crucial to health care delivery in the second half of the 20<sup>th</sup> century as more attention was directed at meeting the psychosocial and developmental needs of children and the importance of families in promoting the health and well-being of their children (Jolley & Shields, 2009; Thompson, 1985). Family centred care can be defined as an approach of caring for patients and their families holistically and the approach emphasises that care is provided and planned around the whole family, not just the patient (Shields, Pratt, & Hunter, 2006). Based on the definition, the family centred care model has several characteristics which are detailed in table 5.3 below.

Family centred care is based on the premise that the family is an active collaborator in the care of their sick family member and their support and input can add significantly to the well-being of this person at all phases of their illness journey (Lewandowski & Tesler, 2003). This approach of health-care delivery is well established in many western countries and is based on sharing information, supporting parents in the decision-making processes and respecting the choices made by the family (Gance-Cleveland, 2006; Lewandowski & Tesler, 2003).

**Table 5.3:**

Characteristics of successful family-centred care delivery model (Institute for Family-Centered Care, 2005; Shelton & Stepanek, 1995; Shields, 2010).

- 
- The family as an integral part of the patient's life and health professionals should involve them in all aspects of care.
  - Families are experts in assessing and evaluating their ill member's abilities and needs.
  - Collaboration between health care professionals and parents should occur during all aspects of the illness journey.
  - Health professionals should respect the racial, ethnic, cultural, and socioeconomic diversity of families.
  - Health professionals should respect the unique characteristics of each family and deal with them based on their abilities and respecting their different methods of coping.
  - Information about the patient should be shared with their parents.
  - Family-to-family support and networking should be facilitated and encouraged.
  - Holistic care includes responding to the patient and family's developmental needs.
  - New policies and practices should be developed that support families with emotional and financial support.
  - Health care delivery should be culturally sensitive and encompass to the family's needs.
- 

The literature identified several advantages for families and patients when they rated care as more family centered. Families felt more emotionally stable and their level of stress was reported as lower (King, Rosenbaum & King, 1996). Furthermore, patients' satisfaction rates increased, length of stay decreased, and medical error rates also decreased (Crock, 2008; Holm, Patterson, & Gurney, 2003; Neff, 2003). A study

conducted to depict a multidimensional family focused intervention for pain and anxiety management with children being treated for acute leukaemia, using the patient's mother and one sibling as co-therapists. Physical resistance was reduced and anxiety responses decreased during therapy sessions. Mother's anxiety and sibling distress also decreased (Barrera, 2000). Ferrari et al. (2010) has reported to maximise the outcomes of the treatment plans, multidisciplinary collaboration between health team members, patients, and their families is required.

Jordanian health care professionals who work with the participants in this current study were unable to provide adolescents with most of the elements of family centred care outlined above in table 5.3. As a result, the participants reported that the hospital rules deprived them from receiving support as well as the ability to keep in touch with their siblings and friends. They also reported that they and their parents did not receive effective and collaborative support from health team members. At the early stage of their diagnosis, the main concern for health team members was to treat the adolescents' physical health without regard for their level of psychosocial health and wellbeing. They also did not engage the participants' families in the treatment plan. However, The International Society of Paediatric Oncology (SIOP) working committee on psychosocial issues in paediatric oncology has stressed the significance of a therapeutic alliance between health team members and the patient's family in order to reduce participants negative experiences (Masera et al., 1998). There is a need to re-evaluate the current approaches to care in Jordanian hospitals and adopt new policies and practices that ensure the delivery of a family centred care approach in all hospitals caring for adolescents.

### **5.3.7: Using effective coping mechanisms**

The last significant finding of this study was the use of effective coping mechanisms by participants and to best of my knowledge this is the first Jordanian study that explored the importance of the use of coping mechanisms by adolescents while living with a HM. Moreover, no previous studies in the Arab region on adolescents have discussed the influence of Islam as a religion in adolescents coping mechanisms in such a deeply interpretation way.

Most of the participants and their parents relied on their Islamic beliefs to empower themselves in coping with their illness. However, this coping method is not limited to Jordanian adolescents, as many other studies have reported the importance of religion to people during difficult times (Abdoli, Ashktorab, Ahmadi, Parvizy, & Dunning, 2011; Alferi, et al., 1999; Barrera et al., 2005; Ben-Zur, Gilbar, & Lev, 2001; Dalal, 2000; Hassan Errihani et al., 2008; Gallup & Gallup, 2005; Michael et al., 2005; Musick, Koenig, Hays, & Cohen, 1998; Sherman et al., 2001; Taylor, 2003). The findings of this current study and previous findings support the importance of religion in empowering the patient during their illness. In general, religious coping was found to provide patients with cancer with multiple benefits such as maintaining self-esteem, providing a sense of meaning and purpose, giving emotional comfort and a sense of hope (Thuné-Boyle, Stygall, Keshtgar, & Newman, 2006).

Islamic belief serves multiple functions to ill patients and is more than just turning to Allah for help. For example, for participants in this study, Islamic belief provided them with answers to certain questions such as “What is the cause of this cancer?” and “Why am I afflicted?” The answer from an Islamic perspective was “it is a test from Allah and Allah tests strong people”. Participants believed that their illness was Allah’s will and that it was a test from him. Therefore, they had to be patient and pray to Allah to cure them. Their fatalist belief played an important role in empowering them during this journey.

Another coping method used by participants in this current study was to play down the severity of having the haematological malignancy. This purposeful style of maintaining hope was specific to Jordanians adolescents as a response to not being provided with enough information regarding their illness. Similarly, maintaining hope and trying to remain positive was a common coping mechanism for adolescents with cancer in previous studies (Enskär & von Essen, 2007; Wu et al., 2009). Enskär and von Essen (2007) found that most of the adolescents kept a positive outlook on the future in order to cope with cancer.

Another coping method that participants in this current study used was re-focusing on inner power and on the relationships that they already had with their family and health team members who were a source of stability for them. Adolescents in a

previous study adopted similar coping mechanisms that empowered their relationship with their health team members and families instead of their friends (Griffiths et al., 2010). *The recreation room* in KHCC and the activities inside were important for some participants as it allowed them to focus on their intellectual ability which empowered them to overcome the pain and other distressing aspects of their illness. Originally established for this purpose, each activity in *the recreation room* is used to attain different goals. However, in Jordan only KHCC has this type of room. There is a need to generalise the KHCC experience to other hospitals in Jordan. In this regard it is important to mention that *the recreation room* in KHCC was originally established for all cancer children regardless of age however there is a need to consider the adolescents needs separately. In general, the coping mechanisms used by participants in this current study were limited and based on Islamic custom and religion. During their interactions with health team members participants were not encouraged to develop additional coping mechanisms based on modern psychological theories.

Lastly, the effectiveness of adolescents coping mechanisms depend on many factors (Enskar et al., 1997; Kyngäs et al., 2001; Larouche & Chin-Peuckert, 2006; Robinson, Gerhardt, Vannatta, & Noll, 2007). Family stress had a significant impact on the adolescents coping with cancer. In this current study and previous studies family stress was common factor that hindered adolescents coping mechanisms (Robinson et al., 2007). Support from friends was another important contributing factor for adolescents to cope with their illness (Enskar et al., 1997; Kyngäs et al., 2001). Most of the participants in this current study did not receive enough support from their friends. Therefore, the participant's coping mechanisms were hindered by the absence of these factors. It is the time for health team members to provide adolescents with family centred care and to establish new effective methods to keep adolescents in contact with their friends in order to enable the adolescents with cancer to effectively cope with their illness.

#### **5.4: Summary**

The application of interpretative phenomenological analysis in this study has allowed the researcher to identify many significant findings regarding the impact of the HM on Jordanian adolescents. This journey depicted three main themes: *Silence of HM*, *life is changing* and *ways of coping*. These findings were discussed and related to the existing body of knowledge. From this discussion, I conclude that participants in this study faced their illness alone and with insufficient education and support from their family and health team members. Their lived experience of cancer was complex and cannot be reduced to any specific experience within the illness journey. Therefore, it is difficult to isolate one experience from another and health team members need to consider all of these experiences when developing an effective educational program to assist Jordanian adolescents to effectively cope with their HM. The implications of these discussions will now be covered in the final chapter of this thesis.

## CHAPTER 6

### CONCLUSION AND IMPLICATIONS

#### 6.1: Introduction and overview

This thesis details the lived experiences of Jordanian adolescents with HM along with the factors that impact on these experiences. The findings demonstrate that these groups of patients are exposed to a variety of physical, social, psychological and emotional experiences throughout their illness journey which impact on their health care outcomes. However, current Jordanian health care policies, agendas and existing research do not highlight the importance of these experiences to patient outcomes and this lack of recognition may compromise the quality of care provided within the Jordanian context.

Specifically, the findings emphasise that:

1. Health policy makers, health care team members and the general public do not fully understand the cancer experience. More importantly, they do not identify the importance of the psychosocial dimension on the illness journey and health outcomes. In Jordan, current practice in adolescent oncology tends to focus on the physical well-being of the patients, for example, administering chemotherapy while undervaluing the impact of the psychosocial dimension of care. Furthermore in Jordan, depending on the availability of beds and physicians an adolescent who becomes ill is treated as either an adult or a child patient. This age inappropriate care further impacts on the cancer experience and the adolescent's ability to cope with the illness journey.
2. The philosophy of a family centred care model is absent in many Jordanian hospitals and this may cause adverse effects for both the patient and their family. The family and patient's well-being is increased through collaboration and effective communication with health professionals and this is a significant factor in the delivery of care.
3. Culture plays an important role in the illness journey for Jordanian adolescents. However, current models of care are largely adopted from Western countries and therefore, they are not sensitive to the specific cultural needs and practices of Jordanian patients.

4. The use of effective coping skills play an important role in assisting adolescents to overcome challenges they face due to their illness and further development of these skills should be the focus of psychosocial interventions with the adolescent during their hospitalisation. Therefore, health team members, particularly nurses required education and training in the delivery of these interventions at the clinical level.
5. To assist this group of patients to cope more effectively during their illness journey and to prevent the development of co-morbidities, such as depression from occurring, new models of care need to be implemented and these need to address all of the dimensions of patient's journey. Policy and practice changes that educate health professionals to assess and manage these dimensions of care are essential for demonstrating best practice in the care of adolescents with a HM.
6. More research is required to clearly articulate the nurses' role in caring for patients with a HM and to facilitate the development of evidence based nursing practice in this area of health care.

In this concluding final chapter I will outline the implications of the findings for policy and practice. These implications are based on the analysis of both the study findings and of supporting literature. Future research is required in this area and suggestions for this will be detailed along with the strengths and limitations of the study. Finally the concluding statement of this thesis is presented.

## **6.2: Implications of the findings**

The implications of this study to policy and practice changes are addressed under two headings: 1) Initiative needed to assist adolescents who are living with cancer, and 2) The provision of culturally sensitive care. Each of these two implications will now be presented in detail.

### **6.2.1: Initiatives needed to assist adolescents who are living with cancer**

The first implications of the findings of this study are initiatives needed to assist adolescents who are living with cancer. It is suggested that these initiatives target five main areas: 1) the general population; 2) health team members; 3) parents and family members; 4) adolescents with cancer; and 5) management strategies used by health team members. Each of these initiatives will now be presented.

#### **6.2.1.1: Initiatives directed toward the general population**

The participants in this study were unprepared for what was happening to them. They did not understand their illness and at times they were overwhelmed by their experiences. Their parents were also unprepared and lacked knowledge and understanding of what was required to care for their child. In general, it appears that the Jordanian public does not have a good understanding of cancer and of the treatment interventions provided to cancer patients. There is a need to increase public education in this area, in regard to the causes, visible symptoms and treatments. This increased education will facilitate improved understanding and this will assist in the early detection of cancer in Jordanian adolescents. It will also improve the level of available support to the ill person from family and friends. This support is viewed as vital to decrease the levels of stress in patients as well as their families (Kreitler & Arush, 2004).

Although in recent years in Jordan there has been an improvement in the survival rate for adolescents with cancer, stigma directed towards patients with this illness prevents many people from receiving support. Cancer is viewed as an infectious and lethal disease and many Jordanian people will not seek to have contact with cancer patients (Jadalla & Sharaya, 1998; KHCC, 2011d). Increased education would assist in resolving the myths that many people hold regarding the causes of cancer. The use of mass media to provide this education would, decrease the level of stigma experienced by cancer patients and increased their level of support.

To raise awareness of cancer, the Jordanian public should be informed of government policies and health strategies in relation to providing modern holistic cancer care. The information should convey to the public advances in cancer treatments,

increased survival rates for cancer patients and of the importance for cancer patients to be able to live productively within their community. The media plays a crucial role in facilitating the education of the general population and it can increase public knowledge about cancer. However, research suggests that the proactive role of the media is limited and furthermore, that it often perpetuates the stigma directed towards people with cancer. The media reinforces that cancer is a lethal disease which is connected to a sense of hopelessness (Faulkner, Peace, & O’Keeffe, 1995). This current study revealed similar negative community perceptions towards people with cancer which amplified participants’ feelings of vulnerability and isolation. Therefore, there is a need to reverse this negativity within Jordanian society through the use of positive media educational cancer programs.

The Friday sermons in Mosques throughout Jordan could provide an opportunity to provide education and gain community support towards people living with cancer by circulating information about the importance of support to the wellbeing of this group of community members. This would be a convenient way to disseminate information to more isolated members of the community. For example, the Bedouin (17% of total population) and rural communities groups who often have high rates of illiteracy when compared to other components of the Jordanian population (Abu-Jaber, 1991).

In summary, collaboration between government departments is required to facilitate the implementation of policies that could alter the general population’s knowledge about cancer. In this regard, the media and Friday sermon are a highly effective medium for this purpose.

#### **6.2.1.2: Initiatives directed toward health team members**

The level of knowledge that health team members imparted to adolescent patients and their families in this study was viewed by participants as being insufficient for their needs. This caused increased feelings of insecurity and vulnerability in participants particularly during the early stage of their illness following their diagnosis. Therefore, it is recommended that health care team members receive education regarding the types of support that are needed by oncology patients and their families. This is particularly important for the profession of nursing, as nurses have ongoing and close daily contact with patients and as such can provide important information and support during these

frequent interactions. Further research on the role of the nurse within this specialty area will promote the development of evidence based practice to shape policy for the profession of nursing.

Hayes-Lattin, Mathews-Bradshaw, and Siegel (2010) stress the importance of health team members who work with adolescents to be well-trained and have specific educational programs to develop expertise to work with this patient group. The education programs for health team members need to focus on the bio-psychosocial dimensions of care as well as the participants' physical experiences of the cancer journey. The bio-psychosocial dimensions of participants' lived experiences are complex, overlapping and each experience cannot be understood without considering the whole cancer experience, its context and the relationship to other experiences. For example, the adolescent's physical condition, their frequent hospitalisations, their experience of social stigma and negative body image are integrated and impact on the totality of participants' experiences (avuolu, 2001; Chao-Hsing, 2002; Hokkanen et al., 2004; Larouche & Chin-Peuckert, 2006; Vance & Eiser, 2002). Woodgate (2008) in her study "Feeling States: A new approach to understand how children and adolescents with cancer experience symptoms" reached the same conclusion describing the overlapping effect of chemotherapy as a domino effect on the whole patient experience.

In fully understanding the bio-psychosocial experiences of patients, health team members also need to appreciate that while each individual's journey is similar it is also different. This variation is due to each participant's developmental age, previous life experiences, coping skills and level of education and understanding of their cancer journey. These similarities and differences when acknowledged by health team members allow them to better understand the needs of each adolescent and to be more responsive and supportive to these needs. In practice, this awareness can assist health team members to decrease the risk of negative experiences and the development of co-morbidities in the patients.

Education for health team members should also focus on preparing these professionals to differentiate between normal behaviours and those that can be interpreted as an adverse reaction to the illness experience. For example, the patient's changes in body image may be a normal process for adolescents but in the cancer

situation if these negative perceptions continue for extended periods of time then they may become an early indicator of a larger unfavourable experience such as depression. As part of daily practice, health team members should observe and report new behavioural reactions in patients and discuss the impact of these behaviours within the context of the patient's illness and care. Care plans should acknowledge these changes and interventions commenced to ensure that they do not become prolonged or exaggerated issues for the patient. To assist in developing these plans Hayes-Lattin, et al. (2010, p.4859) recommended that health team members should possess specific knowledge when they work with adolescents and young adults (AYA) patients and nature of this knowledge is depicted in table 6.1 below.

**Table 6.1:**

Information that health team members should possess when treating AYA patients with cancer (Hayes-Lattin, et al., 2010, p.4859).

- 
- Epidemiology of cancer in the AYA population.
  - Biology and cancer genetics of common AYA malignancies (e.g. sarcomas, lymphomas, leukaemia, testicular cancer).
  - Treatment regimens specific to AYAs for malignancies more common in AYAs
  - Physiology and host biology across the AYA age range (e.g. implications for chemotherapy dosing and toxicity and development of age-related co-morbidities).
  - Psychosocial and neurocognitive development across the AYA age range.
  - Biomedical consequences of cancer treatment (e.g. acute adverse effects and late effects).
  - Fertility preservation options.
  - Secondary and tertiary prevention applied to the AYA age range.
  - Knowledge of research (e.g. basic, translational, and clinical research in AYA).
  - Knowledge of bioethical and legal issues particularly relevant to AYA patients (e.g. consent or assent to research or therapy, sharing of health information with AYA minors and family members).
- 

Universities and health services in Jordan may need to evaluate the current level of education that health professionals receive to care for adolescents with cancer. It may be beneficial to establish postgraduate programs for nurses at a national level to allow

those interested in this area of health care to develop specialised postgraduate skills. This would also allow specialist knowledge development not currently addressed in the undergraduate nursing curriculum to be available to nurses. In-service education should also be provided by health services to graduate nurses to increase their knowledge and skill development in this area. A program currently being run at KHCC while in its infancy prepares new nurses who want to join the team with a short course that covers general topics such as pain, chemotherapy administration and medication calculation. There is a need to expand this course to focus on addressing the bio-psychosocial needs and care of adolescents who are living with cancer.

Academics and clinicians also need to work collaboratively to establish these new educational programs. For example, hospitals in Australia collaborate with universities to design postgraduate certificate nursing courses in specialised areas like mental health, intensive care unit (ICU) and paediatric care, which focus on contemporary practice and the quality of service provided to the patients. This collaboration also encourages the research culture between nurses to reduce the gap between academic researchers and nurses who work in the clinical field. In order to promote this, there is a need to recruit academics to support and promote a research culture in hospital staff. For example, Australian hospitals offer part time contracts to academics making a significant contribution in certain areas of research. These academics join hospital teams to teach and conduct research in collaboration with health team members ensuring practice is based on best available evidence. These collaborations also facilitate capacity building of research skills in clinical staff.

In summary, there is a need for health professionals to have an increased knowledge and understanding of how to intervene professionally with adolescents with cancer to increase their coping skills and overall level of well-being. In addition, health team members have a responsibility to decrease the stigma towards cancer patients held by the general public. Similarly, increased collaboration between members of the health care team can promote best practice and the delivery of evidence based quality care.

### **6.2.1.3: Initiatives directed toward parents of the adolescents with HM**

Parents of patients with HM would benefit from increased knowledge, ongoing emotional support and tangible community aid. This education and support would assist these parents to more fully comprehend what was happening to their child as well as the treatments they were receiving. This would allow them to provide a more informed level of support to their child as well as reducing their level of stress. Therefore, from the onset of their child's illness health team members should include the parents and also focus on the well-being of these important supports to the patient. However, the findings of this study showed that parents were not provided with education about how to respond to their ill child and how to maintain their psychosocial well-being. From observations documented in my field notes where education was provided it was limited to facilitating the parents' ability to complete care tasks such as giving medication. Parents in several other studies have also reported the need for health team members to provide them with informative education regarding their child's illness, management strategies and side effects of medication (Kreitler & Arush, 2004; Ljungman et al., 2003; Sloper, 1996). There is a need for health team members to meet with the parents to discuss their child's diagnosis, allowed them to express their concerns and be encouraged to ask any questions that they have. In this regard, the first meeting between health team members and parents is important to facilitate this ongoing process of meeting as the needs of parents will differ throughout their child's treatment trajectory. This is important in supporting parents and in reducing their level of anxiety, as many parents believe that their child may die as a result of the illness. This meeting will provide time to get to know the parents and to alleviate their wrongly conceived fears or beliefs. As parents as they are often in a state of shock during their first interactions with health team members, much of the information provided during this time should be repeated in later meetings (Kreitler & Arush, 2004).

Following their child's diagnosis, parents are more than likely to enter a cycle of information seeking which will require frequent clarification from health team members. It may be helpful to provide parents with support systems such as hotlines that are available 24 hours a day to answer generalised questions about their child's health. These support services have been found to be an effective method in other countries in

providing information to parents and in reducing their levels of stress (Sawyer, Antoniou, Toogood, Rice, & Baghurst, 2000). When parents are informed about their child's diagnosis it is important to encourage them to be active members in the illness journey as the primary carer to their child. Effective communication between parents and health team members will allow the parents to become confident in their care giving role and with their child to remain in control of the decision making process related to care. Epstein and Street (2007) stress the importance of providing patients and families with effective levels of communication in order to promote their healing and reduce their suffering.

Parents and siblings should also receive structured ongoing emotional support from health care team members as they are exposed daily to stress due to their family member's illness. Research shows that parents of children with cancer experienced stress, self-blame, feelings of guilt and a sense of responsibility regarding what happened to their children (Boman et al., 2003; Dahlquist et al., 1993; Kreitler & Arush, 2004; Langton, 2000; Sawyer et al., 1998; Sloper, 2000). The psychosocial impact of cancer also extended to the patient's siblings (Alderfer et al., 2003; Fanos et al., 2005; Heffernan & Zanelli, 1997; Houtzager et al., 2005). The later studies displayed siblings as exhibiting loneliness, sadness, anxiety, depression, guilt, shame, isolation from the family and portraying attention-seeking behaviours. In addition, these individuals often experience conflicting feelings, for example, jealousy as a result of some loss of attention from their parents and empathy towards their sick siblings (Alderfer et al., 2010; Kreitler & Arush, 2004; Wilkins & Woodgate, 2005).

Ignoring the psychosocial impact on the family and not considering this in current care plans can also negatively impact the adolescent with HM. Similarly, Sawyer et al. (1998) in his article on "the influence of parental and family adjustment on the later psychological adjustment of children treated for cancer" found that when health team members failed to identify and provide distressed parents with adequate support that this distress had a significantly long term impact on the whole family. In general, there is a need for health team members in Jordan to use a family centred care approach to allow all family members to engage in the process allowing them to cope and adapt with their child's illness.

As part of family centred care, health team members should facilitate support groups for all family members, including the ill adolescent to provide improved levels of psychosocial support. These programs should become a routine part of the cancer programs in hospitals to ensure the needs of all family members are met. Othman, Blunden, Mohammad, Hussin, and Osman (2010) reported that such programs increased parents' knowledge and decreased anxiety when compared with the control group. These programs were also found to be valuable to parents in helping them manage their children's illness effectively and reduced their level of stress (Kazak, 2005; Langton, 2000; Othman et al., 2010; Svavarsdottir & Sigurdardottir, 2006).

The provision of tangible aid, for example, education on how to access financial assistance is essential in supporting parents in the cancer journey. Previous research has identified that there are several economic difficulties that arise from having a child with cancer, such as HM (Dockerty, Skegg, & Williams, 2003; Miedema, Easley, Fortin, Hamilton, & Mathews, 2008). These include things such as extra travel costs and work-related issues with one of the parents frequently having to leave their job to care for their child. In addition, the out-of-pocket medical costs not covered by health insurance are a major burden for many families (Brown et al., 2008; Dockerty et al., 2003; Kazak et al., 2003; Miedema et al., 2008). Hospitals should implement an administrative service that provides advice to parents and assists them to plan and manage some of the expected financial burdens in relation to their child's diagnosis. At this stage there is no governmental support for such initiatives. However, in KHCC there is an individual effort to collect donations to financially support people in need and this practice may need to be supported throughout the health care sector.

In summary, initiatives for parents should focus on providing informative education, emotional support and tangible aid. These initiatives would be beneficial in preparing parents to more successfully care for their children who suffer from cancer.

#### **6.2.1.4: Initiatives directed toward the adolescents with cancer**

The participants in this study were unprepared to handle their illness and were overwhelmed by what was happening to them. However, through their narration they displayed the capacity to be reflective and re-evaluate their lives and relationships with people around them. There is a need for health team members to work with and involve

the sick adolescent in the development of their care plan. This plan will assess the adolescent's needs in the area of cancer education, available decision making and support processes and their understanding of treatment interventions they are receiving for their HM. For this to occur, patients need to be provided with the necessary information so they will be able to participate effectively in those decisions which will maximise the effect of their treatment plan. The effectiveness of these practices in promoting adolescent acceptance and coping with their illness has been established by previous researchers (Kreitler & Arush, 2004; Langton, 2000).

Although participants in this study did not specifically express their educational needs, CAYA in western countries actively sought more education about their illness and its impact on their life (Hokkanen et al., 2004; Stegenga & Ward-Smith, 2009; Williamson et al., 2010; Zebrack, Yi, Petersen, & Ganz, 2008). These CAYA wanted practical tips on how to manage their altered body image (Hokkanen et al., 2004; Williamson et al., 2010; Zebrack et al., 2008) and more general information about their illness, for example, exercise, nutrition, complementary and alternative health services, infertility information, mental health counselling, and camp or retreat programs for young adults (Zebrack et al., 2008). They also wanted to know how to cope with embarrassing situations that resulted from changes in their body image (Hokkanen et al., 2004). In addition, they reported a need for more information regarding their illness such as, the possibility of the illness recurring, the effects of drugs on participants (Hokkanen et al., 2004). Therefore, participants in this current study require education on the aforementioned issues commonly identified in western countries. This education will better prepare them to face these commonly experienced problems, which will decrease their stress levels and to increase their self- esteem.

Participants in this current study also expressed that due to their HM they were constrained by their physical disabilities. This made them feel different to their peers and therefore they chose to withdraw from socialising with their friends. It would be helpful for health team members to try to encourage as much physical activity as possible for patients with cancer during hospitalisation. The importance of physical activity in restoring health and alleviating stress is well established in the literature (American Heart Association, 2010; Cancer Council Australia, 2009; Pulu et al., 2007;

WHO, 2010a). The findings also showed the importance of friends' support to the cancer journey. There is a need to maintain participants' social engagement with their peers at all times throughout the journey and peers should be encouraged to visit them frequently. There is a need to establish formal support groups for the adolescents with cancers such as HM in order to facilitate the development of new friendships with people who are experiencing similar problems. This will provide a valuable means of additional support for each other (Stegenga & Ward-Smith, 2009). These authors stress the importance of support groups for both recently diagnosed adolescents and those who are further along the cancer journey. Adolescents felt that they were paying back to others by helping newly diagnosed patients and gain satisfaction and increased self-esteem from taking on this role (Stegenga & Ward-Smith, 2009). Trying to minimise participant's periods of hospitalisation and giving them access to phones and the internet during their stay in hospital will enable them to keep in touch with their friends. Having access to the internet was found to be very important to adolescents who have cancer and hence offering access to such services would reduce their stress and increase their level of satisfaction in the level of service provided to them (Thomas, Albritton & Ferrari, 2010). This would also assist in decreasing the level of social stigma directed towards patients as their friends would be able to speak with the patient on a daily basis encouraging normalisation of cancer within the community.

Adolescents with a cancer such as HM need to remain connected to their schools and their teachers should be kept up to date with their current progress. There is a need to educate their peers with factual information regarding their friend's illness and the expected physical changes and capabilities of the adolescent when they return to school. This way, they will receive a higher level of support to allow them to adjust to their changing life circumstances. KHCC has conducted pioneering work in this area and they have established a partnership with the Ministry of Education in Jordan. This partnership allows adolescents with cancer to complete their final exams. The hospital recruits volunteers to tutor the patients in subjects like mathematics, chemistry and physics as the patient is often unable to complete their school work independently without this support. This partnership has assisted patients to maintain their current

educational program and aids in increasing their self-esteem and sense of achievement while hospitalised.

Lastly, as was evident in this thesis, adolescents developed their own unique coping mechanisms. Accordingly, health team members need to be aware of these mechanisms and empower adolescents to use them to assist them in their cancer journey. Acknowledging and respecting the decisions that they make enable the adolescent to have a sense of control over what is happening around them. In summary, health team members must consider the needs of adolescents with cancers such as HM in order to enable them to adapt with their illness and approach their future more confidently.

#### **6.2.1.5: Initiative that assist health services to normalise the HM journey for adolescents**

Throughout this current study, participants spoke about the management strategies used by health team members that they perceived to have an adverse effect on their cancer journey. In providing quality cancer care the government, policy makers, as well as health team members need to obtain feedback from patients regarding improvement to care. These improvements must also focus on normalising the cancer experience for patients. For example, prolonged periods of hospitalisation increased participants' feelings of isolation from their families and this was exacerbated by rigid visiting hours that exist at some hospitals. Hospitalisation also resulted in a disruption to the adolescents' daily routine which added to their stress of being away from their family. Therefore, there is a need to review the current policies of hospitals to make them more family friendly and lessening the associated stress on both families and patients.

In Jordan, public hospital rules only allow limited visitation rights during certain hours of the day and these rights are limited to adults. As a result the patients are unable to socialise with their peers as visiting hours at the hospital conflict with schools hours and therefore time is limited to visit sick friends in hospital. There is a need to expand visiting hours to patients of this age group to increase opportunities for them to communicate more frequently with their friends. In addition, the rules in governmental hospitals do not allow children younger than 16 years of age to visit their parents, siblings and/ or their friends in hospital and this also has detrimental effects on those concerned. It might also be helpful for the government to provide hospitals with

up to date facilities to allow patients to make phone calls, send emails, and have access to the internet thus allowing them to continue to be part of their vital relationship networks whether they are in hospital or at home.

To further enhance the adolescent's level of wellbeing it is crucial for the Ministry of Health to develop a national website with established networks for patients that are monitored by experienced psychologists and nurses. This website could provide general information about cancer, for example, the types of HMs as well as the opinions of those adolescents who have knowledge of the lived experience of cancer. The website could provide adolescents with the opportunity to discuss various topics related to their illness with other patients in a confidential forum under the supervision of experienced psychologists and nurses. This website could include some educational and entertainment activities to further facilitate the normalisation of hospitalisation for the adolescent. The website may provide links to adjunct therapies such as humour, relaxation techniques or creative outlets such as drawing or writing. It could be a safe sanctuary where adolescents could freely express themselves and share stories with others in a similar situation to themselves in a "closed face book format". Adolescents with HM and other forms of cancer could also have a direct voice on the service user experience to health policy planners to share their evaluation of the health services provided.

There is also a need for health care planners in Jordan to train volunteers and establish a 24 hour hotline service which will provide support and answer the questions of families and children suffering from HM. These volunteers with technical training or a previous lived experience of cancer would reduce the burden on the general hospital system and assist families to care for their child effectively. It is also recommended that special units be established for adolescents when planning future hospitals in Jordan so that this group of patient is separated and not placed in adult or children's wards as is current practice. This will allow them to meet together and discuss their illness and support each other. The transition between childhood to adolescents must be acknowledge in health planning in order for this group of patients to feel comfortable within the hospital environment and to receive quality care from oncologist specialising in this stage of the life cycle.

A playground area could be established so adolescents can participate in physical activities and escape from their “sick” room on a regular basis. This type of recreation room should be developed in all hospitals as these provide adolescents with valuable resources to distract them from the pain and discomfort that they are experiencing. It will also assist the adolescent to further develop new effective coping mechanisms and valuable friendships. Finally, there is a need to establish a visitor’s room in the haematological units that incorporate the use of colourful designs. This room would allow the adolescents to spend time with their guests in an environment away from their “sick” bed and associated medical equipment. This would provide them with a feeling of normality and assist both the adolescent and their family to normalise the illness experience.

Health planners could collaborate with the Ministry of Education to ensure that the educational needs of patients are met and to educate all teachers and students about cancer and how to integrate cancer sufferers into the classroom following discharge from hospital. This step is crucial in order to decrease the stigma associated with this illness in the young generation and to ensure that this group of patients continue to receive their school education.

The findings of this current study stress the importance role that oncology community nurses can play in educating and supporting adolescents with cancer and their parents in community. Although community nursing constitutes one of the major units that undergraduate nursing students in Jordan complete at university, this role is not adopted by cancer hospitals. Community nursing roles are limited to educating women about contraception and family planning. If the community nursing role were expanded to the care of patients with illnesses such as HM then this could lead to more patients being treated effectively in their homes and reduced medical costs for families. This type of care could be expanded to provide a “hospital in the home” concept where patients could be discharged from hospital earlier and cared for by community nurses on a daily basis. This would facilitate family involvement and confidence in caring for their sick family member and decreased the psychosocial impacts of the illness and hospitalisation on the patient. Treating the adolescent at home means that they are able

to maintain contact with their family and friends conveying to them security and normality. Financially it also has advantages to the health care system.

In summary, the current management strategies and policies used in hospitals that treat adolescents with cancers such as HM need to be enhanced based on the findings of this study. There is a need for decision makers in Jordan to create new policies aimed at improving adolescents' health and their ability to cope with their illness in order to improve their quality of life.

### **6.2.2: Initiatives needed to establish culturally sensitive care**

The meaning of illness is different and varies across cultural groups and social class (Helman, 2001; Langton, 2000). Understanding how various cultural groups manage illness is important in order to develop culturally sensitive and safe care. That is, the same illness may be perceived by two people from different cultures in a different way. This difference is due to the individual's interpretation of events and this interpretation will also affect the way the individual resolves their personal health issues (Langton, 2000). The media, folklore, personal and second hand experiences also shape the individual's concept of illness (Langton, 2000; Lupton, 2003) and how the ill person will respond (Helman, 2001). In this current study Jordanian culture was found to have three major influences on how adolescents shaped their experiences of HM.

#### **6.2.2.1: Initiative to alleviate the threat of silence**

The first influence that Jordanian culture had was to create for participants the experience of being surrounded by silence. The effects of this silence lead to an increase in their level of stress, vulnerability, uncertainty and isolation. Hiding and suppressing feelings of stress has a devastating effect on the participants' level of wellbeing as established earlier in the discussion chapter. The culture was found to be a significant contributing factor to the phenomenon of silence. Jordanian culture encourages patients and particularly male patients to conceal their pain, not to share it with others and to display only solidarity (Branden & Broeckaert, 2010; Clark, 1996; Sachedina, 2005). There is a need to influence this cultural belief as this research shows the importance to patient care outcomes of communication between family members when faced with the adversity of events such as cancer.

To promote effective cultural communication with parents, health team members should meet regularly with them and provide them with education and support so they fully understand their child's illness. This will increase their capacity to handle stress and to support their child through the illness journey. Health team members need to reinforce the importance of open and honest communication between parents and their children. Furthermore, they need to assist parents to learn how to cope with and manage bad news and how to communicate this in an effective manner to their children. It may be helpful in preventing the patient from being *surrounded by silence* to discuss with their parents the advantages of informing their child about their diagnosis in the early stages of their illness.

While encouraging the process of communication between parents and their child, health team members should make parents aware that due to the developmental age of their child they will potentially discover their diagnosis by themselves. Therefore hiding this information from them could affect both their relationship with their child as well as the child's health outcomes. Parents need to be informed that globally the emphasis is on informing affected children about their diagnosis and assisting them with family support to adjust to the changes in their lives (Hollen & Hobbie, 1996; Larouche & Chin-Peuckert, 2006; Mager & Andrykowski, 2002; Noll et al., 1999; Slavin, O'Malley, Koocher, & Foster, 1982; Wallace et al., 2007).

In order to support the parents during this difficult time it may be helpful to introduce them to other parents who have a similar experience. These parents can provide support in a group or one on one situation giving practical advice on how they can manage the challenges that they now face. They can assist parents to find culturally appropriate ways to break the silence which was so distressing for patient in this current study. While KHCC has some support groups there is a need to further develop these groups and to establish them in all hospitals in Jordan.

Health team members also need to communicate effectively with patients as they were also silent around the adolescent and did not share with them information regarding their HM. In managing these situations in a culturally sensitive and safe manner, health team members need to firstly establish a trust relationship with the ill person. This relationship facilitates the ability to impart bad news about their illness to

adolescents. It is essential that when this news is given that the patient's parents are present to provide additional support and to assist in answering any questions the adolescent may have (Clarke-Steffen, 1993). At this time health team members should use specific skills to encourage the adolescent to express their feelings and allow them to release suppressed emotions in response to the bad news. These methods need to be sensitive to Jordanian culture and agreed on as routine practice within each hospital. Failing to communicate in a culturally acceptable method resulted in unnecessary stress and affects the trust relationship between the health team members and their patients as established in previous research (Clarke-Steffen, 1993; Pinkerton et al., 1994; Woolley, Stein, Forrest, & Baum, 1989).

In summary, Jordanian culture currently encourages people to be silent regarding their emotions and feelings when confronted with an illness. There is a need for health team members to enable the communication between them and the adolescents at a culturally appropriate level. Communication between health team members, parents and adolescents will facilitate opportunities to provide both the patient and their family with knowledge and understanding of the illness, the treatment and how to assist families to better cope during this stressful time.

#### **6.2.2.2: Initiative to alleviate participants' negative perceptions of body image as a result of cancer**

Adolescents in this study experienced negative body changes as a result of their HM. From a cultural perspective failing to achieve gender expectations in relation to body image was stressful for participants. This has also been reported by other researchers (James, 1993; Langton, 2000). The failure to achieve normal body development as a result of illness combined with strict cultural rules enforcing gender roles caused participants in this study considerable stress. This occurred as the side effects of treatments such as chemotherapy had a direct adverse impact on participants and delayed or accelerated their normal development as well as altering their appearance. Previous research highlighted similar impacts and revealed that these effects can dissuade some people from continuing their therapy (Hesketh et al., 2004; Larouche & Chin-Peuckert, 2006; Münstedt et al., 1997; Roberts et al., 1998; Rosman, 2004; Seitz et al., 2009). Participants altered body image influenced their ability to cope with cancer

and increased their risk of developing co-morbidities such as depression and anxiety (Offer et al., 1981; Parle et al., 1996; Shaffer & Kipp, 2006; Sigelman & Rider, 2009; Wynaden, 2010). When present, these co-morbidities can amplify the adverse effects of the primary illness and create significant additional problems for the patient (Clarke, 2009; Jowsey et al., 2009; Wynaden, 2010). For example, patients who suffer from depression are less likely to adhere to their treatment and less accepting of medical advice. The development of co-morbidities may also impact on the health care system by increasing the length and cost of hospitalisation and increase the financial burden on their family. Health team members should be educated to recognise the early signs of accompanying co-morbidities as the patient's response to changing body image. Wynaden (2010) recommended that nurses who care for patients with a chronic physical illness such as HM need to assess patients for the risk of co-morbidities such as depression during their hospitalisation. Nurses play an important role in the early recognition of such disorders that can impact on the illness journey (Wynaden, 2010).

As a negative body image is responsible for causing many of the co-morbidities in adolescents with cancer, it is imperative to develop effective body image management programs which are culturally sensitive. Education, support groups, and self-care strategies are important components of any effective management programs. There is a need to educate the adolescents about the effective methods to improve their appearance, for example, wearing accessories and/or cosmetics. As this research was conducted in an Islamic country it would be helpful to encourage females to wear the Hijab which is socially more acceptable from a cultural perspective, as alternatives such as wigs which may trigger unwanted attention. The use of cosmetics is another way to hide and improve the person's appearance although some patients in Jordan would argue that it's prohibited from an Islamic perspective to use these.

In general, there is a need to investigate from the participants' perspectives, other effective methods, which are culturally sensitive, to assist the patient to maintain their appearance and counter negative body image changes. Previous research has shown that adolescents who master these issues are more capable and confident to face their life after being diagnosed with cancers such as HM (Larouche & Chin-Peuckert, 2006; Stegenga & Ward-Smith, 2009; Wallace et al., 2007).

In summary, adolescents with cancer complained of many side effects of their cancer treatments. These side effects may prolong the period of hospitalisation and trigger additional illnesses such as depression. There is a need for health team members to be aware of such possibilities and educate patients about the best culturally appropriate methods, to handle their body image in order to lessen the impact of co-morbidity that result from altered body image.

### **6.2.2.3: Initiative to reduce the possibility of misinterpretation of Islamic instruction in cancer care**

Religion defines how a person responds to a situation and being a Muslim, also shapes one's experience of managing and living with cancers such as HM. Muslims are self-empowered through their Islamic beliefs which encourages them to challenge difficulties that face them in their lives. Their faith in "Allah's will" is considered by most Muslims as a form of fatalism which gives them the inner strength to accept the challenges they face. Whether or not health team members share these religious beliefs they must strengthen and include this important belief element in the patient's care plan. The findings of this current study show that participants relied on their religious beliefs to assist them to cope with their illness. Faith was also important to families in providing appropriate support. However, health care members need to be aware that some patients and their families may misinterpret Islamic instructions which may impact on their health negatively. For example, participants in this current study mentioned that their illness was God's will and their cure depended on Allah's will. These thoughts may lead adolescents with HM and their parents to not seek medical attention for their health problems. Therefore, there is a need to work collaboratively with patients to remind them that Islamic instruction encourages people to seek medical treatment as it is stated "God helps him who helps himself" (Minnesota Civil Rights Committee, 1891).

Although their belief in Allah empowered adolescents in this study and answered some of their fundamental questions about the cause of their illness and why they were chosen, these same beliefs deprived many of them from forming new friendships with the patients of the opposite gender during the time they were hospitalised. In previous studies, it was noted that adolescents with cancer who formed new opposite gender friendships benefited from these relationships as they offered the individual different

forms of empathy and encouragement (Chao-Hsing, 2002; Hokkanen et al., 2004; Larouche & Chin-Peuckert, 2006; Wallace et al., 2007; Williamson et al., 2010).

Islamic instruction prohibits the establishment of relationships with the opposite gender except in limited circumstances. Depending on the strength of their Islamic beliefs, some adolescents will not deviate from this rule. Therefore, there is a need for health team members to meet with patients and explain to them that while Islam does not encourage such relationships, it does allow for adolescents regardless of their gender to meet in support groups under their parents and health care team members control and supervision to discuss their cancer experiences.

Murray (1995) divided the use of support groups with cancer patients into four types: 1) Emotional support groups aimed at providing adolescents and their families with love and empathy; 2) Instrumental support groups aimed at providing adolescents and their families with financial support and direct support to help them function better; 3) Informational support aimed at providing adolescents and their families with information to better cope with cancer; and, 4) Appraisal support aimed at supporting adolescents and their families decisions regarding cancer treatments. While all the above groups may be beneficial to cancer patients in Jordan there is also the need for a religious/ spiritual support group aimed at uplifting hope. This type of group would support adolescents and answer their questions regarding any initial conflict between treatments and their Islamic belief. Group members should be provided with access to religious leaders during hospitalisation who support and help them answer any spiritual issues they are experiencing.

In summary, participants' Islamic belief empowered them to face their illness and their beliefs were a powerful method that dominated their ability to cope with their illness. More attention need to be given by health team members to ensure that Islam and its interpretations which may influence care are discussed with patients and their families.

### **6.2.3: Recommendations for further research**

A search of the available literature has revealed a paucity of research studies completed in Jordan to identify the impact of cancers such as HM on adolescents, parents and health team members. In addition, the impact of the disclosure of health related

information to adolescents with HM also requires further investigation. There is also a need to research culturally appropriate techniques and ways for health team members to inform patients that they have HM. Further research is needed to extrapolate an evidence based culturally sensitive model of family centred care for Islamic patients and their families. This model will provide a more holistic picture of the experiences that they encounter and provide a comprehensive care plan for these patients.

Additional longitudinal, prospective research studies are needed to explore the lived experiences of adolescents with HM to further identify the developmental changes that they experience during their illness journey. In this context, there is a need for follow-up studies that test the impact of adopting the recommendations from this study on patient outcomes. There is also a need for interventional research to empower adolescents and their parents' level of confidence to face life with cancer and to strengthen parents' capacity to normalise the care of them.

The finding of this current study showed that the participants considered the treatments as a threat to their developing gender identity and this area requires further research. As this study is one of the first to be conducted in Jordan in the area of adolescents with a HM the researcher recommends further investigations arising from the findings of this study to facilitate the delivery of culturally sensitive quality nursing care. There is a need for further cross-cultural studies in order to compare the experiences of Jordanian adolescents with those adolescents from different cultures and religions.

### **6.3: Strength of the study**

At the time of writing this thesis no other studies were identified that prospectively investigated the lived experience of Jordanian adolescents with a HM. This study provides useful insights into these experiences and into changes that need to occur within the Jordanian health care system to further improve these experiences. Whilst only a few differences were recorded across time, this study established the value of longitudinal studies and the ways people adjust to unexpected illness and subsequent difficulties over time. Moreover, this study is one of a few studies that have explored the lived experience of adolescents in a homogeneous age group (13- 17 years old) with

HM. These findings provide the reader with more focused information regarding this particular group.

#### **6.4: Limitation of the study**

This study has several acknowledged limitations. Firstly, each of the participant's parents were present during the two data collection periods and their presence may have impacted of the experiences expressed. However, as previously discussed they were present because the patient was under their father's guardianship and some of the parents insisted on attending these interviews. Furthermore, ethical approval in Jordan required the presence of a psychologist during the interviews to monitor any distress that may have occurred as a result of the interviews. Therefore, the adolescents' experiences may also have been affected by the presence of the psychologist and this is viewed as a further limitation of this study. However, working within these limitations, the researcher was able to establish rapport with each of the participants which allowed for rich and descriptive data to emerge during the interviews.

#### **6.5: Final statement**

In this thesis I have portrayed the lived experiences' of adolescents with a HM but in reality this experience is far more complex and diverse than I could fully describe. Adolescence is a stage where individuals establish their identity and any unexpected external stressors can impact on this identity forming stage of the life cycle. The experience of cancers such as HM and its treatment occurs at a time when adolescents are experiencing physical and psychosocial changes associated with puberty and maturation. Therefore, the impact of their illness in this group of patients adds to their already challenging and changing world. Furthermore, it impacts on their ability to make realistic choices about their future roles and relationships. Therefore health team members must create an environment in which to ease, isolate and/or minimise the stressors of HM and its treatment to ensure adolescents mental and psychosocial well beings are supported as they work through adolescence and living with HM simultaneously. In closing, I would like to thank each of the participants who allowed me to enter their lifeworld to document their lived experience. Without their willingness to participate in this study I would not have been able to complete this thesis. I thank

you deeply for sharing your experiences so freely and honestly with me. I also wish you all well in the future and Allah will cure you.

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### **Note**

Every reasonable effort has been made to acknowledge the owners of copyright material. I would be pleased to hear from any copyright owner who has been omitted or incorrectly acknowledged.

## LIST OF APPENDICES

### Appendix I: Invitation



# Invitation

My name is Omar Al Omari. I am PhD candidate at Curtin University of Technology in Western Australia. I wish to explore, describe, and document the experiences of adolescents with blood cancers. Should you wish to participate in this study, you will be invited to attend three audio tape interviews that will be held within three months of the diagnosis, and then three months, and nine months after the initial meeting. I am looking for adolescents (13-17) years with blood cancers (leukaemia, Hodgkin's lymphoma, or non Hodgkin's lymphoma). The results of this study are expected to assist health team members in increasing the quality of care provided to adolescents with blood cancers.

The interview will take about one hour. During the interview, I am going to ask you to describe your life before and after the blood cancers. All information we discuss will be held in the strictest confidence.

If you would like to participate in this study and your parents agree to this, feel free to contact me on

Home Phone: +96253985884

Email: [o.alomari@postgrad.curtin.edu.au](mailto:o.alomari@postgrad.curtin.edu.au)

Thank you



### **Appendix III: Questions related to interview**

As the researcher depended on semi-structured interviews, these questions represented a sample of what the researcher asked the participants during the interview.

Questions related to adolescents living with blood cancers

#### **Interview 1**

Tell me about your life before the disease was discovered?

Tell me about your life after the disease was discovered?

#### **Interview 2**

Tell me about your life over the last three month.

Themes

Discovery of the disease.

First experience of the diagnosis.

Experience of chemotherapy.

Experience of haematological malignancies.

Experience of relationships.

Ways of coping.

## **Appendix IV: Parent's information sheet**

### **The experience of adolescents with blood cancers in Jordan**

My name is Omar AL Omari and I am currently completing a research study for my PhD degree at Curtin University of Technology. The purpose of this research is to explore how adolescents with blood cancers live with it. This research has been judged to be safe and acceptable for you to participate in it by your hospital (Approval number HR 109/2009) and Curtin University of Technology Ethics Committee (Approval number HR 109/2009). Although it is not expected that there will be any immediate benefits to your daughter/son, I hope the information resulting from this study will help health team members in the future to provide better care for children with cancer. Findings of this research will assist health team members in Jordan to understand the affects of blood cancers and therefore will increase the quality of care provided to the adolescents and their families.

I am seeking to explore the experiences your daughter/son has had as an adolescent with blood cancers. For this purpose, your daughter/son will be invited to attend three interviews within three months of the diagnosis, and then three months, and nine months after the initial meeting. The interview will be audio tape-recorded and will last for one hour. The interview will be held at a time, and in a private location, convenient for you and your daughter/son. If you would like to join your daughter/son in the interview you are most welcome. The final decision regarding your presence or absence at the interview is left to you and your daughter/son.

#### **Consent to participate**

The involvement of your daughter/son in this research is entirely voluntary. This research is being done independently of the hospital. The health team members that take care of your daughter/son will not know if you decide to participate or not in this research. If your daughter/son participate or decline to participate in this research, the care in the hospital will not be affected in any way. Your daughter/son has the right to withdraw from the research and from the interview at any time without any consequences to them or their treatment. During the interview your daughter/son has

the right to decline any question she/he feels uncomfortable with. By signing the consent form, I assume that you have agreed to allow your daughter/son to participate and will allow me to use the information your daughter/son provides during the interview.

### **Confidentiality**

The information you provide in the interview will be confidential. No names will appear in the study. Your daughter's/son's identity and personal contact details will be known only to the researcher. The researcher will not use your daughter's/son's name or any information that could reveal their identity in this or any future research study. To guarantee confidentiality, a code will be given to each participant and the coding key will be stored in a separate locked cupboard away from the data. All data will be stored in a secure, locked cupboard and computer protected by password at the researcher office during the study and for a period of five years following the date of publication. After five years the data will be destroyed. All tape-recorded interviews and data contained on the USB will be erased; files on the computer will be deleted. Furthermore, transcripts and notes contained on paper material will be shredded.

If there are any further questions regarding this study, you can contact me on 053985884 or at [al.omari@postgrad.curtin.edu.au](mailto:al.omari@postgrad.curtin.edu.au). Alternatively, you can contact my supervisors Professor Linda Shields, and Dr David Wall, at [L.Shields@curtin.edu.au](mailto:L.Shields@curtin.edu.au), and [D.Wall@curtin.edu.au](mailto:D.Wall@curtin.edu.au), respectively.

Or you may contact the Secretary of the Curtin Human Research Ethics Committee on +618 9266 2784.

Thank you for giving your valuable time in reading this letter. I will contact you later to ask about your willingness to take part in this study.

**Regards.**

**Omar Al Omari**

**PhD Candidate**

**School of Nursing and Midwifery**

**Curtin University of Technology**

## Appendix V: Parent's information sheet in Arabic

**جامعة كيرتن التكنولوجية**  
ورقة معلومات لوالد \ والدة المريض  
الخبرات اليومية للمرضى في عمر المراهقة المصابين بسرطان الدم

اسمي عمر شوكت العمري طالب دكتوراه في جامعة كيرتن الاسترالية للعلوم والتكنولوجيا \ ترميز الأطفال و المراهقين. أقوم بعمل هذا البحث كمتطلب للحصول على درجة الدكتوراه في تخصص ترميز الأطفال . يهدف هذا البحث لدراسة الخبرات اليومية (النفسية و الاجتماعية و الروحية ) للمراهقين المصابين بسرطان الدم . لقد قيم هذا البحث على انه بحث آمن وذو قيمة علمية من من قبل المجلس الأكاديمي في كلية التمريض في جامعة كيرتن الاسترالية ومن قبل مجلس تقييم الأبحاث في مركز الحسين للسرطان. على الرغم من انه لا يوجد منفعة مباشرة من اشتراكك أو اشتراك ولدك في هذا البحث في الوقت الحالي إلا ان هذا البحث سيساعدنا في المستقبل كطاقم طبي على تقديم رعاية طبية أفضل لولدك و للمصابين الجدد و أسرهم من واقع لقلتنا بكم.

لتحقيق هذا البحث سيقابل الباحث (12) شاب \ فتاة ما بين 13-17 سنة مصابين بإحدى سرطانات الدم التالية : لوكيميا او ليفوما ساقوم بدعوتهم لحضور ثلاث مقابلات شخصية ، كل مقابلة ستأخذ من ساعة الى ساعة ونصف بتخللها استراحة لمدة نصف ساعة. مواعيد المقابلات ستحدد مسبقا ولكنها بشكل عام الآن وبعد ثلاثة شهور وتسعة شهور من موعد هذه المقابلة. ستعقد المقابلات في غرفة الاستشارات (الطاق الثالث) . حيث سيقوم الباحث بتسجيل المقابلة على جهاز تسجيل صوتي. و سيكون لديك الحق بان تكون موجودا أثناء المقابلة مع ولدك ابنتك إذا رغبت بذلك.

**المشاركة في هذا البحث:**

السيد والد \ والدة المريض أرجو العلم أن موافقتك على اشتراكك \ إشراك ولدك ابنتك في هذا البحث هي موافقة اختيارية تماما. يجب أن تعرف أن المشرفين على علاج ولدك ابنتك ليس لهم علاقة بهذا البحث من قريب أو بعيد مع أنهم سوف يعلمون بإشتراك ولدك ابنتك بالبحث . سواء تمت بإشراكك ولدك ابنتك في هذا البحث أم لا ذلك لن يؤثر على معاملة ولدك ابنتك أو على طريقة علاجها داخل المستشفى . ستقوم المعالجة النفسية ايمان بحضور المقابلات لتجنب أي مضاعفات قد تنتج عن هذه المقابلة ستكون صاحب الحق الأول و الأخير بسحب ابنك \ ابنتك من هذا البحث في أي وقت تشاء و صاحب الحق في عدم ترك ابنك \ ابنتك بحضوري على أي حال أثناء المقابلة و بالطبع فإن ابنك \ ابنتك سيملكون نفس هذا الحق. انسحاب ابنك \ ابنتك من البحث لن يؤثر على الرعاية الصحية المقدمة لهم من قريب أو بعيد . أنا افترض أنك بتوقيعك للورقة المرافقة لهذه المعلومات ستسمح لابنك \ ابنتك بالمشاركة في هذا البحث .

**الموثوقية**

قسط الباحث الرئيسي و الباحث المساعد من مركز الحسين للسرطان سيكون لهم الحق بالاتصال بك او الاطلاع على المعلومات المتعلقة ابنك \ ابنتك. جميع المعلومات التي سيحصل عليها الباحث ستعامل بسريه تامة. لن يظهر اسمك أو اسم ابنك \ ابنتك على أي ورقة ذات علاقة بهذا البحث، لن يستخدم الباحث أي معلومات قد تدل على هويتك أو هوية ابنك \ ابنتك. سيحتفظ الباحث باسم ابنك \ ابنتك والنسب طريقه للاتصال بهم حتى يتمكن من متابعة البحث على ورقه مستقلة و ستكون هذه الورقة في بيت الباحث و سيحتفظ بها في خزانه مغلقة بعده عن الأوراق ذات العلاقة بالبحث. ولضمان سرية المعلومات بطريقة أكثر فعالية سيعطى ابنك \ ابنتك رقم بدلا من اسمه بحيث لا يستطيع أي احد التعرف عليه ولو استطاع الحصول على المعلومات. سيقوم الباحث بالتخلص من اسم و عنوان ابنك \ ابنتك فوراً حال انتهائه من جمع المعلومات. سيقوم الباحث بالتخلص من اسم و عنوان المشارك فوراً حال انتهائه من جمع المعلومات. أما بقية المعلومات المخزنة على أوراق أو على جهاز الكمبيوتر فسيحتفظ بها لمدة خمس سنوات بعد نشر البحث في جامعة كيرتن الاسترالية في مكتب الباحث. وبعد انتهاء هذه المدة سيقوم الباحث بالتخلص من هذه المعلومات حسب الأنظمة المتبعة في جامعة كيرتن الاسترالية.

إذا كنت لديك الرغبة بطرح أسئلة إضافية لها علاقة بهذا البحث بمقدورك الاتصال مباشرة مع الباحث على 053985884 أو الاتصال مع الانسه ايمان ابو حطب في مركز الحسين للسرطان على [p.alomari@postgrad.curtin.edu.au](mailto:p.alomari@postgrad.curtin.edu.au) (8085) 5300460 أو كما يمكنك الاتصال بمجلس تقييم الأبحاث في مركز الحسين للسرطان على [ISwaidan@KHCC.JO](mailto:ISwaidan@KHCC.JO) 5300460 (1669)

شكرا لكم على تقديمكم العون على إنجاز هذا البحث

عمر العمري  
جامعة كيرتن التكنولوجية

King Hussein Cancer Center  
21 NOV 2009  
IRB Approved

## **Appendix VI: Participant information sheet**

### **The experience of adolescents with blood cancers in Jordan**

My name is Omar AL Omari and I am currently completing a research study for higher degree at Curtin University of Technology. I want to learn more about what it is like to be an adolescent with cancer and how cancer affects you. This research has been judged to be safe and acceptable for you to take part in by your hospital (Approval number HR109/2009) and Curtin University of Technology Ethics Committee (Approval number HR 109/2009).

I hope the information resulting from this study will help health team members in the future to give better care for young people like you. What we find out from this research will help health team members in Jordan to understand how blood cancers affect young people. If you agree to take part in this study I will ask you come and talk with me privately on three occasions, which we will arrange to fit in with you, and then three months, and nine months after we meet for the first time. I will record our discussion, which will last for one hour. If you would like your parents to join us they will be most welcome. The decision about whether your parents join us will be left to you and your parents.

#### **Consent to participate**

Your involvement in this research is voluntary. This research is separate from the hospital, which means that nobody in the hospital will know what we talk about. The nurses and doctors that take care of you will not know about your choice to take part, or not take part, in the discussion with me. If you do not want to take part, your care in the hospital will not be affected in any way. You have the right to stop the interview at any time, or say that you do not want to answer questions, and nothing will happen to you. If you sign the consent form, it means that you would like to talk to me about your experiences with the cancer and will allow me to use the things you tell during the interview.

#### **Confidentiality**

The things you tell me in the discussion will be confidential. I will never tell anyone your name and I will never identify you by your name in anything I write. Everything you tell me will be stored securely. I have to keep the information you give to me for five years, but after this time the information will be destroyed.

If you have any questions about this study, you can contact me on 053985884 or at [al.omari@postgrad.curtin.edu.au](mailto:al.omari@postgrad.curtin.edu.au). Alternatively, you can contact my supervisors Professor Linda Shields, and Dr David Wall at [L.Shields@curtin.edu.au](mailto:L.Shields@curtin.edu.au), and [D.Wall@curtin.edu.au](mailto:D.Wall@curtin.edu.au), respectively.

Or you may contact the Secretary of the Curtin Human Research Ethics Committee on +618 9266 2784.

Thank you for reading this letter. I will contact you later to ask about your willingness to take part in this study.

Regards.

**Omar Al Omari**

**PhD Candidate**

**School of Nursing and Midwifery**

**Curtin University of Technology**

## Appendix VII: Participants information sheet in Arabic

**جامعة كيرتن التكنولوجية**  
**ورقة معلومات للمريض**

**الخبرات اليومية للمرضى في عمر المراهقة المصابين بسرطان الدم**

اسمي عمر شوكت العمري طالب دكتوراه في جامعة كيرتن الاسترالية للعلوم والتكنولوجيا \ ترميض الأطفال و المراهقين. أقوم بعمل هذا البحث كمتطلب للحصول على درجة الدكتوراه . يهدف هذا البحث لدراسة الخبرات اليومية (النفسية و الاجتماعية و الروحية ) للمراهقين المصابين بسرطان الدم . لقد قيم هذا البحث على انه بحث آمن وذو قيمة علمية من قبل المجلس الاكاديمي في كلية التمريض في جامعة كيرتن الاسترالية ومن قبل مجلس تقييم الأبحاث في مركز الحسين للسرطان. على الرغم من انه لا يوجد منفعة مباشرة من اشتراكك في هذا البحث في الوقت الحالي إلا أن هذا البحث سيساعدنا في المستقبل كطاقم طبي على تقديم رعاية طبية أفضل لك و للمصابين الجدد و أسرهم من واقع مقابلاتنا معكم.

لتحقيق هذا البحث أنا ابحت عن (12) شاب \ فتاة ما بين 13-17 سنة مصابين بلحمى سرطانات الدم التالية : لوكيميا او ليمفوما ساقوم بدعوتكم لحضور ثلاث مقابلات شخصية، كل مقابلة ستأخذ من ساعة الى ساعة ونصف بتخللها استراحة لمدة نصف ساعة. مواعيد المقابلات ستحدد مسبقا ولكنها بشكل عام ستكون على ثلاث دفعات: الآن ثم بعد ثلاث شهور من موعد هذه المقابلة ثم تسع شهور من موعد هذه المقابلة. ستعقد المقابلات في غرفة الاستشارات (الطابق الثالث). سيقوم الباحث بتسجيل المقابلة على جهاز تسجيل صوتي. سيكون لديك الحق بان تطلب وجود أفراد أسرتك أثناء المقابلة إذا رغبتم بذلك.

**المشاركة في هذا البحث:**

أرجو العلم أن موافقتك على اشتراكك في هذا البحث هي موافقة اختيارية تماما. يجب أن تعرف أن المشرفين على علاجك ليس لهم علاقة بهذا البحث من قريب أو بعيد مع أنهم سوف يعلمون بمشاركتك بالبحث. سواء قد قمت بالاشتراك في هذا البحث أم لا و ذلك لن يؤثر على معاملتك أو طريقة علاجك داخل المستشفى. ستقوم المعالجة النفسية ايمان بحضور المقابلات لتجذب أي مضاعفات قد تنتج عن هذه المقابلة.

علما بأنك ستكون/ ستكونين صاحب / صاحبة الحق الأول و الأخير بالانسحاب من هذا البحث في أي وقت تشاء. إن انسحابك من هذا البحث لن يؤثر على الرعاية الصحية المقدمة لك من قريب أو بعيد .

أنا افترض أنك بتوقيعك للورقة المرافقة لهذه المعلومات توافق على المشاركة في هذا البحث .

**الموثوقية**

فقط الباحث الرئيسي و الباحث المساعد من مركز الحسين للسرطان سيكون لهم الحق بالاتصال بك او الاطلاع على المعلومات المتعلقة بك. جميع المعلومات التي سيحصل عليها الباحث ستعامل بسريه تامة. لن يظهر اسمك أو اسم والديك على أي ورقة ذات علاقة بهذا البحث لن يستخدم الباحث أي معلومات قد تدل على هويتك أو هوية والديك . سيحتفظ الباحث باسمك و اتسب طريقته للاتصال بك حتى يتمكن من متابعة البحث على ورقة مستقلة و ستكون هذه الورقة في بيت الباحث و سيحتفظ بها في خزانه مغلقة بعيدة عن الأوراق ذات العلاقة بالبحث. ولضمان سرية المعلومات، بطريقة أكثر فعالية ستعطي رقم بدلا من اسمك بحيث لا يستطيع احد التعرف عليه في حال استطاع الحصول على المعلومات. سيقوم الباحث بالتخلص من اسمك و عنوانك فوراً حال انتهائه من جمع المعلومات. سيقوم الباحث بحفظ بقية المعلومات: الأشرطة المسجلة و المعلومات المفزعة على الأوراق أو على جهاز الكمبيوتر لمدة خمس سنوات بعد نشر البحث ، ستخزن هذه المعلومات في مكتب الباحث في جامعة كيرتن الاسترالية . وبعد انتهاء هذه المدة سيقوم الباحث بالتخلص من هذه المعلومات حسب الأنظمة المتبعة في جامعة كيرتن الاسترالية.

إذا كانت لديك الرغبة بطرح أسئلة إضافية لها علاقة بهذا البحث بمقدورك الاتصال مباشرة مع الباحث على 053985884  
o.alomari@postgrad.curtin.edu.au الاتصال مع الانسه ايمان ابو حطب في مركز الحسين للسرطان على (8085)  
5300460 ibuhatab@KHCC.jo او كما يمكنك الاتصال بمجلس تقييم الأبحاث في مركز الحسين للسرطان على  
ISwaidan@KHCC.JO 5300460 (1689)

شكرا لكم على تقديمك العون على إنجاز هذا البحث

عمر العمري  
كلية التمريض  
جامعة كيرتن التكنولوجية

King Hussein Center

21 NOV 2009

KHCC Approved

## Appendix VIII: Consent form for adolescents

### Research Title

#### The experience of adolescents with blood cancers in Jordan

I have read the information sheet accompanying this informed consent form relating to this study. I understand that by signing this consent form I am agreeing to be interviewed by Omar Al Omari three times in three different occasions in private place. I understand that I may quit the interview and withdraw from the study at any time with no penalty. I have been given a copy of this consent form. I understand that if I have any further questions regarding this study I can contact Omar on 053985884 (a land-line) or at [al.omari@postgrad.curtin.edu.au](mailto:al.omari@postgrad.curtin.edu.au). Alternatively, you can contact my supervisors Professor Linda Shields, and Dr David Wall, at [L.Shields@curtin.edu.au](mailto:L.Shields@curtin.edu.au), [D.Wall@curtin.edu.au](mailto:D.Wall@curtin.edu.au) respectively.

Or you may contact the Secretary of the Curtin Human Research Ethics Committee on +618 9266 2784.

I ....., agrees to participate in the study as outlined above.

\*I agree for my son/daughter.....to participates in the study.

Signature..... Date.....

Signed .....Researcher

Date: .....

\* Only the father can sign this consent form

## Appendix IX: Consent form in Arabic

**جامعة كيرتن للعلوم و التكنولوجيا**  
**نموذج الموافقة على الاشتراك بهذا البحث**  
**الخبرات اليومية للمرضى في عمر المراهقة المصابين بأمراض الدم**

لقد قمت بقراءة المعلومات الموافقة لهذا النموذج (ورقة المعلومات) . أنا أدرك انه بتوقيع هذه الورقة أوافق على أن يتم مقابلتي من قبل عمر العمري في غرفة الاستشارات (المطابق الثالث) لثلاث مرات في ثلاث أوقات مختلفة 3 ساعات، ساعة كل 3 شهور. أنا أتفهم أني أستطيع الانسحاب من هذه الدراسة متى أشاء بدون تحمل أي مسؤولية وهكذا أقرر . انه يوجد نسخة أخرى من هذه الورقة معي ، أنا أتفهم انه إذا كانت لدي الرغبة بطرح أسئلة إفساحية لها علاقة بهذا البحث يمكنك الاتصال مباشرة مع الباحثة على 053985884 أو على بريده الإلكتروني [o.alomari@postgrad.curtin.edu.au](mailto:o.alomari@postgrad.curtin.edu.au)

و قد أرتغب بالاتصال مع ايمان ابو حطب على 5300460/8085

[labuhatab@KHCC.JO](mailto:labuhatab@KHCC.JO)

كما يمكنك الاتصال بمجلس تقييم الأبحاث في مركز الحسين للسرطان على (1689) 5300460

[ISwaidan@KHCC.JO](mailto:ISwaidan@KHCC.JO)

أنا ..... أوافق على الاشتراك بالدراسة كما ورد في الأعلى .

أنا ..... أوافق على اشتراك ولدي ابنتي في الدراسة كما ورد في الأعلى .

التوقيع ..... التاريخ .....

التوقيع ..... التاريخ .....

توقيع الباحثة ..... التاريخ .....

\*فقط المشارك في هذه الدراسي و ولي امره لهم الحق بتوقيع هذه الورقة

King Hussein Cancer Center  
 21 NOV 2009  
 IRB Approved

**Appendix X: Protecting human subject research participants “online module”**

## Appendix XI: KHCC consent Form



King Hussein Cancer Center

مركز الحسين للسرطان

Institutional Review Board

مجلس تقييم الأبحاث

إقرار بالموافقة على بحث بدون فائدة مباشرة للمشاركين

## Informed Consent for Research with No Direct Benefits to Participant

ملاحظة للباحث: يرجى الأخذ بعين الاعتبار أن بعض المصطلحات والنقاط الواردة في هذا النموذج يمكن ألا تناسب وطبيعة لدراسة التي ستقوم بها. يرجى الاتصال بمجلس تقييم الأبحاث للمشورة بكيفية تحويل (تعديل) هذا النموذج ليتناسب أكثر وطبيعة دراستك.

عنوان البحث : الخبرات اليومية للمرضى في عمر المراقبة المصابين بأمراض الدم في الأردن: دراسة ظاهرية

## الجزء الأول - معلومات للمشارك في البحث:

## أ. الغرض من البحث:

تهدف هذه الدراسة إلى استكشاف الخبرات اليومية (النفسية والاجتماعية، والروحية) للمرضى في عمر المراقبة المصابين بسرطان الدم في الأردن. حيث سيقوم الباحث بدراسة تطور المرض وكيفية تأثير ذلك التطور على الحالة النفسية والاجتماعية والروحية للمرضى في عمر المراقبة ثم سيقوم بدراسة الآلية التي ستلعبها هذه الخبرات في مساعدة المرضى على التكيف مع المرض.

## ب. وصف البحث:

تهدف هذه الدراسة إلى استكشاف الخبرات اليومية (النفسية والاجتماعية، والروحية) للمرضى في عمر المراقبة المصابين بسرطان الدم في الأردن

و لتحقيق أهداف هذه الدراسة ، سيقوم الباحث أولاً باستخدام طريقة الظاهرية (Heideggerian phenomenology) التي تم تطويرها عن طريق العالم هاينجر التي تعتمد على وصف وفهم بيئة المريض. حيث سيقوم الباحث باستدعاء وعمل مقابلات شخصية مع اثني عشر مراقباً ومراقبة على ثلاث فترات مختلفة : خلال ثلاث أشهر من تشخيص المرض، ثم ثلاث أشهر من المقابلة الأولى، و تسع أشهر من المقابلة الأولى. سيعتمد الباحث على مستشفيات خاصة وعامة في عمان \ الأردن ، حيث توفر هذه المستشفيات رعاية صحية متقدمة للمرضى المصابين بسرطان الدم.

يتوقع الباحث من هذا البحث أن يوفر وصفاً دقيقاً للحياة الاجتماعية والنفسية والروحية للمرضى في عمر المراقبة المصابين بسرطان الدم مما سيساعد أعضاء الكادر الطبي على فهم أعمق للمرضى في عمر المراقبة المصابين بسرطان الدم وهذا سينعكس إيجاباً على مستوى الخدمات الصحية المقدمة لهؤلاء المرضى. وعلى حد علم الباحث فإنه لا يوجد دراسات تتناول هذا الجانب على هذه الفئة العمرية من المرضى في الأردن.

## ج. العدة المتوقعة للدراسة:

لغده اللازمة لإتمام الدراسة كاملة : ثلاثة سنوات

مدة مشاركة المريض في هذه الدراسة : 3 ساعات، ساعة كل 3 شهور

د. عدد المشاركين بالدراسة 12 شاب وفتاة، 6 من مركز الحسين للسرطان

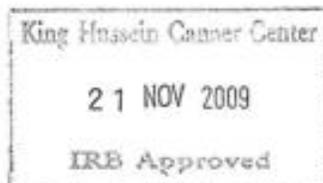
هـ. عدد المراكز المشاركة 3 مستشفيات

## و. المخاطر والائزاعات المحتملة:

لأن يكون هناك مخاطر جسدية ولكن يحتمل أن يكون هناك قلق وائزاعات نتيجة هذه المقابلات.

## ز. الفوائد المرجوة :

على الرغم من أنه لا يوجد منفعة مباشرة للمشاركين في هذا البحث في الوقت الحالي إلا أن هذا البحث سيساعد الطاقم



الطبي على تقديم رعاية طبية أفضل للمصابين الجدد و أسرهم من واقع فهمنا للخبرات اليومية (النفسية والاجتماعية، والروحية) للمرضى في عمر المراهقة.

ح. البدائل عن المشاركة ( إن وجدت ):

لا يوجد

ط. تكاليف المشاركة:

لا يوجد

ي. المكافآت المالية:

لا يوجد

ك. التعويضات / المعالجات:

في حال وجود قلق وانزعاج لدى المشارك في هذه الدراسة ستقوم المعالجة النفسية (إيمان أبو حطب) بمتابعة الحالة وإجراء اللازم لها-----

ل. المشاركة التطوعية:

المشاركة في هذه الدراسة طوعيه وإذا قررت عدم المشاركة فإلك لن تتعرض لأي مضايقات أو لفقدان حقلك المشروع في المعالجة.

م. : السرية

كمشارك في هذه الدراسة ستكون هويتك ومحتويات ملفك الطبي سرية في جميع المنشورات المتعلقة بنتائج الدراسة كما سيبقى رقم سجلك الطبي سري في الحدود التي يسمح بها القانون. ويمكن الإطلاع على ملفك الطبي من قبل مجلس تقييم الأبحاث أو الوكيل الداعم للدراسة في حدود النظم والقوانين المطبقة بهذا الخصوص سيتم تزويدك بنسخة موقعة من هذا الإقرار.

ن. : إنهاء المشاركة:

أن قرارك بالانسحاب من الدراسة لن يؤثر على تنفيذك لخدمة علاجية بديلة متوفرة في مركز الحسين للسرطان. سيتم إبلاغك بأي نتائج هامة جديدة تظهر خلال تطورات البحث وبناءً عليه بحق لك اتخاذ القرار بالاستمرار بالمشاركة أو التوقف عنه.

King Hussein Cancer Center  
21 NOV 2009  
IRB Approved

King Hussein Cancer Centre

21 NOV 2009

IRB Approved

• الأشخاص الذين يمكن الاتصال بهم:

- في حالة وجود أي استفسار عن الدراسة أو أسئلة محددة تتعلق بهذا البحث نرجو الاتصال ب إيمان أبو حطب على هاتف رقم المستشفى 5300460 تحويلة رقم 3010 أو جهاز خلوي رقم 0795651864
- وفي حالة حدوث أي مضاعفات تتعلق بالدراسة، نرجو الاتصال ب إيمان أبو حطب على هاتف رقم (المستشفى) 5300460 تحويلة رقم 3010 أو جهاز خلوي رقم 0795651864
- في حالة وجود أي أسئلة عامة أو أسئلة تتعلق بحقوق المشارك عليك الاتصال باللجنة المؤسسية لتقييم الأبحاث على هاتف رقم 5300460 فرعي 1669.

الجزء الثاني: تفويض من المشارك بالدراسة التي لا يتوقع منها فائدة مباشرة للمشارك:

اسم المشارك: \_\_\_\_\_

1. بهذا أتطوع للمشاركة في هذه الدراسة تحت إشراف أو إيمان أبو حطب، والمتضمن لما يلي: الخبرات اليومية للمرضى في عمر المراهقة المصابين بسرطان الدم في الأردن: دراسة ظاهرانية.
2. أقر بأنني قد قرأت - أو شرح لي بلغة مفهومة لدي - هذه المعلومات المتعلقة بمشاركتي في هذا البحث وأن إيمان أبو حطب قد أوضحت لي طبيعة وأهداف هذه الدراسة ، كما أقر بأنه قد أتاحت لي الفرصة لتوجيه جميع الأسئلة المتعلقة بموضوع الدراسة وتلقيت الإجابات الوافية.
3. أفهم بأن هذه الدراسة ليس لها أي فائدة علاجية مباشرة لي ومع ذلك أتطوع بالمشاركة فيها مع علمي بالمخاطر والازعاجات الناتجة عن هذه الدراسة.
4. وأفهم بأن لي مطلق الحرية بسحب هذا التفويض وإنهاء مشاركتي بهذه الدراسة في أي وقت أشاء مع علمي بجميع العواقب والمخاطر المترتبة على انسحابي من الدراسة (إن وجدت). كما أفهم بأن انسحابي من هذه الدراسة لن يؤثر على حقني في تلقي العناية الطبية اللازمة والتي تمنح للمشاركين بالدراسة أو استحقتها في الأحوال العادية.
5. أوافق على أن يكون هذا الإقرار كمشاركة طوعيه في هذا البحث الطبي
6. كما أؤكد بأنني قد قرأت (أو قرأ لي) هذا التفويض وأن كل المعلومات اللازمة قد تمت تعبئتها بدقة قبل توقيعني عليه.
7. أقر بأنني قد استلمت نسخة موقعه من هذا الإقرار.
8. قد يقوم الباحث الرئيس بطرح بعض الأسئلة عليك بعد الانتهاء من شرح الإقرار.

توقيع المريض أو ولي الأمر: \_\_\_\_\_ التاريخ: \_\_\_\_\_  
 الاسم: \_\_\_\_\_ صلة القرابة: \_\_\_\_\_  
 توقيع الشاهد: \_\_\_\_\_ الاسم: \_\_\_\_\_  
 الرقم الوطني: \_\_\_\_\_ التاريخ: \_\_\_\_\_

إقرار بالموافقة على بحث بدون فائدة مباشرة للمشاركين

3

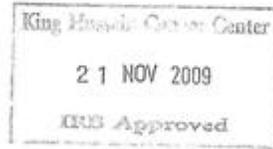
Informed Consent for Research with No Direct Benefits to Participant

أقر بالتالي قد شرحت للمتطوع/ لقريله/ أو ولي أمره المذكور أعلاه بصورة كاملة طبيعة وأهداف مشروع البحث المذكور والمتضمن عدم وجود فائدة مباشرة على المشارك، كما قد شرحت المضاعفات المحتمل حدوثها من جراء هذه الدراسة سواء كانت لأسباب معروفة أو غير معروفة. كما إنه من المفهوم لدي بأنه قد فهم طبيعة الدراسة والغرض منها والمخاطر الناتجة عنها وذلك قبل توقيعهم على الموافقة بالمشاركة ، ولقد قمت بتوضيح استعدادي للإجابة على أي أسئلة متصلة بهذه الدراسة ، وقمت فعلاً بالإجابة الواقيه على جميع أسئلته المتعلقة بالدراسة.

توقيع الباحث الرئيسي: \_\_\_\_\_ الاسم (طباعة): إيمان أبو حطب

التاريخ: \_\_\_\_\_

تمت مراجعة هذا النموذج والموافقة عليه من قبل اللجنة المؤسسية لتقييم الأبحاث في مركز الحسين للسرطان.



## Appendix XII: Curtin University Ethics Approval

### memorandum

<b>To</b>	Dr David Wall, Nursing
<b>From</b>	A/Professor Joan Wardrop, Acting Chair Human Research Ethics Committee
<b>Subject</b>	Protocol Approval HR 109/2009
<b>Date</b>	7 October 2009
<b>Copy</b>	Omar Al Omari, Nursing Graduate Studies Officer, Faculty of Health Sciences



Office of Research and Development

#### Human Research Ethics Committee

TELEPHONE 9266 2784  
FACSIMILE 9266 3793  
EMAIL hrec@curtin.edu.au

Thank you for your application submitted to the Human Research Ethics Committee (HREC) for the project titled *"The lived experience of adolescents with haematological malignancies in Jordan: A hermeneutic interpretive phenomenological study"*. Your application has been reviewed by the HREC and is **approved**.

- You have ethics clearance to undertake the research as stated in your proposal.
- The approval number for your project is **HR 109/2009**. Please quote this number in any future correspondence.
- Approval of this project is for a period of twelve months **06-10-2009 to 06-10-2010**. To renew this approval a completed Form B (attached) must be submitted before the expiry date **06-10-2010**.
- If you are a Higher Degree by Research student, data collection must not begin before your Application for Candidacy is approved by your Faculty Graduate Studies Committee.
- The following standard statement must be included in the information sheet to participants:  
*This study has been approved by the Curtin University Human Research Ethics Committee (Approval Number HR 109/2009). The Committee is comprised of members of the public, academics, lawyers, doctors and pastoral carers. Its main role is to protect participants. If needed, verification of approval can be obtained either by writing to the Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University of Technology, GPO Box U1987, Perth, 6845 or by telephoning 9266 2784 or by emailing hrec@curtin.edu.au.*

Applicants should note the following:

It is the policy of the HREC to conduct random audits on a percentage of approved projects. These audits may be conducted at any time after the project starts. In cases where the HREC considers that there may be a risk of adverse events, or where participants may be especially vulnerable, the HREC may request the chief investigator to provide an outcomes report, including information on follow-up of participants.

The attached **FORM B** should be completed and returned to the Secretary, HREC, C/- Office of Research & Development:

When the project has finished, or

- If at any time during the twelve months changes/amendments occur, or
- If a serious or unexpected adverse event occurs, or
- 14 days prior to the expiry date if renewal is required.
- An application for renewal may be made with a Form B three years running, after which a new application form (Form A), providing comprehensive details, must be submitted.

Regards,

A/Professor Joan Wardrop  
Acting, Chair Human Research Ethics Committee



## Appendix XIV: KHCC ethical approval

	<b>King Hussein Cancer Center</b> <b>Institutional Review Board</b>	<b>مركز الحسين للسرطان</b> <b>مجلس تقييم الأبحاث</b>
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Date: 21/November/2009

Dear Ms. Eman Abu Hatab and Mr. Omar Al-Omari,

In reference to the proposal entitled: The lived experience of adolescents with haematological malignancies in Jordan: A hermeneutic interpretive phenomenological study (Proposal #: 09 KHCC 56).

You are kindly informed that the IRB has reviewed and approved your submitted documents which include the following:

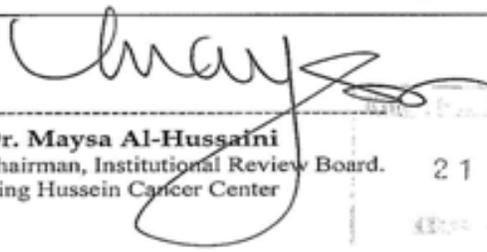
1. IRB Submission FORM B
2. English Protocol Summary
3. Arabic Informed Consent Form for Adolescents
4. Arabic Informed Consent Form for Parents
5. Arabic Information Sheet for Adolescents
6. Arabic Information Sheet for Parents

Kindly Note, that this proposal was approved by convened IRB review.

Kindly note that if the study will extend beyond one year you have to submit a renewal form and an interim update on the study. At the end of the study, you are requested to submit end of study report to IRB.

Please inform the IRB office of any publications/ abstracts that may result from this research.

On behalf of all members of KHCC IRB, I would like to wish you a very successful study.

  
**Dr. Maysa Al-Hussaini**  
 Chairman, Institutional Review Board.  
 King Hussein Cancer Center

21 NOV 2009

Date: 21/November/2009

KHCC IRB/2009/09/056

