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An Investigation into the Psychological Wellbeing of Children and Young People with Cancer in Jordan

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By

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Abstract

Now treatment of paediatric malignancies is capable of extending the life of children with cancer, there is an increase move toward investigating the quality of life and needs experienced by children and young people diagnosed with cancer. Although earlier investigations examined differences in adjustment among children with cancer and their healthy counterparts, the results of these studies were inconclusive, and there is a considerable lack of studies of the psychological wellbeing of children in the Middle East. In this thesis, two central themes are examined: first, the psychological status of children and young people with cancer in Jordan as indicated by their quality of life and symptoms of anxiety and depression; second, patterns of communication of cancer diagnosis in families caring for children with cancer, to develop a better understanding of Jordanian children's experience with cancer.

Fifty eight children and young people and their mothers attending the paediatric oncology services in Jordan participated in this study. In an attempt to explore their psychological wellbeing in greater detail, the study involved another group of fifty six children and young people with chronic illness and a control group of sixty four healthy peers.

Three assessment tools were translated into Arabic, piloted and tested for reliability and validity at a number of schools all over Jordan. Then, the tools were administered to the three groups. Participating children and young people were asked to complete self-reported depression and anxiety scales, as well as an instrument to measure the quality of life. Thirty seven mothers of children and young people with cancer completed a self-report measure of stress, anxiety and depression. Mothers were also asked during the interview about the amount of information they shared with their children and their satisfaction with the way the cancer diagnosis was communicated to their children.

The results showed that children and young people with cancer function at a very similar level to children and young people without cancer. There were no significant differences on the measure of depression, between the scores of children and young people with cancer, chronic illness and the healthy group. On the quality of life measure, the healthy group scored significantly higher than the children and young people in the other two groups. At the same time, the healthy group scored significantly higher on the anxiety measure. It is suggested that children and young people with cancer are able to cope with their illness because they utilise defensiveness as an adaptive mechanism, since higher scores for defensiveness were associated with lower scores for child-reported depression and anxiety in this group and a significant difference in the level of defensiveness exists between the three groups. This supports previous findings.

In addition to these results, this thesis shows that exploring children's and young people's psychological distress in a culture where this is not recognised provides the researcher with a number of concerns. The influence of Arab culture and religion on Jordanian children and young people, the communication patterns of cancer diagnosis, the wisdom of their elders, and the importance of their family result in reluctance to show emotion or to question decisions made on their behalf. The results of quantitative findings and contextual information from the interviews in this thesis go some way to demonstrate the impact that cancer can have on both the patient and family in the Jordanian culture. The child's quality of life can be compromised by the illness. Moreover, communication of the diagnosis of illness has a detrimental effect on both child's and mother's psychological wellbeing.

Dedication

To my father, whose trust and support throughout my studies and life gave me the strength and courage to accomplish this work

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Profile of Researcher

Trained as a general registered nurse at the University of Jordan, and then served two years in the Paediatrics floor of the University of Jordan hospital, and King Hussein Cancer Centre (KHCC). Obtained a master degree in Clinical Nursing, Emergency and Intensive Care from University of Boras/Sweden and University of Jordan, and during this period taught for two years as a research and teaching assistant at the University of Jordan.

List of Abbreviations

ANOVA	Analysis of Variance Statistical Test
ALL	Acute Lymphatic Leukaemia
AML	Acute Myeloid Leukaemia
CMAS	Children's Manifest Anxiety Scale
CDI	Children Depression Inventory Scale
CNS	Central Nervous System
CRF	Chronic Renal Failure
DM	Diabetes Mellitus
DSM-IV	Diagnostic Statistical Manual-IV
DSM-III	Diagnostic Statistical Manual-III
DD	Depression Disorder
HRQoL	Health Related Quality of Life
КНСС	King's Hussein Cancer Centre
KR	Kuber-Richardson-test
MDD	Major Depression Disorder
NHL	Non Hodgkin's Lymphoma
PTSD	Post Traumatic Stress Disorder
PCQL-32	Paediatrics' Quality of Life for Cancer
PedsQL [™]	Paediatrics Quality of Life Inventory Scale
QoL	Quality of life
ROC-analysis	Receiver Operating Chacteristic-test
RCMAS	Revised Children Manifest Anxiety Scale
STAIC	State-trait Anxiety Inventory for Children
SPSS	Statistical Package for Social Science
SD	Standard Deviation

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Chapter 1 Introduction

1.1. Background of the study

The development of successful treatments for childhood cancer has resulted in paediatric oncology patients and their families dealing with severe chronic disease rather than an inevitably fatal illness (Bessell, 2001). Issues of quality of life, psychological distress and coping are therefore important when helping adaptation to this illness (Cremeens, Eiser, & Blades, 2006a; Varni, Limbers, & Burwinkle, 2007b). Historically, there has been a significant increase in European survival rates at five years after diagnosis (Coleman et al. 2003) and in the US from 1% of children with Acute Lymphocytic Leukaemia (ALL) in the year 1960 (Stehbens, 1988) to 81% during 1990-1994 (Stiller & Eatock, 1999). Success has been achieved through with chemotherapy, radiotherapy. and bone-marrow aggressive treatment transplantation, which are associated with physical late effects and problems in psychological, educational and behavioural functioning (Eiser, 1998).

In this thesis the main focus is the impact of the illness on the quality of life and wellbeing of children and young people with cancer. A body of research has developed but there is a lack of studies undertaken in Jordan. For sick children in Jordan the emphasis remains on the medical management of disease with little attention given to social and emotional needs. A recent study of children diagnosed with cancer in Jordan found that over half the children did not know the nature of their illness (Khatib, Neamat, Sundus, & Salhi, 2005). The meeting of emotional needs may therefore fall short of the ideal.

Given the contribution of cancer and communicating of cancer diagnosis to both behavioural and emotional adjustment, it is clearly important to document the nature and extent of the difficulties experienced by these children and young people. Further motivation to do this research was my personal experiences at the oncology floors of hospitals at Jordan, and remarks made by children and young people or their parents concerning the range of educational and behavioural problems experienced by children and young people with a long term illness. Consequently, this study was undertaken to obtain insight into children's own perceptions of the impact of cancer on their quality of life and wellbeing.

1

In this thesis some important issues that initially emerged from similar cancer research in England, the United States and around the world are described and investigated with reference to Arab children and young people. A main part of this thesis is devoted to the patterns of communication of the cancer diagnosis and the psychological wellbeing of the child. One of the main questions to be answered here is the degree to which children and young people with cancer experience psychological problems as they traverse the path from diagnosis through treatment to hoped-for cures in the hospitals of Jordan.

1.2. The research questions, aims and hypothesis of the study

The study seeks to answer the following research questions:

- What is the quality of life in children and young people diagnosed with cancer in Jordan as compared to those with less life threatening illnesses and their healthy peers?
- What are the levels of anxiety and depression in terms of number and intensity for children and young people with cancer in Jordan?

• Do children and young people with cancer and chronic illness in Jordan show more depressive symptoms and higher levels of anxiety than their healthy peers?

The above questions sought to examine the psychological wellbeing of children and young people diagnosed with cancer in Jordan, compared with data obtained for children and young people with chronic illness and their healthy peers. Anxiety, depression and quality of life in children and young people diagnosed with cancer were measured and compared to those with chronic illness, and their healthy peers. It was hypothesised that quality of life will be lower in children diagnosed with cancer signifying worse quality of life and higher in anxiety and depression level.

Further more, to develop a better understanding of children's and young people's experience with cancer in Jordan, where no significant studies available about how cancer is communicated to children and how this may affect their psychological wellbeing, the aim of the second part of this study was to explore the patterns of communication of cancer diagnosis in families caring for children and young people with cancer in Jordan. In accordance with this, it was expected that the amount of

information shared with children about their illness would influence their adaptation to their illnesses. The study tried to describe patterns of communication among families caring for children or young people with cancer in Jordan through integrating open ended questions besides the questionnaires

1.3. Overview of the thesis

This study was set in the context of children and young people and the diagnosis and treatment of cancer in Jordan. These aspects of the context are discussed in the first two chapters to establish the significance of the study.



Figure 1.1. Overview of the Research Structure

The literature review in Chapter Two incorporates three main sections. In the first section, the prevalence and types of cancer in Jordan are discussed with a description that includes the prevalence of the most common childhood cancer in Jordan. In order for the reader to obtain some insight into the wide variety of childhood cancer and the complexities of diagnosis and treatment procedures, a concise description of their treatment is given; this provides some idea about what sick children and young people in Jordan may experience.

In the second section, the cognitive theory of stress and coping (Lazarus and Folkman 1984) is used as a conceptual framework for the study. It will be seen that the translation from adult coping and stress is not straightforward and the importance of developmental aspects will be described. A confident awareness about these developmental theories and considerations is necessary when one tries to grasp what it really means for a child to be diagnosed with and treated for cancer.

The third section reviews and summarises the literature on children's and young people's psychological adjustment to cancer. Studies are critically analysed and reviewed, with special attention to the methods that have been used. The review includes studies about the psychological impacts of cancer published between 1980 and 2006 in nursing, paediatrics and social science journals. The methods reported in the literature are discussed to justify the particular approach to the topic.

Chapter Three focuses on the cultural values of Arab and Islamic beliefs. Its purpose is to illuminate the values embedded in the Jordanian culture, and provide information that may be relevant for understanding the context of child development in Jordan. The developmental aspects of children and young people will be discussed in both general and cultural domains, leading to an overview of the unique requirements of Jordanian children and young people with cancer later in this chapter.

The research methodology is discussed in Chapter Four, which includes the research design, and instrument translation and the cross-cultural validation of the instrument in an Arabic context. Another main issue addressed in this chapter is the ethical issues involved in conducting this research. The final group of chapters, namely Chapters Five, Six and Seven describe and discuss the findings of the main study in comparison with published research.

This thesis should be regarded as a pioneering study into the investigation of quality of life and psychological wellbeing during cancer treatment in the Middle East. Very little research, if any, has addressed psychological wellbeing as a multidimensional concept or has addressed the ethical issues encountered when assessing children and young people with cancer. The ethical issues encountered within this thesis are not necessarily new to psychological research in children. Yet, this thesis can be regarded as an important investigation of a new area within childhood cancer in the Middle East, an area that has already proven its importance within childhood cancer all around the world.

1.4. Overview of methodology

The current debate over the impact of cancer on children's and young people's psychological wellbeing is a debate about ideas, about different interpretations of how cancer affects the child's psychological state. There is also another debate about whether it is the hospital environment which affects the child, or the disease itself, and what should be done to differentiate the effect of the disease from the hospital environment and painful procedures. Thus, the debate regarding the effect of hospitalisation was overcome by including a control group of healthy children and a group of children with chronic illness who were at least one year post diagnosis of any chronic medical conditions such as diabetes mellitus, chronic renal failure, rheumatoid arthritis or cystic fibrosis and who had experienced recurrent hospitalisation. Therefore, the present study involved three populations, including a group of healthy children and young people as a reference group which would help to draw more firm conclusions about the quality of life and the psychological sequelae of cancer diagnosis versus chronic childhood illness.

Despite the existence of large number of measures, there are as yet no "gold" standards for designing child measures, in regard to the content and format of instruments (Eiser and Morse, 2001b). For the purpose of this thesis the following tools were used to measure the variables under investigation:

- The Socio-demographic Data Questionnaire (Appendix E.6.)
- The PedsQL™(Varni et al.1999, 2003)The Paediatric Quality of Life Inventory-(Arabic Version) (Appendix C.2.)
- The CDI; (Kovacs 1980/1981, 1992). The Children Depression Inventory-(Arabic Version) (Appendix E.9.)
- The RCMAS; (Reynolds & Richmond, 1985). The Revised Manifest Anxiety Scale-(Arabic-Version) (RCMAS; Reynolds & Richmond, 1985) (Appendix C.2.)
- The DASS-42; (Lovibond & Lovibond, 1995b). The Depression, Anxiety, and Stress Scale-(Arabic Version) (Appendix C.3.)
- The list of open-ended questions (Appendix E.6.).

To support the quantitative data, unstructured interviews through open ended questions were conducted. The interviews explored mothers' pattern of communication of the cancer diagnosis, which served as background information about the child's perceptions and understanding of the illness (Appendix E.6.).

1.5. Definitions of variable under investigation

I used two approaches to the study of psychological adjustment in children and young people; the study of psychological disturbances such as anxiety and depression, and assessment of quality of life (Boeving, 2000). The term "psychological adjustment" as a scientific outcome measure represents a relatively new paradigm. For some time this concept has been used as a way to describe the overall results of cancer diagnosis and treatment efforts in a way that makes sense. The conceptual formulation defining these psychological disturbances during the course of cancer or chronic illness is best conceptualized as a crisis occurring in the course of normal development, rather than as some type of consistent psychology (Glazer, 1991).

One of the main issues of discussion in the literature, which is considered in detail in section two of the literature review, has been the use of several different terms to describe psychological adjustment, and the lack of differentiation between these concepts. The purpose of the present discussion is to set the context for the following chapters by introducing the reader to the concept in our present understanding.

In this study, since virtually all assessments of quality of life include some measures of emotional wellbeing, such an association between anxiety, depression, and quality of life is essential to be addressed. Previous studies have shown that anxiety and depression are associated with impaired quality of life (Smith, Gomm, & Dickens, 2003). Moreover, previous existing research literature suggests that depression and anxiety contribute to impairment in the social and physical dimensions of quality of life. Nonetheless, differentiation between anxiety and depression remains one of the most persistent issues in differential diagnosis. Clinicians and researchers consistently see a high co-occurrence of depressive and anxiety symptoms, high correlation between self-report anxiety and depression measures, and high rates of comorbidity between depressive and anxiety disorders (e.g. Barbee, 1998; Cole, Peeke, Martin, Truglio, & Seroczynski, 1998; Eley & Stevenson, 1999; Weems, Hammond-Laurence, Silverman, & Ferguson, 1997). These observations have led some to question whether there is in fact a valid distinction between these two constructs (Kendall & Brady, 1995). Therefore, although separate definitions are provided of the terms quality of life, anxiety, and depression, these categories are merged when presenting results of research on the psychological adjustment in children and young people during cancer treatment.

1.5.1. Health-related quality of life (HRQoL), definition and conceptual issues

The concept quality of life (QoL), itself, has been widely used in research but no universally accepted definition is so far available. Cella (1998) argued that the integrity of the term QoL has been challenged on the grounds that it cannot be validly measured as, first, it is too general to have a meaning, and second, it is so vague that it means different things to different people. There is truth in both of these perspectives. However, there is wide consensus that health related quality of life (HRQoL) can be used in providing minimum requirements for defining QoL (Eiser & Morse, 2001a; Cella 1998; Varni, Seid, & Rode, 1999). Equally, Hinds et al. (2006) and Varni et al. (2007b) argued that children aged five years and older are able to report their cancer-related QoL; as well that reliable and valid QoL instruments exist for all phases of treatment except end of life.

In this instance, with relation to medicine and nursing, quality of life is clearly related to health and defined as the subjective well-being of a patient with regard to his/her sense of wellbeing and treatment. According to Varni, Seid, and Rode (1999), HRQoL can be conceptualised as "a patient's perceptions of the impact of disease and treatment functioning in a variety of dimensions, including physical, mental, and social domains. HRQoL is viewed as a multidimensional construct which aims to improve paediatric

patient health and well-being and determine the value of healthcare services (Varni et al, 2007b). Varni et al. (2007c) stressed that although the term QoL is sometimes used interchangeably with HRQoL, QoL is a broader construct that encompasses aspects of life which are not amendable to health care services. Yet, consensus has been reached with regard to the four core domains of HRQoL, namely, disease state, functional status, psychological and social functioning (Spieth & Harris, 1996; Varni, Seid, and Rode, 1991).

1.5.2. Childhood anxiety, definition and conceptual issues

According to Stewart (1997), anxiety is a distressing feeling of uneasiness, apprehension or dread. The fear may be rational, based on an actual event, or irrational, based on an anticipated event which may or may not take place. Importantly, anxiety is a normal emotional state that is experienced across the developmental spectrum (King, Hamilton, & Ollendick, 1988). In childhood research, the term anxiety is often used interchangeably with fear, and a number of factors are considered when differentiating normal fear from anxiety, such as the severity and duration of symptoms, and the level of impairment or interference in a child's life (Beidel & Turner, 1984).

The Diagnostic and Statistical Manual of Mental Disorders (DSM-IV; American Psychiatric Association [APA], 1994), represents a categorical approach to defining anxiety. According to the DSM-IV system the following anxiety disorders can be distinguished in children and adolescents:

(1) Separation anxiety disorder, which is characterised by excessive anxiety concerning separation from the home, or from significant attachment figures, to a degree that is beyond that typical of the child's developmental level.

(2) Generalised anxiety disorder, formerly termed overanxious disorder, which refers to persistent and excessive anxiety and worry, accompanied by motor tension and vigilance.

(3) Social phobia, which involves marked fear of social or performance situations in which embarrassment may occur.

(4) Panic disorder, which is characterised by the presence of panic attacks (i.e., discrete periods of intense fear), accompanied by persistent concern about their recurrence or their consequences.

(5) Obsessive-compulsive disorder, which is characterised by the occurrence of obsessions (i.e., intrusive ideas, thoughts, images, or impulses that cause marked anxiety or distress) and compulsions (i.e., repetitive behaviours or mental acts which serve to neutralise anxiety).

(6) Specific phobia, which is defined by marked and persistent anxiety provoked by exposure to a specific feared object or situation, often leading to avoidance behaviour.

(7) Acute stress disorder and post-traumatic event which both involve the experiencing of an extremely traumatic event accompanied by increased arousal and avoidance of stimuli associated with the trauma.

However, the DSM system represents only one way of understanding and defining childhood anxiety. One of the criticisms of the categorical approach of the DSM-IV is the largely dichotomous nature of diagnosis, which requires a minimum number of symptoms for any one diagnosis (Frances, Widiger, & Fyer, 1990).

1.5.3. Childhood depression, definition and conceptual issues

The term "depression" itself, as opposed to "depressive symptoms" and "level of depression" is considered to be undesirable and confusing. Depression generally refers to either an emotional state or a clinical diagnosis (Rycroft, 1968). In studies of childhood and adolescent depression, depression is used to identify those with a set of symptoms meeting the criteria for a depressive disorder, those with symptoms of depressed mood and those with a combination of depressed mood and other symptoms forming a syndrome (Compas, Ey, & Grant, 1993), which is probably parallel to the lay public's understanding of the term clinical depression"(Hotopf, Chidgey, Addington-Hall, & Lan-Ly, 2002).

Brown & Pedder (1979) defined depression as a mood disturbance characterized by feelings of sadness, despair, and discouragement resulting from and normally proportionate to some personal loss or tragedy. Each view of depression represents somewhat different assumptions and assessment procedures. The definition of depression selected for this study, based on previous research on this topic, encompasses the dimensional approach. This model views depression as a constellation of mood symptoms falling along a continuum of severity, with level of depression being typically rated via self-report questionnaires. In contrast, those with depressive disorder have been assessed according to the categorical approach embodied within the DSM system. As noted in relation to defining anxiety, the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV; American Psychiatric Association [APA], 1994), represents a categorical approach to defining depression. Depressive disorders are contained exclusively within the adult Mood Disorders section of the DSM-IV. They are classified as Major Depressive Disorder (MDD), which is an acute and severe form of depression, with minor modification for children's depression in the diagnosis of MDD, irritable mood may be substituted for depressed mood, and failure to make expected weight gains might be substituted for weight loss; Dysthymic Disorder (DD), which is a less severe but more chronic depression, of one years duration instead of two for adults, and Depressive Disorder Not Otherwise Specified.

2.1. Introduction

This chapter discusses important considerations that need to be addressed in the area of psychological wellbeing of children and young people with cancer in Jordan. Following an explanation of the research strategy, the chapter is divided into three sections beginning with an overview of the incidence and treatment of childhood cancer in Jordan. The second section presents a conceptual framework to the study and considers psychological theories of child development in order to describe coping and impact of cancer on children's and young people's wellbeing. This section does not offer an analysis, nor indeed a detailed list of hospitalisation impacts on the child or of child development theories, but summarises adverse reactions to the hospital environment and cancer treatment. In addition, it discusses the notion of defensiveness and methodological considerations, in order to provide a general background to the topic. The third section of the literature review presents a review of studies published between 1980 and 2006 in nursing, paediatrics and social science journals about the psychological effects of cancer. The association between psychosocial problems in the parents and the child with cancer is considered.

2.2. Literature search strategy

Current relevant research articles were identified and retrieved from a systematic search of computerized databases:

- Med-line (U.S. National Library of Medicine),
- EBSCohost (CINAHL, PsychINFO)
- Google Scholar
- Zetoc database for periodicals in the British Library.

The literature search started in September, 2004 and continued until January, 2007. The electronic database was searched by using "depression", "anxiety" and "quality of life" as keywords. A large number of studies showed that the terms "depression" and "anxiety" were frequently used interchangeably with "psychological distress", "psychological functioning" or "adjustment" (For example; Hedström, 2005).

However, literature derived from this combination of keywords was mostly oriented toward adult oncology patients. Therefore addition of the search term "children" to the keywords proved necessary (Table 2.1).

Table 2.1. shows literature traced from 1980 to 2006. The results showed that research on psychological consequences of cancer in children and young people is very scarce, and no studies addressed directly the psychological adjustment of Arab/Jordanian children or young people with cancer.

Variables	NUMBER OF PAPERS for all in title				NUMBER OF RELATED PAPERS	
	Med- line	EPSCO- host	Google Scholar	Zetoc	Total	
Anxiety+ Children +Cancer	481	67	36	11	26	
Depression +Children +Cancer	514	52	16	7	37	
Adjustment + Children + Cancer	1417	113	68	32	13	
Distress + Children + Cancer	627	78	48	33	13	
Quality of Life +children +cancer	1344	86	70	61	16	
Coping +children + cancer	255	33	44	31	9	

Table 2.1.Literature traced from 1980 to 2006

A number of theses were obtained around one or two of the current study variables. Of the five PhD theses obtained, three were from the United Kingdom, namely two concerned with quality of life in children with cancer (Vance, 2002; Havermans, 1996), and one discussing psychological problems and adaptive style in children with cancer (Wurr, 2001). Of the other PhD theses found, one was from Australia, about the adolescent coping with cancer (Till, 2004) and one from Sweden (Hedstrom, 2005) regarding distress among adolescents with cancer. In addition, a few master dissertations were found (e.g. Boeving, 2000) from the United States about adjustment to childhood chronic illness, in which cancer was integrated with other childhood chronic illness. Preliminary analysis of the literature showed that psychosocial effects of cancer in children and young people were assessed in a number of ways, including one or more of:

- Issues of quality of life (Eiser et al. 1997; Challinor et al. 1999; Levi and Drotar 1999; Bessell 2001; Langeveld et al. 2002; Apter et al. 2003; De Clercq et al. 2004; Mataz et al. 2004; Eiser et al. 2005).

- General mental health issues, including anxiety or/and depression (Tebbi et al. 1988; Fossen et al. 1989; Varni et al. 1995; Varni et al. 1996; Allen et al. 1997; Barbee 1998; Berard and Boermeester 1998; Benedito et al. 2000; Cavusoglu 2000; Von-Essen et al. 2000; Cavusoglu 2001; Deimling et al. 2002; Zebrack et al. 2004).

- Learning, intelligence, and academic achievement (Novakovic et al. 1996; Enskar et al. 1997; cavusoglu 2000; Vance and Eiser 2002; Hokkanen et al. 2004).

- Social and peer acceptance and relations (Noll et al. 1990; Ellis 1991; Noll et al. 1991; Noll et al. 1993; Novakovic et al. 1996; Noll et al. 1999).

However, the issue of the impact of the illness on parents and siblings of children with cancer was relatively broad, and there was insufficient evidence to justify a review. Therefore, a set of criteria was established for the selection of appropriate studies in the literature review:

- Studies involving quality of life, and general mental health issues of depression or/and anxiety in children,
- Studies including standardised measures, and conduct statistical tests to compare scores with population norms or matched controls.

Before proceeding to in-depth critical analyse of this literature, it should be noted that general listings for studies that discussed cancer and medical management of cancer were reasonably straightforward, child mental health disorders were also straightforward. The review also incorporates broader literature discussing the patterns of communication and coping of children and young people with cancer. However, it was more difficult to ensure that the search for literature on coping was comprehensive.

2.3. Section one: Medical overview of childhood cancer in Jordan

2.3.1. Introduction

It is suggested in this thesis that the diagnosis of cancer and cancer treatment is not only physically demanding, but also it affects the psychological adaptation of children and young people. Thus, before this pathway is explored and discussed empirically, it is important to understand the medical experience of being diagnosed with cancer. The current section gives a medical overview of childhood cancer in Jordan. The subsequent section presents a conceptual framework illustrating how this medical condition affects the child's psychological adaptation.

2.3.2. Prevalence of childhood cancer in Jordan

In Jordan, the incidence of all cancers in children fifteen years of age and younger is estimated to be 11 per 100,000 (National Cancer Registry, 2003). In the United Kingdom, cancer has an annual incidence of 9.4 per 100,000 children under fifteen (Gurney at al, 1996). In 2003, 205 children between 1-14 years old were diagnosed with new cancer all over Jordan. The male to female ratio is 1.4:1, with male childhood cancer cases equalling 121 (59%) and female cases 84 (41%) with a higher incidence in boys than in girls (e.g. Leukaemia, Lymphoma, and CNS).

Leukaemia is the most common cancer, comprising 33.7% of all childhood cancers, followed by brain and spinal tumours (14.1%) and lymphomas (10.2%). This prevalence is comparable to that in the United Kingdom (Gurney at al, 1996). It is also consistent with the international distribution of childhood cancers (Samuelsson 1999) of which the majority are Acute Lymphocytic Leukaemia (ALL), the second largest group is the brain tumours, followed by soft tissue sarcomas and lymphomas.

The geographical distribution of new cancer cases in 2003 by governorates shows that Amman, the capital, has the highest reported incidence, with 61.2% of all cancer cases in Jordan (localised within the central region), followed by Irbid with 15.2% (localised within the northern region), Zerqa with 9.0% in the eastern region and Balqa governorate (4.4%). This pattern may be related to the population and geographical position of the central region of the country, which includes 62.8% of the total population.



Figure 2.1. Distribution of new cancer cases by governorates of Jordan, 2003

2.3.3. Treatment procedures

Cancer treatment in Jordan is similar to that in other countries and is often part of national and international chemotherapy protocols. The treatment may include chemotherapy, radiation therapy and/or surgery. As a rule, surgery has two main aims, either diagnostic or used for the complete resection of a tumour. Chemotherapy, which refers to the use of toxic agents, is associated with a number of complications, including nausea and vomiting, diarrhoea, neutropenia, mucositis, anorexia, and alopecia (loss of hair). Long term side effects may include damage to vital organs such as the kidneys (Samuelsson 1999). Radiotherapy involves the delivery of ionising radiation to cause damage to both cancerous and normal cells. In general, side effects of radiation depend on the type of radiation, the dose, the duration, and the anatomical site treated. The side effects can be acute, including nausea and vomiting, skin reactions and bone marrow depression, or develop later, like abnormal growth, abnormal function of organs and the induction of second malignancies (Eiser, 1998; Samuelsson 1999; Hinds et al. 1992).

Current chemotherapy practice generally employs more drugs, in higher doses, for longer periods of time than were used 10 years ago (Crist and Kun 1991). These treatment regimes are commonly known as protocols. In Jordan, King Hussein's Cancer Hospital (the largest specialised centre for cancer treatment in the Middle East) treats children and young people with a modified St.Jude Children's Research Hospital protocol. In the military service hospitals, children and young people with cancer have a common staging, classification and treatment approach in accordance with multi-agent chemotherapeutic protocols, and are treated on research protocols that are treatment arms of randomised phase III clinical studies (Bleyer 1997). Each of these protocols includes different types and dosage of chemotherapy and radiation therapy, surgeries, inpatient versus outpatient therapy and painful procedures such as lumbar punctures and bone marrow aspiration (Noll et al. 1999). Other common protocols of chemotherapy are the German BFM and the French LMB protocols. These protocols vary also in their intensity and duration (Samuelsson 1999).

The main treatment schedules today for cancer patients aim to devise a treatment plan which might include radical treatment given with the intent to cure or control the disease long term, or palliative treatment to improve patient quality of life, or control symptoms (Hogg and Christie 2003). Treatment for cancer may last for up to two years (typically in ALL). All treatment protocols of cancer include three phases of standard chemotherapy regimens (see Table 2.2.): the induction, consolidation and maintenance phases.

CHEMOTHERAPY PHASE	WHEN INSTITUTED	GOALS
Induction	Initial therapy	To eliminate as many cancer cells as possible To obtain a complete remission
Consolidation	Given after remission is complete	To ensure complete eradication of disease
Maintenance	Given for several months to years after consolidation, depending on disease	To maintain a complete remission To minimize late effect To prevent drug resistance from developing

Table 2.2. Phases of standard chemotherapy regimens (Source: Wolownik, 2002)

2.4. Section Two: Theoretical framework

[A very brief medical background of cancer is provided in this section. The description includes the prevalence and treatment of childhood cancer in Jordan]. The impact of cancer treatment is described by presenting Lazarus and Folkman (1984) as a conceptual framework of child stress and coping. Despite the fact that the classical transactional model of stress was based on adults, it is important to realise that several studies adopt this model, wholly or part, is to describe coping in children (e.g. Vance, 2002; Boeving, 2000).

2.4.1. Introduction

To date, although many frameworks have been shown to explain coping with stress and child's adjustment, no single predictor of psychosocial outcomes has been identified, and literature on how children and young people cope remains scarce.

Within this thesis, the cognitive and stress theory developed by Lazarus and Folkman (1984) was used as a base to explore the child's adaptation to cancer diagnosis and treatment. The cognitive theory of stress and coping of Lazarus and Folkman (1984) emerged as an appropriate framework for this study because it incorporates stress appraisal and coping system, concepts which have been tested repeatedly by various researchers (e.g. Folkman et al, 1986; Boeving, 2000; Aldridge & Roesch, 2006; Franks & Roesch, 2006).

Numerous articles have been published that contain forceful criticisms of the Lazarus and Folkman coping theory (for review see the author response, Lazarus, 1990). It has been subjected to a number of criticisms, notably by those who argued that while this model is a milestone in coping research; its complexity makes the empirical evaluation difficult. For example, the emphases on cognitive processes leaves no explanation of the effect of more subtle stressors below the awareness level or physiological mechanisms that might moderate or mediate the coping process (Snyder and Dinoff 1999), in addition to the role of personality traits in stress, coping and emotion. A second criticism is that, since this model was based on adults, there are concerns that it lacks understanding related to child cognitive development. Thus, additional theoretical support was needed within this thesis. However, this model presents an optimistic view of the potential for children's resistance and coping. It gives a practical application for coping and resilience. In other words, Lazarus and Folkman's model hypothesised a way in which individuals may cope with adversities during stress.

2.4.2. Cognitive theory of stress and coping (Lazarus and Folkman 1984)

Lazarus and Folkman (1984) contend that the central function of coping is oriented towards reducing tension and restoring equilibrium through using a variety of coping strategies. Lazarus and Folkman (1984) defined coping as a complex process that is:

"Constantly changing cognitive and behavioural efforts to manage specific external and /or internal demands that are appraised as taxing or exceeding the resources of the person" (p. 141).

In the context of cancer, stressors include the nature of disease, treatment regimen including side effects of radiation and chemotherapy, body image, missing school and taxing/challenging tasks and demands. Once the child is faced by a stressful encounter, such as cancer, the child assesses its significance to his/her personal well being, that is *primary appraisal*. This is followed by *secondary appraisal*, whereby the child evaluates his/ her coping resources and options for managing it.

For example, according to Lazarus and Folkman (1984), *primary appraisal* may classify the encounter as irrelevant, having no significance, being positive, lying within the range of the individual's coping resources, or stressful. Consequently, a perceived stressful encounter is further categorised as harm/loss, threatening or challenging to the child's wellbeing. Thus a threatening situation yields negative emotions such as anxiety and depression, or positive emotions such as enjoyment and eagerness. Still, during *secondary appraisal* the individual evaluates the possible coping strategies to meet the demands of the situation, and just like adults in this case, children use a variety of coping strategies to deal with disease related stressors, according to their age group (Boekaerts and Roder 1999). For example, young children use more problem-focused coping, whereas older children display a preference towards emotional coping, and as they get older, they use more coping strategies (Band and Weisz 1998).
The most commonly used dimensions of this model are the problem versus emotionfocused coping approach. Lazarus and Folkman (1984) focus their work on the delineation of two categories of coping behaviour: problem-focused (involving strategies such as discussing solution alternatives) and emotion-focused (involving crying or palliating feelings) coping. Problem-focused coping effort directly targets the stressor in an attempt to resolve the stressful situation. Emotion-focused coping efforts are the individual's attempts to regulate the negative emotional state that is aroused by the stressor, without directly targeting the stressor itself.

The assumption underlying the Lazarus-Folkman model is that problem-focused coping is active, resulting in a positive outcome, whereas emotion-focused coping is not adaptive, leading to negative outcomes (Quittner et al. 1996). However, this notion is not supported uniformly in the literature (see Aldridge & Roesch, 2006; Franks & Roesch, 2006). For example, some studies have indicated that problem-focused coping efforts lead to decreased psychological distress more so than emotion-focused (Billings and Moos 1981; Strauss and Wellisch 1981), but others indicated that in some situations, the problem-focused dimension is associated with poorer adjustment in children (Aldridge & Roesch, 2006).

Another conceptualisation is the differentiation approach (engagement) versus avoidance (disengagement) where people tend to either evade or avoid stressors. In this instance, individuals who appraise their cancer as a harm/loss are likely to use more avoidance coping strategies and those who appraise their cancer as a challenge are likely to use approach coping strategies (Franks & Roesch, 2006). The approach – avoidance paradigm assesses the child's stress response as *engaged* in ameliorating the stress process (including both "problem-focused" and "emotion-focused" strategies) or as *withdrawn* from participation in the process (e.g., with denial or disengaged distraction strategies). With this orientation toward coping as approach (or engaged) coping strategies, both strategies can be employed in an interactive way to regulate oneself actively in the context of a stressor (Spirito et al. 1988).

2.4.3. The child's adaptation to cancer: theoretical perspectives

This section is an amalgamation of key concepts drawn from earlier influential psychosocial theories of child development. A number of theories have been proposed to describe how children grow emotionally, psychologically, and intellectually such as Freud (1894), Erikson (1964) and Piaget (1976) and psychosocial studies of cancer impact resulting in theoretical perspectives of adaptation to chronic illness and cancer. While integrating these theories in describing how children and young people are coping with cancer diagnosis, we should bear in mind the shortcomings of these theories and the cultural barriers which make generalisation of these theories inappropriate at some points. For example, despite the fact that Freud's psychoanalytic theory offered the first real theory of personality development, Freud based his theory on his observations of mentally disturbed adults, thus the base of this theory described human behaviour as being the result of instinctual derives (libido) from within the person and the conflicts that develop between these instincts (id), reality (ego), and society (superego). Whereas, one of the main tenets of Erikson's theory, that a person's social view of himself or herself is more important than instinctual derives in determining behaviour, allows for a more optimistic view of the possibilities for human growth. Piaget introduced concepts of cognitive development that are similar to those of both Freud and Erikson and yet separate from each as will be further presented in child adaptation to cancer. The integration of the three theories in this section compensates for the deficit of taking each as a separate unit.

In accordance, child adaptation was defined as representing the child's mental health, social functioning and physical health (Wallander et al, 1989). Wherever possible, the research presented in this section will be presented in terms of age group, i.e., whether children are school age or adolescents. Previous studies of psychological adaptation to cancer diagnosis have involved adults or adolescents; there is evidence to suggest that school age children have been most of the time excluded (Brage, Grossman, and Dunkel, 1995). Moreover, some studies of cancer treatment provide preliminary evidence at a directional relationship between symptoms of psychological distress, and aspects of cancer treatment (Spiegel, and Giese-Davis, 2003; Langton, 2000; Valant, Saunders, and Cohen, 1994), where reactions and adaptation to a long term illness often depend upon the developmental stage of the child(Langton, 2000). Studies will be grouped together according to cancer impact, for example, the impact on physical

domain, social or cognitive domains. The studies cited within this section and those related to psychological domain and mental health are summarised and critically analysed in a separate section.

2.4.3.1. Cognitive domains

According to Piaget's theory, children progress through four developmental stages. One of these is the Concrete operation stage at 7-11 years; during this time the child learns, adjusting to the social environment outside the home, absorbs the culture, forms beliefs and values, develops same-sex friendships, and engages in sports. Concrete thinking at this stage influences knowledge acquisition (Piaget, 1976). According to Santrock (2004) children and young people develop their ability to process information gradually, building their abilities of memory and thinking, and this explains how children perceive and understand their illness. According to Faulkner et al. (1995) children at age 9-14 years realise that cancer is a serious and life threatening disease, and capable of understanding their diagnosis of cancer. This is of great influence when discussing the way of communicating illness to children and young people with long term illness later in this thesis

Cognitive development is also a key feature of young people. Piaget (1976) describes the cognitive development of the adolescent years as a progression and construction of concrete operations to a new level termed "formal operations"; by this point, the child's cognitive structures are like those of an adult and include conceptual reasoning. Thus, adolescents understand abstract and complex concepts. Consequently, we need to bear in mind that during cancer, adolescents or young people have similar informational needs to adult cancer patients, and feel empowered if they are given the opportunity to have access to their own records, or allowed to choose options if they exist (Hampson 2000), and thus developing improved coping mechanisms to cope with their illness (Whyte and Smith 1997).

2.4.3.2. Physical domains

Symptoms from cancer and treatment side-effects vary tremendously depending on disease and treatment. Nevertheless, physical side-effects of cancer treatment are often regarded as the worst aspects of disease, especially pain from treatment and medical procedures (Albano and Odom 1993). Hinds et al. (1992) compared the perceived distress of various aspects of cancer and its treatment, using the symptom distress scale (McCorkle and Young 1978) among 33 newly diagnosed adolescents; the top three sources of distress were feeling tired, concerned with appearance, and lessened ability to get around. Manifestly, adolescents or young people with cancer have been reported to be more troubled by physical restrictions and changes than younger children (Claflin and Barbarin 1991; Stam et al, 2006).

For adolescents or young people, a major developmental task is the "formal operations" which permit the internalization of self-image, self-concepts, and identity (Erikson, 1964); in this instance, the establishment of body image involves the adolescent integrating their fantasy of an ideal body and their real body image (Carr-Gregg and White 1987). However, cancer treatment, hair loss, weight gain, "moon-faced" appearance and acne can affect their ability to do this, and self consciousness may be exaggerated due to the physical changes caused by their treatment (Roberts et al. 1998). Importantly, hair loss caused by chemotherapy and radiation has been reported as a major cause of concern in young people, not only as a transient cosmetic effect, but with a deep influence on peer relationships (Novakovic et al. 1996). However, for cancer survivors, Pendley et al. (1997) reported no differences between adolescent cancer survivors and healthy controls on measures of body image.

In summary, previous work on physical appearance and body image has shown that young people with cancer have been reported as feeling more negatively about their bodies compared with younger children with cancer (Price, 1992) and healthy peers. It might be expected here that children and young people who are disfigured as a result of cancer treatment like limb amputation or brain surgery, would have poorer body image than children and young people who have no such disfigurement. However, many researchers in the field of paediatric oncology have excluded these particular children from studies of body image (Pendley et al, 1997).

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Similarly, sexuality issues are of concern. In Freud's psychosexual development theory the genital phase lasts for seven years from ages eleven to eighteen. According to Freud, this phase brings a renewed interest and pleasure in excretory activity and this might be affected by cancer and chronic illness. Roberts et al. (1998) and Cavusoglu (2000) reported fears and worries related to cancer treatment include effects on sexuality and production, relapse and death. Fritz and Williams (1988) reported that body concerns were problematic for young people with cancer, particularly related their sexuality, sexual attractiveness, and reproductive capacity. There are concerns that cancer treatment can cause gonadal damage and affect future fertility. However, young people may feel uncomfortable talking about sexual issues in relation to cancer treatment (Carr-Gregg & White, 1987).

It is quite remarkable that so few studies are conducted on the sexuality and sexual preoccupation of young people with cancer. In Jordan, no patient is confronted with sexual and reproductive issues at diagnosis, during the entire treatment period or as a long term survivor and this applies to both children and adolescents. It can be argued here, that the ethical and practical problems in asking children and young people about these issues make it difficult for parents to talk to their child about possible infertility problems. Surprisingly, Khatib et al. (2005) described, in one of the few articles that are published on children with cancer in Jordan that over half the children did not know the nature of their illness. Thus, it is quite understandable that parents will not to want to give permission to talk about this to their child, especially if he/she has no idea that he/she is diagnosed with cancer.

2.4.3.3. Social domains

According to Erikson, each individual passes through eight developmental or "psychosocial" stages. At the age of 6-12 years (the latency phase), the child needs to resolve a psychological crisis of "industry versus inferiority". If the child is able to discover pleasure in intellectual stimulation, being productive, and seeking success, he/she will develop a sense of competence; if not, he/she will develop a sense of inferiority (Erikson, 1964).

A large part of the child's socialisation and sense of industry usually occurs in school; thus, schooling is the important event at this stage; as the school age period is a time of increased self-control, and concrete thinking. However, because of repeated hospitalisation and lengthy treatment of both cancer and many chronic illnesses such as renal failure, the child may miss the opportunity of attending school in a regular basis. Vance and Eiser (2002) state that school absences and missing classes remain the greatest concern for many children and young people with cancer. The lengthy treatments, susceptibility to infection and poor health status lead to social problems for young people with cancer through interruption of school and decrease in relationship with peers and others (Cavusoglu 2000; Hokkanen et al. 2004).

In a social context, most of the studies researching the child's social functioning perceived children and young people as being more socially withdrawn, isolated and shy than matched peers (Noll et al, 1990, 1991, 1993; see next section for a more detailed discussion). Rudin et al. (1988) investigating the psychosocial concerns of young people with cancer, found that peer relationships either strengthen or weakened with the diagnosis of cancer. Therefore, a lengthy period of separation from peers during cancer treatment can add to the sense of isolation, and can add more constraints on the child development. This point can be further explained and discussed through Erikson's theory of child psychosocial development. Erikson (1964) describes the central task of adolescents as the development of "identity vs. role confusion", where most adolescents develop life goals and plans for their career path. However, cancer can limit possible opportunities for career development, as young people with cancer may set themselves unrealistic goals at school, and become disappointed when they are not able to achieve them (Perrin and Gerrity 1984).

Young people, during the adolescence stage, struggle to develop ego identity (sense of inner sameness and continuity). However, the diagnosis of cancer may impede development of independence from their families, so that children's and young people's sense of independence can be lost. Thus, young people may display hostility as a way of rebelling against this unwanted dependency and protective actions of their parents (Carr-Gregg & White, 1987). Considering those studies which have examined the child's social functioning and adaptation to school, there are a number of concerns which limit discussion of these studies in this section, and they will be discussed in more detail in the next section of this chapter.

2.4.4. Conclusion

The literature in this section serves to illustrate one of the key themes in this thesis, namely the associations between cancer treatment (reviewed in section 1) and the child's psychological adaptation. Overall, the conceptual model of stress and coping in addition to the findings of studies on treatment related aspects that were reviewed stress the importance of how children and young people may experience their treatment and how this may affect their perception of the impact of the illness. The next section summarises studies on childhood psychological adjustment and discusses its measurement.

2.5. Section Three: Research on childhood psychological adjustment during cancer

2.5.1. Introduction

A review of studies published between 1980 and 2007 of the psychological effects of cancer in nursing journals, as well as in paediatrics and social science journals was identified through computer based searches. No comparable review was undertaken about children and young people currently undergoing cancer treatment. Whilst there have been a number of narrative reviews on psychological outcomes of cancer in children and young people (Eiser et al. 2000; and Varni et al, 2007c), only one review has reported its method section and can be considered systematic (Eiser et al. 2000). Eiser et al (2000) used an extensive search strategy and identified twenty potential articles. However, the inclusion criteria of the study were relatively narrow, confined to survivors, and included studies that involved child, and adult survivors of childhood cancer. In Varni et al. (2007c), however, the review purposed to examine the ages at which HRQoL (Health Related Quality of Life) or QoL (Quality of Life) were measured for children with cancer and survivors by child self-report and parent proxy-report.

The main aim of this review is to produce unbiased information related to the findings of previous studies of psychological outcomes for children and young people with cancer during and after cancer treatment; moreover, whether there are differences in psychological outcomes dependent on time since diagnosis, and treatment protocols. Articles were included on the basis of methods used for assessment. Studies were

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included if they assess general mental health issues such as anxiety and depression, psychological adjustment and quality of life. Studies that included adult survivors or children younger than eight years old were excluded mainly related to developmental issues with conceptualising cancer diagnosis. Faulkner et al. (1995) argued that the term "cancer" is defined and understood differently by adults and children. For most adults the meaning of cancer is death, whereas children's understanding of cancer as a serious and life threatening illness is not developed till they are above 8 years old of age. Consequently, adaptation to cancer diagnosis and adjustment to illness differ differe between children and adults.

To address the main result, the reviewed studies are presented in tables under three grouping of outcomes: increased risk (Table 2.3.), no risk (Table 2.4.), and no identified relation (Table 2.5.). In adding up to listing the findings, the sample size, ages of subjects, data sources, data collection, and the use of control group are listed. While many diverse intriguing problems have been reported for several studies here, it is difficult to describe the interrelationship between these problems.

Reference	Sample	Age of sample	Parent sample	Study origin	Time since diagnosis
Adamoil et al, (1997)	N= 291 teachers of children with cancer N= 291 healthy	6-16 years	No	Italy	On treatment
(Barrera et al. 2005)	N= 800 cancer N= 923 control	< 17 years	Yes	Canada	Survivors
(Bessell, 2001)	N=51 cancer	8-17 years	No	USA	3.59 years
(Cavusoglu, 2001)	N=50 cancer N=50 healthy	9-13 years	No	Turkey	One year or more passed after the initial diagnosis
(Challinor et al., 1999)	N=43 cancer	Children and adolescents	Yes	USA	Currently receiving chemotherapy for at least one year, or who had completed chemotherapy for no more than three years (on and off treatment)
(Eiser, Eiser, & Stride, 2005)	N= 87 cancer	2.6-16.3 years	Yes	UK	Three months after diagnosis (on treatment)

Table 2.1.Studies that have identified high risk for psychological dysfunction in children with cancer

Reference	Sample	Age of sample	Parent sample	Study origin	Time since diagnosis
Greetnberg et al. (1989)	N=138 cancer N= 92 healthy	8-16 years	Yes	USA	Long term cancer survivors
Hockenberry- Eaton et al. (1995)	N= 44 cancer (N=29 on treatment, N=15 relapse, or off treatment)	6.5-13.5 years	No	USA	Mixed sample of children on and off treatment with some relapse case
(Moore & Mosher, 1997)	N=74 cancer	9-18 years	No	UK	(off treatment)
Noll et al, (1990)	N= 24 teachers of children with cancer N= 24 matched controls	8-18 years	No	USA	Mixed on-off treatment
Olson et al. (1993)	N=20 cancer N= 40 healthy	6-16 years	Yes	USA	survivors

Table 2.1.Studies that have identified high risk for psychological dysfunction in children with cancer

Reference	Sample	Age of sample	Parent sample	Study origin	Time since diagnosis
Rynard et al, (1998)	N= 67 cancer	5- 19 years	Yes	Canada	36 children on-treatment
Sanger et al. (1991)	N=48 cancer	4-17 years	Yes	USA	
Sheppard et al. (2005)	N=58 cancer	8-16 years	Yes	UK	All retinoblastoma diagnosed between 1987 and 1995
Vannatta et al, (1998a)	N= 48 cancer N= 48 healthy	8-16 years	No	USA	Survivors
Vannatta et al. (1998b)	N=28 cancer N=28 healthy	8-18 years	No	USA	Survivors
Van Dongen- Melman et al. (1995)	N= 95 cancer N= 90 healthy	8-12 years	Yes	Netherlands	<2 years=32% 2-5 years= 42% >5 years= 26%
(Vannata et al. 2006)	N= 82 cancer	9-17 years	Yes	USA	Survivors

Table 2.1. Studies that have identified high risk for psychological dysfunction in children with cancer

Reference	Sample	Age of sample	Parent sample	Study origin	Time since diagnosis
Anholt et al. (1993a)	N=62 cancer N=120 healthy	7-18 years	No	USA	20 months
(Anholt et al. 1993b)	N= 120 cancer N= 120 healthy	7-18 years	No	USA	Survivors
Canning et al. (1992)	N= 31 cancer N= 83 healthy	12-18 years	Yes	USA	Newly diagnosed children
Cetingul et al. (1999)	N= 19 cancer N= 17 healthy siblings	5-15 years	No	Turkey	Survivor, one year after treatment finished and five years after diagnosis
(De Clerq et al. 2004)	N= 67 cancer N= 81 healthy	8-14 years	Yes	Flemish	Children diagnosed between 1989 and 1998, and free of signs for 3 years
(Hagg et al. 1991)	N= 30 cancer N= 20 not chronically ill patients	Children and adolescents	No	Germany	Mixed on-off treatment
(Kaplan et al, 1987)	N= 38 Norms	7-18 years	No	USA	Mixed on-off treatment.

Table 2.2.Studies that have identified low risk for psychological dysfunction in children with cancer

Reference	Sample	Age of sample	Parent sample	Study origin	Time since diagnosis
(Noll et al., 1999)	N= 76 cancer N= 76 healthy	8-15 years	Yes	USA	Average 11.1 months after diagnosis, currently receiving chemotherapy
(Phipps & Steele, 2002)	N= 130 cancer N= 121 chronic illness N= 368 healthy	7-18 years	No	USA	More than 4 weeks from the date of diagnosis of cancer, and one month after diagnosis for chronic illness
(Phipps & Srivastava, 1997)	N= 107 cancer N= 442 healthy	6.5-13.5 years	No	USA	Mixed on-off treatment
Radcliffe et al. (1996)	N= 38 cancer Norms	6-18 years	Yes	USA	2-5 years (survivors)

Table 2.2.Studies that have identified low risk for psychological dysfunction in children with cancer

Reference	Sample	Age of sample	Parent sample	Study origin	Time since diagnosis
(Allen et al, 1997)	N= 53 cancer N= 173 healthy	Adolescents (M= 15.4 years)	Yes	UK	On treatment
(Anderson et al, 1994)	N= 100 cancer treated with chemotherapy and cranial irradiation N= 50 cancer treated with chemotherapy N= 100 matched healthy controls	Group 1 (m= 12.1year) Group 2 (m= 11.7)	Yes	Australia	Survivors
(Berard & Boermeester, 1998)	N= 43 Cancer	Children adolescents	No	South Africa	Newly diagnosed
(Chao, Chen, Wang, Wu, & Yeh, 2003)	N= 24 cancer	8-17 years	Yes	Taiwan	Average of 14.5 months after diagnosis

Table 2.3. Studies that have identified no relation between psychological dysfunction and cancer

Reference	Sample	Age of sample	Parent sample	Study origin	Time since diagnosis
(Gartstein et al, 1999)	N= 64 cancer N= 49 Sickle cell disease N= 21 Haemophilia N= 35 Rheumatoid arthritis N= matched healthy controls	8-15 years	Yes	USA	On treatment
(Grootenhuis & Last 2001)	N= 84 cancer		No	Netherlands	43 in remission, and 41 not in remission
(Kashani & Hakami, 1982)	N= 35 cancer	6-17 years	Yes	USA	From 1 month to 10 years post diagnosis.
(Mulhern et al, 1994)	N= 99 cancer Norms	8-16.8 years	Yes	USA	0.7 years post-diagnosis Mixed on-off treatment, mainly on treatment
(Noll et al, 1991)	N= 24 cancer N= 24 healthy	8-18 years	No	USA	Mixed on-off treatment

Table 2.3. Studies that have identified no relation between psychological dysfunction in children and cancer

Reference	Sample	Age of sample	Parent sample	Study origin	Time since diagnosis
(Noll et al, 1999)	N=70 cancer N=70 healthy	8-15 years	Yes	USA	On-treatment
Noll et al. (1993)	N(T1)= 19 cancer N(T2)= 17 cancer N= 17 healthy	11-18 years	Yes	USA	62.5 months off-treatment
Sloper et al. (1994)	N=31 cancer N=31 healthy	8-18 years	Yes	UK	5 years/ Survivors
Stern et al. (1993)	N= 48 cancer N=40 healthy	14-23 years	No	USA	Survivors
Spirito et al. (1990)	N= 56 cancer N= 52 healthy	5-12 years	Yes	USA	Survivors
Tebbi et al. (1988)	N= 30 cancer	Adolescents	No	USA	
Von-Essen et al. (2000)	N= 51 cancer N= 51 healthy	8-18 years	No	Sweden	Children on and off treatment
(Varni & Katz, 1997)			No	USA	<u>Time 1;</u> within 1 month after diagnosis <u>Time 2;</u> 6 months post diagnosis <u>Time 3;</u> 9 months post diagnosis
(Worchel et al, 1988)	N= 76 cancer N= 42 psychiatric patients N= 304 healthy	7-18 years	No	USA	Mixed on- off treatment

Table 2.3.Studies that have identified no relation between psychological dysfunction in children and cancer

The majority of the published studies were carried out in the United States, although some were done in the United Kingdom, and various other countries. Critical analysis of listed studies highlights the key points of the review, as well as the probable explanations for the variations in the findings. Generally, studies have found little evidence of serious mal-adjustment or mal-adaptation in children and young people with cancer. Moreover, some studies demonstrate that children and young people with cancer seem to function better than their healthy peers. Portteus et al. (2006) argued that despite several case series having revealed high rates of psychiatric difficulty in children and young people with cancer, the true incidence of mood disorders in children and young people with cancer is difficult to obtain. Portteus et al. (2006) found that the estimated prevalence of antidepressant medication in children diagnosed with cancer is higher than the reported rates for depression in the USA. This finding suggests that the number of children and young people with cancer receiving treatment with antidepressants without a proper diagnosis of depression is high and gives evidence that estimates of prevalence of depression and anxiety in children with cancer still have far to go.

Reviewing these studies reveals either contradiction as to the true extent of depression and anxiety problems in children and young people with cancer, or under-diagnosis and under-treatment of depression. This may be accounted for, in part, by an "adaptive style" purpose of avoiding conflict, anxiety or shame, which was ignored in several methods of measurement. Thus, the consideration of methods of measurement is essential when measuring psychological wellbeing of children and young people with cancer. The conflicting results were mainly due to complicated design issues which make it difficult to compare studies with one another. Problems includes, for example, lack of appropriate control when evaluating psychosocial wellbeing and cancer (Bessell, 2001: Sanger et al, 1991; Sheppard et al, 2005), variable sample size and inclusion of adult and children cancer survivors in the same sample (Barakat et al, 1997; Eiser et al, 1997; Elkin et al, 1997; Kupst et al, 1995), and inclusion criteria of children on and off treatment with different types and severity of cancer (Challinor et al, 1999; Von-Essen, 2000; Kashani et al, 1982; Grootenhuis et al, 2001). In addition, studies often used instruments that were not specifically designed for children with cancer, or they did not obtain self-reports from children (e.g. Sanger et al, 1991), thus not listening to the voice of the children and young people. Each of the methods used to study the psychological

impact of cancer in children and young people in the previous studies has strengths and weaknesses; together, they complement and compensate for one another.

2.5.2. Review of measures

When prevalence figures are presented for "depression" or "behavioural problems" in previous studies, it is important to understand the diagnostic criteria that the researchers used in defending the term of depression or behavioural problems, as this will have major effects on the prevalence estimate (Hotopf et al. 2002). Significantly, using diagnostic interviews in opposition to questionnaires defines the diagnostic criteria the researcher used for depression. For example, some often restrict the term "depression" to patients with major depressive disorder, which is probably akin to the lay public's understanding of the term "clinical depression" which is usually measured by the Diagnostic Interviews and the DSM-IV system. This approach represents a categorical approach to the assessment of mood and depressive disorders. It seems few studies used this approach (e.g. Brown et al, 1993; Dunitz et al, 1991). A number of criticisms can be related to this approach; these include issues related to validity of the diagnostic categories. In addition, there is considerable overlap with respect to their defining symptoms and associated features (Angold and Costello 1993). More important, is the lack of consistent criteria for assigning diagnosis when symptoms from more than one disorder are present (Kendall and Brady 1995). For example, if symptoms of different diagnoses are present in a child, but the child does not display the minimum number of required symptoms, then no diagnosis is assigned (Frances et al. 1990).

A second alternative for measurement, is self-report questionnaires which aim to identify specific symptoms and behaviour related to anxiety and/or depression, and to quantify their occurrence (Silverman and Serafini 1998). Although a detailed review of the available assessment tools used in the studies is beyond the scope of this chapter, some of the issues surrounding the limitations of the main assessment tools used in previous research with children and young people will be briefly discussed, taking the Child Behaviour Checklist, CBCL (Achenbach and Edelbrock 1983; Achenbach 1991) as an example.

In a study by Mulhern et al. (1992), the CBCL(Achenbach and Edelbrock 1983; Achenbach 1991) was used to estimate depression level; similarly in Anderson et al (1994); Noll et al, (1999); Gartstein et al, (1999); and Rynard et al, (1998). The diagnostic criteria within this context were mainly behavioural problems referred to as externalising or internalising problems in social relations, in particular peer interactions.

Despite the fact that the CBCL is the widely used behaviour rating scale for children and young people, it should be noted that the CBCL scales are not specific to childhood anxiety neither to childhood depression. The main limitation of the CBCL is the lack of focus on specifically identifying anxiety as opposed to the presence of general childhood psychopathology (Silverman and Serafini 1998), as the CBCL scales fail to successfully discriminate between childhood anxiety and depression (Wadsworth et al. 2001). Thus, caution must be exercised here, although it appears that if a researcher is generally investigating behavioural difficulties of children and young people with cancer, it is worth considering the quality of the measurements used in these studies, and diagnostic criteria of prevalence estimates.

The diagram below (Figure 2.2.) identifies the common DSM-IV symptoms of depression (American Psychiatric Association, 1994) and compares them with the common criteria of depression definition in the questionnaires approach. The two overlapping circles form three sections: the scored middle circle incorporates the symptoms common to the categorical approach of the DSM-IV and the questionnaires method, thus, defining the actual criteria used by the research in defining depression and prevalence in consequence. The circle of clinical depression represents all categories of the DSM-IV which should be present to assign a diagnosis of depression (Major Depressive Disorder), while the questionnaires approach registers more depression and pre-existing internal manifestations to the experience of depression. This approach takes more account of internalising coping such as defensiveness (this will be further discussed in the following sections)

Figure 2.2. Common and differentiating symptoms in between common DSM-IV symptoms

Common DSM-IV symptoms



2.5.3. Sample size, age group and on versus off cancer treatment

Some studies found that children and young people with cancer were at higher risk for problems than were children and young people with less life threatening diseases or healthy peers (e.g. Ĉavuşoğlu 2001; Bessell, 2001), but the small sample size of 50 children used in such studies prevents the findings from being generalized to a larger population. As one can see in Table 2.3, Table 2.4 & Table 2.5, the samples included between 20 and 138 children. The practical problems of obtaining a large average sample of children with cancer are numerous and well known to researchers working in this field, yet, samples of fewer than 30 patients in a quantitative study may be considered too small to obtain reliable data (e.g. Olson et al; 1993, Hagg et al, 1991; Noll et al, 1990; Vannatta et al, 1998b).

In addition, a number of confounding variables must be addressed when studying children's and young people's anxiety and depression, for example the age group of the child, time elapsed since diagnosis, and type of treatment. When associations between these variables have been studied, it has been reported that self- reported psychological distress among children and young people with cancer did not change with sex and age

(Neville; 1996; Canning et al, 1992; Grootenhuis, 2001). Others have demonstrated that girls reported higher levels of anxiety (Allen et al, 1997) and depression (Allen et al, 1997; Tebbi et al, 1988) than boys. Inconsistency has also been reported for other variables such as time elapsed since diagnosis and type of treatment.

For children and young people on treatment for cancer, most estimates of self-reported psychological distress have been consistent in demonstrating similar levels of anxiety (Allen et al, 1997; Von Essen et al, 2000) and depression (Allen et al, 1997; Noll et al, 1993) to those reported by healthy controls. Von Essen et al (2000) investigated 51 children with cancer for self esteem, depression, and anxiety levels for children on and off chemotherapy treatment. Data were compared to healthy children. The result showed no significant difference between healthy children and those with cancer. Von Essen et al. (2000) reported a depression prevalence of 6% among children and young people on cancer treatment, and 17% among youngster off treatment. These findings suggest that the period after treatment termination is characterized by a higher risk of psychosocial problems than the actual treatment period. However, the prevalence of self-reported a depression has varied somewhat between studies. Tebbi et al. (1988) reported a depression prevalence of 13% among young people on/off treatment for cancer, whereas Canning et al. (1992) reported prevalence of 6%, compared to 25% among a healthy control group.

Conversely, some studies showed that children off therapy and their mothers have better adjustment responses than those on therapy. This finding was obtained by Moore and Mosher (1997), in their study to examine the adjustment of children known to have cancer and their mothers through using the Children's Self care Performance and Children's State-trait Anxiety Inventory (STAIC) to assess self care and level of anxiety in 74 children and young people diagnosed with cancer, aged between 9-18 years. The same assessment was done of the children's mothers using the Dependent Care Agent Performance questionnaire and STAIC. A significant correlation emerged between children's responses and those of their mothers. Multivariate analysis of variance indicated that children off therapy and their mothers have better adjustment responses than those on therapy. Hockenberry_Eaton et al. (1995) found positive correlations between child trait anxiety and duration of cancer experience, and with the presence of a relapse. The 44 children included in their study were 6.5 to 13.5 years. Fifteen of them had experienced a relapse of the disease either on or off therapy. Other findings show no relation with time relapsed since diagnosis (Phipps & Srivastava, 1997).

It would seem then, that taking a heterogeneous sample of children on and off chemotherapy is a major issue in a study. Studies evaluating child psychological distress during hospitalisation need to exclude as many confounding factors as possible, but few studies did so. This led the way to recognition of the importance of assessing the influence of confounding variables on psychological wellbeing of children with cancer. There is evidence in the literature review that problems in family relationships as parents divorce and financial issues, increase the risk of depression in children (Brage, 1995, Cavusoglu, 2001). Taylor et al. (1999) distinguished two forms of anxiety, one related to their developmental stage as separation anxiety and worries; the other is directly influenced by the parent fear and anxiety, as well as the parent guilt following any diagnosis or treatment for their child. Similar conclusions have been reached by other researchers (Mulhern et al. 1992; Moore and Mosher, 1997). But there is little evidence as yet therefore that can child reported anxiety or depression be distinguished at the etiologic source from others influenced by child parent and environment.

Furthermore, the amount of information shared with children about their illness. Lansky et al. (1993) argued that being openly informed about the diagnoses and prognoses benefits the emotional well-being of children with cancer (Lansky et al. 1993). For example, Last and Van-Veldhuizen (1995) reported children who received open information about their diagnosis and prognosis at the initial stage of the disease showed significantly less anxiety and depression, his results on children with cancer showed that 64% of cancer paediatric preferred being openly informed about their illness, nevertheless, 36% preferred to know as little as possible about their illness. Studies using measures of depression which fail to take account of the confounding variables and overlap in symptoms of depression and cancer, and defensiveness (as will be discussed in the following sections) will eventually report contradictory results.

2.5.4. Source of information: self-assessment versus proxy assessment

As seen in Table 2.3, Table 2.4 & Table 2.5, most researchers obtained information directly from children. Other sources of information used were observational assessments or report from significant others such as parents (e.g. Eiser et al. 2005) and teachers (e.g. Adamoil et al, 1997; Noll et al, 1990).

A point of critique in relation to source of information in these studies is central, and highlights some important issues involved when analysing the results. First, in most studies where researchers predominantly or exclusively rely upon children's self-reports alone there is a high risk of "subjective bias" (La Greca, 1990) where children may be very keen to please others and answer in a way they think desirable (see defensiveness). Second, where parental reports are used as the main or contributing source of information, findings may be prone to being coloured by mother's emotional responses (Eiser et al., 2005; Sheppard et al. 2005). This points to the pervasive effect of the mother's mental health, and adds evidence to support the view that controlling for the mother's psychological wellbeing at diagnosis of cancer would have solved any "depressive bias" when assessing the child's wellbeing (Vance, 2002).

Manne et al. (1995) attempted to eliminate the effect of "depressive bias" by controlling for mental health problems in the parents where the mother gave self-reports of her own mental health and her child's behaviour; however, parental depressive symptoms at diagnosis (three- and six months post diagnosis) remained strongly related to child behaviour problems. Yet, it must be taken into account that this study is one of a limited number of studies that were able to account for the influence of "depressive bias" in mothers of children with cancer.

Another issue of parent-proxy report is parent-child agreement, to have some indication of the extent to which parents and children agree on an issue (Havermans, 1996). For example, in a recent study on mother's and children's quality of life, Eiser et al. (2005) found that there was a significant correlation between mothers' worries and their ratings of their own and child QoL. Mothers who rated their own QoL to be poor also rated their child's QoL to be low. Results like these suggest that caution is required when mothers rate their child's QoL. The extent to which parents and children agree or disagree will be further discussed in the cross cultural validation of PedQL. Besides the parents, the child's teachers were thought preferable sources of information in some studies (Adamoil et al 1997; Noll et al, 1990). However, relying on their rating raises a risk of bias in their expectations of the impact of illness, as they lack understanding of the illness and treatment and this makes them less reliable (Havermans, 1996)

2.5.5. Resilience in children and young people

Previous studies listed in the tables may have failed to differentiate between respondents who are truly healthy and those who are distressed, but whose report suggests an absence of distress, primarily as a function of resilience. Resilience is the maintenance of competent functioning despite an interfering emotionality (Newman &Blackburn, 2002). Applying Lazarus and Folkman's theory of coping, some children and young people may have been able to cope effectively and become strengthened by the challenge of cancer diagnosis by being positive and making effort to normalise their social world (see Rechner, 1990). Children may often be able to overcome and learn from single or moderate risks (Newman &Blackburn, 2002), while for others, the challenge has exceeded the child's resources, especially where these stressors are prolonged, multiple and impact on the child during sensitive developmental stages. This has been referred to in some literature as a multidimensional concept of resilience (e.g. Haase et al, 1999; Haase, 2004; Hedstrom, 2005, Newman &Blackburn, 2002) where the child manages stress through a process of identifying or developing resources and strengths to manage stressors. Thus, resilient children are hypothesised to be better equipped to resist stress and adversity and cope with change and uncertainty, and to recover faster and more completely from traumatic events or episodes (Newman &Blackburn, 2002).

The factors that promote resilience are strong social ties and supportive family. Resilience is suggested to be stronger among children who are more socially active, which considerably influences experienced stress, well-being, and way of coping. In Noll et al's (1999) study of social, emotional and behavioural functioning of children with cancer, the children scored remarkably similarly to case controls on measures of emotional well-being, and better on several dimensions of social functioning. As will be further discussed in relation to defensiveness, children whose illness or treatment is painful and/or interferes with normal activities, and children who experience embarrassing side effects or are visibly different from their peers are at higher risk for emotional difficulties. Thus, for those children, in order to manage the burden of illness, both children and families have to maintain a sense of normality (Green and Ray, 2006).

While the concept of resilience has been well developed in studies of chronic illness, it is less familiar in studies of children with cancer. Wang and Barnard (2004) reported that children with chronic illness in general express a desire to be normally and to be treated normal. This concept of "resilience" and "normalising" involves recognition of the seriousness of the diagnosis, yet viewing the child and family as normal, Importantly, cancer research and studies lack this view of conceptualisation, except for a few which include "repression" and "defensiveness" to explain how or why some children behave or act normally towards their peers (see defensiveness). Several attributes that are consistent with the family's view of normal or their "normalcy lens" were described among patients with cardiac transplant surgeries (e.g. Green and Ray, 2006), children newly diagnosed with type one diabetes mellitus (e.g. Lowes, Gregory and Lyne, 2005) and children dependent on machine technology such as ventilators (e.g. Wang and Barnard, 2004). The effects of these attributes (e.g. age, time elapsed since diagnosis, source of support, financial issues) were generally modest but positive on the child and family coping and their emotional wellbeing, and thus blunted the impact of the illness. It is hypothesised that there is no single association between stress and adaptive coping and resilience. Some stressors may trigger resilient assets in children and young people; others may compound chronic difficulties (Newman &Blackburn, 2002).

2.5.6. Defensiveness and ada ptive style

A number of studies in this field showed children with cancer at lower risk for problems (Phipps and Steele, 2002; Noll et al, 1999; Srivastava et al, 1997). Phipps et al. (2002) have posited a repressive adaptive style to explain the lower levels of distress on self-report measures. Phipps and Steele (2002) have pointed out that children with cancer and chronic illness reported significantly lower levels of anxiety than did the healthy control participants. This research involved a large representative sample. It included three groups of children; 130 children diagnosed with cancer, 121 with chronic illness, and 368 healthy control participants.

Similar findings of low distress and indications of repressive adaptive style have been suggested in other studies (Phipps & Srivastava 1997; Canning, Canning, and Boyce 1992). Phipps & Srivastava (1997) investigated 107 paediatric oncology patients between 7-16 years old, and 442 healthy control participants for measures of depressiveness, trait anxiety, defensiveness, and approach avoidant coping. Findings were consistent with other studies, as oncology patients scored significantly lower on level of depression and anxiety, and higher on defensiveness. Canning, Canning, and Boyce (1992) explored the relationship between a repressive style adaptation and depressive symptoms in 31 adolescents with cancer, compared with 83 healthy high school students. Subjects with repressive adaptation were identified through a measurement of low anxiety and high defensiveness. The results showed that children and young people with cancer reported significantly lower levels of depression, and a significantly higher proportion were identified as repressors. This finding supports Phipps and Srivasava (1997) by revising the use of both blunting and repressive adaptation by children and young people with cancer. Both Canning et al. (1992) and Phipps and Srivastava (1997) used the Children Social Desirability and the State-trait Anxiety Inventory to define repressor status in children. They concluded that depression and repressor status are associated with lower levels of depression.

Thus, it has been suggested in previous work that defensiveness is one of the strategies that children and young people with cancer and chronic illness use to adjust to their diagnosis and treatment and as a possible protective factor against psychosocial difficulties in children and young people with cancer, possibly by promoting positivity and hope. Importantly, in children and young people, the link between a defensive adaptive style and level of depression is well documented. In general, most of the literatures in this field found that social desirability scores (defensiveness) were inversely related to depression scores (Canning et al, 1992; Joiner, 1996; Phipps and Srivastava, 1997). This may be due to denial, which has been suggested as a possible protective factor against psychosocial difficulties, especially in children with chronic illness and cancer (Phipps and Steele, 2002). High social desirability was also found to be combined with low self-reported anxiety, and has become the empirical marker for a "repressive" emotional processing style, which is defined as a pervasive tendency to avoid processing negative emotions (Weinberger, 1990).

On the other hand, Joiner, Schmidt, and Schmidt (1996) challenged the hypothesis that defensiveness would affect self-report measures of emotional distress (Anxiety and Depression). Children's Depression Inventory (CDI) and the Revised Children's Manifest Anxiety Scale (RCMAS) were used with 96 child and adolescent psychiatric patients, aged 8-16 years. The results supported the view that defensiveness would affect self-report measures of depression, but not self-report measures of anxiety, with a marked tendency to deny symptoms of any distress and to try to appear in a favourable light.

At this juncture, one might argue that failing to consider the role of defence mechanisms in the phenomena of anxiety and depression might alter the perspectives, interpretations, and research practices. Do self-reports accurately represent the child's psychological condition, or are such self-reports coloured by "self-deception", that is, influenced by the defensive process? Taking for example a child with a high score on the RCMAS (The Revised Children manifest Anxiety Scale), which was designed not only to measure symptoms of self-reported anxiety, but the tendency of the reporting person to "fake good" in a socially desirable direction (the lie scale). Is the person who denies having any undesirable traits and thus obtains a high score on defensiveness scale and low in anxiety really less troubled than the child who acknowledges lacking socially desirable characteristics?

It seems then that issues of defensiveness and repressive personality in children and young people with cancer have not been well addressed in previous studies and this can be seen as a major limitation, especially if children with cancer and other chronic illness adapt to their conditions by repressing their emotions, covering overt feelings of depression and anxiety. Phipps & Steele (2002) point out that children are more likely to score high on defensiveness and tend to avoid or deny negative thoughts about themselves, and are much less likely to appear depressed or anxious, (based on common screening tools). Results of earlier work on children coping indicated that avoidance and even denial may be adaptive in some situations (Compas, Worsham, and Eye, 1992), and in differentiation between denial and defensiveness, Canning et al. (1992) suggests that denial is about deception of others with a clear deliberate intent, while repressive adaptation is self-deception. Discrepancies and inconsistencies as to whether and which of these mechanisms are considered conscious and purposeful have not yet been answered. Moreover, whether children and young people with cancer and chronic

illness are self-repressors (refusing to recognise or acknowledge as defined by Weinberger et al,1979) or not, and what are adaptive or maladaptive coping strategies are still the fundamental divides in psychological wellbeing (Canning et al. 1992; Phipps and Steele 2002).

2.5.7. Communication of cancer diagnosis

Several studies have discussed disclosure or non-disclosure of the diagnosis of cancer, yet, a global consensus on this issue still does not exist. Kendall (2006) reported that there is considerable variability in the reported rate of cancer diagnosis disclosure across studies and countries. In general, an open disclosure of cancer diagnosis, as opposed to information avoiding has been associated with better adjustment to cancer treatment, as communication is believed to influence how children and young people cope with a stressful situation.

The listed previous research does not address the impact of being informed or not about cancer diagnosis; however, it should not be concluded that an effect of communication has been overcome in the more recent studies, but may be viewed as a catalyst for future investigations. In different countries, there is marked variation in how and what a patient may be told about their diagnosis and prognosis (Kendall, 2006), but this point was addressed only in a few studies. The "protective approach" of not telling the child of the cancer diagnosis or "conspiracy of silence" (Patenaude and Kupst 2005) does exist, and will be further discussed and analysed through this research.

2.5.8. Conclusion

Studies were reviewed in this section that examined the effects of diagnosis and treatment of cancer on children's and young people's wellbeing. Several conclusions can be drawn from this systematic review of results. While group means of most studies indicate that indices of child's wellbeing are within normal ranges on standardised measures of anxiety, depression and social adjustment, it is often difficult to describe the interrelationship between these problems. So many diverse intriguing problems are reported, for example, cancer related aspects of steroid therapy and psychological functioning (Drigan et al, 1992), or mothers' adjustment and psychological functioning

(Allen et al, 1997; Brown et al, 1993) that research efforts lack consistency. Therefore, while some researchers may give the impression that children and young people with cancer are functioning well, others stress the number of children and young people at risk related to cancer treatment. Both accounts are correct; however, as each gives a different impression of a different aspect of child's wellbeing.

Finally, as discussed previously, one of the key themes in this thesis is to investigate the impact of cancer diagnosis and treatment on children's and young people's wellbeing in Jordan. Therefore, as this chapter was concerned with cancer impact on the child's development and wellbeing, the next step is to review research that has examined the impact of Arabic culture and Islamic faith on children's development and wellbeing in Jordan. This review completes the theoretical portion of the thesis.

In conclusion, the findings and recommendations of these studies supported the need to understand better the psychological and medical issues affecting the quality of life and psychological adaptation of children and young people with cancer during and after treatment, with greater national and international collaboration (Black et al. 2000). Patenaude and Kupst (2005) added that:

"The newest generation of researchers in pediatric psycho-oncology need not to fear that all the interesting questions are solved. On the contrary, it seems likely that these investigators will have many interesting and important research agendas to pursue (p.20)".

Chapter 3 Islamic Beliefs and Cultural Issues in Child Development

3.1. Introduction

In order to illuminate the values embedded in the Jordanian culture, and provide information that may be relevant for understanding the context of child development in Jordan, this chapter focuses on two domains of inquiry: Arabic cultural values and Islamic beliefs. To set a broad as well as culture-specific understanding of children's development within this thesis, the review of this chapter has been divided into two sections. The first section relates to the Arab-Jordanian cultural and ethnographic background which is presented addressing two major areas of (1) culture and life style, and (2) socioeconomic status. In the second section, a brief description of Islamic faith and jurisprudence in relation to child development in Jordan is presented.

3.2. Child development within Arab-Jordanian Culture

There is limited scholarly literature about Jordanian-Arab culture. Therefore, literature about Arab and Middle Eastern culture that shares similarities with Jordanian culture will be integrated. Gustafson (2002) reported a list of some interactive forces that may influence child development (see Table 3.1). The presentation of the cultural domain and child development is organised in relation to these forces for a more comprehensive view.

Table 3.1. Some interactive forces that may influence child development (source: Gustafson, 2002).

Culture and life style	Socioeconomic status
Culture input	Poverty
Gender socialisation	Lack of parental education
Family structure	High unemployment
Single-parent families, blended families	Residential crowding
Styles of parenting	

3.2.1. Arab culture and life style

Jordan can be described as having a heterogeneous population; the Jordanians of Palestinian origin are not a minority in this country, with a population numbering three million and comprising 50% of the total population. The Palestinians make up such a large proportion of the population where it was estimated to be more than five millions inhabitants. The partition of Palestine in 1948 and the creation of the state of Israel ignited a large immigration of homeless Palestinian families to Jordan as refugees where they settled down in Jordan. The 1991 Gulf war and the political situation after the failing of the old Iraqi regimens provoked conflict among the Arab countries and created another wave of Palestinians and Iraqi refugees from both Kuwait and Iraq (CIA World Fact book, 2004). This is why about 50% of the population are from Palestinian origin, which descended from the people who lived in Palestine before the Arab conquest in the 7th century, where as the inhabitant of east Jordan are of predominantly Arab ancestry who immigrated from Saudi Arabia (The Columbia Electronic Encyclopaedia, 2003), the remain 1% are minority of Circassian and Chechen.

The Jordanian people are mostly of Arab descent, with a few of Circassian (Caucasian)., Chechen, and Armenian descents When talking about Arab as an ethnic origin or race, it is important to bear in mind that the term "Arab", prior to the rise of Islam in the seventh century, was exclusively applied to a homogenous people limited to the peninsula and adjoining Fertile Crescent. However, in the recent century, a population is named Arab based on their language and culture and not on their ethnic origin. An Arab could be any Arabic-speaking individual from Turkestan and Persia in the east to Morocco and the Iberian Peninsula in the west, regardless of original race and nationality, as they are a multiracial and multiethnic mosaic population (Abudabbeh and Nydell, 1993; Hitti, 1943).

The majority of the Jordanian population are Muslims and Christians remain a minority, comprising around 6% of the overall Jordanian population; however, they are described as having the same characteristic and values. Islam arrived in Jordan in the seventh century, just after being part of the old Romanian civilisation. However, the impact of Islam religion on the Jordanian culture varies, as Muslims vary in their degree of education, faith, and application of religion (Hedayat, and Pirzadeh, 2001). According to the CIA Fact Book (2004), religious practices vary among segments of the Jordanian population, and unevenness of Islamic practice does not correlate with a rural-urban

division, or differing levels of education. Some of these differences among Muslims are attributable to differences of opinion by various schools of jurisprudence, mainly between Sunni or Shiite Muslims, but Islam remains a monotheistic culture that actively submits to and implements the will of God.

In the social structure of the Jordanian culture, the basic element of the Jordanian-Arab social structure is the family, and despite moves toward a more westernized nuclear family, the extended family remains important in Jordan. This gives rise to "the tribe laws" whereby whatever befalls one member of the family affects the whole family, and this includes both shame and honour. Hedayat and Pirzadeh (2001) described the eastern culture as patriarchal and authoritarian with great emphasis based on deference to elders and suppression of personal interests for the good of the family. This typically applies to Arab society in general, as well as Jordanian society and may involve the needs of the individual being suppressed for the good of society. This can result, sometimes, in unquestioned authority of the father or the eldest of the tribe, consistent with Barakat's (1984) comment that the style of communication in such Arabic families is hierarchal, creating vertical as opposed to horizontal communication between those in authority and those subservient to that authority.

In Lazarus and Folkman (1984), the social networks from which one receives emotional or social support have been generally perceived as a coping resource in stress research. Thus, in Arab society the family can be seen as the immediate support system. Family is especially important in Muslim society. Harmony and balance in family relationships, especially with parents, should override individual need and further contribute to social harmony. Throughout the Arab world the family remains the main system of support, and no institution has replaced the family as a support system (Fernea, 1985). Due to a strong sense of group affiliation within Arab families and their neighbourhood and community, problems are not generally brought before formal institutions, unless all other informal alternatives have failed (Barakat, 1985). Concomitant with the common source of support in Arab families, there is evidence suggesting that depression can be intensified by a greater amount of social support and that sharing crises with friends and neighbours may be associated with anxiety (Hobfoll and London, 1986). However, no studies are available to support this view among Arab society.

3.2.2. Socioeconomic status

Brage et al. (1995) reported that financial issues increase the risk of depression in children, and Cavusoglu (2001) found that level of depression in children with cancer correlated with parent financial issues, such as class and income. In an attempt to understand the socio economic status of Jordanian families and how it might affect a child's psychological wellbeing, two main factors are addressed in this thesis: the sociopolitical context, and the geographic characteristics of Jordan, which fall into two main geographical regions:

- Eastern Jordan which encompasses about 92% of the country's land area, including a section of the Arabian Plateau, and the Syrian Desert.
- The western part of Jordan, the Jordanian Highlands, and made of a segment of the Great Rift Valley (The Columbia Electronic Encyclopaedia, 2003).

Jordan is divided into 12 administrative governorates. Amman is the country's capital; other cities are Zerqa, Petra, Irbid, Aqaba, and Al-Salt. Almost all cities are located in the western part; however, some variation exists between the northern and southern part of Jordan in terms of geography and life style. Poverty and a large foreign debt remain a major problem in Jordan, as less than 5% of the country's land is arable, and that forces a large percentage of the population to support their families by raising sheep, goats, and poultry, especially in the southern areas of Jordan. The unemployment rate is also high, at almost 25% according to the CIA World Fact-book (2004); of those who are employed, nearly 50% are on the government payroll, mainly the army service.

Recent evidence shows that the continuing Arab-Israeli conflict creates conditions in which a wide range of social and psychological problems can develop (Savaya, 1997, Savaya and Malkinson, 1997), thus, it is essential in data collection to pay particular attention to this variation in the population of Jordan. For example, the partition of Palestine in 1948 and the creation of the state of Israel prompted large-scale migration of homeless Palestinian families to Jordan as refugees. Most of these people live in refugee camps at Al-Baqaa, Zerqa and Al-Wehdat, and usually rely on government and the united nations aid, and usually suffer more social and economic constrains than those based in the western part of Amman and the main cities. On the other hand, the 1991 Gulf War, which provoked conflict among the Arab countries, created another wave of Palestinian and Iraqi refugees from both Kuwait and Iraq. However, these

enjoyed a better standard of living, and a better social class in the Jordanian community, especially with advanced changes in the Jordanian policy with regard to foreign affairs. This difference is evident in the western and eastern parts of Amman, where a difference in type of houses and social class is evident.

3.3. Impact of Islamic faith and jurisprudence on child development in Jordan

Universal human needs, individual differences, and contextual influences of environment, culture, and subculture groups are the main aspects of children's and young people's development (Mussen, 1990), and all need to be taken into account for a full understanding of the emotional and behavioural construction of children's and young people's development in Jordan. However, articles examining contextual influences based on Arab child development fail to distinguish between idiosyncratic beliefs, cultural norms, and religious principles. Such ignorance may confuse eastern culture with the Arab and the Middle Eastern, each of which has its unique context. More over, it may fail to distinguish between what is based on folk customs and that derived from Islamic customs. Importantly, those multiple interactive forces of culture and religion that might influence child development have not been well addressed in previous studies and will be referred to, briefly, in this section.

3.3.1. Family structures in Islam

The Islamic family is patrilineal, but not patriarchal, contrary to some cultures which are authoritarian and patriarchal related to societal norms (Hedayat and Pirzadeh, 2001). The child has rights as an individual, although the parent maintains authority and guardianship. Relationships are expected to be characterised by respect and considering opinions of others; there is less autonomy and/or separation than in western families. In Islam, the family starts with marriage; marriage in Islam is a sacred bond and a mighty attachment that is based on and empowered by specific duties assigned to men and women. The men in Islam are "heads of the household" and responsible for providing economic and emotional support for their wives and children. The woman is under no obligation in Islamic "shari'ah" (Islamic Law) to spend her own money on household living costs, even if she has the financial means to do so, and if she does, it is merely out of kindness (European Council for Fatwa and Research, 2002). Both men and women are expected to maintain the sanctity of the family. In the event of divorce, the mother retains custody of her children until they are 18 years old, and it is the father's duty to meet all the financial needs of the mother and the children unless she marries another man (Jordan Civil Law, Article 154).

Muslim mothers consider of their mission to be the primary care giver to the child. The mother's status is higher in Islam than that of the father, although both are highly regarded. Children's relation to their parents is expressed in the holy book of "Al Our'an" which Muslims take to be the literal word of God.

"Thy Lord hath decreed that ye worship none but Him, And that ye be kind to parents. Whether one or both of them attain old age in thy life, say not to them a word of contempt, nor repel them, but address them in terms of honour (23). And out of kindness, lower to them the wings of humility, and say: My Lord! Bestow on them the mercy even as they cherished me in childhood (24)." Surat Bani Isra-il 17, Juz' 15. (Ayah 23-24).

Parents in Islam are legal agents, and are expected to treat their children gently, fairly, and well, and in case of neglect, they lose their right of custody over them. However, even in that case, a child in Islam is not permitted to mistreat his parents. God's words in the Qur'an say:

"And even if thou hast to turn away from them in pursuit of the mercy from thy Lord which thou dost expect, yet speak to them a word of easy kindness (28)." Surat Bani Isra-il 17, Juz' 15. (Ayah 28).

3.3.2. Status of children in Islam

The status of children in Islam reveals no preference for boys over girls, contrary to the customs of some Muslim countries (Hedayat and Pirzadeh, 2001). However, differential treatment of boys is not uncommon at Jordan; thus, understanding the Arabian context within which children are brought up in Jordan is significant to the present study in so far, as it reflects merely the cultural rather than religious development that they experience. Hedayat and Pirzadeh (2001) cited Prophet Mohammed's "Hadeath" about child rearing in Islam, which is summarised as:

"For the first seven years, leave them alone (i.e., do not be strict in manners, discipline, and formal education). For the next seven years (i.e., 7-14 years of age) teach them, and in the later seven (14-21 years of age) the child is your advisor and companion".

However, some cultural norms common in Muslim countries differ from the religious principles of Islam. For example, in Arab culture, children are raised in different ways, with some getting mild punishment for unacceptable behaviour, and others a great deal of unconditional love. This pattern between parents and children, mostly, ends with anger and punishment from the parent and the response of the child by crying, self censorship, covering up, or deception (Barakat, 1985).

In Jordanian Civil Law which is derived from both Islamic sharia'ah and the French Law, the father is responsible for his children's education and all financial needs. This responsibility ends when a son reaches 18 years old (unless he is a student, then it is when he finishes his first university degree), and for a daughter until she is married (Jordan Civil Law, Article 168).

For children during their teens, "adolescence" is a concept that may not have functional equivalence across cultural groups, because the behaviour and meanings associated with being adolescent in Western cultures may be either non-existent or very different in other cultures (Jones et al, 2001). In this instance, concerns of functional equivalence of adolescent between Arab and Western societies emerge due to the interaction of specific developmental tasks of that age, and the impact of the Islamic religion. For example, in Islam, the teen years are seen as a period of apprenticeship and companionship for parent and child (Hedayat & Pirzadeh, 2001); importantly, adolescents in Islam are viewed as adults with independence and responsibilities.

However, this rule is a theoretical one based on the Islamic view of adolescents as the reality of Arab societies shows less independency and responsibilities for the child during the teen years but with less vulnerability than that shown in Western cultures. For example, Bauld et al. (1998) argued that concerns of adolescents in western cultures were mainly due to the breakdown of family and social support, the easy access to drugs, alcohol and weapons, and early sexual activity. This prohibition applies to both cultures and not very different; however, adolescents are more prone to these problems in western cultures related to easy access to drugs and alcohol, and more importantly,
related to breakdown of family bonds which bring these issues to a more open discussion rather than "sweeping things under the carpet" as it happen in most of the Arab and Muslim's world.

Significantly, the contextual influence of the Islamic viewpoint on late adolescents revealed that once a person is considered intellectually mature (aaqil), then they are considered to be adults (usually at age 15 years old for boys and 9 years for girls), in particular, with regard to religious responsibilities. For medical and legal decisions, however, there is great variation depending on individual differences (Hedayat and Pirzadeh, 2001); this includes also their right to get married. In Jordan, the minimum age for marriage is 15 years old for girls, and 16 years old for boys (Jordanian Civil Law, number 5).

In conclusion, it should be emphasised that Arab culture has a great influence on child's development, as does the Islamic faith. However, it is stressed that Arab culture and Islam are closely related, although, there are still aspects in which they are distinguished from each other.

4.1. Introduction

The methodological background of this thesis is described in this chapter. The purpose of this study was to obtain insight into cancer impact on children's and young people's wellbeing as represented by their level of anxiety and depression and overall quality of life, in Jordan. To show how these issues were investigated, the chapter is presented in three sections: the first section presents the research design, target population, and procedure of data collection. In the second section, the data collection instruments are reviewed, with reference to the validity and reliability reported in previous studies, in order to avoid limitations and deficiencies that were encountered in similar studies. In addition, the validity of the Arabic translated versions established in the pilot study is described, the justification of the specific anxiety, depression and quality of life measures and their cross-cultural validation into Arabic are also discussed. The final section of this chapter discusses the ethical issues and practical considerations that arose during the fieldwork.

4.2. SECTION ONE: Research design and sampling techniques

4.2.1. Research Design

A descriptive within-group study design applies to this research, as the aim was to describe and document perspectives of a situation as it naturally occurred and generate hypotheses (Polit and Hungler, 1999). A predominantly quantitative approach was implemented to the search for more complete answers to the research questions. Quantitative research, as defined by Polit and Hungler (1999), involves the systematic collection of numerical information and data analysis by the use of statistical procedures. Thus, the three variables of quality of life, depression and anxiety were investigated in the quantitative part of this research, which was oriented towards the rigorous measurement of these variables.

Equally, to enrich this quantitative data with some understanding of children's and young people's perception of their diagnosis, a few open-ended questions in a semistructured face to face interview were implemented. Those open ended questions were added to the study, beside the quantitative measures, because it seemed important, in the absence of a coherent body of knowledge regarding the emotional wellbeing of children and young people in the Middle East, to utilise different research approaches, including qualitative research.

A number of distinctions have been made between quantitative and qualitative research, and are summarised in the following table;

Table 4.1.Distinctions between qualitative and quantitative research paradigms(Source: Bryman, 2001)

Qualitative Paradigm	Quantitative Paradigm
Point of view of participants.	Point of view of researcher.
Researcher is close.	Researcher is distant.
Theory and concepts emergent from data	Theory and concepts tested in research
process.	static.
Rich, deep data.	Hard, reliable data.
Small scale aspects of social reality as	Large scale social trends and connections
interaction.	between variables.

There are certain aims recognisable within quantitative paradigms that are necessary to this study for achieving rigour. For example, piloting the study before the actual phase of data collection involved a forward-backward translation of the study tools into Arabic; secondly, cross-cultural validation of the Arabic-versions of the tools in number of cities and schools of Jordan; and thirdly, data collection in hospitals and oncology settings.

In the following diagram (Figure 4.1.) the three stages of the data collection through the quantitative and interview sections are summarised. The overarching design of this study is quantitative in nature, but with contextual data and diagrams to explain how the confound variables were measured and analysed. This approach adds rigour to the investigation of cancer impact on children's and young people's wellbeing. The issues investigated in the current study were possible extraneous factors emerging from previous studies, and covered topics such as what children knew about the illness, beliefs about the illness, and finally, whether the mothers felt able to talk with the child and siblings about this illness. This is because culturally defined beliefs may alleviate anxiety and fears that accompany otherwise inexplicable events, and similar cultural factors influence how disease is discussed and how physical symptoms and psychological distress are reported (Die-Trill, 1998).



Figure 4.1. Overview of all data collection stages

According to Creswell (1998), the qualitative approach is a problem solving process based on the formulation of questions; thus, questions should be more specific and take the form of issue questions with the purpose of extracting as much information as possible from the informants. The main question and sub questions could then be refined throughout the whole study (Darlington and Scott, 2002). The importance of qualitative research lies not only in answering the research questions but also in the capacity to identify potential issues or questions during the interview in order to explore things of interest (Arksey and Knight, 1999). Qualitative research is often addressed in terms of what quantitative research is not. That is, that qualitative research is too subjective, difficult to replicate, there are problems of generalisation and lack of transparency (Bryman, 2001), thus, it can be argued that pure utilisation of this approach in this study, such as diaries or drawing analysis inappropriate here because people in Jordan are not used to writing diaries, thus it would be difficult for children to be taught how to start writing one if they are not familiar with this approach and this will result in the children being less expressive of their true emotion, in addition to the financial and time constraint of collecting diaries from parents.

Study	Age	Gender		Diagnosis		
groups	group	Male	Female			
Cancer	7-16	33 (57%)	25 (43%)	Chronic renal failure 14 (25%)		
group	years			Thalasemia 24 (42.9%)		
(1- 38)				Others (Diabetes mellitus, Cystic fibrosis, Asthma, Rheumatic fever, G6PD) 18 (32.1%)		
ļ				Chronic renal failure 14 (25%)		
Chronic	6-16	25 (45%)	31 (55%)	Acute leukaemia 34(58.6%)		
illness (n=56)	years			Non Hodgkin's Lymphoma 5 (3.4%)		
				Hodgkin's Lymphoma 12(20.5%)		
				Other solid tumours 6 (10.3%)		
Control group (n=64)	8-15 years	29 (45%)	35 (55%)	Healthy children		
Validating group of the PedsQL (n= 150)	8-13	36 (24%)	114 (76%)	Healthy children		
Validating group of the RCMAS (n=98)	8-13	19 (19.4%)	79 (80.6%)	Healthy children		

Table 4.2.Demographic characteristics of the total study sample

Table 4.2. shows the demographic characteristics of the total study sample for all the children participated in validating the tools and in second phase of the data collection at hospitals of Jordan and schools. The second part of the study, however, was qualitative and included open ended questions. The aim of the open ended questions used in the interview was to augment our understanding of patterns of communication used to describe children's and young people's illness and its relatedness with the impact of cancer diagnosis and treatment. Four dimensions were investigated in this part: communicating the diagnosis of cancer to the child, sense of openness and satisfaction with the communication pattern used to tell the children and young people about their

cancer diagnosis, beliefs about the causes of the illness, and finally, the impact of the child's illness on the family. The mothers were only included in this study and not fathers as some studies suggested that mothers are more liable to emotional problems than fathers of children with cancer (Salander & Hamberg, 2005), in addition to the fact that mothers are more emotionally expressive than fathers (Bull, 2002), thus interviewing mothers of children with cancer will help to give more information to understand child's adjustment to cancer diagnosis in the Arab world.

4.2.2. Target Population

The reference population for this study was children and young people aged between 8-16 years old, divided into three groups: children and young people with cancer, children and young people with chronic illness, and a matched group of healthy children and young people. Statistical Power Analysis revealed that a sample of 52 participants in each group would be sufficient to secure a one-tailed significance criterion of 0.05, a power of 0.80, and a median effect sized of 0.05 (Cohen, 1992; Polit and Hungler 1999). The number for sample size was double checked and approved by another statistician, whereas, for the purpose of validation, a sample size of at least 50 participants was necessary to have the power to say with confidence that a correlation of 0.7 was different from 0.30 (77% power) (Cohen, 1992).

The sample included 58 children and young people and 37 mothers attending paediatric oncology services in Jordan, 56 children and young people with chronic illness and a control group of 64 healthy peers. In the phase of cross-culturally validating the tools in Arabic, 98 children and young people participated in the first pilot study, 47 participated in the validation of the Depression, Anxiety, Stress Scale (DASS-42), and 153 children and young people and their parents in the second attempt of validating the PedsQL[™], as will be discussed in detail in the next section of this chapter.

In the current study design, children and young people were sampled from schools that more likely to provide a good demographic match to the cancer gr. Complete matching was difficult because it was not possible to ask questions about place of origin. However, I was able to match all demographic details about age, sex and place of residence. Specifically; it implies the participation of Iraqi and Palestinian children and young people in the cancer group (those children carry a Jordanian passport and were identified informally through their dialect and accent), this is significant particularly in the light of the significant relationship between some demographic variables and the measures, and will be further discussed in the last chapter. However, these limitations and rates of matching between groups are comparable to prior studies that used similar designs (Phipps &Steele, 2002). In this instance, the absence of a demographic match suggests a differential rate of participation in the three groups as a function of nationality, place of residence, and gender, is not unique to this work, and will be further discussed in the final chapter.

4.2.3. Settings and Procedure of Data Collection

The major hospitals of Jordan that are known to have clinics caring for children and young people with cancer and chronic medical conditions were selected to recruit patients. Written approval to conduct the study at the different hospitals was obtained through formal channels (see Appendix B). A review of the study by the authors' institute, directors and in-charge personnel was done to ensure understanding of the study. Prior to data collection, participants' informed consent to involvement was obtained. Participants' families were assured that their names and responses would be kept confidential, and would be used only for the purpose of this study. For the purpose of validating the tools into Arabic and recruitment of control group, permission was obtained to interview and administer the study questionnaires from the Ministry of Education and the local ethics committee of education at Amman, and then local approval was obtained individually from each of Al-Salt, Zerqa, Aqaba, and Ein-Albasha school ethics committees.

For the cancer group, the names and addresses of children and young people diagnosed with cancer within the desired age group were obtained from records and files of paediatric oncology from the cancer paediatric wards at the main hospitals of Jordan:

- King Hussein Cancer Centre (KHCC; the largest specialized centre for cancer disease in the Middle East).
- The Ministry of Health (Al-Basheer Hospital; the largest public hospital in Jordan).
- The Military Service Hospitals (Al-Madeana/ King Hussein medical Centre).
- The Jordan University Hospital (JUH; one of the largest hospitals in Amman).

The names and addresses of the families who met the study criteria were recorded for inclusion in the study. Details of children and young people with chronic illnesses (diabetes, renal failure, cystic fibrosis, and juvenile rheumatoid disorders, Thalasemia...) were obtained from the records and files of the main Ministry of Health main hospitals, Military hospital, and the Jordan University Hospital. The selection procedure was recorded in the same manner. Matched pairs of healthy control participants of same age group and sex were recruited, matched pairs were only possible for age group and place of residence, place of living and monthly income were taken into consideration. In view of the wide gap in socio-economic status between the southern and northern cities of Jordan, the control group of children and young people was chosen from the same geographical area as the patients.

Administration of the protocol was completed in one session lasting approximately 60 minutes for both child and mother. The interviews with the cancer group were conducted either in the chemotherapy clinic, specifically at the play room or patient's hospital room at the bedside of the patient. At the time of interview, the child and his/her mother were seen to record demographic data and establish rapport.

Initially, the procedure and the purpose of the study were described to the mother and child participants, with an explanation of the types of question they would each be asked. The information sheet was used to explain the study and if the mother agreed to participate the mother was asked to sign a consent form. Before written parental consent and child assent were obtained, some items were deleted upon the mother's request, specifically the suicide item of the Children Depression Inventory (CDI; Kovacs 1980/1981, 1992). The mothers were first asked if the child knew his/her cancer diagnosis, and while the mothers completed the maternal self-report forms, the children and young people were interviewed. Most subjects could read and write alone, however, a few mothers were unable to complete the questionnaires for themselves as they were illiterate, and thus the questionnaires were read to them and their responses were recorded. The last fifteen minutes of the session consisted of interviewing the mothers regarding pattern of communication and the perception of the child's illness within their family, it took place after the mothers completed the questionnaires and consisted of answering open ended questions. At the end of the session, the children and their mothers were given a chance to ask any question that arose or raise any concerns elicited during the course of the protocol.

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4.3. SECTION TWO: Cross Cultural Validation of Research Instruments

4.3.1. Introduction

This section discusses the instruments used in this study and presents the systematic process of testing the reliability and validity of the research instruments to enhance the rigour of the research study. The following issues will be discussed: the justification of choice of measures and their reliability and validity, additionally, the process of translation into Arabic is outlined, and the test-retest reliability of the research instruments is discussed.

For the purpose of this thesis the following tools were used to measure the variables under investigation:

- The Socio-demographic Data Questionnaire (Appindix E.6.)
- The PedsQL[™](Varni et al.1999, 2003)The Paediatric Quality of Life Inventory-(Arabic Version) (Appindix C.2.)
- The CDI; (Kovacs 1980/1981, 1992). The Children Depression Inventory-(Arabic Version) (Appendix E.9.)
- The RCMAS; (Reynolds & Richmond, 1985). The Revised Manifest Anxiety Scale-(Arabic-Version) (RCMAS; Reynolds & Richmond, 1985) (Appendix C.2.)
- The DASS-42; (Lovibond & Lovibond, 1995b). The Depression, Anxiety, and Stress Scale-(Arabic Version) (Appendix C.3.)
- The list of open-ended questions (Appendix E.6.).

These measures were used as the most suitable instruments, bearing in mind that to the best of our knowledge, most previous researchers adopted cross-sectional studies with similar tools, the majority of previous studies have traditionally used self-report questionnaires to assess children's anxiety and depression. The CDI, the RCMAS and the PedsQL all have been used in cultures other than western one for example Egypt and Zimbabwe. This shows that the instruments are applicable beyond Westeren cultures. It can also be argued that they address universal human needs. Furthermore, for the purposes of validating those tools into the Arab culture those tools were further underwent a cross cultural validation to guard against this as will be explained in this chapter.

Although the DSM-IV (Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition; APA, 1994) and diagnostic interviews are among the most commonly used

tools for classifying and diagnosing childhood anxiety and depression disorders, questionnaire assessment methods are often used as a means of screening for symptoms of anxiety and depression in the general community, as they are relatively quick and cost-effective to administer. The selection of questionnaires versus the DSM IV criteria in defining the anxiety and depression prevalence in this group depended to a large extent on the purpose of the assessment and the way that anxiety and depression are defined. In the following section, the validity and reliability of each tool will be discussed.

4.3.2. The Paediatrics Quality of Life Inventory (PedsQL™)

The PdsQL[™] measurement model was designed as "a modular approach to measuring pediatric health-related quality of life (HRQOL)" (Varni and Burwinkle, 2004, p.3). The PedsQL[™] was selected for this study for a number of reasons. Firstly, it was designed for use with children and adolescents, and is developmentally appropriate for children ages 2 years up to 18 years old. Secondly, it is suitable for use with healthy school and community populations, as well as with paediatric populations with acute and chronic health conditions. Thirdly, this multidimensional instrument encompasses the essential core domains for giving a clear conceptualization of the HRQOL construct in paediatric population, as the PedsQL[™] measurement encompasses the physical functioning, emotional functioning, social functioning, and school functioning.

To sum up, the given design of the PedsQLTM provides measurement sensitivity for circumscribed clinical population, such as children with cancer, diabetes, or arthritis, with an additional module for renal failure in the planning stages, which makes it suitable for this study, thus, as measures are frequently justified in terms of value in clinical trials, the PedsQLTM measurement model combines this clinical utility and sensitivity which make it a suitable choice for this study.

A significant practical advantage not typically found all-in-one paediatric HRQOL instruments is the multiple languages this instrument has been translated into, including broadcast Arabic language in Egypt for the cancer module, and Kuwait for the diabetes module. However, we should bear in mind that despite the existence of a forward-backward translation into Arabic for the cancer and diabetes mellitus (DM) module, the generic core of the PedsQL[™] was not previously translated. Therefore, forward-

backward translation and cross-cultural validation was conducted in the pilot study of the current work, and the status of each version was checked and re-evaluated with the author of the tool. Details of the translation work and the linguistic validation are presented the following subsections, after reviewing the validity and reliability of the tool in the country of its origin.

4.3.2.1. The PedsQL[™] 4.0 Generic Core Scales



Figure 4.2. Domains of health-related quality of life

The 23 item PedsQL[™] Generic Core Scales were designed to measure the core dimensions of health as delineated by World Health Organization, as well as role school functioning. The PedsQL[™] incorporates four multidimensional scales measured in two scores:

- The health summary score: physical functioning (8 items).
- The psychological health summary score (15 items): emotional functioning (5 items), social functioning (5 items), and school functioning (5 items). It is the sum of the items over the number of items answered in the emotional, social, and school functioning.

Instrument measuring HRQoL, in general, can be divided into generic and condition specific measures (Eiser et al., 2001b; Guyatt & Jaeschke, 1990; Guyatt, Jaeschke, Feeney, & Patrick, 1996; Varni & Burwinkle, 2004). While generic instruments measure HRQoL across health conditions, condition-specific measures do so with regard to a specific disease, treatment or symptoms.

Another classification into the measures of QoL in children is self-report versus proxy report. In self-report measures, information can be obtained from the children or adolescents themselves, whereas in proxy-report, information can be obtained from significant others like the parents. Both self-report and proxy-report can differ from each other (Eiser & Kopel, 1997).

In the case of the PedsQL[™] scale, it was developed to integrate the relative merits of generic and disease-specific approaches by Varni and his associates. They successfully integrated seamlessly both generic core scales and disease-specific modules into one measurement system, making it the most common used tools in the measurement of QoL in children. The PedsQoL[™] always has been recognised as contributing to an increased reliability by cross-culturally comparable results, as will be further discussed in the cross-cultural validation subsection, and gives a voice to both child and parent in measuring the quality of life.

The disadvantage of generic measures may be that small changes in HRQoL might not be detected, whereas, condition-specific instruments may provide clinically relevant information. However, comparison across illnesses is not possible with condition specific instruments for this study as comparison between groups in this study, which is largely heterogeneous in terms of diagnosis, is difficult. For example comparing HRQoL between children diagnosed with cancer and those with less life threatening illness such as diabetes mellitus, renal failure, asthma and others using specific condition instrument can be inappropriate related measuring specific disease related symptoms and treatment which is unique and specific to the disease it self. Thus, using generic instrument that measure HRQoL across general health condition is more applicable.

In consequence, both types of measures have strengths and weaknesses; the choice of which type of measure to use depends on the study aim, and since this study incorporates different diagnoses such as cancer, chronic renal failure, diabetes mellitus...etcetera, the generic core scale would be more suitable to compare results across these different diagnoses.

4.3.2.2. Reliability of the PedsQL[™]

Field trials were undertaken to assess the psychometric properties (reliability and validity), responsiveness, and practicality of the PedsQLTM generic core scale in healthy populations, as well as for those with acute and chronic medical conditions, where all results showed that the PedsQLTM generic core scale was reliable.

In a study conducted by Varni, Burwinkle, Seid, and Skarr (2003) among 10241 American families, a high reliability ($\alpha = 0.89$ in child-report, and $\alpha = 0.92$ parent report) for the total score of PedsQLTM 4.0 was reported. Another earlier study by Varni, Seid, and Kurtin (2001) supported applicability and utility for healthy school and community populations as well as populations with acute and chronic health conditions. A total of 963 children, and 1629 parents were recruited from health care settings. Results showed a high internal consistency for the total scale score ($\alpha = 0.88$ for child, $\alpha =$ 0.88 parent report), and for the physical health summary score ($\alpha = 0.80$ child, $\alpha =$ 0.86 parent), as well as for the psychosocial health summary score ($\alpha = 0.83$ child, $\alpha =$ 0.86 parent) across all groups of the study. These results supported the PedsQLTM generic core scale performance in healthy children.

The results of other studies demonstrated the reliability and validity of the PedsQLTM 4.0 as a measurement in children with chronic illness. For example Varni et al. (2002) investigated the reliability, validity, and responsiveness of the PedsQLTM 4.0 Generic Core Scales, and the PedsQLTM 3.0 Rheumatology module in paediatric rheumatology, among 231 children and 244 parents recruited from a paediatric rheumatology clinic. Internal consistency reliability for the PedsQLTM Generic Core total score was $\alpha = 0.87$

for child, $\alpha = 0.93$ for parent proxy-parent. Internal consistency reliability for the PedsQLTM Generic Core Scales was $\alpha = 0.91$ for child self report, $\alpha = 0.93$ for parent proxy report. Physical health summary score was $\alpha = 0.87$ for child self report, $\alpha = 0.89$ for parent proxy report. Psychological health summary score was $\alpha = 0.87$ for child self report, $\alpha = 0.89$ for child self-report, $\alpha = 0.90$ for parent proxy report. These results were acceptable for group comparisons.

In a more recent study by Varni, Burwinkle, Jacobs, Gottschalk, Kaufman, and Jones (2003) with children having type I or type II diabetes mellitus (DM), the PedsQLTM 3.0 type 1 Diabetes Module was administered to 300 paediatric patients with type I or type II diabetes, and 308 parents. Internal consistency reliability for PedsQLTM Generic core total scale score was $\alpha = 0.88$ child, 0.89 parent-report and most diabetes module scale scores were average $\alpha = 0.71$ child, 0.77 parent proxy report. The results of both studies were acceptable for group comparisons, and indicated that the PedsQLTM 0.4 Generic Core Scales are reliable for use with children with rheumatology and diabetes.

In the UK, Eiser et al., (2001a) reported Cronbach's alpha of 0.70 and 0.89 for the Pediatric Quality of Life self-report form and total scale value of 0.93 (child) and 0.93 (parent). The internal consistency of the Paediatric Cancer Quality of Life Inventory was 0.91 for the patient form, and 0.92 for the parent report. It remains here to establish the reliability of the PedsQL[™] among Arab countries, and children in Jordan.

4.3.2.3. Validity of the PedsQL[™]

To ensure accuracy and consistency in measuring the variables under investigation, Polit and Hungler (1999) proposed four aspects to test the ability of the instrument test exactly what it is supposed to be measuring. The four major aspects were face validity, content validity, criterion-related validity, and construct validity.

The validity of the PedsQLTM was demonstrated through known groups' comparisons and correlations with other measures of disease burden. The PedsQLTM self and proxyreport distinguished between children with and without chronic health conditions, and within the group of children with chronic health conditions, distinguished disease severity within a chronic health condition. However, clinical validity for cancer patients had revealed significant differences (p < 0.004) between patients on and off treatment on the scale (Eiser et al, 2001a). This validates the instrument's ability to distinguish between healthy children and those with acute and chronic illness. The difference between the scores of healthy children and children with other chronic illness is related differences in the mean scores. Thus children who scored high on HRQoL can be distinguished from those with low scores similarly to the way children with illness can be distinguished from healthy children.

Face validity refers to what the test appears to measure. Face validity pertains to whether the test "looks valid" to the examinees who take it, thus a group of personnel were asked to offer an opinion on whether the test looks valid to them, the quantitative face validity procedure provided apparent support for a validity claim. Whereas content validity investigates the ability of the test to sufficiently cover the area that it is intended to cover. Content under-presentation occurs when important areas are missed and construct-irrelevant variation occurs when irrelevant factors contaminate the test. Pervious studies provided no detailed data of how content and face validity were assured

4.3.2.4. Scoring of PedsQL™

The response options of the PedsQL[™] require the subjects to rate each item using the following system:

0 = Never. 1 = Almost Never. 2 = Sometimes. 3 = Often. 4 = Almost Always.

Each item is reverse scored and linearly transformed to a 0 - 100 scale, so that higher scores indicate better HRQOL. To reverse score, the 0 - 4 scale items have to be transformed to 1 - 100 as follows:

To create Scale Scores, the mean is computed as the sum of the items over the number of items answered (accounting for missing data also). According to the guidelines to the use of the PedsQLTM, to ensure an unbiased and precise method, if more than 50% of the items in the scale are missing, the scale score should not be computed. To create the Total Scale score, the mean is computed as the sum of all the items over the number of items answered on all the scales.

4.3.3. Translation of the Paediatrics Quality of Life Inventory (PedsQL™) 4.3.3.1. Cultural equivalence of the Arabic-PedsQL[™] version

Translation and validation of the PedsQL[™] began with an examination of the cultural relevance of a concept like quality of life in Arab children and young people. Philips et al (1994) suggested a five-phase process of establishing cultural equivalence which starts by determining the relevance and function of the phenomena in the population being studied, translation of the instruments, back-translation, testing, and finally re-evaluation. Black et al. (2000) and Eiser et al. (2005) pointed out the need for culturally competent scholarship and culturally appropriate measures in the field of quality of life in children and young people. However, a cross-cultural study requires selecting conceptually appropriate research instruments and translating them into the language of the participants in ways that ensure valid and reliable data (Jones et al. 2001). This presentation includes an overview of the translation process adopted in translating the PedsQL[™] into Arabic, and results of the statistical analysis among a sample of Jordanian children and young people.

4.3.3.2. Translation of the PedsQL™

PedsQL[™] was translated into Arabic using the Mapi Research Institute guidelines (2002) for Linguistic validation of the PedsQL[™] and recommended guidelines by the author for translation and validation of instruments for cross-cultural research. Preliminary changes to the original questionnaires were made after piloting the tools and were reviewed by Dr. Varni and the Mapi Research Institute for legal and copyright issues (see Appendix A.).

The first pilot testing of the questionnaires included 98 children and young people and was rejected by thr Mapi Institute for failing to include both child and parent forms for the age-group used in translation (see Mapi Research Institute contract). The second pilot test was administered to 153 children and young people (70% were between 10-12 years, and 30% adolescents) and their parents. Mean age of the sample was 11.44 with a standard deviation of 1.58. Children and young people were asked to give feedback about the interpretation and understanding of items and response rating. Dr. Varni and the Mapi Research Institute received a copy of the revised measures and authorised all changes.

The Mapi Research Institute guidelines for linguistic validation of the PedsQL[™] recommended an iterative process of at least three steps that include:

- Forward translation (includes the production of a "reconciliation" version),

- Backward translation,

- Patient testing.

Figure 4.2. shows an algorithm of the whole process as given by the Mapi Research Institute (2002). The project required translation and validation of instruments using the illustrated process into Arabic, which has different dialects among the Middle Eastern countries but one written language. Although this process is sound, it is not the most efficient or even most accurate for Arabic, which has multiple dialects or regional interpretations of the same words. Thus, translators from a variety of dialects of a particular language are needed to develop an easy-to-read, cross-dialectal version (Jones et al, 2001) and to avoid a potential limitation of previous PedsQL m translation studies which lacks retest reliability and responsiveness (for example, Upton et al, 2005). An attempt to increase efficiency, strengthen the integrity of the process, and achieve the goals of cultural and functional equivalence was made by doing a test-retest and the adaptation of the questionnaire was considered as a whole, as the wording of the response choices may influence the translation of the items, and vice-versa (Mapi Research Institute, 2002).

Figure 4.3. Algorithm of the linguistic validation process (source: Mapi Research Institute, 2002).



The PedsQL[™] was translated into Arabic by two bilingual experts and blindly back translated by a second bilingual expert. In an attempt to reduce the cultural and social bias that may result when only one or two authors are responsible for the translation, a copy of the translated instruments was sent to an authorised translation office in Amman, and also reviewed by four Arab research students from Jordan, Syria, Egypt, and Iraq, who approved the level of written standard Arabic level. The backward translation into English and report with comments was sent to Dr. James W. Varni for review and comment.

The back translated versions were compared with the original American version and retranslated where error in meaning was found. Although the adaptation of the questionnaire was considered as a whole, a literal translation was possible in some items and inappropriate in others. For example, 78 children reported two significant problems with item comprehension in the PedsQL[™]; both were culturally relevant. As a result of pre-testing, these two items were re-translated: first, the physical functioning item, "It is hard for me to walk more than one block", posed a problem since most children did not understand the translated term of block as "a building" or "a group of buildings in a town which has streets on four sides". Thus, an alternative term was used to render the concept with "a short distance".

Another item that needed re-translation based on pre-testing was item (6), "It is hard for me to do chores around the house". Two major points of difficulty arose with this item, the translation of "chores" into "routine works", and specifying what kind of task that was not interesting but had to be done at home for both boys and girls, taking into consideration the cultural background, and developmental age group of the target population. In the second attempt at developing an easily understood Arabic version of the PedsQLTM, each new item in the re-translated items was back-translated and checked for consistency with the original concepts in order to detect any misunderstanding, mis-translations or inaccuracies in the intermediary forward version of the questionnaire.

4.3.3.3. Instrument validation procedure

The target language versions were tested for reliability and validity (e.g. internal reliability, stability, face validity and content validity) on 153 children and young people for pre testing purpose and then post tested among 109 children and young people (a subset of the original 153 children and young people) all around Jordan. The healthy participants and their parents were recruited through eight schools all around Jordan. This included the east and west parts of Amman including the Palestinian refugee camps, Salt, Zerqa, and Aqaba).

Permission was obtained to conduct interviews and administer these questionnaires from the local ethics committee of the Ministry of Education. Parents were sent information about the study and were asked to return the questionnaire along with the signed consent; they filled the forms at home, however, children and young people filled the questionnaires in the classroom, then responded to closed and open formal questions about each chart. In piloting this study, the Arabic version of PedsQLTM was administered twice to each participant at an interval of two weeks. The purpose of pre-test was to obtain data on the acceptability, appropriateness, and comprehensibility of the Arabic version of PedsQLTM. For the purpose of validation, a sample size of at least 50 participants was necessary to have the power to say with confidence that a correlation of 0.70 was different from 0.30, 77% power (Cohen, 1992).

For the purpose of validation of this study, there were in total 58 children and young people with cancer and 56 children and young people with chronic health conditions who were invited to participate in the actual data collection, but very few mothers actually managed to rate their children or young people. The data therefore was far from complete and it was decided not to include it here, mainly due to time and finance constraints and the lack of parent-proxy report forms for those children and young people, it was therefore difficult for these children and young people to be interviewed again for post test. They were excluded from the correlational reliability testing, and used for discriminate validation only.

4.3.3.4. Internal consistency reliability of the PedsQL™

The results of the internal consistency reliability were highly acceptable in all self report and proxy report versions for both child and adolescent age groups. The internal consistency (Cronbach's alpha) of each scale of the PedsQL[™] self-report and parent proxy report form was quite favourable (as seen in Tables 4.3., and 4.4.). Table 4.5. shows the internal consistency in this study is similar to the values given by Varni et al. (2000, 2001, 2002, 2004); Upton et al. (2005); and Felder-Puig et al. (2005).

	No of	Child self-report			Parent proxy form		
PedsQL™	items	Pre- test	Post- test	Pre-post total	Pre- test	Post- test	Pre-post total
Physical functioning	8	0.78	0.80	0.79	0.89	0.76	0.87
Emotional functioning	5	0.76	0.82	0.79	0.77	0.62	0.74
Social functioning	5	0.82	0.82	0.82	0.79	0.88	0.82
School functioning	5	0.66	0.71	0.69	0.85	0.62	0.78
Psychological health summary	15	0.86	0.89	0.88	0.83	0.88	0.87
Total score	23	0.90	0.92	0.91	0.93	0.88	0.92

Table 4.3. Reliability Analysis: Reliability coefficients (Cronbach's alpha) for the PedsQLTM (n=47)

The study authors	Origin of study	Alpha Child- self report	Alpha Parent proxy form
Varni et al. (2006)	USA	0.89	0.92
Vami (2004)	USA	0.88	0.90
Varni et al. (2003) a	USA	0.89	0.92
Vami et al. (2003) b	USA	0.88	0.88
Varni et al. (2002)	USA	0.91	0.93
Eiser (2001)	UK	0.93	0.92
Upton et al. (2005)	UK	>0.90	>0.90
Felder-Pulg et al. (2005)	Germany	>0.70	≫0.70
Cremeens et al. (2006)	UK	0.81	0.91

Table 4.4. Previous reports on internal reliability of the PedsQL[™] generic core scale

Table 4.5. Previous reports on internal reliability of the PedsQLTM generic core scale between child self-report and parent proxy form to the PedsQL.

	No of	Child self			Parent proxy form				
PedsQL™	items	Current study	Varni et al 2001	Varni et al 2002	Cremeens et al. 2006	Current study	Varni et al 2001	Varni et al 2002	Cremeens et al. 2006
Physical functioning	8	0.79	0.80	0.87	0.46	0.87	0.88	0.80	0.73
Psychological health summary	15	0.88	0.83	0.86	0.76	0.87	0.86	0.90	0.89
Total score	23	0.91	0.88	0.91	0.81	0.92	0.88	0.93	0.91

4.3.3.5. Test-retest reliability

Findings of test-retest reliability (pre-post test) confirmed the satisfactory reliability of the $PedsQL^{TM}$ and showed the instrument to posses satisfactory psychometric properties in Jordan (see Table 4.6.).

Table 4.6 .	Reliability of the PedsQL [™]	temporal stability (2	2weeks, n=47).
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	Correlation between child and parent form					
PedsQL TM	Pre-test	Post-test	Pre-post test			
Physical functioning	1.000**	1.000**	1.000**			
Emotional functioning	0.679**	0.778**	0.607**			
Social functioning	0.429*	0.886**	0.693**			
School functioning	0.825**	0.868**	0.838**			
Psychological health summary score	0.691**	0.887**	0.757**			
Total items	0.76**	0.918**	0.80**			

** Correlation (spearman) is significant at the 0.01 level (2-tailed)

* Correlation is significant at the 0.05 level (2-tailed)

PedsQL TM scale	Correlation between child and parent form Jordan and English healthy sample				
	Current study	Upton et al, 2005			
Physical functioning	1.000**	0.61**			
Emotional functioning	0.607**	0.51**			
Social functioning	0.693**	0.60**			
School functioning	0.838	0.56**			
Psychological health summary score	0.757**	0.63**			
Total items	0.80**	0.67**			

Table 4.7.Parallel studies for correlation between self-report and parent proxyreport (Jordan and UK).

****** Correlation is significant at the 0.01 level (2-tailed)

* Correlation is significant at the 0.05 level (2-tailed)

As shown in Table 4.7. consistency between child and parent proxy reports on the PedsQLTM was low with intra_class correlation coefficient for most studies. Cremeens et al. (2006) investigated the agreement between child and parent proxy-reports using the PedsQLTM and argued that the level of parent-child agreement about children's lives and functioning are quite poor (ranging from 0.02 to 0.23). Similar discrepancies between parent and child report were explained in the light of parents' lack of knowledge and insight into their children's lives and opinions. Whereas in the current work, it is important to re-emphasise that the perfect correlation obtained in few cases of the PedsQLTM validation into the Jordanian culture may be due to the nature of the population who participated in this study. These which where obtained from a special school for gifted students at Al-Salt city (n=47). Thus, re-examination on a more representative sample would be necessary in any future research.

Before we proceed to the validity testing of the PedsQLTM, it is important to acknowledge another limitation encountered in this study. Ideally, it is recommended to confirm the psychometric properties of any translated PedsQLTM whenever it is used in a new population by using parallel child self-report and parent proxy-report forms. However, due to practical issues in this study, it was inconvenient to use the proxy form of the PedsQLTM for the total study sample, such as to those with cancer and chronic illness. Therefore, the psychometric properties of the Arabic PedsQLTM version were assessed in the current study among healthy population with little reference to the cancer and chronic illness groups. However, as the PedsQLTM is already validated, the hypothesised structure analysis and internal consistency reliability are not presented here in detail for the cancer and chronic health conditions groups. Data were collected from children with cancer, but only healthy children were used for the reliability and

validity testing of the instruments. This is because low prevalence of cancer in Jordan makes obtaining a large sample size from this group difficult. It is also difficult to obtain the same subjects in the cancer group for the purposes of doing pre-post tests.

4.3.3.6. Validity testing of the PedsQLTM.

The validity of the PedsQLTM was demonstrated through known groups' comparisons, as to check the instrument ability in distinguishing between children and young people with and without chronic health conditions, and within the group of children and young people with chronic illness through distinguishing disease severity.

The PedsQL[™] discriminant validity showed that overall, comparison of the healthy children and young people with those with cancer and chronic health conditions is possible for the child self report form. A multivariate analysis of variance (MANOVA) was undertaken in order to determine differences in sub-scale rating depending on child age, sex or health status. The advantage of the MANOVA over a number of separate ANOVA is to keep the overall probability of a type I error fixed at a chosen level (Hinton et al, 2004). Analysis of variance (ANOVA) was then used to discover the location of the differences causing the overall significant F value. Results showed significant differences in reported HRQoL across the three groups (see Table 4.8.). The mean and standard deviation of cancer group, chronic illness and healthy referents are reported in Table 4.9. The ANOVA demonstrates a main effect for sample, indicating that the healthy group have significantly higher HRQoL than children and young people with cancer and chronic illness (F (15.99), p < 0.0001). This significant difference extended to all HRQoL subscales except for social functioning, as children and young people with cancer reported a higher score in social life than other groups. The chronic illness group reported more problems with physical, emotional and school functioning (all significant at p < 0.0001) and scored worse on the HRQoL compared with children and young people with cancer and the control group.

variable	Cancer group		Chronically ill group		Control group		F	р
	Mean	(SD)	Mean	(SD)	Mean	(SD)		
Total items of Quality of life	66.98	19.47	61.16	19.58	78.97	14.81	15.99	0.0001*
Physical functioning	69.35	26.02	61.10	25.73	81.05	15.00	11.90	0.0001*
Emotional functioning	63.94	28.92	62.23	20.58	73.59	20.42	4.13	0.018
Social functioning	81.66	19.69	71.42	25.20	79.76	18.15	3.78	0.025
School functioning	46.92	32.34	49.91	30.18	80.23	18.54	27.78	0.0001*
	1					1		

Table 4.8. Group differences on PedsQL[™] measure

* Correlation is significant at p < 0.001

Table 4.9. Parallel studies for mean and SD for the PedsQLTM among US, UK sample.

Builipie					
scale	Mean (SD) UK sample (Upton et al, 2005)	Mean (SD) US sample (Varni et al, 2001)	Mean (SD) US sample (Varni et al, 2007c)		
Self-report					
Total score	82.25(13.09)	79.62(15.26)	83.84 (12.65)		
Physical health	86.08(14.06)	80.19(19.30)	87.53 (13.50)		
Emotional functioning	76.99 (18.43)	78.10(20.66)	79.33 (18.15)		
Social functioning	86.85 (16.86)	84.09 (18.50)	85.15 (16.76)		
School functioning	77.29 (16.92)	75.87 (19.71)	81.12 (16.45)		
Proxy-report					
Total score	81.12 (13.85)	80.87 (16.73)	82.70 (15.40)		
Physical health	84.99 (16.08)	81.38 (23.18)	84.48 (19.51)		
Emotional functioning	74.67 (17.67)	77.95 (20.67)	81.31 (16.50)		
Social functioning	84.62 (17.24)	85.38 (19.17)	83.70 (19.43)		
School functioning	77.72 (18.50)	77.80 (22.00)	78.83 (19.59)		

4.3.4. The Children's Depression Inventory

By far the most common self-report scale used for the assessment of depression is the Children's Depression Inventory (CDI; Kovacs, 1981; 1985b). The CDI has been designed to measure self-related assessment of depressive symptoms for school age children and young people (8-17 years) and is known to cover the consequences of depression as they relate to children and functioning in school and with peers. It consists of 27 items on which respondents place an X next to one score of three statements that best describe them over the past two weeks. The CDI yields five subscale scores, including:

- Negative mood (six items)
- Interpersonal Distress (four items)
- Ineffectiveness (four items)
- Anhedonia (eight items)
- Negative Self-Esteem (five items) (Schapman and Heidi, 2002).

4.3.4.1. Reliability of CDI

Psychometrically, it is a strong instrument. The internal consistency reliability has been found to be good, with coefficients ranging from 0.71 to 0.89 with various samples. Test-retest reliability correlations appear to be acceptable, but estimates have generally been found in the 0.80.

Reliability and validity of the CDI in a nonclinical sample was investigated by Wierzbicki (1987). The CDI was administered twice to 50 children and their mothers at an interval of one month. Child's and mother's CDI rating were correlated significantly at both time 1 (r= 0.37) and time 2 (r=0.59). Test-retest reliability of the parent-CDI over the one month interval was good (r= 0.75). Internal consistency of the parent-CDI was demonstrated by both a split-half and an item-total analysis.

4.3.4.2. Validity of CDI

Numerous research studies have supported the CDI as assessing important constructs both for explanatory and predictive uses for characterising symptoms of depression in children and adolescents. Studies of validity found significant differences of Negative Mood factor scores (p < 0.05) in a sample of outpatient and normal control prepubertal children with a high discrimination between children diagnosed as depressed and those with nondepressive disorders (Knight, Hensley, & Waters, 1988). Furthermore, the CDI was validated by Kresanov, Tuominen, Piha, & Almqvist (1998) using ROC-analysis (Receiver Operating Chacteristic); the material was collected from an epidemiological study of a normal population of 5664 children between 8-9 years old. The screening results were compared with the corresponding parent, teacher and child (DISC) interview. Results of the study supported the validity of CDI, but not as a sole screening instrument for psychiatric disturbances in children. Cole, Hoffman, Tram, & Maxwell (2000) investigated the structural differences in parents' and children's symptoms of depression and anxiety using child and parent forms of the Children's Depression Inventory (CDI) and the Revised Children's Manifest Anxiety Scale (RCMAS) in a sample of 562 children of the 6th grade. Factor analysis revealed three factors of each measure. Two of the three parent CDI factors manifested some degree of congruence with their counterparts from the child CDI and can make qualitatively different contributions to the multiaxial assessment of children.

Although studies have presented data supporting the reliability and validity of the CDI, the measure has at times been criticised for lacking discriminant validity (e.g., Tannenbaum, Forehand, & McCombs Thomas, 1992; Wolfe et al. 1987). In a more recent study, Comer & Kendall (2005) investigated the ability of the Children's Depression Inventory (CDI) to correctly detect depression in a sample of 44 treatment-seeking anxious youth. Using ROC with the ADIS-C/P, the results supported the CDI as a continuous measure of depressive symptomatology, but not as a sole assessment for a diagnosis of depression within a sample of anxiety-disordered youth.

4.3.4.4. Scoring of the CDI

Responses are assigned scores of 0, 1, or 2; 0 indicating an absence of symptoms, 1 indicating mild symptoms, and 2, definite symptoms. The total score can range from 0 to 54, with higher scores indicating greater depressive symptoms. Kovacs (1981) recommends a score of 19 and above be used to designate a clinical level of depression. However, it is not uncommon for studies using the CDI to drop the item pertaining to suicidal ideation (e.g. Hannon, Rapee, & Hudson, 2000; Shochet et al., 2001; Weiss et al., 1991). Dropping the suicide item in these studies was justified in terms of being inappropriate question to be asked for children and upon parent's request.

4.3.4.5. The Arabic-CDI version

The Arabic CDI was used previously in other studies. Abdel-Khalek (1998) validated the Arabic version of CDI among Arab children in Kuwait. The Arabic Children's Depression Inventory and the Beck Depression Inventory were administered to 109 Kuwaiti school students whose ages ranged from 14 to 18 years; the Beck Depression Inventory was used to validate the CDI through comparing the scores for depression in both tools, which should be highly correlated. Pearson correlations for total score on the two scales were 0.57, 0.83, and 0.75 for boys, girls, and the combined group, respectively, denoting the convergent validity of the new Arabic inventory against the Beck Depression Inventory as criterion (Abdel-Khalek, 1998); this would support the validity of the Arabic-CDI.

4.3.5. The Revised Children's Manifest Anxiety Scale (RCMAS) "What I Think and Feel"

The RCMAS (Reynolds & Richmond, 1978; 1985) includes items that assess anxiety symptoms, as well as items that assess a child's social desirability. The 37-item of the RCMAS is a self-report inventory used to measure anxiety in children aged from 6 to 19 years for clinical purposes (diagnosis and treatment evaluation), in educational settings, and for research purposes. The RCMAS consists of 28 Anxiety items and 9 lie (social desirability) items. Each item is purported to embody a feeling or action that reflects an aspect of anxiety, hence the subtitle, "What I think and feel".

4.3.5.1. Reliability of RCMAS

The RCMAS is psychometrically sound and has been used by a variety of practitioners, including clinicians, teachers, and researchers. Several types of reliability have been demonstrated with the RCMAS, in terms of stability, internal consistency of the instrument, and possible equivalence. Cronbach's alpha was reported by Gerard & Reynolds (1999) with relatively high alpha coefficients for the total Anxiety Scale score ($\alpha = 0.80$ range). Similar reliability ($\alpha = 0.82$) was reported by Reynolds, Bradley, & Steele (1980).

In another study, 97 kindergarten children were administered the RCMAS. Correlations ($\alpha = 0.79$ with males, and $\alpha = 0.85$ with females) were high, and supported the internal consistency of the RCMAS in young children, two cross-sectional comparisons to the Kuber-Richardson (KR) analysis of variance method were used by Reynolds et al. (1978) to establish coefficients of internal consistency. A KR₂₀ reliability estimate of 0.83 was yielded for the 37 items selected for the RCMAS; a second cross validation assessment yielded a KR₂₀ reliability estimate of 0.85. Finally, with regard to the lie scale of the RCMAS, Wilson, Chibaiwa, Majoni, and Masukume (1990) reported that

the RCMAS lie-scale displayed the highest reliability of the RCMAS subscales. Joiner et al. (1996) provided similar support to the tool.

4.3.5.2. Validity of RCMAS

A total of 28 Anxiety items out of the 37 items of the RCMAS were found adequately representative for all aspects of the Anxiety construct, thereby indicating content validity. Reynolds & Richmond (1979) conducted a factor analysis of the 28 anxiety items in a sample of 329 subjects. Anxiety factors were identified as "physiological", "worry/ oversensitivity", and "concentration".

In a replication by Reynolds & Paget (1981b) with a larger sample of 4,972 children, factor analysis was conducted for all 28 items of the anxiety scales. Factors extracted by factor analysis were rotated via Varimax procedure to maximise the variance accounted for by each factor, and to increase the distinction between factors.

Three to eight factors were identified. The pattern of factor loading with the five-factor solution revealed two lie scale factors (accounting for 75%, and 25% of the variance), and the three distinct Anxiety scale factors (accounting for 34%, 42%, and 24% of the variance).

The five factors confirmed by Reynolds and Paget (1981) are as follows:

Anxiety Scale Factors:	Item Numbers				
The Physiological Factor	1, 5, 9, 13, 17, 19, 21, 25, 29, 33				
The Worry/Oversensitivity Factor	2, 6, 7, 10, 14, 18, 22, 26, 30, 34, 37				
The Concentration Anxiety Factor	3, 11, 15, 23, 27, 31, 35				
Lie Scale Factors:					
Lie 1	4, 8, 12, 16, 20, 24				
Lie 2	28, 32, 36				

However, subsequent studies have failed to replicate this factor structure, instead recommending its use as a general measure of trait anxiety (Wilson, Chibaiwa, Majoni, Masukume, & Nkoma, 1990). The State-trait Anxiety Inventory for Children (STAIC) which is designed to measure two types of anxiety in children (train and stait) were correlated with the RCMAS to validate the tool. Convergent and divergent validity of the RCMAS were supported through large positive correlations between the RCMAS

and the trait measure of anxiety, the STAIC (State-trait Anxiety Inventory for Children), but not with the state measures of Anxiety, where Reynolds (1980) reported (r = 0.85, p < 0.05) between RCMAS and STAIC trait, but not with the STAIC state measures (r =0.24, p > 0.05). These findings were supported by other studies, for example, Reynolds & Paget (1983) reported good psychometric properties and good convergent validity with the STAIC trait anxiety scale. Moreover, the results of Varela & Biggs (2006) provide evidence for the reliability and validity of the RCMAS with Mexican and Mexican American youth, supporting its use with a different countries and cultures.

Utility of the RCMAS in terms of predicting a child's anxiety level was supported by Pina, Silverman, Saavedra, & Weems (2001), likewise, analysis of the RCMAS lie scale with 284 anxious children indicated that lie scale scores were also predictive of children's level of anxiety, and they were able to distinguish children with anxiety disorder from children with externalising disorders. However, its discriminant validity is considered open to discussion, as it has failed to discriminate between children with anxiety disorders and those with depression (Brady & Kendall, 1992; Dierker et al., 2001). A possible explanation for the low level of discriminant validity observed among commonly used self-report anxiety questionnaires is that they tap into a general negative affectivity component that is common to all anxiety disorders (Brady & Kendall, 1992)

Nonetheless, the clinical relevance of the RCMAS as a tool used to discriminate between children with a DSM-III anxiety disorder and other DSM-III psychiatric diagnoses was investigated by Mattison, Bagnato, & Brubaker (1988). They found that the RCMAS Worry/ Oversensitivity sub-factor of the anxiety scale can significantly discriminate between those children who do not have a diagnosable anxiety disorder, and those children who do not have any anxiety disorder. Thus, the use of the RCMAS was recommended as a diagnostic tool and for screening those children who may be in need of counselling, as those evidences suggest that it can discriminate between clinical and non-clinical children (Perrin and Last, 1992).

Finally, Devilly and Gilory (2004) reviewed a large number of studies for issues related to cross cultural validity of the RCMAS, the reported studies mostly have been in North America, although other studies were in Zimbabwe (Wilson et al., 1990), and Australia. Devilly and Gilory (2004) pointed out that Britain, Canada, and the United States were considered to be "similar" or comparable, with relatively comparable rates in Asian countries. However, data from eastern European countries and Australia identified much higher rates of scoring using the RCMAS, although the reported difference was not clinically significant. Importantly, no clear result has been collected from Middle Eastern countries or Arab children as an ethnic minority within any Western country, except for one Arabic study reported using the RCMAS, and it was among Palestinians children of the refugees' camp in Gaza strip (carried out by Thabet and Vosanis, 1998). However, no cross-cultural validation was done, nor was any data was provided in the published research regarding issues of validity and reliability of the Arabic RCMAS-version for children, which necessitate piloting this version and cross culturally validating it among children in Jordan.

4.3.5.3. Scoring of RCMAS

Each item is given a score of one for a "YES" response, yielding a total anxiety score. An overall cut-off point of 19 out of 28 can be used to identify children experiencing clinically significant levels of anxiety. The total score of the RCMAS is 37 including both the 28 anxiety items and the 9 lie scale items, the highest possible score for the anxiety scale is 28, and however, a score of 19 is used as a cut-off point to indicate a critical level of anxiety in the child. There are three empirically derived anxiety subscales scores. High scores on the sub-scales can be used to develop hypotheses about the nature of the child's anxiety:

A. Physiological factors:

- 1. Physiological Anxiety: would yield high scores on physiological factor (items 1,5,9,13,17,19,21,25,29,33).
- B. psychological factors:
 - Worry/ Oversensitivity: high scores on the items
 2,6,7,10,14,18,22,26,30,34,37 would usually indicate that the child may

be overwhelmed and feel withdrawn, as the child internalises his/her experience of anxiety.

 Social Concerns/ Concentration: high scores on items 3, 11, 15, 27, 31, 35 would suggest that the child is likely unable to meet the expectations of other important people.

In research, social desirability scale, and lie-scale are names for instruments used to measure defensiveness, as these are thought to measure the tendency of a subject to answer in a manner that they believe to be culturally accepted and approved. For example, the lie-scale of the RCMAS (Reynolds and Richmond, 1979) was devised from those items of psychological scales judged to have socially desirable characteristics. Consequently defensiveness has been measured continuously using the lie-scale of the RCMAS in children, and categorically by designating children as "repressors" and "non-repressors" dependent on the relationship between how they score for social desirability and how they score for anxiety.

Reynolds and Richmond (1979) found a low but significant positive correlation between child's level of anxiety and social desirability on the lie-scale of the RCMAS. It has been suggested that wanting to appear perfect may be a characteristic trait of anxious children, thus, a positive correlation between lie-scores and anxiety levels could be expected, as seen in the original study of the RCMAS (Reynolds and Richmond, 1979). On the other hand, in Wilson et al's (1990) study, examination of the relationship between the lie-scale and anxiety score using the same RCMAS showed negative correlation, which suggested that those children who answer in a manner that they believe to be culturally accepted and approved might not be able to recognise and acknowledge certain intrapsychic difficulties, and thus appear less anxious than the child who has insight. Few studies have used the lie-scale of the RCMAS in a clinically or theoretically meaningful way, and the majority of clinical studies omit reporting on the lie measure entirely.

4.3.6. Translation of the RCMAS into Arabic

4.3.6.1. Instrument validation procedure of the Arabic-RCMAS

To determine the instrument's acceptability, reliability and validity in Jordan, a crosscultural validation was performed in three phases; forward-backward translation, pilottesting, and estimation of reliability and validity (Brislin, 1970, 1986; Mapi Research Institute, 2002). The Arabic version of the RCMAS was created through the same stages previously described in translating the PedsQL in Figure 4.3.

A convenience sample of 98 children and young people completed the assessment to determine ease of comprehension, possible ambiguity, and alternative wording. Respondents indicated how long it took them to complete the charts, and for each question whether it was confusing or difficult to answer and intrusive or annoying. The acceptability and utility of this instrument in Jordan were discussed further by a group of school and hospital social workers. The charts were considered highly acceptable.

Two weeks later the same 98 children did the test again to obtain data on the acceptability, appropriateness, and comprehensibility of the Arabic versions of the tools, the results were then compared. The children were interviewed to determine whether any questions were difficult to comprehend. As a result, the RCMAS "version five" was produced, which was expected to be easier to administer and more readily understood by Jordanian children and their mothers.

4.3.6.2. Descriptive statistics of the samples

The Statistical Package for Social Science (SPSS) was employed to compute descriptive statistics and reliability coefficients. Two reliability tests were performed; test-retest measuring temporal stability through calculating the correlation between the two scores of pre and post test, and another test of internal consistency performed by Cronbach's alpha to ensure that all the items are measuring the same concept.

In assessing the RCMAS, girls constituted the larger portion of the sample (79 girls, and 19 boys). The average age of the sample was 11 years. The 98 children and young people were recruited from regular primary schools in Jordan. These children were 43 students in the 5th, grade, 49 students in the 6th grade, and 6 students in the 7th grade at

two local schools of east Jordan (Yafa Primary School. And Abed Alhaleem Al Nemer School / Salt);

4.3.6.3. Internal consistency of the Arabic-RCMAS version

For score distribution, the mean and standard deviation (SD) of the scores for the scales were calculated, and the internal consistency of each scale was estimated by Cronbach's alpha coefficient. Means of the RCMAS ranged from 0.20 ("My hands feel sweaty") to 0.94 ("I always have good manners"). Most items (21 out of 37) were slightly negatively skewed. However, appreciable positive skewness for 16 items was observed.

Alpha coefficients were evaluated for both pre and post anxiety score (Table 4.10.). The post-test demonstrated better internal consistency, with an alpha of 0.81, and 0.79 for pre-test. The lowest internal consistency of was for the Physiological Anxiety subscale, with 0.58 in the pre-test, and 0.70 in the post-test. The other subscale alphas were 0.72 for Worry /Oversensitivity and Concentration in the pre-test, and 0.80 and 0.73 respectively in the pre-test. This result supports the internal consistency of the RCMAS.

RCMAS	No of items	Range of scores	Pre-test			Post-test			
			Mean	Standard deviation	α	Means	Standard deviation	α	
Total score	37	0-37	18.66	5.97	0.79	18.29	6.65	0.81	
Anxiety scale factor									
Physiological anxiety	10	0-10	4.23	2.22	<u>0.58</u>	4.29	2.55	0.70	
Worry/oversensitivity	11	0-11	5.71	2.77	0.72	5.67	3.19	0.80	
Concentration	7	0-7	2.5	2.07	0.72	2.49	2.08	0.73	
Total anxiety scale	28	0-28	12.45	6.78	0.89	12.86	6.22	0.86	
The lie scale factor									
Lie 1	6	0-6	4.66	1.42	<u>0.61</u>	4.37	2.00	<u>0.51</u>	
Lie 2	3	0-3	1.54	0.89	<u>0.26</u>	1.47	0.95	<u>0.38</u>	
Total lie scale	9	0-9	6.26	1.85	<u>0.58</u>	5.84	2.58	<u>0.61</u>	
Total Cronbach's alpha	for pre an	id post te	st		0.7	9			

Table 4.10.Reliability Analysis of the Arabic RCMAS

The values of Cronbarch's $\alpha < 0.70$ indicate inappropriate internal consistency is underlined, the value < 0.70 is underlined.

4.3.6.4. Test-retest Reliability of the Arabic-RCMAS version

Test-retest reliability of the RCMAS was investigated by calculating Spearman's correlation coefficients of subscales. Inspection of the correlation (pre values with post values) yielded a weak positive correlation between pre and post items. These results might suggest problems of instrument reliability with Jordanian children and young people, and that a similar problem may exist when using this tool in assessing the level of the anxiety later on.

The RCMAS demonstrated significant correlation in eight items, in which

rho (n=98 children and young people) ranged from 0.210 to 0.349. Several points of concern emerged with the Spearman's coefficient of correlation between the remaining pre and post items values, in which rho < 0.1. The establishment of test-retest reliability for the RCMAS negates the need to address the nature of variables in terms of expressing mood states, and attitudes, which naturally change over time irrespective of the stability of the tool itself, and in such cases, a low correlation might still be accepted (Pallant, 2001).

However, comparisons can be made between the reliability coefficients of the RCMAS in previous studies, in which Pearson correlations ranged from 0.60 to 0.88, significant at $p \le 0.01$ (Wisniewski, Mulick, Genshaft and Coury 1987, p. 67) and an insignificant difference between test and retest mean raw scores. These results would support the stability of the scale over brief periods. Reynolds (1981) found a 0.68 correlation between RCMAS Anxiety Scale scores and a 0.58 correlation with the Lie Scale scores, for 534 children in Grades 4 to 6. This would be indicative of relatively high temporal stability. Pilot and Hungler (1999) believed the reliability of a tool is a property of the tool when administered to a certain sample, under certain conditions, rather than the property of the specific tool itself.

Because of this problematic test-retest reliability noted above, and failure to find a strong association between pre and post values, despite the approved stability of the tool in previous studies among American, English and Canadian children, reliability of the RCMAS in Jordan needs further assessment. It is essential also to acknowledge the limitations of the convenience sample used in this test-retest procedure and the need of the instrument to be adapted. It may be questioned to what extent these two schools

were representative of a cross-section of all school-attending population in Jordan, including the inner city as east of west and east Amman, and high poverty districts and refugee campus such as Al-Baqa'a, as this tool was validated among two schools of Al-Salt city. Further testing of the instrument on a more representative sample of all geographic regions of Jordan is recommended.

Table 4.11.	Test-retest	Reliability	of RCMAS	items
Variable				

spearman's p

1.	I have trouble making up my mind.	
2.	I get nervous when things do not go the right way for me.	
3.	Others seem to do things easier than I can.	0.210*
4.	I like everyone I know.	
5.	Often I have trouble getting my breath.	
6.	I worry a lot of the time.	
7.	I am afraid of a lot of things.	
8.	I am always kind.	
9.	I get mad easily.	
10.	I worry about what my parents will say to me.	
11.	I feel that others do not like the way I do things.	
12.	I always have good manners.	
13.	It is hard for me to get to sleep at night.	
14.	I worry about what other people think about me.	
15.	I feel alone even when there are people with me	
16.	I am always good.	
17.	Often I feel sick in the stomach.	0.330**
18.	My feelings get hurt easily.	0.221*
19.	My hands feel sweaty.	
20.	I am always nice to everyone	
21.	I am tired a lot.	
22.	I worry about what is going to happen	
23.	Other children are happier than I am.	
24.	I tell the truth every single time.	0.223*
25.	I have bad dreams.	
26.	My feelings get hurt easily when I am fussed at.	0.221*
27.	I feel someone will tell me I do things the wrong way	
28.	I never get angry.	
29.	I wake up scared some of the time.	
30.	I worry when I go to bed at night.	
31.	It is hard for me to keep my mind on my schoolwork.	
32.	I never say things that I shouldn't.	
33	I wriggle in my seat a lot.	0.206**
34	I am nervous.	
35	A lot of people are against me.	0.343**
36	I never lie	0 349**
20.	Laften worry about something had hannening to me	0.047
57.	routen worry about something our nuppening to me.	

Sum of anxiety variables pre and post

The association between the pre and the post values of each item in the RCMAS is assessed using Spearman's coefficient of correlation measure of reliability.

* Correlation is significant at the 0.05 level (2-tailed

****** Correlation is significant at the 0.01 level (2-tailed).

RCMAS	Spearman's correlation rho	
Sum of Anxiety Scale Factors pre and post	0.096	
Physiological Anxiety	0.233*	
Worry/oversensitivity	-0.084	
Concentration	0.10	
Sum of Lie Scale Factor pre and post	0.224*	
Lie 1	0.082	
Lie 2	0.226*	
Pre Anxiety Scale to pre lie scale	-0.326**	
Post Anxiety Scale to post lie scale	-0.405**	

Table 4.12.Test-retest Reliability of RCMAS subscales

* Correlation is significant at the 0.05 level (2-tailed).

** Correlation is significant at the 0.01 level (2-tailed).

Further inspection of the highest and lowest subscale correlations yielded further evidence regarding reliability of the RCMAS in Jordanian culture. The Anxiety Scale factors show the lowest correlation in the RCMAS, suggesting its items did not refer to a common affective process, as did items in the Lie Scale factors. In addition, the Lie Scale factors demonstrated the highest correlations. In fact [rho (98) =0.226, p<0.05] items "I never lie", "I never say things that I shouldn't", and "I never get angry" appear to be related to cultural and religious arousal, a construct that is thought to be taught at school, or to a concern for social desirability, which force defensiveness. Support for the content validity of the RCMAS items has been thought to be related between both pre-post Anxiety scale factors and Lie scale factors (see Table 4.11).

In general, the RCMAS 37-item scale appears less reliable than is desirable, although it still acceptable because:

"a scale designed to measure current mood states is not likely to remain stable over a period of a few weeks; the test-retest reliability of a mood scale, therefore, is likely to be low" (see Pallant, 2001, p.6),

Thus, such questionnaires especially over an average of two weeks are expected to show correlations lower than desirable.
4.3.6.5. Face validity and content validity of the Arabic-RCMAS version

For content validity, which tests the adequacy of the content area measured (Polit and Hungler, 1999) a multidisciplinary panel from schools and university teachers were asked for feedback on the wording of statements. The acceptability of using this instrument in Jordan and its utility were discussed further with a group of school children and hospital social workers. Most of the children's and young people's feedback was on the wording of statements. A literal translation was cumbersome, or inappropriate in some items of the RCMAS, and minor modifications were necessary for some concise English expressions to improve their clarity in translation. Further adaptation of the instrument was necessary to make it more culturally relevant to Jordan, and more suitable according to the developmental age group of the children. All the sent recommendations received were taken on board, and the scales were amended accordingly, and tested again. However, there was no disagreement on the content of the instrument, which supports the validity of the questionnaires.

4.3.6.6. Construct validity by confirmatory factor analysis for the Arabic-RCMAS version

The factor structure of the Arabic-RCMAS was tested with confirmatory factor analysis, which indicated that the two scales of anxiety and lie scale provided a better fit to the data than either one-factor solution. The result also demonstrated, however, that while the Arabic RCMAS significantly discriminates between anxiety and lie items, there is less differentiation between the scales in comparison with the English RCMAS reported by Reynolds and Paget (1981a,b&c).

Moreover, the factor loadings are generally comparable to those reported by Reynolds and Paget (1981b) for the lie scale factor, but less sensitive to the anxiety factor. Factors extracted by factor analysis were rotated via Varimax procedure to maximise the variance accounted for each factor, and to increase the distinction between factors. The pattern of factor loading revealed two lie-scale factors accounting for 30% and 70% of the variance, but less sensitivity with the anxiety scale factor. Consistent with Wilson, Chibaiwa, Majoni and Masukume's (1990) study, the RCMAS lie-scale displayed the highest reliability and validity for the tool. The moderate-to-low factor loading of the anxiety scale factor for the Arabic translation of the RCMAS indicates that the items are tapping into the constructs under study, but generally unable to distinguish the anxiety factors of "physiological", "worry/oversensitivity", and "concentration". However, the factor loadings of the Lie scale factor are generally comparable to those of Reynolds and Richmond (1979), and Reynolds and Paget (1981).

4.3.7. The Depression, Anxiety, Stress scale (DASS-42)

The Depression, Anxiety, Stress Scale (DASS-42) is a self-report inventory of 42-item that was designed to measure factors of depression, anxiety, and stress in normal subjects during negative emotional state (Lovibond, 1998; Lovibond& Lovibond, 1995a&b). Each sub-scale contains 14 items, divided into subscales of two to five items with similar content. Subjects are asked to use four-point severity/frequency scales to rate the extent to which they have experienced each state over the past week, then points are calculated by summing the score for each item in the three scales which include:

- The Depression Scale: assesses Dysphoria, Hopelessness, and Devaluation of Life, Self-Depreciation, and Lack of Interest/Involvement, Anhedonia, and Inertia.
- 2. The Anxiety Scale: assesses Autonomic arousal, skeletal muscle effects, situational anxiety, and subjective experience of anxious affect.
- 3. The Stress Scale: is sensitive to level of chronic non-specific arousal, it assesses difficulty relaxing, nervous arousal, and being easily upset/agitated/irritable/over-reactive and impatient.

4.3.7.1. Scoring of the DASS-42

Table 14.13. shows how the sum of the scores for each of the seven questions completed by each participant, in each of the sub-scales, are evaluated as per the severity-rating index below.

······································	Depression	Anxiety	Stress	
Normal	0-9	0-7	0-14	
Mild	10-13	8-9	15-18	
Moderate	14-20	10-14	19-25	· · · · · · ·
Severe	21-27	15-19	26-33	
Extremely severe	28+	20+	34+	

Table 4.13.	The scoring	guidelines	for t	the DASS-42
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4.7.2. Translation of the DASS-42 into Arabic language

The development of an Arabic version of the DASS-42 for the purpose of getting valid assessment and evaluation of the negative emotional states of depression, anxiety, and stress in mothers of children with cancer included the same guidelines that were previously discussed in translation of the RCMAS and the PedsQL into Arabic (the Mapi Research institutes guidelines of translation and Brisling model 1970/1986).

4.7.3. Descriptive statistics of the participating sample

Twenty four men (50.0%) and twenty three women (47.9%) from all around Jordan volunteered to participate in this study. Ages were 18-60 years with a mean age of 30.55, and a standard deviation of (SD= 11.5). 72.9% of participants said that all items were clear, and not difficult to understand, whereas 25% said that some items were difficult to understand, and 8.3% believed that the same few items were in conflict with the culture of Jordan.

4.7.4. Internal consistency of the DASS-42

This study yielded means and standard deviations similar to those observed in previous studies (see Table 4.14.). The internal consistency (Cronbach's alpha) of each scale of the DASS was quite favourable (as seen in Tables 4.14., and 4.15.) but well below the values given by Brown et al. (1997).

Table 4.14.Reliability Analysis of the Arabic DASS-42 version;Means (standard deviation), and reliability coefficient (Cronbach's alpha) for the DASS-42

	No of Range of		Pre-test			Post-test			
DASS-42	items	scores	Mean	SD	α	Mean	SD	α	
DASS-Depression	14	0-42		11.40	8.15	0.89	10.17	7.18	0.87
DASS-Anxiety	14	0-42		11.94	6.07	0.73	10.94	6.33	0.77
DASS-Stress	14	0-42		16.02	8.11	0.87	13.87	7.08	0.83

Table 4.15.Previous reports on psychometric properties of the DASS-42

	Lovibond & Lovibond (1995)			Brown et al. (1997)		
sample	DASS Depression	DASS Anxiety	DASS Stress	DASS Depression	DASS Anxiety	DASS Stress
Descriptive Statistics						
Mean	7.19	5.23	10.54	10.55	10.90	21.10
SD	6.56	4.83	6.94	9.30	8.12	11.15
Reliability						
Alpha	0.91	0.81	0.89	0.96	0.89	0.93

4.7.4.1. Test-retest Reliability of the DASS

Findings of test-retest reliability of the DASS-42 using Spearman's correlation show consistency with other studies and support DASS-42 performance in Jordan. Table 14.1 shows that although DASS performed reasonably well psychometrically it is less positive than those of its originators. This test confirmed the satisfactory reliability of the three scales and they were shown to possess satisfactory psychometric properties in Jordan.

Table 4.16.Reliability of the DASS: temporal stability (2weeks, n=47)

DASS-42	Spearman's correlation
DASS-Depression	0.654**
DASS-Anxiety	0.602**
DASS-Stress	0.675**

** Correlation is significant at the 0.01 level (2-tailed).

4.7.4.2.. Validity testing of the Arabic-DASS-42 version

For item convergent and discriminant validity, a factor analysis was conducted. Promax rotation was used to extract factors. Multi-trait scaling analysis was carried out to evaluate the hypothesised scale structure of the questionnaire, which was extracted by estimating the validity of English DASS-42 and constructed as Depression, Anxiety, and Stress Scales. This technique to test discriminative validity is based on the examination of Spearman's correlations of an item with its own scale and other scales. Item discriminant validity was supported by a comparison of the degree of correlation of an item with its own scale as compared with other scales.

The psychometric properties of the DASS have been demonstrated to be good in numerous studies (Antony at al, 1998; Brown et al, 1997). Test-retest reliability and factor analysis show consistency with other studies and support DASS-42 performance. Lovibond and Lovibond (1995a) have confirmed that that DASS items can be reliably grouped into three scales of depression, anxiety, and stress. However, Brown et al (1997) reported higher values for internal consistency (Cronbach's alpha) of each scale of the DASS. The results also demonstrate better discrimination between the scales, and the relatively higher association between the three scales. It maybe argued here that these results are unlikely to be due to the scales failing adequately to measure three separate structures. Rather, they might be related to the difference in sample size and the inclusion of a clinical sample, which resulted in higher correlations between the items.

Finally, there remains a need to conduct further studies with larger samples, both for healthy samples and clinical samples. Only by comparing these studies will we fully investigate the utility of the Arabic DASS-42 in assessing and evaluating treatment outcomes. Further validation of the instrument will also enhance cross-cultural comparisons. In addition, the emotions of Arab participants seem also to be mixed with their sorrows and the political issues of Iraq and Palestine, which made them appear as stressed personalities. Under such circumstances, rigorous scientific methodology in assessing the psychological distress of Arabs is extremely complicated.

4.4. SECTION THREE: Ethical considerations and practical issues

While discussing the ethical aspect of conducting this research, it is important to consider briefly the main problems that were encountered during piloting the translated tools into Arabic, and during the data collection. The ethical conduct of similar studies with children and young people has been comprehensively discussed in previous studies (e.g. Alderson, 1995) which show that ethical principles such as informed consent, and confidentiality are not the only essentials in research, as many ethical issues are more difficult than it was previously assumed. In addition, underestimation of psychological issues of emotional and mental wellbeing of children and young people may adversely contribute to biased and ignorant attitudes based on misconceptions of a community who might lack education and understanding. The necessity to take an ethical stance in such cases may encounter difficulty and a number of issues had to be addressed and sorted case by case.

First of all, although it seemed that all children enjoyed answering questions by themselves, strategies for ensuring confidentiality and privacy of children should extend beyond their anonymous responses. For example, during the piloting of the RCMAS at one of the schools, the presence of the social worker while children were filling in the questionnaires in the classroom raised a problem. It is important to bear in mind that the social workers referred to at schools are in fact teachers who have taken on a more pastoral role in the school and not what may be considered social workers in the UK. The teacher's general comments to the children, "You are from nice good families", "You've got to answer well and help the researcher to get good results" indeed were made with the good intention of obtaining perfect answers. However, the question arises whether these comments invaded the children's right to privacy and independent answers? Might the questions themselves lead to problems in the child if he felt responsible for my thesis outcome? If such comments are made to children, will it lead to a sense of guilt about the way they felt about themselves or their relations with their parents and environment?

Second, it seemed very important for some of the children to take the results of the items on the scale seriously. For example, the fact that scoring instructions were not provided with the questionnaires presented difficulty, as most students who participated in this study would not usually think of filling in a questionnaire without being told how

the questionnaire was scored. In most cases, students view test scores as a meaningful exam, and expected to pass or to fail. To avoid the impact of being referred to as having given right or wrong answers, additional explanation of the study was given. Nevertheless, a significant percentage of returned questionnaires had names on them, and most students sought individual feedback about their answers anonymously, importantly, no feedback was given. Although it might be assumed that children and young people will feel more confident to answer anonymously, the child participants interpreted the anonymous responses as lack of affection, and as being treated like inanimate objects, which could lead to their feeling vulnerable, powerless and deserted.

Third, another important problem is the applicability of the CDI scale to children and young people with cancer in Jordan. In section two of this chapter it was stressed that this tool has been previously tested and validated in the Arab culture (Abdel-khalek, 1998). Moreover, it was mentioned that it is not uncommon for studies using the CDI to drop the item pertaining to suicidal ideation (e.g. Shochet et al., 2001; Hannon, Rapee, and Hudson, 2000; Weiss et al, 1991). Indeed, most of the mothers at the cancer hospital refused permission to ask this question to their child (65.5% of cancer group, n= 58 and 53.6% of chronic illness group, n= 56), as they argued it would put ideas of death into the child's mind.

Although some children and young people got annoyed or laughed when they were asked the items "I will kill myself", "I have thought about killing myself, but I will not do that", and "I don't think about killing myself", 45% (n= 64 children and young people) of the healthy sample answered that they had thought about killing themselves but they were not going to so. It might be argued here that this is a very inappropriate item to ask of children and young people with cancer and long term illness, who may, in some cases, view their illness as a death sentence, but where does the ethical responsibility of the researcher end, if three children answered that they wanted to kill themselves? Do parents or school and hospital social workers have the right to be given information about things children and young people have answered in confidence, and which might reflect a problem? It is important to note here that this matter was reported to the social worker at one of the hospitals. I was told that I should not take the children's responses seriously, as they were affected by the news media and they wanted to present themselves as heroes and not afraid of death.

It can be argued that if these children did not know they had cancer, and if it was culturally inappropriate for them to be told, how it was possible to present the study to them when recruiting them into the study, without alerting them to the fact that they had cancer? This has been explained in methodology chapter under the section of settings and procedure of data collection. It is important to acknowledge that no child was approached before the mothers were first asked if the child knew his/her cancer diagnosis, each child was then asked what brought him to the hospital and what he/she complaining of. This gave a direction of how to ask the child about the impact of his/her illness on their psychological wellbeing. The information sheet and the informed consent were all written without a direct referral to "impact of cancer" instead it was replaced with the "impact of illness" on their psychological wellbeing.

It can be argued here that Piaget and Eriksson theories have been used in the theoretical framework of the study, but how relevant are they to Arab children? Is there any work which has tested them in anything but Western cultures? A review of available literature on Piaget and Eriksson theories has yielded no studies that have tested these theories in Arab cultures, neither any similar studies of child psychosocial development in the Middle East. The majority of studies and theories were from the USA and the UK. No studies so far, were reported for developing countries like Jordan.

A longstanding debate exists regarding the degree to which such responses among children and young people about the "suicidal item" are universal to depression symptoms or culture specific to the Middle Eastern countries. This has been previously presented by the Panorama programme on the BBC and is a current topic for many news papers in the Arab world. Those who take the position that the suicide issue is culture-specific argue that a suicide issue in the Middle East is linked to the concept of "martyrdom" where young people are encouraged to be suicide bombers.

The political crises in Palestine/the West Bank and Gaza strip and then in Iraq create the phenomena of the "suicide bomber" for fighting a mismatched army, and have shown that such people specifically at the West Bank are highly respected after their death. On the other hand, it can be argued that children and young people's responses toward the suicide item are universal human experience. For example, numerous studies document facing issues with using the suicide item of the CDI among children, and have shown that these responses are a reaction to the protective approach of families. Jordan is no

exception; as a culture, it is widely known that families avoid any discussion of related topics of death and dying, and usually children are sent away to a relative's or a friend's house when some close person dies or during funerals. Consequently, it is unwise to make cultural assumptions using such comments without further validation of those responses and comments.

Apart from these political considerations, when conceptualising and operationalising issues of psychological variables such as symptoms of anxiety, and depression across cultures, it is not appropriate to assume that presentation of symptoms of children's distress is common, as there are some suggestions that symptoms may be expressed differently in different cultures. For example, as a response to psychological stress, some people tend to somatise their symptoms, especially in non-western cultures (Zhang, 1995), and it has been suggested that a lot of stress and anxiety within some Arabs of Middle Eastern culture is presented in psychosomatic mode, or people generally express distress somatically (Al-Lawati, et al, 2000; Tobin, 2000).

Such a difficulty was experienced during the attempt to test-retest the instruments in Arabic at one of the schools. A twelve-year old female student burst into tears; she started complaining of headaches, and pain in her knees. The same pattern of communication was repeated with another female student, although no medical problem was a matter of concern for either of them. The observed explanation for this case has been established beyond a shadow of doubt as somatization. A thorough review of psychological distress and affective disorders in developed countries including the Arab world reveals similar clinical phenomena in previous studies. However, this clinical phenomenon is far from being understood or addressed in the Arab world (Ghubash 2001). It is therefore important to be sensitive to local cultural issues, especially as all previous studies involved adult Arabic patients, and further studies and counselling might be needed if further cases were to be encountered again.

Chapter 5 Results of Quantitative Data and Contextual Information

5.1. Introduction

This chapter will present the results of the study. The aim of this research project was to obtain insight into the impact of cancer on children's and young people's wellbeing in Jordan as presented by their level of anxiety and depression and overall quality of life. This was investigated by using questionnaires and semi structured interviews. The first section of this chapter presents the quantitative findings of the study, and incorporates subsections that describe the personal characteristics of participants derived from the demographic data and the group differences on quality of life, depression and anxiety measures for children and young people and their mothers. The second section presents the contextual information gathered with the open ended questions, with the aim of augmenting our understanding and explanation of the groups of results in the light of the different patterns of communication of cancer diagnosis.

5.2. SECTION ONE; Quantitative data

5.2.1. Distribution and Treatment of quantitative data

Quantitative data were processed using the Statistical Package for Social Science (SPSS 13 for Windows). Each measure was explored and descriptive statistics presented. Second each measure was assessed for its relationships with demographic and medical variables, and where possible, comparison with previous published studies was made.

A parametric test was used as the scores from each group were drawn from a normally distributed population. This type of analysis is more powerful and uses the actual scores; whereas nonparametric tests make fewer assumptions about the data and usually perform an analysis on the ranking of the scores rather than on the scores themselves (Hinton, Brownlow, McMurray, and Cozens, 2004).

Normality of distribution was checked by plotting each group's data on a histogram first, and then more precisely by conducting a one sample Kolmogorov-Smirnov test (Table 5.1.) which statistically assessed the normality of data.

The measure	Kolmogorov-Smironv test		
The PedsQL	Z= 1.08	P=0.190	
The CDI	Z = 1.256	P=0.085	
The RCMAS	Z= 0.868	P=0.439	

 Table 5.1. Normality of data obtained by the measures for the study population

Internal reliability coefficients were examined in the pilot study, and were calculated for each measure again in the three sample groups to support the Arabic versions used in this study among the children and young people with cancer and chronic illness. Subscale scores on each measure and standard deviation (SD) were computed, and a series of t-tests was conducted to establish significant differences in the scores of boys and girls. Comparisons between boys and girls and analysis of any effect of age are not listed as research questions, but the use of age, gender, diagnosis, standardised scores for the CDI, RCMAS, and the PedsQL[™] ensure developmental considerations were built into the analysis. The pooled variance estimate was calculated in order to take into account the fact that the sample sizes were unequal. Then, a one-way analysis of variance (ANOVA) was used to compare the means of the three samples. The coefficient F is an estimate of the between- groups' variance (or mean-square) divided by that of the within-groups variance:

F = <u>between groups estimate of variance (mean-square)</u> Within-groups estimate of variance (mean-square)

The test was finally supported by a Post Hoc test, since ANOVA (F-test) tells only whether there is a significant difference between related means without revealing where the difference lies.

5.2.2. Internal consistency: Cronbach's alpha estimates of the instruments for the three groups of the study

Cronbach's alpha is a measure of internal consistency and assesses the correlations between the items in a scale. The higher the correlations between the items, the greater the internal consistency. Cronbach's alpha was estimated to assess the utility of the measures in the cancer and chronic illness populations and compared to the results of the pilot result test which were presented previously on a healthy population (see section two of the methodology chapter). **Table 5.2.**Internal consistency estimates (Cronbach's alpha) for the measures usedin the actual phase of data collection.

Measure	Group	Number of items	Cronbach's Alpha
CDI	Children and young people with cancer	27	0.92
CDI	Children and young people with chronic illness	27	0.80
CDI	Healthy control group	27	0.77
RCMAS	Children and young people with cancer	37	0.71
RCMAS	Children and young people with chronic illness	37	0.74
RCMAS	Healthy control group	37	0.69
PedsQL™	Children and young people with cancer	23	0.84
PedsQL™	Children and young people with chronic illness	23	0.86
PedsQL™	Healthy Control group	23	0.88
DASS-42	Mothers of children and young people with cancer	42	0.96

5.2.3. Descriptive and preliminary statistics

In total, 178 children and young people were eligible to be entered into this study. The overall response rate was 92% for the cancer group and100% for both chronic illness and healthy groups. In group 1 (children and young people with cancer), 58 children and young people with cancer and their parents were approached. Five children refused, citing a reluctance to discuss feelings. Two parents were unable to complete the questionnaires at the clinic because of time constraints and rejected the idea of returning them later by post and three mothers consented to participation but the children refused to talk or to be interviewed. Those children appeared distressed; among them were a 16-year-old girl with an amputated leg, diagnosed with osteosarcoma, and an eight-year old girl with leukaemia. Of the 58 children and young people with cancer, only 37 mothers were interviewed and completed the DASS-42 due to time constraints or father's not mother's presence during interview. Of the chronic illness group, 56 children and young people and in the healthy controls group 64 participated; interestingly none of them refused to participate.

5.2.4. Personal characteristics of participants derived from the demographics data

5.2.4.1. Gender

The gender distribution for the whole sample was 87 (49%) boys and 91 (51%) girls. The gender distribution by group is shown in Table 5.3. The difference between the groups in gender distribution is not significant (chi-square= 0.09; df= 1; p = 0.764). Mean age did not differ significantly between groups and ages ranged from 6 to 16 years.

	Total (N= 178)	Cancer Group (N= 58)	Chronic (N= 56)	Disease	Healthy Group (N=64)
Males	87 (49%)	33 (57%)	25 (45%)		29 (45%)
Females	91(51%)	25 (43%)	31 (55%)		35 (55%)

5.2.4.2. Age

The median age for the whole sample was 11.32 years (inter quartile range 6 to 16 years). There is no significant difference between the ages for boys and girls (Mann-Whitney U test, Z = -0.031, 2-tailed p = 0.975). This non-parametric test was used for assessing whether the difference in median between two samples of observation is statistically significant as both samples were drawn from a single population and therefore the medians were assumed to be equal.

For group 1 (cancer group), median age was 11 (inter quartile range 7 to 16 years). The ages of boys and girls did not differ significantly (Mann-Whitney U test, Z= -1.564, 2-tailed p =0.118). For group 2 (chronic illness) it was 11.3 years (inter quartile range 6 to 16 years); the ages of boys and girls did not differ significantly (Mann-Whitney U test, Z= -0.597, 2-tailed p =0.551). For group 3 (healthy group) it was 11.5 years (inter quartile range 8 to 15 years); the ages of boys and girls did not differ significantly (Mann-Whitney U test, Z= -2.283, 2-tailed p =0.22). As an extension of the Mann-Whitney U test for three groups, the Kruskal-Wallis one-way analysis of variance was used for testing equality of population medians among groups. It was found that the ages of children and young people in the three groups differ significantly (Kruskal-Wallis analysis of variance, chi-square= 158; df=16, p <0.001). This was expected, despite the equality of mean and median age between groups, specifically related to the difficulty of matching the age group of the chronic illness group with the cancer and control group.

	Cancer Group	Chronic Disease	Healthy Group
	(N= 58)	group(N= 56)	(N=64)
Total	11y (SD= 2.6)	11y 3m (SD=2.6)	11y 5m (SD= 1.8)
	(7-16 years)	(6 - 16 years)	(8 -15 years)
Males	11y 6m (SD= 2.5)	11y 6m (SD= 2.5)	10y 9m (SD= 2)
	(8 - 16 years)	(8 -16 years)	(8 - 15 years)
Females	10y 6m (SD= 2.7)	11y (SD= 2.7)	11y 9m (SD= 1.4)
	(7 - 16 years)	(6 - 16 years)	(10 - 15 years)

Table 5.4.Age of the subjects for the total sample and for each group (median andinter quartile range; years and months)

5.2.4.3. Diagnosis

The distribution of diagnosis across the cancer group was 34 (58.6%) haematological malignancies and 23 (34.2%) for solid malignancies. The median age of children and young people with haematological malignancies was 10 years (inter quartile range 7 to 16 years). The median age for children and young people with solid tumours was 11 years (inter quartile range 7 to 16 years). Table 5.2 shows the diagnostic categories, with acute leukaemia predominating in the cancer sample (58.6%) and thalasemia in the chronic sample (42%). A variety of other chronic illnesses was reported, 24% of respondents reporting chronic renal failure (CRF) and 32% reporting other forms of chronic illness (diabetes mellitus, cystic fibrosis....).

Subgroup differences across the entire population of the chronic sample were explored, there were no statistically significant differences, nor trends toward differences between children and young people with chronic renal failure, children and young people with thalasemia, and other chronic illness on measures of defensiveness, anxiety, or quality of life, consequently, these data were combined into a single chronically ill group for all subsequent analyses. Table 5.5. shows the cancer group was heterogeneous in terms of cancer diagnoses. The mean length of time elapsed since diagnosis in the cancer group was 12.5 months, (SD=9 months). The mean length of time since diagnosis for the chronic illness group was 5.7 years (SD=4.59), with means of 2.89 years, (SD=2.44) and 10.5 years, and (SD=4.1) for CRF and thalasemia, respectively.

Diagnoses, N (%)	Cancer group (n=58)	Chronically ill group (n= 56)
Acute leukaemia	34 (58.6%)	
Non Hodgkin's Lymphoma (NHL)/Hodgkin's Lymphoma (HL)	5 (3.4%)	dy oncentrations and
Other solid tumours (e.g.)	12 (20.5%)	
Brain tumour	6 (10.3%)	he finiteridae heing
Chronic renal failure	determination of the	14 (25%)
Thalasemia		24 (42.9%)
Others (Diabetes mellitus, Cystic fibrosis, Acthma Rheumatic fever (G6PD)	a the cancer gree	18 (32.1%)

 Table 5.5. Diagnoses of cancer patients and chronic illness patients

5.2.4.4. Marital status

For children and young people with cancer, 87.9% lived with two parents. 3.4% were orphans, and in 8.6% of cases, their fathers had a second wife (men are entitled to have up to four wives under certain conditions). Similar proportions were found among children and young people with chronic illness and the healthy group; the difference between the groups was not significant.

Figure 5.1. Frequency of marital status by gender of cancer group (n = 58)



Marital status

Figure 5.1. shows a very low percentage of children and young people whose parents were widowed (n=2), or remarried (n=5). It is noted that no children were living with divorced or single parents. The family in Jordan, being part of the wider Arab culture, is dominated by men, and in Islam the marriage system is mostly consanguineous and polygamous for men but not for women. However, although this practice is accepted, it is not widely practiced. This is referred to as previous studies found that children living with a divorced or single parent are more likely to experience psychological distress.

5.2.4.5. Child's perception of illness in the cancer group

Information was gathered at interview regarding whether the children or young people knew about the cancer diagnosis and treatment. Similarly, data were collected regarding the child's perception of the illness from both child and parent (this information was collected for 54 children and young people and 51 parents of the total 58 children and young people). The analysis approach was quasi-statistical analysis style (Polit, Beck, and Hungler, 2001), sometimes referred to as Manifest content analysis, where the content of the narrative data were searched for particular themes and words that were used by mothers in communicating the child's illness. The results of the search were then analysed statistically by counting the frequency of occurrence of each specific theme, and cross-tabulated.

When children and young people with cancer were asked about their illness, only 37.9% of them (n=22) reported they knew they had cancer. Sixty two percent (n=32) defined the location of the illness such as," my abdomen hurts", or "my lymph nodes are affected", without knowing it was cancer. The meaning of diagnosis was important in understanding the patterns of disclosure parents used and children's and young people's understanding of their diagnosis. This point will be further discussed in the contextual information analysed from the mothers' interviews.

In contrast, mothers expressed a range of views about the forms of disclosure: a few were not as clear as at first thought, and eventually could not be categorised in black and white terms as will be discussed further in the next section. The data presented here were categorised into four main forms of disclosure, where 34.5% (n=20) indicated that the children and young people knew their cancer diagnosis and were informed about its treatment. 13.8% (n=8) indicated that the children and young people knew nothing and

the cancer was not subject to any form of discussion. Among the sample, 25.9% (n=15) described the illness by its location 5.2% (n=3) or using such terms as lymph diseases, tumour, gland mass 20.7 %(n=12), avoiding the word cancer. Finally 13.7 %(n=18) gave miss-conceptualised accounts of the illness, defining it as a virus in the bloodstream 10.3% (n=6), anaemia 1.7 %(n=1), or kidney stones 1.7 %(n=1).

5.2.5. Children's Depression Inventory (CDI)

5.2.5.1. Categorical analysis of the CDI scores

The three subject groups did not differ significantly in their depression scores. Table 5.6. displays the means and standard deviations for the three groups

Table 5.6.Group differences on CDI measure

Cancer group		Chronically ill group		Control group		ANOVA	
Mean	(SD)	Mean	(SD)	Mean	(SD)	F	р
13.758	9.27	14.107	6.519	14.937	6.618	0.394	0.675

Table 5.6. shows the mean score for the total sample was (14.29) with a standard deviation of (SD=7.53). The median CDI score for the whole group was (13.5), inter quartile range (1 to 42). Using a score of 20 as the cut point on the raw CDI scores gives a prevalence of 20.68% (n= 12) for child-reported depression in the cancer group, 17.85% (n= 10) in the chronic illness group, and 20.3% (n=13) in the healthy control group. The total depression scores ranged from 1 to 42 for the cancer group (m= 13.758; SD =9.276). For the chronic illness group, the scores ranged from 3 to 34 (mean= 14.107; standard deviation =6.519), and from 2 to 31 for the healthy group (m= 14.937; SD =6.616). There was no significant difference between the scores for the boys and the girls (independent samples t-test, t=-0.903; 2-tailed p = 0.367). There was no correlation between age of the sample and CDI-Scores (Pearson rank correlation coefficient = 0.059; p = 0.434). This suggests that age of children and young people does not affect their score for depression.

In the validated norms, Kovacs (1985) defines the cut off point of 20 on the raw scores of the CDI as the most appropriate for general depression screening purposes. Using a score of 20 as the cut off point on the raw CDI scores gives a prevalence of 20.68% (n= 12) for child-reported depression in the cancer group, and 17.85% (n= 10) for children and young people with chronic illness, and 20.3% (n=13) for the healthy group in the current research. However, the prevalence of self reported depression in studies that

used the CDI varied somewhat between studies for other countries. For example, in the UK, Wurr (2001) using the same cut off point for CDI scores in measuring children's depression during cancer treatment found a prevalence of 5%. In Turkey, the proportion of children who have scores of 19 or higher on the CDI is 22% (Cavusoglu, 2001). It is important not to jump into assumptions or conclusions about any cultural or religious effects when justifying the high results among some eastern and Muslims cultures. No scholar studies looked into justifying these results in terms of the similar religion or cultural contexts and this merits further investigation in future researches. In the USA, a prevalence of 6% for self-reported depression has been found in children with cancer, and 25% for a healthy group (Canning et al, 1992). In Sweden, a prevalence of 6% was reported for children on treatment for cancer, and 17% for those off treatment (Von-Esson et al, 2000), while 13% for children off treatment was reported in a similar study in the USA (Tebbi et al, 1988). In a more recent study, a prevalence of 8.3% was reported for children with cancer in Taiwan (Chao, Chen, Wang, Wu & Yeh, 2003).

5.2.5.2. Group differences on Depression Measure (CDI)

One-way analysis of variance (ANOVA) was used to compare the means of the three samples and revealed no statistical differences between the three groups. The mean value for the CDI scores in the cancer group was 13.75 compared with 14.10, and 14.93 for the chronic and control groups respectively. The distribution of depression scores among children and young people in the three samples is shown in Table 5.7. While score distribution is compared to those reported in other countries are reported in Table 5.8. The inclusion of these studies for comparison was based on the fact that they were the only studies utilised the CDI in assessing depression among children with cancer, and the only studies that provided data of score distribution.

CDI scores	Children with cancer		Children w	ith chronic illness	Healthy children		
	No.	%	No.	%	No.	%	
0-5	6	10.3	3	5.4	6	9.5	
6-10	20	34.5	17	30.4	11	17.3	
11-15	17	29.3	13	23.2	18	28	
16-20	3	5.2	15	26.8	17	26.6	
21-25	5	8.6	5	8.8	8	12.5	
> 25	7	12.1	3	5.4	4	6.3	

 Table. 5.7. The distribution of CDI scores among the three samples

	Jordan (n=58)		<u>Taiwan</u> Chia-Ch	<u>(n=24)</u> ien. et al. 2003	Turkev(50) Cavusoglu, 2001	
CDI acores	No.	%	No.	%	No.	%
0-5	6	10.3	3	12.5	0	0
6-10	20	34.5	5	20.8	34	68
11-15	17	29.3	9	37.5	5	10
16-20	3	5.2	5	20.8	8	16
21-25	5	8.6	2	8.3	3	6
> 25	7	12.1	0	0	0	0

Table 5.8. The distribution of CDI scores for children with cancer in Jordan as compared to children with cancer in Taiwan and Turkey.

5.2.6. Revised Children's Manifest Anxiety

5.2.6.1. Interval analysis of the RCMAS/anxiety scores

The RCMAS scores of the study sample did not differ. Using a score of 19 as the cut off point on the raw anxiety subscale of the RCMAS scores gave a prevalence of 2.32% (n=4) for child-reported anxiety in the cancer group. The prevalence rates for the chronic illness group and the healthy group were 3.92%, and 3.84% respectively. The anxiety subscale scores ranged from 2 to 23 for the cancer group (m = 10.6; SD = 26). For the chronic illness group, the scores ranged from 2 to 25 (m= 13; SD = 30), and from 1 to 24 for the healthy group (mean= 13; standard deviation = 26). There was no significant difference between the scores for the boys and the girls (independent samples t-test, t=-1.098; 2-tailed p =0.274). There was no correlation between age and RCMAS scores (Pearson rank correlation coefficient = -0.018; p =0.826). When analysed separately for each gender, RCMAS scores did not differ significantly by group, either for the boys or for the girls.

When the anxiety scores are analysed by group using a cut point of 19, the point prevalence rate was 2.32% for the cancer group, 3.92% for the chronic illness group, and 3.84% for the healthy group. The RCMAS-Scores did not differ significantly by group. When analysed separately for each gender, the cancer group (independent samples t-test, t=-1.035; 2-tailed p =0.306), the chronic illness group (independent samples t-test, t=-0.897; 2-tailed p =0.374), and the healthy group (independent samples t-test, t=-0.036; 2-tailed p =0.971). These results show that the RCMAS-Scores did not differ significantly by group, either for boys or for girls.

Although the former finding has already been reported for depression scores, where children and young people with cancer report lower on psychological disturbances, the anxiety score has not been reported and as such makes a further contribution to the overall picture of psychological adjustment and wellbeing in children and young people with cancer. In a study by Frank et al. (1996) both the CDI and the RCMAS were used as part of their investigation to the influence of children's attribution style on the child's psychological adjustment. Using only the total anxiety score of the RCMAS for 86 paediatric oncology patients, they reported a mean of (11.2), and standard deviation of (3.9). In the current work a mean of (m=10.6) and (SD=26) was found for the 58 children with cancer, which seems to be similar to previous research. However, no control group or published norms were used in the previous listed studies, and no data for the lie scale which limited any possibility of further comparison with the current research data.

Interestingly, a higher incidence of anxiety symptoms was found among healthy children in Gaza strip. Thabet and Vostains (1998), using the RCMAS among 237 Palestinian children, reported 21.5% (n=51 children) with scores above the cut off score for anxiety disorder. Similar incidences of anxiety symptoms also were found from Western studies, for example, Kashani and Orvaschel (1990) found a prevalence of 21% of anxiety disorders in a community survey carried out in the USA, using the same measure of the RCMAS, and the same cut off point.

These results suggest that a lower incidence of anxiety symptoms is reported for Jordanian children and young people as compared to previous research from Western and some Arab societies. Unfortunately, no data were given related to the lie scale of the RCMAS in Thabet and Vostains (19989) study, neither in Kashani and Orvaschel (1990). In this study, however, the lie subscale of the RCMAS was employed to try to investigate whether defensiveness could explain the relatively low depression and anxiety scores of children and young people with cancer which has already been reported in other studies, for example in Canning et al. (1992) study. It is important here to stress that in a cross-sectional study, causal links cannot be established between any associations that are found. This will be further discussed and explained in the following sections.

5.2.6.2. Interval analysis of the RCMAS/lie scores

Defensiveness was measured in the children and young people using the lie subscale or social desirability scale of the RCMAS, which consists of 9 items answered in a true-false format. The statement are written in such a way that answering in a positive direction is "too good" to be true for most people. The responses are scored such that higher values indicate a stronger tendency to portray oneself positively. According to Table 5.9, there was a significant difference (p=0.003) between the three groups for defensiveness, with the control group showing a lower mean score than the cancer or chronic illness group. The scores of the lie-scale ranged from 0 to 9 for the cancer group (mean= 6.29; standard deviation =2.25). For the chronic illness group, the scores ranged from 1 to 9 (m= 6.28; SD =2.06), and for the healthy group from 4 to 9 (m= 5.09; SD =2.27). The median score was 7 for the cancer and chronic illness groups, compared to 5 for the healthy group.

Table 5.9. shows that the scores were statistically significantly different between groups ((F (2) = 6.02, p < 0.05). These results suggested that healthy children and young people score less on defensiveness measures. There was no significant difference between the scores for the boys and the girls for the total sample (independent samples t-test, - 0.58=m; 2-tailed p =0.56). In addition, by gender, the RCMAS scores for defensiveness did not differ significantly by group. However, when analysed by age, there was a weak but significant inverse correlation between age and level of defensiveness in children and young people (Pearson's correlation coefficient = 0.213; p =0.004). This suggests that the younger the age of the child, the higher the level of defensiveness. When analysed separately by group, only the healthy group yielded this significant correlation (r =0.284, p = 0.023). Importantly, the correlation coefficient, although statistically significant, is quite weak.

Figure 5.2. Histograms to show frequency of RCMAS/ defensiveness scores of cancer group, chronic illness group and healthy group respectively



5.2.6.3. Group differences on Anxiety Measure (RCMAS)

Anxiety subscales were analysed to explore differences between the three groups. There were significant differences between groups on the group physiological factor (F (2) =8.636, p < 0.0001), worry/ oversensitivity factor (F (2) = 29.24, p < 0.0001), and concentration factor (F (2) =159.772, p < 0.0001). The main significant post hoc comparison indicated that the healthy group reported significantly higher levels of anxiety on the worry/ oversensitivity factor (p < 0.0001) than both the other groups, while higher anxiety in both concentration (p < 0.0001) and physiological factor (p < 0.0001) were found for the chronic illness group.

Group differences in defensiveness level across the entire population were further analysed using ANOVA. Group means are presented in Table 5.8. The groups differed significantly in defensiveness (F (2) = 6.03, p < 0.003). As predicted, post hoc tests revealed that both cancer (p = 0.012) and chronically ill (p = 0.014) groups obtained significantly higher defensiveness scores than the healthy control group.

Moreover, there were statistically significant differences between the cancer, chronic illness, and healthy groups on anxiety measure (F (2) = 3.51, p < 0.05). Significantly, there was a trend for the cancer group to obtain lower scores than the healthy and control groups suggesting that children and young people with cancer score moderately lower than children and young people with chronic illness and their healthy peers

variable	Cancer group		Chronically ill group		Control group		F	р	
	Mean	(SD)	Mean	(SD)	Mean	(SD)			
Defensiveness	6.29	2.25	6.28	2.06	5.09	2.26	6.02	0.003*	
Total Anxiety	10.63	5.14	13.04	5.50	13.0	5.10	3.51	0.032*	
Physiological anxiety factor	3.55	2.21	5.35	2.59	4.43	2.14	8.63	0.0001*	
Worry/ oversensitivity factor	4.65	2.25	2.63	2.15	6.0	2.39	29.24	0.0001*	
Concentration anxiety factor	2.53	2.02	13.04	5.50	2.56	1.76	159.7	0.0001*	
]	

 Table 5.9. Group differences on RCMAS measure

* The mean difference is significant at the 0.05 level

* The mean difference is significant at the 0.05 level 0.001 level

5.2.6.4. Defensiveness and relatedness to psychological measures

The correlations between the child-report measures of depression and anxiety, and the child report measures of defensiveness were examined using Pearson's correlation coefficient by correlating the depression scores with the defensiveness scores and then correlating the anxiety scores with the defensiveness scores. Pearson's correlation coefficient was used as both were normally distributed. It can be seen from Table 5.11. that the child-report measures of depression and anxiety correlate significantly with each other (p < 0.001).

Table 5.10. Correlations between child's level of defensiveness and expressed level of anxiety and depression for the whole sample

	Pearson's r	
Total anxiety score and defensiveness score	-0.312**	
Depression score and defensiveness score	- 0.268++	·····- · -

** Correlation is significant at the 0.001 level (2-tailed).

Table 5.11. Correlation between defensiveness and depression level and between defensiveness and anxiety level by group

	Cancer group	Chronic illness group	Healthy peers
Total anxiety scores	-0.328*	-0.273	-0.306*
Depression scores	-0.371*	-0.58	-0.293*

** Correlation is significant at the 0.05level (2-tailed).

Table 5.10. shows that there was a significant inverse correlation between CDI scores and the lie scale of the RCMAS for the whole sample (correlation coefficient = 0.268, p =0.001). Therefore higher self-reported depression scores were associated with lower defensiveness scores and vice-versa. When the results were analysed by group, as it shows in table 5.11. there was a significant inverse relationship between the CDI scores and defensiveness only for the cancer group cancer group (correlation coefficient= - 0.371, p=0.004) and the healthy control group (correlation coefficient= - 0.293, p= 0.019).

Table 5.10. shows that there was a significant inverse correlation between RCMAS-total anxiety scores and the lie scale of the RCMAS for the whole sample (correlation coefficient = 0.312, p=0.001). Therefore, higher self-reported depression scores are associated with lower defensiveness scores and vice-versa. When the results were

analysed by group, there was a significant inverse relationship between the RCMAStotal anxiety scores and defensiveness only in the cancer group (correlation coefficient= 0.328, p=0.021) and the healthy control group (correlation coefficient= - 0.306, p = 0.014).

When analysed by gender, there was a significant inverse correlation between CDI scores and scores on the Lie scale of the RCMAS (correlation coefficient = 0.312, p=0.003) for boys. For girls, those was a significant inverse correlation between CDI scores and scores on the Lie scale of the RCMAS (correlation coefficient = 0.228, p=0.03). For girls only, there was a significant inverse correlation between RCMAS-total anxiety scores and Lie scale of the RCMAS scores (correlation coefficient = 0.450, p=0.001). For boys, no significant correlation between RCMAS-total anxiety scores and scores on the Lie scale of the RCMAS scores (correlation coefficient = 0.450, p=0.001). For boys, no significant correlation between RCMAS-total anxiety scores and scores on the Lie scale of the RCMAS was established.

5.2.7. The Paediatric Quality of Life Inventory

5.2.7.1. Interval analysis of the PedsQL[™] scores

The PedsQLTM scores ranged from 17.39 to 96.74 for the cancer group (m= 65.98; SD = 19.47). For the chronic illness group, the scores ranged from 13.04 to 94.57 (m= 61.16; SD =19.58), and for the healthy group from 31.52 to 100 (m= 78.97; SD =14.81). There was no significant difference between the scores for the boys and the girls (independent samples t-test, t=1.66; 2-tailed p =0.098). By group, there was a significant difference between girls and boys, where boys scored higher on quality of life measures (independent samples t-test, t=2.279; 2-tailed p =0.027)

5.2.7.2. Group differences on quality of life measure (PedsQL[™])

The mean and standard deviation of the cancer group, chronic illness group and healthy referents are reported in Table 5.12. The ANOVA demonstrates a main effect for sample, indicating that healthy group have significantly higher QoL than children and young people with cancer and chronic illness (F (2) =15.99, p < 0.0001). This significant difference extended to all QoL subscales except social functioning, as children and young people with cancer and control group reported higher scores for social life. The chronic illness group reported more problems with physical, emotional, social and

school functioning (all significant at p < 0.0001) and reported the worst QoL, compared with children and young people with cancer and the control group

variable	Cancer group		Chronically ill group		Control group		F	р
	Mean	(SD)	Mean	(SD)	Mean	(SD)		
Total items of Quality of life	66.98	19.47	61.16	19.58	78.97	14.81	15.99	0.0001*
Physical functioning	69.35	26.02	61.10	25.73	81.05	15.00	11.90	0.0001*
Emotional functioning	63.94	28.92	62.23	20.58	73.59	20.42	4.13	0.018*
Social functioning	81.66	19.69	71.42	25.20	79.76	18.15	3.78	0.025*
School functioning	46.92	32.34	49.91	30.18	80.23	18.54	27.78	0.0001*

Table 5.12. Group differences on PedsQL[™] measure

* mean is significant at the 0.05 level

5.2.8. Maternal distress using the DASS-42

These data were treated normally distributed (Kolmogorov-Simirnov Z= 0.632, p = 0.819 for the depression subscales, Kolmogorov-Simirnov Z= 1.128, p = 0.157 for the anxiety subscales, and Kolmogorov-Simirnov Z= 0.807, p = 0.533 for the stress subscales), and were all analysed parametrically. The mean and standard deviation of these scores, representing the level of depression, anxiety, and stress in the mothers who filled out the DASS-42 is presented in Table 5.13.

Table 5.13.Mean and standard deviation of the DASS-42

DASS-42	Mean	(SD)
Depression scale	18.36	11.21
Anxiety Scale	16.166	9.06
Stress Scale	22.5	10.05

Table 5.13. shows result for the DASS-42, the depression score was (m=18.36, SD= 11.21), whereas (m= 16.166, SD= 9.06) for anxiety score, and (m=22.5, SD= 10.05) for stress. Illness group, number of children and young people in the home, and gender of the child were not significantly correlated with the mothers' self-reported measures of anxiety, depression and stress. Preliminary analysis of variance (ANOVA) also indicated that the mothers' level of distress did not differ by disclosure of cancer diagnosis to the children and young people. Based on these preliminary results, the only significant association was between mother's level of anxiety and mother's marital status (F (4.37, p = 0.007).

5.2.9. Summary of the main quantitative results

A summary of the quantitative results is provided here. Overall, the hypotheses were not supported in this study. The findings established that depression in children and young people with cancer is similar to children with other chronic illness and a healthy control group, where the results shows no significant differences as it shows in table 5.14.. Whereas anxiety scores are lower for children and young people with cancer and chronic illness. Table 5.14. displays the means and standard deviations for the three groups, and shows that there was a significant difference between children's reported anxiety and quality of life, but not for depression.

for the three gro	oups							
Measures	Cancer group		Chronically ill group		Control group		ANOVA	
	Mean	(SD)	Mean	(SD)	Mean	(SD)	F	р
CDI	13.758	9.27	14.107	6.519	14.937	6.618	0.394	0.675
RCMAS- Anxiety scale	10.63	5.14	13.04	5.50	13.0	5.10	3.51	0.032*
RCMAS-Lie scale	6.29	2.25	6.28	2.06	5.09	2.26	6.02	0.003*
PedsQL	66.98	19.47	61.16	19.58	78.97	14.81	15.99	0.0001*

Table 5.14. Group differences on the measures of the CDI, RCMAS and the PedsQL

 for the three groups

Further more, maternal depression, anxiety and level of stress were investigated primarily to ascertain how they affected children's and young people's adjustment with cancer diagnosis. The mothers of children and young people with cancer scored high on the three scales, and when these scores were correlated with children's and young people's scores; there was an association between maternal depression and children's and young people's depression, and between mother's level of stress and children's and young people's anxiety. These positive correlations suggest that the higher the depression score in mothers, the higher the depression score in children and young people, and the higher the stress score in the mother the greater the anxiety in the children and young people.

5.2.10. Maternal distress and relatedness to child's psychological measures

Further analysis was used to explore the mother's level of distress in relation to the child's level of depression and anxiety. Preliminary correlational analysis signified a positive correlation between mother's level of depression and children's or young people's depression score ($\mathbf{r} = 0.47$, $\mathbf{p} < 0.01$). A similar correlation was also evident between mother's level of distress and children's or young people's reported level of anxiety ($\mathbf{r} = 0.48$, $\mathbf{p} < 0.01$). These positive correlations suggest that the higher the mother's level of stress, the higher children's and young people's level of anxiety. Moreover, the higher the depression scores in mothers, the higher the depression scores in children and young people. This is congruent with the findings of Frank et al. (1997), and Wurr (2001) who found a positive relationship between mother's level of distress and child's level of distress.

5.2.11 Relation between demo graphic characteristics and psychological measures

There was no significant correlation between the instrument scores on quality of life, depression, or anxiety and the demographic characteristics of the sample such as age, sex, diagnosis and time from diagnosis. An absence of age effects has been described previously in the CDI (Kovacs, 1992).

Age of the child correlated inversely with defensiveness in the healthy children and young people, with younger children scoring higher on the social desirability scale. This supports previous literature where older children and young people obtained significantly lower scores for defensiveness or "self-deception" (Wurr, 2001).

With regards to the sex variable, no gender differences were found for the PedQLTM or on any of other scales for the total sample, except for the emotional functioning subscale of the PedQLTM inventory. This supports previous studies that reported gender differences in emotionality measures, with girls always scoring higher distress than boys (Eiser et al, 1995b; Walker and Greene, 1991). For example, Eiser et al. (1995b) found that girls reported more physical and psychological symptoms than boys on quality of life measures. In contrast to Eiser et al. (1995b) only girls with cancer reported significant differences in their score of emotional functioning, and we can not find alogical explanation for the differences between boys and girls. In Eiser et al. (1995b) gender differences in symptoms were reported for healthy children and were accounted for by the situation in which both girls and boys find themselves in, as gender differences in symptom reporting would diminish, taking into account the effect of experience and social circumstances around the child (Eiser et al, 1995b), this would explain why no significant differences between the sexes were found in the healthy group, however, it is an interesting point for future research.

Finally, a noteworthy correlation between the instrument scores and the demographic characteristics of the sample concerned the scores of Iraqi children and young people on the PedQLTM and the CDI. Iraqi children and young people scored higher on depression and lower on quality of life measures. Several studies of children of war have found association between trauma and psychopathology. For example, in a study of Croatian children during the war, Zivcic (1993) found significantly higher depressive and phobic symptoms in displaced than in local children in stable and social conditions. Thabet and Vostanis (1998) asserted that children's experience of trauma in war zones is often directly related to the development of anxiety symptoms such as fear and nightmares. Nader and colleagues (1993) established a moderate to severe rate of post traumatic stress reaction in 70% of Kuwaiti children following the first Gulf war and Iraq invasion to Kuwait in 1990. A similar pattern of anxiety symptoms and a prevalence of 25% of Post Traumatic Stress Disorders (PTSD) were also reported among displaced Kurdish children in Iraqi Kurdistan (Ahmad, 1992).

In this instance, the inclusion of Iraqi children and young people may have biased the findings toward lower quality of life in the cancer group, and could account, in part, for the observed group differences. However, it can be said with confidence that the current findings reflect real between-group differences and are not an artefact of demographic match.

5.3. SECTION TWO: Contextual data

5.3.1. Analysis of the interview

Data analysis of the interviews with mothers was based on the editing analysis style (Strauss & Corbin, 1998). Content analysis (Holsti, 1969, Strauss & Corbin, 1998) was used to analyse the interview data, as answers to open ended questions are suitable for this technique. According to Weber (1990), content analysis can be used to draw valid conclusions about a message in a statement by objective and systematic identification of statement characteristics. The process of content analysis is outlined in the diagram below (Figure 5. 3).

Figure 5. 3. Process of content analysis and mother's interview



The process of content analysis (Strauss & Corbin, 1998) proceeded through four stages: the first stage was to identify patterns and categories within the mother's data, thus, transcripts were read several times and open codes were generated in search of meaningful segments. According to Strauss & Corbin (1998) in open coding, the data are first broken down into discrete parts and closely examined and compared for similarities and differences. An example of open coding from the mother's interview follows:

Figure 5.4. An example of identifying patterns and categories



The text above is quoted from one of the mothers' semi structured interviews, looking at how mothers manage communicating with their child about his/her illness. Before analysis, these interviews were transcribed verbatim; translated into English and grouped according to the emerged themes. The translations were checked by another person competent in both languages. Strauss and Corbin's method was used to analyse the current data in English as no current reference for qualitative analysis is available in Arabic. It is unlikely however that the results would have been any different if the analysis was done in Arabic.

The second stage was to look for consistent patterns, for example, the consistent pattern in these quotes along with others quotes (Strauss & Corbin, 1998). The third stage was to identify patterns of categories that would be similar to each other. Once segments were identified, a categorisation scheme and corresponding codes were used to sort and organise the data. Words and sentences in the interviews were classified into mutually exclusive categories, which are supposed to reflect the central message in the interviews. In this stage, words used by the mothers were retained in order to stay as close as possible to their pattern of answers. In this extract of the text, the adopted sub-category/category construction is presented.



The fourth stage was to interpret the information and themes in a way that contributed to the development of knowledge. That is, the following sections are organised around the principle themes generated by the data, and include illustrative quotations from the translated transcripts of the interviews. Various English translated quotations, based on these themes and categories, would seem to help in the interpretation of the possible relationship between pattern of communication inside the family and the children's and young people's level of distress. Each case is identified by a personal code number, so that participants cannot be identified. The code number describes the age and gender of the child whose mother is interviewed (F= female, M= male), and the medical diagnosis. The findings are presented in lists of themes and categories and direct quotations along with the discussion of findings.

5.3.2. Conveying the diagnosis of cancer



Figure 5.5. Sub-categories generated from conveying the diagnosis of cancer to the child.

Through reading of categories, a number of issues can be identified, which seem noteworthy. A number of issues can be extracted. For example, Figure 5.5. shows that the theme of *conveying the diagnosis of cancer* is highlighted when mothers talked about what their child knew about his/her illness. There is the idea of a sound communication where the children or young people were told about the illness and treatment side effects and a flawed communication when the children or young people by coincidence read or heard about their illness. The mothers made a distinction between the type and amount of information their children or young people would handle; this is explored in more depth by mothers defining the illness by the location of

the illness (such as: tumours, lymph node) and avoidance of the word cancer. The verdict between false reassurance and avoidance of discussion is also touched on and the way in which children and young people were deceived by misinformation about the illness (for example: severe anaemia, flu, and virus/germ in the blood...).

Some of these patterns are parallel with the literature, where it is reported that the constituents of communication with children and young people who have a potentially life threatening chronic illness incorporate an executive, controlling role, where parents manage what, when, and how their children are told about their illness, and a partnership-based model, with the young child and parent roles becoming more equal and communication becoming more open (Young et al, 2003). The last pattern of communication, where children and young people were deceived by the avoidance of discussion of their disease was found 30 years ago (Patenaude and Kupst, 2005).

Mothers' narratives emphasised how the diagnosis of cancer was explained to children and young people. Mothers expressed a range of views about the form of disclosure: for example, a few thought it was better to tell the child the diagnosis:

"My child knows his diagnosis, he knows he has leukaemia, he knows the whole story about his illness, and he named it cancer in the blood" 12. M (8/ALL)

Mothers described assuming an open approach of communication with the children and young people, managing to use the word cancer in describing the child's illness, and customising information so that the children and young people could better assimilate their illness. As in Young et al's (2003) study, some mothers described adjusting their communication towards a partnership based model, with the communication between parent and child becoming more open.

In contrast, some thought it was more appropriate to mutually pretend that nothing was wrong, for the adult to keep silent while knowing that the child knew about his/her illness, but choosing not to talk about it (Patenaude and Kupst, 2005).

"My child knows he has got cancer in the blood. No one told him the diagnosis. He read a paper here and knew he had cancer in the blood. After that he didn't ask, no one talked or explained an thing about it." 31. M (10/ALL)

"My child hears us talking about his illness, so I think he knows he has cancer." 2. M (7.5/ALL)

Other mothers conveyed their dread of their child being told the death word of cancer, and preferred to deal with the diagnosis by a nick-name and to set limits on what information was given and how, according to what they thought the children and young people could deal with. Cultural norms govern children's and young people's role during illness, in terms of when a child is considered mature enough to learn about a cancer diagnosis and participate in medical care (Die-Trill, 1998)

"My child knows he has ALL, but doesn't know what the seriousness of his illness is...he is sick with leukaemia... but they are kids; they don't know what this word means... We don't talk about it, they can't understand it" 11. M (10/ALL)

This case showed how children and young people were often perceived as incompetent, and how parents were often involved in setting information boundaries. The emerging concept of children and young people as incompetent, immature and vulnerable has until recently dominated in motherhood studies (Young et al, 2002). Although cultures that focus on achieving autonomy and independence encourage children and young people to participate actively in their medical care (Die-Trill, 1998), the existing literature on pattern of communication in parents with sick children is dominated by this approach- an approach that has emphasised an executive-like role, managing what, when and how their children were told about their illness (Young et al, 2003).

In contrast, some chose to deceive the children and young people with false reassurance and not to burden them with bad news. Die-Trill (1998) argued that "in many cultural groups open discussion of cancer diagnosis and prognoses are thought to be inhumane and cruel and are avoided at all cost" (p.859).

"My child doesn't know or understand what cancer is, we told him 'you have hepatitis, an infection in your liver'. Internally he feels that he has cancer like the other children in the ward. But he hates the word (cancer), he has refused to come to this hospital because of the name (King Hussein Cancer Centre)...internally he knows. Once he told the doctor,' I know that my medications are similar to cancer patients, but it is my mother who keeps saying it is hepatitis'. My son feels the fear. I don't talk about his illness with anyone." 18. M (12/ALL)

This quotation shows how in some cases, children knew the seriousness of their condition as well as its name, but were left to cope with their fears alone. Patenaude and

Kupst (2005) reviewed research into illness communication and reported a number of studies which showed that children and young people understood more than was originally thought. The children and young people appeared to re-evaluate their illness and strive to break the adults' silence about the diagnosis of cancer. However, the lack of professional support impedes families in exploring and coping with these intimate and challenging issues.





Figure 5.6. Sub-categories generated from the impact of child's cancer on the mother and marital conflicts.

Culture determines how different family members cope with illness, and provides unwritten definitions of what constitutes a family and how families respond to illness (Die-Trill, 1998). Figure 5.6. shows that some mothers described a stronger bond with their families. Mothers talked about being closer and better united after the child's illness.

"I don't feel it's affecting us negatively or influencing my relationship with my husband, we are just over caring and so afraid for her... my daughters are mature enough to help in sharing some of the responsibility for the house... I feel our family bonds are getting closer and stronger then ever" 8. F (8/AML)
In some cases, mothers verbalised the risk of magnifying siblings' feelings of exclusion and jealousy.

I can't say it was a bad or negative impact, but all the attention and care is all directed toward her at the expense of other things, I felt the family bond getting stronger, and we started to care more for each other. But it is difficult with her younger brothers, I feel they are jealous. I think we spoiled the girl" 1. F (8.5/AML)

Similar concerns about children's illnesses being blamed for" spoiling" were suggested in previous studies. For example, Young et al (2002) found in their study that mothers often faced the dilemma of balancing their emotional work in helping their sick children and the risk of raising siblings' feeling of exclusion or neglect.

It is important to note, however, that the influence of a child's illness on the mother's perceived relations with the family was reported with indifference and lack of concern in a comparable group of mothers.

"My husband has a second wife, nothing has changed, and nothing has affected his half brothers either." 7. M(13/ALL)

"Everything is as usual with the family, I didn't notice any changes, there is nothing at all..." 40. F(9/ALL) (The mother started crying while filling in the DASS-42 scale).

The high scores of mothers on the three scales of anxiety, depression, and stress sheds light on high level of distress in the above cases. Moreover, children's and young people's comments while filling the questionnaires, which will also be referred to later in the discussions, are embedded in a classical repression framework and they draw attention to the seriousness of the issues that the child and the mother might experience as a form of a denial or altered coping mechanism.

Mothers who had expressed a state of disequilibrium in their relations commented around a number of issues that can be categorised as obligation of proximity, role-strain and reconciliation, broker of information, emotional exhaustion, and marital conflicts.

For mothers, the child's illness brought an intense emotional interdependence with their sick child, including an obligation of physical closeness to the child at hospital, and this was, sometimes, achieved by compromising their relations with other siblings and husband.

"I am with my child most of the time, my husband is working in Kuwait and it is hard when I have to travel with my sick child alone. For example, he had an operation in Holland, and again I had to leave my family to stay beside my sick child" 6. M (16/eosteosarcoma)

The cost of "proximity" as described by Young et al. (2002) compromises the mothers' ability to function in their roles as mothers of other children, spouses, housekeepers, and their employment. Clearly, in the following quotation, the strain was particularly great:

"It was like a nightmare, we were crying all the time and we didn't have any hope for a cure. My son himself was really psychologically distressed and tired. I was tired at the same and we were crying both. At home my children's studies were affected; they left their homework and cried... My husband displays his anger at this and that... Our family is scattered between house and hospital, even my youngest son has rejected me and doesn't accept me any more." 12. M (8/ALL)

With few exceptions, most of the information related to illness was usually disclosed and explained by the mothers. Mothers acted as communication brokers; they customised, clarified, or reiterated information to the child (Young et al, 2003).

"No-one told or explained anything to my daughter about her illness, and then I started to gradually talk to her, and began trying to explain it, I told her, 'you will have to go more often to the hospital and you will lose your hair'..." 16. F (14/ ALL).

Several mothers commented that marital conflicts had increased since their child illness. Dahlquist et al (1993) reported a similar aspect of marital distress among couples with children with cancer. It is important to note that in Jordan men are entitled to have more than one wife without the need to divorce the first wife, and despite several claims in Muslims and Arab cultures that children born out of wedlock and single mothers are close to non existent (El-Shanti, 2001) some mothers actually play the role and carry the responsibilities of their children as a single parent without being addressed as a single parent.

"Lots of problems and screaming happened after my child's illness. We were a very united family, but my husband has married a second wife. The girl and the oldest son chose to stay with the father. I am alone at home with the sick child and his young brothers. It was totally negative impact, the family is scattered. But now I am stronger, don't think I feel bad or weak, I am taking care more of myself, and I enjoy more travelling..."47. M (9/NHL). Although cancer treatment is free in Jordan, nevertheless the financial pressure was an important aspect of role strain mentioned frequently by the mothers in this study.

"After his illness our problems and misunderstanding increased. Compared to people we have gone far and experienced more difficulties between me and my husband...sometimes we have income, others no income at all". 18. M (12/ALL)

"We have been affected deeply from the last year till today. All troubles and problems increased, more nervousness, more financial constraints, and even I can't eat or swallow any food. No income and my husband have a second wife and has four children by her..." 49. M (14/ NHL)

5.3.4. Sense of openness and satisfaction



Figure 5.7. Sub-categories generated from mothers sense of openness and satisfaction.

Figures 5.7. shows that mothers expressed a general sense of satisfaction about the form of disclosure they used with their children and young people. However, mothers' sense of openness and satisfaction did not include discussion of the cancer diagnosis, and in this way, the child's best interest mediated mother' sense of satisfaction, particularly about the impact of the disease on the child's psychological health.

"I feel satisfied with the limit of information I have to share with her, but I don't like discussing these issues with anyone outside the family" 8. F (8/AML)

"I don't know... but I can't say it to her, no one can tell her, she might not accept the diagnosis, or refuse the treatment. Her psychological wellbeing is better while she doesn't know" 40. F (9/ALL)

Mother' beliefs about children's and young people's development as a time of increased vulnerability, immaturity and emotional dependence have been seen to limit children's and young people's ability to understand their illness (Young et al, 2002; Die-Trill, 1998). More commonly among mothers in this sample, mother' beliefs about the nature of childhood implicitly and explicitly mediated how mothers communicated with their children and young people and eventually their sense of openness.

"I feel indifference if they don't know, I think it is better not talking about these issues, lots of things are so hard for children to understand...."16. F (14/ ALL)

These quotations suggest that apart from telling the children and young people nothing about their illness, some mothers did not essentially sense dissatisfaction or a lack of openness with their child. In some cases having relatives who had died from cancer could also have a major impact on how mothers managed communication with their children and young people (Young et al. 2002) and hence their sense of openness and satisfaction. Some mothers appeared deeply worried about the impact of having a close relative who had died of the same disease, on the child's psychology.

"I don't want him to know anything more; he will not accept it, his uncle died after having (it) in the blood. His brothers know, and the school, but they won't say anything to him..." 47. M (9/NHL)

An important aspect of mothers' sense of openness and satisfaction was "fatalism", the belief that the individual can do little to alter fate. As will be seen later in relation to mother' beliefs about their children's or young people's illness, concepts of "fatalism" or "God's will" helped mothers to feel more satisfied about the level of openness with their children and young people.

"My child says it is something from God... I accept and am satisfied with God's will, and I am discussing all these issues in a good way... everything is from God, and all praise to God all the time. No objection to God's will". 57. M (15/ Brain tumour) Another particularly strong theme running through the mother's comments was their sense of disgruntlement, which was directed to two targets; the blameworthiness of doctors and their sense of their own inadequacy and their children's immaturity. It seems obvious that mothers were in crucial need to understand the disease themselves and were in need of nurses' and doctors' support in order to be able to communicate with their children or young people.

"I am not that satisfied. But the doctors don't say or explain anything to me. His lifespan is short, about seven to eight months and then he will be gone. It is a hard diagnosis, and I count the days. I feel he gets angry very easily. Before his illness he used to obey us and do everything we asked him to. He was obedient, now he is always nervous, angry, and crying. He can't understand what the illness is, he can just understand it is just like flu" 9. M (11/ Ewing's sarcoma)

A sense of dissatisfaction toward members of the health care team was manifested in several comments:

"But we have no access to any pamphlets or books that would seem to help explain or say anything to her about this disease" 52. F (16/NHL)

"I never talked about this disease with him, neither with any siblings... But I am not satisfied. I wish doctors and nurses could help to explain this to my child and his brothers" 42. M (16/ALL)

Communication barriers between patient and members of the health care team influence how disease is discussed and how physical symptoms and psychological distress are reported (Die-Trill, 1998). With few exceptions, it was obvious that mothers who found it difficult to break news of the diagnosis to their children or young people, and eventually withheld the diagnoses from them, were dissatisfied and uncomfortable with the communication approach they had used with the child. Difficulties with communication experienced by mothers were not simply emotional, related to informing the children or young people of the diagnosis of cancer itself, but more deeply rooted in cultural beliefs.

"I don't talk about his illness with anyone. His brothers have their own beliefs that any time he will be gone; as it is not stable situation... I wish there was a simpler way to explain things to him" 18. M (12/ALL)

As in some developing countries, the authority of a physician is never questioned, and patients are not likely to ask for or provide information that would contradict the doctor or be disrespectful (Die-Trill, 1998). A tendency toward a similar hierarchical, authoritarian patient-physician relationship in Jordan forced the mothers towards silence, and gave children and young people no confidence to ask questions. When doctors and nurses withheld information from the mothers, children and young people started to shield their parents from the burden of questions to which they might not know the answers.

5.3.5. Beliefs about the causes of illness



Figure 5.8. Sub-categories generated from mothers beliefs about the causes of illness.

Several authors have emphasised the need to consider the cultural beliefs and practices of people when assigning meaning to illness (Die-Trill, 1998; Pachter, 1994; Zaher and Hatter-Pollara, 1998, 12-18). The need to understand the culture of Arab and Muslim populations arises from the fact that the meaning of illness, and behavioural responses to illness, are basic factors influencing the coping in such cases. Die-Trill (1998) argued that beliefs about cancer causation affect the psychological adjustment to the disease as well.

In the study by Young et al. (2002), some mothers blamed environmental causes for their child's cancer; some even blamed themselves for having failed to protect their

children or young people. However, figure 5.8. shows that most mothers believed that cancer is God's will, and a form of test to try their faith. This indicates that human beings have no control over their health or illness (Zahr and Hatter-Pollara, 1998) and thus gave mothers a sense of relief.

"It is God's will, and all praise to God always. This illness is a test from God to try our faith" "8. F (8/AML)

"I don't know what causes the disease, it is God's will". 40. F (9/ALL)

Dodd et al (1985) reported a similar finding in a study performed in Egypt, where over 90% of the cancer patients surveyed reported not knowing what had caused their cancer, suggesting no sense of control over health among members of Arab and Muslim groups. Die-Trill (1998) suggested that cultures which ascribe supernatural causes to cancer will most likely believe that there is little they can do to prevent or treat it, and will be likely to adopt more passive attitudes .

Another key theme that emerged from analysing the mothers' comments was belief in the "evil eye", which occurs when a person with "strong eyes" intentionally or unintentionally looks at a child (Pachter, 1992).

"Hassan was a very naughty boy and very wicked, envious eyes took him. I have never taken him to a doctor before." 18. M (12/ALL).

Many cultures have supernatural explanations for disease causation (Die-Trill, 1998). In Jordan, pain and illness are believed to be the harmful effect of the evil eye when admiring a child without mentioning the name of God (Gharaibeh, and Abu-Saad, 2002). Similarly, in Hispanic cultures, the illness is believed to occur because a spell has been placed on the child by an individual who secretly covets him or her (Risser and Mazur, 1995). Mothers try to prevent or reverse the effect of the evil eyes by reciting certain versus of the Qur'an, the Muslim's holy book, or just taking the child to a folk healer for herbal remedies and ritual cures.

In some cases, mothers blamed the second Gulf War in Iraq for causing their child's cancer.

"...he was born in the year 1990 during the Gulf war time, all the foods we had were from Iraq at that time" 40. F (9/ALL)

"It is the influence of the Gulf war, and the nuclear radiation from Iraq." 9. M (11/ Ewing's sarcoma)

It is important to note, however, that the themes of "viruses" "air and food pollutions" were used in explaining causes for children and young people's illness, or the disease was ascribed to multiple causes without referring to a specific reason.

"That tumour is related to smoking and bad odours... My child says it is something from God..."57. M (15/ Brain tumour)

"I think her illness is caused by a virus". 34. F (13/ ALL

"Many causes like the nuclear radiation, food and all those hormones and chips we eat, but it is still fate from God. The cancer is caused by evil eye, envy, or a test from God to the human, or to forgive our sins... it is a fate from God" 12. M (8/ALL)

Emphasis on external causes of disease such as germs or viruses, has been described among British and North Americans, while Germans and French regard disease more frequently as a failure of internal defences, whereas in the United States, late stage cancer patients believed that past behaviour such as smoking was clearly responsible for causing their cancer (Die-Trill, 1998).

As we have seen from the various quotations above, sometimes there are parallel and interweaving beliefs about the cause of children's and young people's illness. An exclusive belief about causes of illness should not be assumed and fitted into one pattern. A rigid pattern over simplifies and reduces our understanding of mothers' perceptions of their children's or young people's illness.

5.4. Communication of cancer diagnosis and child's wellbeing

However much it was aimed to reach a degree of standardisation in the interviews by asking the same range of open ended questions to each child with cancer and their mother, this was not always possible. First of all, although most mothers were open about their experiences, there was no private place to interview the children or young people and their mothers. Thus most of the interviews were at the bedside of the patient or the play room area of the outpatients' clinic. As a result, some mothers were not enough at ease to talk in details about all their experiences. For some mothers, the fact that this was the first time they had had the chance to talk or ventilate certain matters affected their feelings. The interviews became emotional for most mothers, and ended with the mothers starting to cry while filling the questionnaires or during the interviews. In such cases, mothers were reassured that it was okay to cry, and they could choose not to answer any question if they did not feel ready to think about it or felt uncomfortable to talk about certain things.

It is important not to be confused by the fact that the contextual information of this research was for the purposes of augmenting our understanding of communication patterns among families in Jordan and thus explain some of the quantitative data and not what we may call a rigorous qualitative approach. A few comments were taken from children and young people while they completed the questionnaires. Children and young people's comments in this case and other similar cases provided a richness of data not yet reported in the quantitative data. This data can help to explain the quantitative results and illustrate the limitations of current assessment (see methodological issues). Specifically, a number of themes emerged from the interviews that mothers discussed while completing the assessment tools and the open ended questions. These patterns were fully discussed in the previous section and highlighted the discrepancy between what parents felt was appropriate and suitable for their child's understanding related to cancer treatment and the child's actual understanding.

Importantly, when it is determined that children and young people primarily employed defensiveness in dealing with illness, we can provide support for those studies indicating that open disclosure of cancer information may facilitate adaptation to a variety of stressors associated with cancer diagnosis, and that children and young people who knew least about their illness are prone to more distress (Howarth, 1972). While previous studies have indicated that the "protective approach" or "conspiracy of silence" of not telling the child of the diagnosis is not helpful and actually leads to depression, withdrawal and anxiety (Bozeman, Orbach and Sutherland, 1955), due to the limitation of study design and no clear data related what the children actually knew about their illness, this study cannot fully support such findings. For example, in a few cases the mothers said the child had cancer that she did not want him or her to know about, and at the same time, the same child was saying" *I know I have cancer and don't want my mother to know that I know*". There is a risk in assuming that only a few children and young people in this investigation actually knew their cancer diagnosis. Thus, it would seem difficult to detect a clear association between the used pattern of

communication, the child's perception of cancer and child's psychological disturbances, and these further limits of this study.

Bozeman, Orbach, and Sutherland (1955) assumed that when child and adult reciprocally protect each other, this eventually will lead to depression, withdrawal, and anxiety. Thus it can be hypothesised that the use of an open communication style would be associated with a lower level of distress. However, no such association can be confirmed in this study. This is due to a statistical artefact as the disclosure criteria of what the children and young people knew and what the mothers assumed their children or young people knew about the cancer diagnosis were not clearly conceptualised, thus limiting the chance of finding the pattern of communication and degree of openness variables to be significant predictors. Although it is only conjecture, referring to what mothers assumed their children know, 16 children and young people who were completely deprived of information related to their cancer diagnosis and treatment (those children were told they had a virus in their blood streams, or severe anaemia) scored higher on depression and anxiety, thus promoting behavioural difficulties in these children and young people. Whether this finding is specific only for Jordanian children and young people with cancer, or whether it is a general to all Arab families is a topic for future research. This will show motivation, relevance to Fritz et al (1988), and Fritz and Williams (1988) who related the importance of openness and clear communication when parents are communicating cancer diagnosis to their children. This association between communication, openness and child's wellbeing is consistent with what might be expected. Although the association was relatively small, this finding does suggest that the children and young people with cancer who are misled by their diagnosis are at greater risk for adjustment difficulties. Therefore, it can be asserted that more knowledge leads to less depression (Kvist et al, 1991).

6.1. Introduction

The results of data analysis will be discussed according to the original aims set out in Chapter One, namely, to obtain insight into the impact of cancer on children's and young people's wellbeing in Jordan as presented by their level of anxiety, and depression and overall quality of life, as well as to develop a better understanding of children's and young people's experience with cancer in the light of the different patterns of communication of cancer diagnosis in Jordan.

Overall, the hypotheses were not supported in this study, and the results here are discussed with reference to the main research questions. The discussion compares the findings of the study with previous studies and seeks to answer the following research questions:

- What is the quality of life in children and young people diagnosed with cancer in Jordan as compared to those with less life threatening illnesses and their healthy peers?
- What are the levels of anxiety and depression in terms of number and intensity for children and young people with cancer in Jordan?
- Do children and young people with cancer and chronic illness in Jordan show more depressive symptoms and higher levels of anxiety than their healthy peers?

Further interpretation of these results will be offered in this chapter, supported by possible rationale and interpretation in the light of the conceptual framework of Lazarus and Folkman (1984), the cultural context of Jordan, and the contextual information on the pattern of communication of cancer diagnosis, derived from the interview analysis.

6.2. What is the quality of life in children and young people diagnosed with cancer in Jordan as compared to those with less life threatening illnesses and their healthy peers?

In this study, QoL in children with cancer in Jordan was compromised when compared with children with a chronic illness and with healthy controls. This is similar to work by Eiser et al. (1997, 2005); Michopoulou et al. (2006) and Varni et al. (2007a), who found that the control group had a better quality of life than the ill children, especially in the school life domain. The results revealed that the mean scores and standard deviations on the total PedsOL[™] measure were low for children and young people with cancer, as well as children and young people with chronic illnesses, indicating that the children and young people described themselves as impaired, which suggested that the OoL is compromised for children and young people with illness in Jordan. It was discussed in this connection that scores for children and young people with chronic illnesses were worse than those for children and young people with cancer and healthy children and young people on all self-report scales, with most differences reaching significance. Lower score on the measures of school functioning was associated with lower scores on physical, emotional and social functioning which was anticipated related to lack of school follow-up at the hospitals of Jordan, leading to children's and young people's quality of life being intensely compromised by their illness experience and its effect on their education. In addition, it was found that the total score on the quality of life scale was significantly correlated to scores on the physical, emotional, social and school functioning subscale. Thus, the more the children and young people perceived their lives to be impaired (lower scores on the total PedsQL[™]), the more they reported physical complaints, and school absence.

The current study may be different to Vance (2002) and Eiser et al. (2005), however, because previous cancer research on quality of life has focused on comparing QoL for children with central nervous system (CNS) tumours with other malignancies (Vance, 2002), or focused on comparing child self-reported of quality of life with mothers reported proxy rating of their child's QoL or their own (Eiser et al. 2005). Thus, a number of issues emerged while trying to compare the current work with previous literature, suggesting that it is not wise to group together children's and young people's norms in this sample with previous norms published in previous QoL literature. This is mainly because the tool used in measuring QoL is different; for example, within Vance's (2002) study, the paediatric Quality of Life Inventory-32 (PCQL-32 for Varni

et al, 1998) was used and not the generic version of the PedsQLTM inventory. In addition, the lack of a control group makes it difficult to compare data with the cancer group.

The fact that low scores were mainly found for the school functioning subscale in children and young people with cancer and chronic illness may indicate the impact illness may have on the child's quality of life in Jordan and thus needs attention. A number of studies have described and evaluated programmes for re-entry or reintegration of children and young people with cancer into schools (Upton & Eiser, 2006; Mayer et al, 2005), where school re-entry has three phases: initial hospitalisation. contact and education of school personnel and follow-up contact (Leigh et al, 2002). However, due to financial reasons and lack of educational resources in Jordan, and the lack of any collaboration between the two governmental sectors of education and the Ministry of Health, no programme or education facilities are available to these groups. Further, as an attempt to reconceptualise this problem we may face the need to address the similarities and differences between school experience for children and young people with cancer in Jordan and that in the UK and the US, where it is common to communicate cancer diagnosis in an open manner to the child, friends and school officials (Die-Trill, 1998, Kendall, 2006). In contrast, in Jordan, this is not common, as it is believed that cancer is incurable. This resulted in supporting children with cancer and other chronic illness with little attention to the potential future, in addition to lack of national effort or programme to provide educational support to this group of children. Similar limitations were reported elsewhere in UK (Upton & Eiser, 2006) and Japan (Mayer et al, 2005).

In a social context, contrary to previous studies, the results showed that the children and young people with cancer did not report lower HRQoL than healthy children and young people for social functioning; as for the cancer group, scores were higher on social functioning, suggesting that children and young people with cancer in Jordan do not perceive themselves socially isolated. Whether this is due to the cultural support system, the positive support of the family or other factors remains unclear. What is apparent, however, is that this issue merits further investigation.

Finally, with relation to the PedsQLTM used in measuring the child's QoL in Jordan, we should bear in mind that the PedsQLTM had only been validated in the general

population in Jordan. Can we assume that a child filling the PedsQL[™] within the context of a life threatening illness such as cancer or long term illness (for example thalasemia, chronic renal failure...) would perceive the items in the same way as a healthy child? This may be the case for the items of the physical functioning. For example, the PedsQL[™] contained the item "it is hard for me to do sport activities or exercise", which had four response options. A child with cancer may perceive this item as relating to cancer treatment, or to the time spent at hospital (e.g. it is hard for me to do sport activities or exercise since I am at hospital). A child from the general population may have no clear point in time or event with which to compare him/her self to some prior level (it is hard for me to do sport activities or exercise at school). All other items on the physical functioning have such "disseminate back references". These items may systematically underestimate scores in the quality of life for both cancer and chronic illness groups, because respondents do not have a clear point of reference for the response. Thus, the PedsQL[™] scores obtained from healthy children and young people may not be directly comparable to scores from children and young people with cancer and chronic illnesses. Importantly, though this critique is framed in terms of the item ambiguity, the argument here is equally applicable (either in whole or in part) to the other measures (the CDI, the RCMAS...) and will be further discussed in the next chapter.

6.3. What are the levels of anxiety and depression in terms of number and intensity, in children and young people with cancer in Jordan?

Section 1 of Chapter Five has attempted to answer this question; thus, to avoid repetition this section will try, only, to reconceptualise the problem as it is grounded in the results, and will not present the numbers and scores previously mentioned. Looking retrospectively to the Arabic-CDI and the Arabic-RCMAS scores, the scores found in children and young people with cancer in Jordan appear valid. They reflect a considerable amount of psychological distress among children and young people, but the levels tend to be somewhat higher than in most published studies for depression, and lower for anxiety level when compared with previous studies. Reviewing previous data, the results showed that the mean scores for depression in children and young people depression with cancer in Jordan were evidently higher than those found in two previous American studies (Tebbi et al, 1988; Canning et al, 1992) and one British study (Wurr, 2001). However, they were similar to estimates reported elsewhere for

Turkish and Taiwanese children (Cavusoglu, 2001; Chao, Chen, Wang, Wu & Yeh, 2003).

In this study, defensiveness, as measured by the lie-scale of the RCMAS, is inversely related to self-reported depression and also to self-reported anxiety. When the CDI-scores and the RCMAS-scores were analysed separately for the two groups, all scores were significantly inversely related with defensiveness scores, except the anxiety scores of the chronic illness group. Either this is a type two error (failing to detect a significant difference when one exists), or it means that self-reported anxiety in children and young people with chronic illness is not inversely related to defensiveness. In addition, that children and young people with cancer and healthy peers maybe more prone to repress their anxieties and depression more than the children and young people in the chronic illness that he children and young people in the chronic illness that he children and young people in the chronic illness group.

Although one critique while discussing this point is formed in terms of explaining this variation of depression intensity, it is believed that the argument is equally applicable, either in whole or in part, to the anxiety measure and defensiveness measures which may have covered overt feelings of distress. Alternatively, this may be because some of these children and young people had been told that they were not sick, and that they required no invasive, systematic treatment. It is well documented in the literature that the psychological impact of cancer treatment depends largely on how the illness is explained to children; is it at a level they can understand, and most importantly, are they being told the truth? (Langton, 2000).

On the whole, it is important to suspect a potentially tautologous situation when analysing the defensiveness data. This happens when defining high defensiveness by low anxiety scores and then trying to use this to explain low depression scores (Wurr, 2001). As previously in Wurr (2001) study, "repressor status" was attributed to those subjects scoring below average for anxiety and above average for defensiveness, which poses a risk of such tautological error. However, we need not fear this kind of error in the current work, as the actual anxiety and depression scores were calculated and then correlated to the measured level of defensiveness.

6.4. Do children and young people with cancer and chronic illness in Jordan show more depressive symptoms and lower levels of anxiety than their healthy peers?

Contrary to previous expectations, the results showed no more psychological distress in the children and young people with cancer than in the healthy group or those with chronic illnesses. The proportion of depression cases was not significantly different between the three groups. Nevertheless, the mean scores for depression on the Arabic-CDI, as well as for anxiety on the Arabic-RCMAS version, were actually lower than those in the control group, indicating better psychological functioning for children and young people with cancer when compared with the control group.

At this juncture, it is difficult to compare the results against the many studies cited in the literature review, which used different assessment methods for depression and anxiety prevalence, but the main impression is that this study indicates less anxiety and more depression than the majority of published studies. The lower levels of depression and anxiety in children and young people with cancer when compared to healthy peers found in some studies (Canning, Canning, & Boyce, 1992; Phipps & Srivastava, 1997; Phipps & Steele, 2002; Worchel, Nolan, Wilson, Purser, Copeland, & Pfefferbaum, 1988) has been explained as a reflection of the low-end specificity problem of the assessment tools. Thus, it can be assumed that the self-reports of children and young people with cancer are biased in some way, due to minimising distress related to this proposed deficit and limitations of the depression and anxiety measures in this sample. The main question raised here is whether the comparison of the scores of the Arabic-CDI and the Arabic-RCMAS for children and young people with cancer against the scores obtained from the group of chronic illnesses and healthy peers is valid. It can be argued that despite the possible sources of bias in this study, it is possible that that the low self-reports for depression and anxiety for the cancer and chronic illness group may be a valid reflection of their resilience and high level of coping and psychological wellbeing.

It can be argued, on the other hand, that selection bias and problems with sampling may affect the mean scores in the children and young people with cancer, as those children and young people declining participation had more symptoms than children and young people participating in the chronic illnesses group or the control group. If the five children who refused to participate in this study had more psychological distress, the prevalence figures obtained in the population sample would be inflated show greater depression and anxiety for children and young people with cancer. However, assuming that those children and young people with cancer had half the mean score or more, this is unlikely to have affected the results, since to affect the outcome of the comparison, the selection bias would have to be of a different magnitude or direction. The response rate was actually different among groups: 92% in the children and young people with cancer and 100% in the control group and the children and young people with chronic illnesses, and this is unlikely to bias the results.

Second, in a validation study including a subset of Turkish children with cancer, Cavusoglu (2001) found that some children did not know they had cancer, similarly for Japanese patients, where Mayer et al (2005) argued that historically, it is not common to tell the Japanese children their diagnosis of cancer; and the same is true for Chinese patients (Kendall, 2006). Similar to these countries, some mothers of children and young people with cancer in Jordan actively avoided the use of the term "cancer" when communicating the cancer diagnosis to their children. This issue can complicate the research as children and young people with cancer who do not know the nature of their illness may have a different perception toward their illness and therefore may report less information related the impact of illness on their psychological wellbeing. This may bias comparison within the same cancer group, as well as with the other two groups.

An alternative explanation to these low results for depression and anxiety is that these findings are a reflection of the low-end specificity problem of the anxiety and depression measures, and that self-reports of depression and anxiety for children and young people with cancer are biased in some way toward minimization of distress (Phipps and Steele, 2002). Briefly describing the argument on this point, Canning et al. (1992); Phipps & Srivastava (1997) and Phipps & Steele (2002) assumed that defensiveness and selective reporting may explain low scores for depression and anxiety among children and young people with cancer, with children and young people hiding their true feelings and pretending normality. These results suggest that a shift toward increased defensiveness and more repressive styles of adaptation may be a general characteristic of children and young people with cancer.

For further explanation, it seems appropriate to discuss this point in the light of some children's comments while completing the study instruments. For example, one child said at the very beginning of the interview:

"I feel really different and tired, but don't tell my mom, I force myself to study so I'll become a doctor and cure this disease. I will do it, too, because my mother wants it". F (15, ALL).

Quoting Cook (1992) in his book, Supporting Sick Children and their Families: "Children often protect their parents from further hurt by concealing certain thoughts and refraining from asking (P. 64)". It can be assumed that some children and young people with cancer may have actively excluded pre-morbid symptomatology from their responses, while children and young people in the healthy sample probably described their feelings in an uncensored manner. Thus, selective reporting may result in some symptomalogy being excluded from the responses of children and young people with cancer, whereas the controls report more completely. Selective reporting and responseshift may also affect the degree to which scores for children and young people with cancer for other questionnaires are directly comparable to control groups. If selective reporting affects the results as suggested, the RCMAS and the CDI scores also may be underestimated for the cancer group. This makes simple comparisons between cancer patients and control groups conceptually invalid; the cancer scores will appear artificially low because of repressive adaptation. Based on these considerations, the validity of the common depression and anxiety tools to specific disease may be debatable. Until the validity of standard tools is further investigated for Arab culture, and for children and young people with cancer, such data should not be perceived as norms, and this point will be further discussed in the final chapter.

It should also be noted that estimates based on groups may mask important differences between individuals; for example, anxiety and depression scores for children and young people with cancer may average out the effect of defensiveness and adaptation to illness in some children and young people with chronic illness and severe distress maladjustment in others. An example is the response of a 9 year old child with chronic renal failure, with a disfigured arm. When he was asked (the CDI, item number X, " I think I am good looking"), he circled I am good looking and pointed to his arm and said, "especially my arm". In this case, where the child was sarcastic, it could be suggested that defensiveness and its symptomatic presentation by being ironic, repressive, suppressive, or in denial should, at the very least, not be actively discouraged in this group of children and young people as it reflect resilience (Newman and Blackburn, 2002). According to Worsham and Eye (1992), avoidance and denial in similar cases may be adaptive in some situations. Importantly, indeed, similar comments of other children and young people in this study reflected the way parents and the culture expected children and young people to act, especially when it came to showing strength and the shame of showing sign of weakness or complaining.

Canning et al. (1992) argued that denial is about deception of others in a clear deliberate intent, while repressive adaptation is self-deception. In this child's case, for example, the response was motivated by positive values, such as faith and social desirability with which children lived. These reinforced the defensiveness of children and young people who sought to protect their mothers from feeling bad, and limited the degree to which children and young people could discuss their true feelings, and led them to adapt a repressive adaptation style. It should be emphasised that maybe this produced no sense of frustration. Rather, it can be interpreted as a coping strategy and the children and young people felt comfortable and protected, and this merits more investigation in future coping studies.

Anxiety and depression fluctuate over time, especially as those children and young people are the centre of their parents' caring and "spoiling" during the cancer treatment, and thus, the reaction to illness may be delayed or repressed. A single assessment probably yields an under-estimate of the proportion of children and young people experiencing psychological distress.

In summary, this study replicates the earlier reports of higher level of repressive adaptive style in children and young people with cancer relative to their healthy peers. Crucially, the results of the Arabic-CDI and the Arabic-RCMAS applied in the cancer group are possibly not directly comparable with the results from the healthy peers. These data should not be used to question the well-documented need for open and honest communication for cancer diagnosis, and effect of various kinds of psychosocial support and intervention for children and young people with cancer, as well as children and young people with chronic health conditions.

6.5. Relation between quality of life measure and psychological measures

The child-report measures of anxiety, depression and quality of life significantly correlate with each other. Children's and young people's quality of life was inversely related to their reports of depression and anxiety, with children and young people who scored lower on quality of life reporting more symptoms of depression and anxiety. However, age and sex were not related to any of the dependent measures.

This is again by no means a universal finding (Wurr, 2001; Grassi, Indelli, Marzola, & al, 1996; Smith, Gomm, & Dickens, 2003), This has been proposed in the literature as a reason to integrate the three variables of depression, anxiety and quality of life in operationalizing child's adjustment or psychological wellbeing. This may be explained by the a high co-occurrence and high correlation between self-report anxiety and depression measures (Barbee, 1998; Cole, Peeke, Martin, Truglio, & Seroczynski, 1998; Eley & Stevenson, 1999; Weems, Hammond-Laurence, Silverman, & Ferguson, 1997). An alternative explanation is that anxiety and depression are associated with impaired quality of life (Grassi et al, 1996; Smith et al. 2003), and so the two do correlate.

6.7. Relation between defensiveness and psychological measures

The association between scores on the social desirability scale and scores of psychological adjustment found in this study is consistent with what might be expected. Previous studies showed that children and young people with cancer reported less depression and scored higher on defensiveness (Phipps &Steele, 2002). Consistent with past work on the relationship of defensiveness with children's and young people's expressed level of depression (Joiner, 2001), self-reported depression was correlated with defensiveness, although the association was relatively small, accounting for only 0.268% of depression scores and 0.312% of anxiety scores. These findings suggest that children and young people were utilizing a repressive adaptation style, a concept which has traditionally been described in the psycho-oncology literature and has been found to be an important predictor of low depression and anxiety score in children and young people. However, neither defensiveness nor depression and anxiety were moderated by gender or age group in this study.

The results of the correlational analysis revealed a significant effect for defensiveness over depression and anxiety score in the total sample, as well as for the children and young people with cancer and the healthy group. Canning et al (1992) and Wurr (2001) have shown this to be so with regard to child reported depression in children and young people with cancer. Interestingly, in the current work it was found that for children and young people with chronic illness, defensiveness scores did not have the same inverse relation to their psychological disturbances.

The results of Pearson's correlation by group indicate that children and young people with chronic illness were less affected than were their peers who were healthy or diagnosed with cancer. Although too little is known about the precise nature of the lie scale, except that it is used to measure defensiveness or to measure the tendency of a subject to answer in a manner that they believed to be culturally accepted and approved, those children and young people who were mainly diagnosed with thalasemia and chronic illness may seems to have a low tendency to dissimulate. By correlating scores on the social desirability scale to scores on depression and anxiety, the correlation was less significant in the chronic illness group for both anxiety and depression, which indicated that there was little motivation for the children and young people in this sample to dissimulate as compared to those with cancer and healthy peers.

This may be explained by the unusually stressful situation that these children and young people are in, resulting in less sensitivity on dissimulating their feelings or behaving in a socially accepted way. An alternative explanation is that the children and young people in the cancer group are under-reporting their affective symptoms due to the parent's presence, whereas the children and young people with chronic renal failure and thalasemia whom I met and interviewed, were not accompanied by with parents or relatives.

6.8. Relation between maternal distress and child's psychological measures

The self-report measures of anxiety, depression and quality of life for children and young people correlate significantly with each other, as do the mothers' report measures. In this study a positive correlation was found between mother's level of depression and children's and young people's depression score. A similar correlation was apparent between mother's level of distress and children's and young people's reported level of

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anxiety. These results are congruent with those of Frank et al. (1997), and Wurr (2001) who found parental anxiety to be associated with depression and behavioural problems in the child. Children's and young people's psychological wellbeing has been directly related to that of their mothers on several other occasions. For example, Sawyer, Streiner, Antoniou, Toogood and Rice (1998) found maternal adjustment just after cancer diagnosis had a significant relationship with the child's later adjustment.

Hence, the positive correlation suggests that the higher the mothers' level of stress, the higher the children's and young people's levels of anxiety and the higher the depression scores in the mother, the higher the depression score in the children and young people. This points to the pervasive effect of the mother's mental health on the adjustment of children and young people with cancer, suggesting that controlling for the mother's psychological wellbeing at diagnosis would solve any "depressive bias" when assessing children's wellbeing (Vance, 2002).

This is by no mean a universal finding, although in the studies of Mulhern et al. (1992) and Brown et al. (1993) on parental psychological wellbeing and adjustment among paediatric oncology patients, children's level of distress correlated positively with maternal level of distress. Support for such an investigation has been found in studies of chronic illness also. For example, Varni and Setoguchi (1993) found that for children with congenital or acquired orthopaedic impairments, parental anxiety and depression predicted child anxiety and depression.

6.9. How appropriate is the cognitive theory of stress and coping by Lazarus and Folkman (1984) for explaining the current results?

This study supports the findings of previous studies that children and young people with cancer function as well psychologically as their healthy peers. Within Lazarus and Folkman's (1984) cognitive theory of stress and coping, the concept of coping was used to help explain why some children and young people with cancer fare better than others do in the chronic illness and the healthy groups, despite life threatening illness in their lives. Many other concepts, such as culture, developmental history, or personality, can also help explain these individual differences, but coping is unlike these other concepts in that it lends itself to cognitive-behavioural intervention. As such, its appeal is not only as an explanatory concept regarding variability in response to stress, but also as a portal for interventions.

In the literature review, Chapter Two, Lazarus and Folkman's (1984) theory of stress and coping was introduced, followed by key findings from psychological theories of child development such as the theories of Freud (1894), Erikson (1964), and Piaget (1976). Within this thesis, cancer/ chronic illness (stressors) and cognitive-behavioural effort (primary appraisal and secondary appraisal) were assessed in relation to the children's and young people's wellbeing. This section discusses whether the current findings provide evidence for these pathways, and how the results can build upon the existing model.

While Lazarus and Folkman (1984) define stress as thoughts and behaviour that people use to manage the internal demands of situations that are appraised as stressful, they failed to find any strong empirical evidence for this pathway. A number of findings that conflict with this approach have emerged from both the current work and previous cancer literature, suggesting that despite a large volume of research, the exact functions that specific coping actions serve are based largely on theoretical assumptions rather than on empirical findings (Shiloh & Orgler-Shoob, 2006; Franks & Roesch. 2006: Aldridge & Roesch, 2006). Snyder and Dinoff (1999) argued that the model's complexity makes empirical evaluation difficult, due to the emphasis on cognitive processes which leaves no explanation of the effect of more subtle stressors below the awareness level or physiological mechanisms that might moderate or mediate the coping process. Similar criticism was raised in a previous article by Lazarus (1990) where he argued that coping indeed is embedded in a complex, dynamic stress process that involves the person, the environment, and the relationship between them, such that we cannot really understand the way in which coping actually affects psychological, physiological, and behavioural outcomes, both in the short and the longer-term.

In the current work, two factors were studied in relation to the children's and young people's wellbeing as applied to the Lazarus and Folkman's coping theory (1984): the person's adaptation and environment. Within the former model, the environment was operationalised as the influence of mother's mental health, and the communication of cancer diagnosis in Jordan. Support for this influence between the environment and children's and young people's adaptation has been provided in a number of ways in this thesis, both theoretically and empirically. Theoretically, the relationship between the children's and young people's environment as well as adaptation was clearly shown in section three of Chapter Two and in Section Two of Chapter Five. These chapters

demonstrated the relationship between children's and young people' adaptation, cancer treatment, communicating of cancer diagnosis, and mother's level of distress.

It should not be assumed, however, that individual differences among children and young people play no role in determining the degree to which a given coping strategy is engaged at any given point in the transaction, nor should the primary challenges for coping measurement by using the Lie scale of the RCMAS alone be entirely discounted. The fact that such measures may have been poor predictors in the past may tell us more about the predictive value of specific personality differences than it tells about the role of individual differences in general. Thus, two separate questions underlying this broad set of issues emerged. The first is whether children and young people have preferred coping strategies that they use relatively consistently across a range of situations (for example: repressive adaptive style). The second is whether these coping preferences relate in a systematic way to personality and cultural variables. Die-Trill (1998) argued that culture provides unwritten definitions of what constitutes a family and how families and patients respond to and cope with cancer diagnosis. Thus, it may be assumed that psychosocial differences determined by cultural background can make a major difference in the responses of children and young people to cancer.

In Figure 6.1, support to the process of appraisal and secondary appraisal proposed by Lazarus and Folkman (1984) is given, whereby the diagnosis of cancer leads the individual to appraise it either positively as a challenging situation or negatively when considered as exceeding his/her resources of coping and thus ending with depression and anxiety. This ongoing process makes the children and young people to keep on revaluating their illness and modify their coping strategies accordingly.

Figure 6.1. The possible impact of the cancer diagnosis on the child's adaptation



The arrows indicate relationships found between defensiveness level and the variables under investigation. The arrowed line shows the possible correlation between defensiveness and anxiety and depression. The continuous line joins the two sets of personal characteristics together. The significant correlations identified between defensiveness and anxiety and depression scores, as well as between the mother's mental health suggests that the diagnosis of cancer itself may not trigger overt psychological distress (Figure 6.1). Therefore, other factors may be responsible for this, such as the environment, and its demands and resources, and personality dispositions that influence the appraisal of stress and resources for coping (Lazarus, 1993). One

concern, however is the relevance of Lazarus and Folkman cognitive theory (1984) to the Arab culture and how would this influence this study and its theoretical basis.

Figure 6.1. shows that a threatening situation such as cancer may yield negative emotions such as anxiety and depression. According to Lazarus & Folkman (1984), on being faced by a stressful encounter, such as cancer, the individual assesses its significance to his/her personal wellbeing, that is, by primary appraisal which depends on the cognitive development of the individual. Thus, the perception of a stressful encounter, such as cancer, will depend on the age group of the child and how cancer diagnosis was communicated to the child (for example as a fatal illness, a germ in the blood stream, anaemia...etcetera). Then the individual may classify the encounter (cancer) as irrelevant and having no significant to his/her wellbeing, being positive and lying within the range of the individual's coping resources, or stressful. Consequently, a perceived cancer diagnosis is further categorised as harm/loss, threatening or challenging to the child's wellbeing.

Folkman and Lazarus (1980) argued that problem focused coping tends to predominate where people feel that the stressors is something about which constructive action can be taken, whereas emotion-focused coping tends to predominate when people feel that the stressor is something that must be endured. In this instance, the Arab culture and religious beliefs foster children with cancer to use avoidance and repressive adaptation style to cope with their illness which suggests, somehow, a sense of locus of control over external forces and passiveness in this group of children and young people to protect their mothers from feeling bad and to show faith and patience.

This is followed by secondary appraisal, whereby the individual evaluates his/her coping resources and options for managing it according to their age group. These two types of appraisals occur on an ongoing basis as the individual is continuously consciously or unconsciously receiving feedback from the process and evaluating the balance between perceived demands and the limitations of his/her coping resources. Detailed cognitive appraisal of children and young people with cancer in this study should ideally bear in mind cultural beliefs as to what has caused the illness (for example God's will, Evil eye, the Gulf war...etcetera) as this will help give meaning to the illness and enhance or embedded the coping resources. Mothers' distress and religious beliefs and practices should also be well understood. The contextual part of the

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current study adds evidence to this approach, indicating that parents often find it very difficult to explain the illness to their children and young people where the family type in the Arab world is usually authoritarian with a vertical communication approach, resulting in some parents actually being dishonest with their children and young people about their cancer diagnosis. It is, however, important that children are good at detecting stress and worry in their parents, and thus deception, even if well meaning, may cause these children and young people to be reluctant to show their true emotions, which may result in avoidance and utilisation of a repressive adaptive style in this group of children and young people.

6.10. Conclusion

The weight of evidence indicates that as a group, children and young people with cancer, when compared to children and young people with chronic illness and to healthy controls, do not exhibit any overt psychological impairment in Jordan. Nevertheless, there is marked impairment in their physical and school functioning which hugely compromise their QoL when compared to healthy children and young people. These facts indicate that attention needs to be directed toward the emotional needs of children and young people with chronic illness and those diagnosed with cancer, to improve not only quality of life, but also their psychological wellbeing. Analysis has illustrated the influence of mother's level of distress over children's and young people's adjustment, with defensiveness arising as factor that must not be ignored. These results, along with previous analysis of the contextual information, highlight the need to become more aware of the experiences and needs of children and young people being treated for cancer, as well as those with less life threatening illness. Subsequently, in the next chapter, all findings will be further discussed in the light of their implications for practice in Jordan and research.

7.1. Introduction

In this thesis, a study of the psychological wellbeing of children and young people with cancer in Jordan was presented, with special attention to the methodological and cultural difficulties encountered. Issues of quality of life and psychological wellbeing in childhood cancer and other chronic illness have only recently gained interest at an international level, and some issues that initially emerged from communication with children and young people diagnosed with cancer have been investigated here for children and young people with cancer in Jordan. The main purpose of this chapter is to draw together the findings of the empirical work and contextual information of the study and to consider their theoretical implications for children and young people with cancer in Jordan and the research process. A fundamental issue will be whether the results of this research project have contributed to the knowledge of psychological adjustment in childhood cancer.

In part 7.2 of this final chapter, the main results that were presented in this thesis will be reviewed. In part 7.3, the discussion will focus on methodological issues including methodological critiques and the strengths of the study. The final section of this thesis, before the final conclusion, will focus on how this study might be useful and contribute to the research process in Jordan, as well as at an international level.

7.2. A review of the main results found in this research

This study adopted a descriptive design and recruited three groups, a group of children and young people with cancer (n=58), a group of children and young people with chronic illness (n=56), and a healthy control group (n=64). The contextual data about communication of cancer diagnosis and the quantitative data obtain by questionnaires sought to obtain insight into cancer impact on children's and young people's wellbeing as represented by their level of anxiety, depression and overall quality of life.

The findings demonstrated that the prevalence of child-reported depression in children and young people who have been diagnosed with cancer is similar to that of children and young people with other chronic illness and a healthy control group; whereas childreported anxiety is lower for children and young people with cancer and chronic illness. These results support previous studies all around the world that children and young people with cancer are coping with their illness despite the physical and psychological effects.

However, the results of previous studies underscore the importance of defensiveness in predicting children's and young people's adjustment with the cancer experience. The present study extends this line of research by suggesting that a repressive adaptation style also is a fairly robust predictor of adaptation for children and young people with cancer in Jordan, as it was found that higher scores for defensiveness are associated with lower scores for depression and anxiety in the cancer and the control group. This is congruent with the existing research which reported similarities in higher level of defensiveness and a lower level of anxiety and depression. This suggests that the findings of this study are neither typical nor indicative of a problem with the questionnaires used, but rather present a meaningful difference in the levels of anxiety and depression of children and young people with cancer and those with other chronic health problems and their healthy peers.

On breaking down the expected extraneous factors which may have enhanced or hindered the rigour of the study, two main issues were identified; mother's level of distress and patterns of communicating the cancer diagnosis. In the current work, maternal depression, anxiety and level of stress were investigated primarily to ascertain how they affected children's and young people's adjustment with cancer diagnosis. The mothers of children and young people with cancer scored high on the three scales, and when these scores were correlated with children's and young people's scores; there was an association between maternal depression and children's and young people's depression, and between mother's level of stress and children's and young people's anxiety. These positive correlations suggest that the higher the depression score in mothers, the higher the depression score in children and young people, and the higher the stress score in the mother the greater the anxiety in the children and young people.

7.3. Methodological critique

In this thesis, self-reported questionnaires were used to obtain information about the QoL, anxiety and depression for children and young people with cancer, including semi structured interviews about communication of cancer diagnosis and questionnaires to the mothers of children and young people with cancer. Data were collected from children and mothers of children and young people with cancer who had been with their child at time of interview, in addition to comparison groups of healthy peers and those with chronic illness.

The methodology for such a study is inherently problematic, not least because of issues related to the psychometric properties of tools translated from English into Arabic but even more widely in relation to the qualitative approach and limitation of the study. Methodological triangulation, by the use of both qualitative and quantitative methods, enhanced comprehension of the pattern of communication of a family living with children and young people with cancer and generated further research questions and extraneous factors. However, it was not possible to interview the mothers of children with chronic illness, as most children and young people in this group were alone, or accompanied by other relatives. Thus only mothers of children and young people with cancer were interviewed. Another limitation was that it was not possible for the child with cancer to complete the questionnaires without the mother present as no private room are available and mothers are overprotective in the Arab world, so they were not comfortable for the child to be interviewed alone. Initially, the procedure and the purpose of the study were described to the mother and child participants, with explanation of the types of question they would each be asked. Before written parental consent and children and young people's assent were obtained, some items were deleted upon mother's request, for example, the suicide item of the CDI.

7.4. Limitations

Looking back to the thesis, it is important to draw attention to the limitations of the current work. These limitations, beside the previously mentioned, are mainly due to sampling difficulties, in particular the heterogeneous character of the sample, the wide age range of the children and young people, and the fact that the samples were relatively small. Furthermore, although considerable care was taken over the selection of the

measures that were used, there is a major limitation due to the lack of appropriate measures for children and young people with cancer. Although all the questionnaires were cross-culturally validated into Arabic, the use of questionnaires was central in this thesis, and in the following sections the focus will be on some methodological critiques, including the population of the study, issues of reliability and validity, the use of selfassessment or proxy-assessment, and the necessity of developing a new scale. In the following is a brief discussion of the above issues with regard to the methodology of this thesis.

7.4.1. The study population

Despite the extensive recruitment efforts, three primary sample problems were apparent: (a) inadequate sample size, (b) mixed illness composition in the chronic illness group, and (c) varied stages and severity of illness within the two illness group (cancer and chronic illness). First, it could be argued that the design of this study would be improved if the target population of all children and young people in the cancer group were homogenous in their cancer diagnosis and within the same age group; possibly also for the chronic illness group. However, although the survival rate was improving for children and young people with cancer, it was still difficult to obtain large samples of children and young people, making finding a large sample of the same diagnosis particularly challenging. Thus, the inclusion of children and young people with solid tumours such as brain tumour and haematological malignancies in this study was to increase the sample size and related to difficulties in controlling for the neuropsychological effects of the tumours and treatment with steroids, not just for brain tumours, but with all cancer diagnoses, and this have been previously discussed in the literature review.

Second, the inclusion of Iraqi and Palestinian children in the cancer group was also to increase the sample size. Indeed the influence of war and political issues for children and young people from Iraq and those from the West Bank is worthy controlling, but the fact that some of these children and young people held a Jordanian passport and had moved to Jordan made it difficult to control. At the same time, a longitudinal study would complicate the design, taking into consideration the long period of cancer treatment, the risk of relapse and the mortality rate in such a sample. Thus, to overcome

those restrictions and limitations, these children and young people were included in this study, but first they were analysed separately.

7.4.2. The necessity of developing a new scale for QoL, Depression and Anxiety to the Middle Eastern Countries

Besides these issues related to the population in terms of their diagnosis, age, and nationality, it is important to point out a number of concerns that emerged from this study, specifically, regarding using measures of depression, anxiety and quality of life in a population of Middle Eastern children and young people. Overall, the literature provided no satisfactory data of a multidimensional scale to assess the emotional wellbeing of children and young people with cancer, as well as for the cultural differences, if any, between children and young people from different cultures.

The literature searches that were discussed in the Chapters Two and Five of this thesis, as well as the ethical issues encountered while translating the assessment tools into Arabic, discussed in Chapter Four made it clear that no suitable measure of QoL, anxiety and depression as yet exists for children and young people with cancer. Thus, there is a need for better measures to assess symptomatology and emotional wellbeing in healthy children and young people as well as those with life threatening illness within the context of cancer treatment and cultural values. A main doubt about the existing scales was that they did not necessarily assess the precise level of psychological distress in children and young people with cancer, because they primarily assessed physical functioning and occasionally emotional functioning, and ignored the coping of children and young people. In addition, although the assessment of the subjective experience of OoL, depression and anxiety is of crucial importance, Middle Eastern children and young people differ substantially along these domains from those who are acculturated in Western and European societies, and the criteria of inclusion relevant items in the questionnaires were not often met at a universal standard. An ongoing development of any future research should consider answering the question of how children and young people with cancer cope with disease and treatment related aspects of distress.

7.4.3. Issues of reliability and validity

As one of the main works of this thesis was the translation of the instruments into Arabic language and the cross-cultural validation of these tools, the issues of reliability and validity have been very important. As was mentioned before, the RCMAS (child's data only), the PedsQL[™] (mother and child's data), and the DASS-42 (mothers' data only) showed reasonable levels of internal reliability and test-retest reliability. However, although the results on these tools were promising, the Arabic-PedsQL[™] version and the Arabic-RCMAS version were validated by using children's and young people's own assessment alone, and were assumed to have considerable validity based on correlational analysis with mothers' proxy assessment (only with the PedsQL[™]), or with measures of physical and psychological functioning for healthy children and young people during the pilot study.

To further validate those scales, one could relate children's and young people's selfassessment to ratings of the impact of the illness on them done by nurses, parents, or friends who directly interact with them on a regular basis, for the cancer and chronic illness group. Hence, several issues need to be addressed in this context, essentially, the practical limitations within this study, the difficulty of obtaining a large sample of children and young people with cancer, and difficulties of approaching them during their clinic visit (which made it impossible to standardise a test-retest for these children and young people). Thus, although preliminary evidence of reliability and validity was established, some doubts remain with regard to the validity of some of these instruments for children and young people in Jordan.

With regards to the semi structured interviews, it may have been better if the contextual information in this study were audio taped to minimise bias and add rigor to the qualitative part to the study design, or if more privacy with less interruption had been possible during the interviews. However, the justification for all of these departures from an entirely uniform protocol is a combination of maximising convenience, adjusting to restricted resources, and maximising compliance and hence response rate.

7.4.4. Self-assessment and or proxy assessment

Levels of depression, anxiety and stress experienced by mothers of children and young people with cancer were discussed in the literature review. The significance of this was clear, as it was intended to "determine the impact of maternal distress on child's wellbeing". However, the main aim was somewhat general and broad such as "impact of cancer diagnosis on child's wellbeing and adjustment". This issue was a vital topic in this thesis; however, it may have been beneficial, in order to gain deeper insight, if the current research had sought to answer more probing questions in the approach. In this instance, questions to the mothers could have been customised to obtain mothers' rating of children's and young people's psychosocial wellbeing instead of obtaining mothers' rating of their own psychosocial wellbeing. These problems were acknowledged and a proxy rating was used to assess the Qol for healthy children and young people in the pilot study, but there was no proxy form for the RCMAS and the CDI.

The justification of "why include the mother?" and "who will complete the questionnaires, the child or the mother?" were discussed in Chapters Two and Four. For example, with regard to the first question, it was hypothesised that children's and young people's level of psychological distress would be predicted by their level of defensiveness, pattern of communication of cancer diagnosis, maternal level of distress, and by demographic factors including various disease parameters. The sample size was not adequate for the testing of the a priori hypotheses with the proposed analytic techniques. Analyses employed in both the measure development and hypothesis testing phases of the study -factor analysis and hierarchical regression, respectively- require additional subjects for reliable results. As a conservative estimate, the number of items factor analysed on the DASS-42, for example, necessitates at least two times the number of respondents as indicated in this analysis. Additionally, the multiple regression models are not reliably interpretable with the small number of participants in each group. A multiple regression model in this case for the prediction of child quality of life and presentation of symptoms of anxiety and depression could have been evaluated to check this hypothesis, but again this would complicate the study design and distract us from the main aims of the study. However, this would be an important link for future research.

7.5. Strength of the study

In an ideal study, which would never be possible to achieve, all the limitations previously discussed would be avoided. Importantly, one of the main strengths of this research is the respectable number of each sample, which minimises type two errors, where a difference does exist, but the study does not have the power to detect it. More important is its response rate of 92% in the cancer group and no refusal rate for the chronic illness and healthy control groups which may not signify representativeness, but present a good response rate for studies with similar design.

Parents, children and young people were enthusiastic about taking part in this study. Moreover, giving the mothers a chance of putting events in a context, and telling their story without being judged was likely supporting for those mothers. However, the child participants interpreted the anonymous responses as lack of affection, and as being treated like inanimate objects which may lead to a sense of being vulnerable, powerless and deserted. In addition, with certain cases, I was aware that the child and mother interview became emotional; almost every mother I interviewed cried while completing the questionnaire and some children asked me to be friends.

Finally, although no rating scales can claim to be "gold standard" diagnostic instruments –and this study is no exceptions- the scales used in this study were commonly used in previous studies, which makes it easier to compare results with previous figures. The instruments used within this study, with the exception of the CDI, were all rigorously translated into Arabic and tested for validity and reliability before being applied. The use of age, gender, diagnosis standardised scores for the CDI, RCMAS, and the PedsQL[™] ensure developmental considerations were built into the analysis. The mother's mental state was also assessed via the DASS-42 in case this affected the rating of the child. What the children and young people knew about their illness and the suicide question of the CDI were always checked with the parent before interviewing the child. All children and young people in the cancer group were on cancer treatment, all terminally ill patients and those who had a history of relapse or bone marrow transplantation were excluded.

This study seems to support previous work that suggested that the psychological functioning of children and young people with cancer can at least be as good as if not better than that of healthy peers. However, it would not be correct to assume that such children and young people would be at less risk of experiencing psychological disturbances.

One of the key findings of the study is that defensiveness in children and young people with cancer in Jordan appears to be associated not only with lower self-reported depression and anxiety scores in the child, but also with poor self-reported scores on quality of life measures. This would appear to be particularly true for children and young people with cancer, but not for children and young people with chronic illness. This would imply that such a defence might be eliminated in children and young people with chronic illness, with time.

These results also suggest that mothers of children and young people with cancer are more likely to experience high levels of psychological distress. This indicates a need for the same vigilance with this population, as is given to the children and young people or children and young people will have added difficulties allied to their illness. Stam et al. (2006) argued that during cancer diagnosis and a few months after the end of successful cancer treatment, both children and parents appeared to experience worse well-being and worse HRQoL than the norm, to a clinically relevant extent. Thus, support for children and parents should not stop when treatment ends.

Although the mothers of children and young people with cancer used various ways of communicating the cancer diagnosis to their children, the results of the satisfaction questions would suggest that families, who were not satisfied with the amount of information they had to share with their child, were also not satisfied with the amount of information the doctors and nurses shared with them. The mothers who were totally dissatisfied with their pattern of communication were those scoring highest for affective symptomatology. Such an association is difficult to be identified in a study of this design, but it is an association which is worth being aware of in practice.
Finally, with relevance to clinical practice in Jordanian hospitals, much doubts exits regarding whether any effort would actually be able to change the reality of communication practice. The identified care episode and the nurse-patient relationship, as well as the significance of having awareness and acknowledging the existed debates are significant. Patenaude & Kupst (2005) and Kendall (2006) suggested that effective coping with cancer diagnosis may be promoted by open communication, honesty, maintaining hope and adaptive coping mechanisms including denial. Certainly these are constant themes throughout the literature on coping with childhood cancer and should receive more professional awareness in the Jordanian health care settings.

7.7. Research implications

There are several variations in the methodology of this study which may further the line of enquiry pursued here. For example, the use of longitudinal design looking at how psychological disturbances and defensiveness scores vary in children and young people from diagnosis through treatment and follow-up, and indeed whether the range of values for defensiveness in survivors of cancer would be similar to those with chronic illness.

It may be interesting to explore the notion of defensiveness by using more advanced tools, and utilising an in-depth qualitative approach, to explore more precisely how it works, and whether there are any ways to differentiate adaptive defensiveness from maladaptive defensiveness. Slightly more at a tangent to this study would be the investigation of parental style and how this affects children's and young people's level of defensiveness.

Another line of inquiry that may be useful to pursue would be the use of parental rating of children's and young people's behaviour and adjustment. This could be done using a very similar methodology, by simply adding parent proxy forms. Similarly, with Qol measures, nurses can involve children and young people in rating their QOL for research and clinical purposes and can apply theory-based QOL models to direct care (Hinds et al, 2006).

Reaching the end of this chapter, it is important to address the issue of how this research has contributed to the knowledge of adjustment to childhood cancer at an international and local level.

In the introduction of this thesis, it was mentioned that studies into psychological adjustment and quality of life among children and young people with cancer are still at a very early stage of its development and equivocal in their findings. Moreover, in the Middle East, no body of research into childhood cancer and adjustment exists yet. Thus, an important contribution of the present research is that it presents a comprehensive investigation of children's and young people's wellbeing in an Arab country, specifically, Jordan.

Another important contribution of the present research is the methodological part of this thesis, as it presents a systematic investigation into the process of translation of the questionnaires from English into Arabic. For example, an important part of the research was dedicated to the discussion of the problems one encounters while cross-culturally validating the tools used in assessing quality of life, and emotional wellbeing in children and young people with cancer, as well as children and young people with chronic illness and their healthy peers.

Importantly, the fact that several issues have been distinguished is important to consider when assessing the wellbeing of children and young people in a country like Jordan. For example, preliminary findings in the contextual analysis of the mother's interviews point to major differences of child's perceptions of cancer diagnosis between Western and Eastern cultures, and although the generation of this finding to other neighbouring Arab countries may be premature at this stage, the issues of communication they present could be included in the assessment of children's and young people's wellbeing. Still, children diagnosed at Iraq or West Bank/Palestine hospitals were fully informed about their cancer diagnosis by their oncologists, suggesting that people in these areas of the Middle East experience more openness and disclosure than Jordan. Therefore, it is strongly suggested that future research should focus on and compare differences in communication pattern between countries with the same culture and values, as well as to those of Western cultures. Finally, throughout this thesis, the methodological and practical limitations of this study have been pointed out on several occasions and suggestions made for further research. The overall results of this thesis seemed to indicate the importance of situational factors which may mediate children's and young people's adjustment to cancer and self-reports of wellbeing. Future research with regard to wellbeing of children and young people with cancer should take into account a broader perspective of child's wellbeing; by taking into account the strong relationship between scores on the QoL scale and emotionality subscales, as well as anxiety and depression scales. This would help to establish a universal criterion for defining psychological adjustment, and help in return with comparing findings among studies.

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THE UNIVERSITY OF HULL

Mr. James, W. Varni, PhD Professor of Architecture and Medicine College of Architecture Texas A&M University 3137 TAMU College Station Texas, 77843-3137 United States of America

3rd, December, 2004

<u>Permission to use PedsQL Measurement Model for the Pediatric Quality of Life</u> and the PedsQL Family Impact Module

Dear Prof Varni,

I am a PhD student at the University of Hull Yorkshire, UK. And I am conducting a study on *Quality of Life among Jordanian Pediatric Oncology and Chronic Illness, Parental level of Distress and Sibling in Symptoms Presentation.*

Following revision of large number of tools, I found that PedsQL 4.0 Generic Core Scale and PedsQL Family Impact Module are the appropriate instruments for my study.

Aims of the research study are to assess quality of life and psychological distress among healthy children, and compare data obtained for children diagnosed with cancer versus chronic illness. Second to examine level of anxiety and the cross sectional prevalence of depression for child, and verify how it relates to mother and siblings level of distress. Specifically, the study will explore whether child anxiety value is directly affected with type of treatment and mother level of distress.

Finally; this study will help to have better understanding related Jordanian family experience with cancer or chronic illness, and that necessitate translation of the tool into Arabic language. So would you kindly grant me permission to use the instrument for my study. I am aware of the linguistic validation, and the PedsQL-Core-User Agreement with you and with the MAPI RESEARCH INSTITUTE. A copy of both scales will be much appreciated, and I am welling to cover any expenses due.

Whilst thanking you, I am looking forward to receive a positive reply from you.

Yours sincerely Jious Strabia Diana H.Arabiat School of Nursing, Applied Health Studies and Social Work. University of Hull. G7/Skidby House Taylor Court Salmon Grove Hull/HU6 7SW UKE-mail Address: D.Arabiat@2004.hull.ac.uk

Faculty of Health and Social Care

Appendix A.2.

From:	Christelle Berne [cberne@mapi.fr]	Sent:	Thu 27/01/2005 15:41
To:	Diana H Arabiat		
Cc:			
Subject:	PedsQL		
Attachments:	D PedsQLA-Core-A-uk#.doc		

Dear Diana,

Thank you for your fax dated 19 January. As per your request, please note that we have no Arabic for Jordan versions of the PedsQL. I am very pleased to send you attached the UK version of the Core scales, of the cancer and of the diabetes modules (Adolescent and Child age-group). As we have no UK version of the Arthritis, of the Pain and of the Family Impact module, I am pleased to send you attached the US English versions. Should you wish to perform Arabic versions of these scales, we would be pleased to give you the permission for performing them. For this purpose, please note that we established -in collaboration with the author of the PedsQL, Dr James Varniguidelines and recommendations as to the process to be followed in order to obtain a conceptually equivalent translation in the language requested (please find the leaflet attached).

Please read the leaflet carefully and if you agree with the procedure, please complete the last page of this leaflet and return it to Mapi Research Trust (to my attention at +33 472 13 66 82, again original must follow by mail). As soon as I receive the the signed "Linguistic Validation Form", I will send you the corresponding templates of the PedsQL.

Finally I am please to send you attached the scoring manual.

I hope this information will be helpful. Please do not hesitate to contact me should you have any request.

Kind regards, Christelle

Linguistic Validation of PedsQLTM Form

Please complete, sign and return this form to Mapi Research Institute

By Fax: +33 (0) 4 72 13 66 82 or e-mail: cberne@mapi.fr

<u>NB</u>: This form should be returned before any PedsQLTM material can be released to you and before your translation work can begin.

Date: 1ST, FEBRUARY, 2005

Your first name: DIANA Your LAST NAME: ARABIAT

Your title: Miss. Your current position: PhD Student

Organization: UNIVERSITY OF HULL.

Your contact details:

• Address: Room G-7

SKIDBY HOUSE/TAYLOR COURT SALMON GRVE HULL/ HU6 7SW

- Country: UNITED KINGDOM
- Telephone no. : 00441482303053
- Fax no. : _____
- E-mail address: <u>D.Arabiat@2004.hull.ac.uk</u>
- You intend to work on the linguistic validation of the following PedsQL[™] Generic Cores Scales/Modules:

Questionnaires	Peds	QI 4.0	Arthri	tis	Asthm	а	Cance	er	Card	iac	Diabe	etes	Fatig	jue	Pa	in	Rheur	natology	Impact	Sat
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For the	13-18		13-18		13-18		13-18		13-18		13-18		13-18		13-18		13-18		Parent version	Pare
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Grouper	5-7		5-7		5-7		5-7		5-7		5-7		5-7		5-7		5-7			
groups:	2-4		2-4		2-4		2-4		2-4		2-4		2-4				2-4			
			A																	

AGE-GROUPS: 13-18: Adolescent - 8-12: Child - 5-7: Young Child - 2-4: Toddler (parent form only).

You intend having it/them translated into the following language: **ARABIC**

- For use in the following country: JORDAN
- You expect the linguistic validation process to be completed and all documents to be ready

By: 1^{ST,} FEBRUARY, 2006.

<u>NB</u>: Dr. James W. Varni holds the copyright of the original PedsQLTM Generic Core Scales and Disease-Specific Modules and all translations of the PedsQLTM. Any improvements, modifications, or enhancements to the PedsQLTM which you may conceive or develop, including translations and modules, shall become the property of Dr. James W. Varni. You are not authorized to modify, retype, copy or otherwise duplicate the PedsQLTM except with further and written permission of Dr. James W. Varni.
I hereby acknowledge the information presented in this document and agree to send paper and electronic copies of the final translated version and all reports documenting the translation process to Mapi Research Institute in order to help Dr. James W. Varni keep track of all work being done on the PedsQLTM.

Signature: _____

Thank you very much for your co-operation.

1st, November, 2005

Re: Linguistic Validation of the PedsQL into Arabic

Dear Sir/ Madam,

I read with great interest the contract I signed with you dated 8th, December, 2004, I feel compelled to share some concerns relevant to translating the PedsQL into Arabic.

First, the basis of my study was to include Disease Specific Modules of diabetes, Arthritis, Asthma, and cancer, but a reviewer cited sample heterogeneity as a major limitation, and advised to use the PedsQL 4.0 Generic Core Scales alone in measuring the children quality of life for the whole sample, I hope with your permission I would be able translating the PedsQL 4.0 Generic Core Scales into Arabic for the present time, other Disease Specific Modules will be translated into Arabic hopefully the next year after I finalise my recent PhD study.

Second, the Arabic version of the PedsQL 4.0 Generic Core Scale was created through an iterative forward-backward translation sequence, as two native speakers of Arabic language fluent in English translate independently the PedsQL into Arabic and then back translation of the Arabic version into English by a bilingual panellist who is residing in UK and competent in both English and Arabic language.

Finally, I am please to send you attached the first and second version of the questionnaire. However, cross-cultural validation including both child and parent form will be pre-tested in few schools of Jordan for assessment of ease of comprehension, possible ambiguity, validity and reliability.

In closing, I would like to reemphasise my appreciation for you and for Dr. Varni. For any questions about the study, please feel free and do not hesitate to contact me.

Sincerely,

Diana H. Arabiat

E-mail: <u>D.Arabiat@2004.hull.ac.uk</u> dnarabiat@yahoo.co.uk

- To: <u>Mr. James, W. Varni, PhD</u> Professor of Architecture and Medicine College of Architecture/ Texas A&M University 3137 TAMU/ College Station Texas, 77843-3137, USA
- Cc: <u>Mapi Research Institute</u> 27, rue de la Villette 69003 Lyon- France

Dear Prof. Varni,

My name is Diana Arabiat, and I am a PhD student who would like to voice my concerns about a few issues that are being faced in the process of translating the PedsQL[™] inventory into Arabic, and eventually to report for you the preliminary data and results obtained from the study. While I understand the need to improve the process of translation, I have certain concerns:

1. Psychometric properties of the instrument. The PedsQL[™] was translated into Arabic using the Mapi Research Institute guidelines (2002) for Linguestic validation of the PedsQL[™] and recommended guidelines by you Dr. Varni, (1988) for translation and validation of instruments for cross-cultural research. To determine the instruments acceptability, reliability and validity in Jordan, a crosscultural validation was performed in three phases; Forward-Backward translation, Pilot-testing, and Estimation of reliability and validity.

The PedsQL[™] was translated into Arabic by two bilingual experts and blindly translated back by a second bilingual expert. Along with an attempt to reduce the cultural and social bias that may result when only one or two authors are responsible for the translation, a copy of the translated instruments were sent to an authorised translation office in Amman, and auxiliary reviewed by four Arab research students from Jordan, Syria, Egypt, and Iraq (current residence in the United Kingdom) and approved the written standard Arabic level of the tool.

The back translated versions were compared with the original US version and retranslated where error in meaning was found. Although an adaptation of the questionnaire was considered as a whole, a literal translation was possible in some items and inappropriate in others. For example (78) Children reported (2) significant problem with item comprehension in the PedsQL, none have been culturally irrelevant. As a result of pre-testing these two items were re-translated; translation of the PedsQL, the first physical functioning item "It is hard for me to walk more than one block" pose a problem, most children didn't understand the translated term of Block as "a building" or "a group of buildings in a town which has streets on four sides", alternative term was used to render the concept with "a short distance".

Another requirement of the re-translations based on pre-testing was altering the translation of item (6) "It is hard for me to do chores around the house", two major points of difficulty arose with this item, the translation of "chores" into

"routine works", and specifying what kind of not interested job but had to be done at house for both boys and girls, taking into consideration the cultural background, and developmental age group of the target population. In the second attempt of developing an easily understood Arabic version of the PedsQLTM, each new item in the re-translated items was back-translated and checked for consistency with the original concepts in order to detect any misunderstanding, mis-translations or inaccuracies in the intermediary forward version of the questionnaire.

2. Pre-testing. The purpose of pre-test was to obtain data on the acceptability, appropriateness, and comprehensibility of the Arabic version of the tool and face validity. The first piloting testing of the questionnaires included 98 children and was rejected for failing to include both child and parent forms for the age-group used in translation (see Mapi Research Institute contract). The second piloting testing was administered to 153 children and their parents, 70% were between (10-12 years), and 30% adolescents. Mean age of the sample was (11.44) with a standard deviation of (1.58). Children were asked to give feedback about the interpretation and understanding of items and response rating. Acceptability of using this instrument in Jordan and utility was discussed further by a group of school and hospital social workers, the acceptability of the charts were highly accepted. The Mapi Research Institute received a copy of the revised measures and being waited to authorise all changes.

3. Instrument validation procedure. The target language versions were tested for reliability and validity on 153 children for pre testing purpose and then post tested among 109 children all around Jordan. The healthy children and their parents were recruited through 8 schools all around Jordan (east and west part of Amman including the Palestinians refugee's camps, Salt, Zerqa, and Aqaba); permission had been obtained to interview and filled these questionnaires by the ethical local committee of ministry of education. Parents were sent information about the study and were asked to return the questionnaire along with the signed consent, where they felt the forms at home. However, children filled the questionnaires at the classroom, then responded to closed and open formal questions about each chart.

Children with cancer (n=58) and chronic health conditions (n=56) with a control group that matched age, sex and place of residence (n= 64) were invited to participate in this study. Nevertheless, due to time and finance constrains with lack of parent-proxy report form, those children were difficult to be interviewed again for post test, and were excluded from the correlational reliability testing, and used for discriminate validation only. One of the main limitation of this study that it was recommended to confirm the psychometric properties of any translated PedsQLTM whenever it is used in a new population to use parallel child self-report and parent proxy-report forms. Therefore, the psychometric properties of the Arabic PedsQLTM version was assessed in the current study using the healthy population with little reference to the cancer and chronic illness groups. However, as the PedsQLTM is already validated, thus details of the hypothesised structure analysis and internal consistency reliability are not presented here in details for the cancer and chronic health conditions groups.

<u>4. Internal consistency reliability of the PedsQL</u>. The results of the internal consistency reliability were excellent in all self report and proxy report version for both child and adolescent age groups. The internal consistency (Cronbach's alpha) of each scale of the PedsQLTM self-report and parent proxy report form was quite

favourable (as seen in Tables 1, and 2), and similar to the values given by Varni et al (2000, 2001, 2002, 2004); Upton et al,(2005); Felder-Puig et al (2005).

Table (1) Reliability Analysis

	No of	Child s	self-report		Parent pi	roxy form	
PedsQL™	items	Pre- test	Post-test	Pre-post total	Pre-test	Post-test	Pre-post total
Physical functioning	8	0.78	0.80	0.79	0.89	0.76	0.87
Emotional functioning	5	0.76	0.82	0.79	0.77	0.62	0.74
Social functioning	5	0.82	0.82	0.82	0.79	0.88	0.82
School functioning	5	0.66	0.71	0.69	0.85	0.62	0.78
Psychological health summary	15	0.86	0.89	0.88	0.83	0.88	0.87
Total score	23	0.90	0.92	0.91	0.93	0.88	0.92

Reliability coefficients (Cronbarch's alpha) for the PedsQL™

Table (2) previous reports on internal reliability of the PedsQL[™] generic core scale

The study authors	Origin of study	Alpha Child- self report	Alpha Parent proxy form
Varni et al. (2006)	USA	0.89	0.92
Varni .(2004)	USA	0.88	0.90
Varni et al. (2003) a	USA	0.89	0.92
Varni et al. (2003) b	USA	0.88	0.88
Varni et al, (2002)	USA	0.91	0.93
Eiser, (2001)	UK	0.93	0.92
Upton et al, (2005)	UK	>0.90	>0.90
Felder-pulg et al, (2005)	Germany	>0.70	>0.70

Table (3) previous reports on internal reliability of the PedsQL[™] generic core sub scales

	No of	Child self	report		Parent pro	oxy form	
PedsQL™	items	Current study	Varni et al 2001	Varni et al 2002	Current study	Varni et al 2001	Varni et al 2002
Physical functioning	8	0.79	0.80	0.87	0.87	0.88	0.80
Psychological health summary	15	0.88	0.83	0.86	0.87	0.86	0.90
Total score	23	0.91	0.88	0.91	0.92	0.88	0.93

5. Test-retest reliability. Findings of test-retest reliability confirmed the satisfactory reliability of the PedsQLTM and shown to posses satisfactory psychometric properties in Jordan (see Table 4). Because the number of the recruited sample are so large and distributed around large area around Jordan, the participants were selected by the teachers and described as the highly motivated and pioneer students. The nature of the students chosen to this study contributed to the understanding of the high correlation between child and parent

form and questioned the presentation of the current sample, this may explain the high difference of correlation between the current study and previous studies. Table (4) Reliability of the PedsQLTM temporal stability (2weeks, n=47).

	Correlation be	etween child and pa	arent form
PedsQL ^{1**}	Pre-test	Post-test	Pre-post test
Physical functioning	1.000**	1.000**	1.000**
Emotional functioning	0.679**	0.778**	0.607**
Social functioning	0.429*	0.886**	0.693**
School functioning	0.825**	0.868**	0.838**
Psychological health summary score	0.691**	0.887**	0.757**
Total items	0.76**	0.918**	0.80**

** Correlation (spearman) is significant at the 0.01 level (2-tailed)

* Correlation is significant at the 0.05 level (2-tailed)

Table (5) parallel studies for correlation between self-report and parent proxy report (Jordan and UK)

PedsQL [™] scale	Correlation between English healthy san	n child and parent form Jordan and nple
	Current study	Upton et al, 2005
Physical functioning	1.000**	0.61**
Emotional functioning	0.607**	0.51**
Social functioning	0.693**	0.60**
School functioning	0.838	0.56**
Psychological health summary score	0.757**	0.63**
Total items	0.80**	0.67**

** Correlation is significant at the 0.01 level (2-tailed)

* Correlation is significant at the 0.05 level (2-tailed)

<u>6. Validity testing of the PedsQL</u>. The validity of the PedsQL was demonstrated through known groups' comparisons to distinguish between children with and without chronic health conditions, and within the group of children with chronic health conditions through distinguishing disease severity within a chronic health condition (Varni, 2004)

The PedsQLTM Discriminant validity showed that overall, a comparison of the healthy children with those of cancer and chronic health conditions are possible for the child self report form. Analysis of variance (ANOVA) was used to discover the location of the differences causing the overall significant F value. Results shows significant differences in reported HRQL across the three groups (see table 6). The mean and standard deviation of cancer group, chronic illness and healthy referents are reported in table 6. The ANOVA demonstrates a main effect for sample, indicating that healthy group have significantly higher HRQL than children with cancer and chronic illness (F (15.99), P <.0001). This significant difference extended to all HRQL subscales except for social functioning as children with cancer reported more problems with physical, emotional and school functioning (all significant at p<.0001) and reported the worse HRQL compared with children with cancer and control group

variable	Cancer	group	Chronie group	cally ill	Contro	l group	F	Р
	Mean	(SD)	Mean	(SD)	Mean	(SD)		
Total items of Quality of life	66.98	19.47	61.16	19.58	78.97	14.81	15.99	.0001*
Physical functioning	69.35	26.02	61.10	25.73	81.05	15.00	11.90	.0001*
Emotional functioning	63.94	28.92	62.23	20.58	73.59	20.42	4.13	.018
Social functioning	81.66	19.69	71.42	25.20	79.76	18.15	3.78	.025
School functioning	46.92	32.34	49.91	30.18	80.23	18.54	27.78	.0001*

Table (6) Group differences on PedsQL measure

* Correlation is significant at P<0.001

At the end, I would like to thank you Dr. Varni and the Mapi Research Institute, I hope that all of you reading it will find it valuable. I would appreciate any feedback or comment from you regarding the translation process, and thus produce a final report for publication purpose.

Warm regards

Diana H. Arabiat University of Jordan Nursing College Maternal and Child Health Department Jordan/ 11942 Amman E-mail: D.Arabiat@2004.hull.ac.uk Subject: RE: The Arabic version of the PedsQL

Date: Mon, 19 Jun 2006 14:56:55 -0500

From: "Varni, James" <JVarni@archmail.tamu.edu> Inview Contact Details

To: "Diana Arabiat" <dnarabiat@yahoo.co.uk>

CC: cberne@mapi.fr

Dear Diana Thank you for such an excellent report. I enjoyed reading your careful description of the findings. I would be happy to review your manuscript as you prepare it for publication.

Best, Jim James W. Varni, Ph.D. Professor and Vice Chair for Research Department of Pediatrics, College of Medicine Professor Department of Landscape Architecture and Urban Planning College of Architecture Texas A&M University 3137 TAMU College Station, Texas 77843-3137 Tel: (979) 862-1095 Fax: (979) 862-1784 jvarni@archmail.tamu.edu

From: Diana Arabiat [mailto:dnarabiat@yahoo.co.uk]
Sent: Sun 6/18/2006 3:48 AM
To: Varni, James
Subject: The Arabic version of the PedsQL

Dear Prof. Varni

I am please to send you attached the Arabic version of the PedsQL. I hope this information will be helpful. Please do not hesitate to contact me should you have any request.

Kind regards Diana Arabiat



THE UNIVERSITY OF JORDAN كلية التمريض

Faculty of Nursing

حضر ة مدير مركز الحمين لأسر طان المحترم . تحية طيبة وبعد:

أنا طالبة دكتور الآمن University of Hull/Yorkshire في يريطانها , وموفدة من الجامعة الأردنية , أر غب في إجراء دراسة استيانية حول University of Life, and Psychological Distress in Jordanian في إجراء دراسة استيانية Oncology Pediatrics or Chronic Illness, Parental level of Distress and Siblings in Symptoms Presentation).

أرجو من حضر تكم تسهيل مهمتي بالسماح في بقوزيم استبيان مقياس القلق(&RMAS, Reynolds). علما" بأن المشاركة (Richmond) والإكتذاب (CDI, Kovacs) ومقياس نوعية الحياة (PedsQL, Vami). علما" بأن المشاركة اختبارية ولا تتعارض بأي شكل مع أداب وأخلاق البحث العلمي. مرفقا" لحضر تكم موجز ا" من البحث والإستبيان.

هذه الدر اسة تعد من الدر اسات الذائرة في الشرق الأوسط , وستساعد في تشخيص ومساعدة الأطفال الذين . يعانون من اور ام سرطانية أو أمر اض مزمنة و عائلاتهم خلال مرحلة العلاج وما بعدها .

وتفضلوا بقبول فانق الإحترام

ديانا فاشم عربيات

ون عاماً من التميز مالحينا المحتمي

Diana H. Arabiat School of Nursing, Applied Health Studies, and Social Work University of Hull G7 – Skidby House Taylor Court Salmon Grove Hull/ HU6 7SW UK E-mail Address: D.Arabiat@2004.hull.ac.uk

> های - ۲۱۱٬۲۰۰ ناکی - ۲۱۰٬۹۱۱٬۲۰٬۲۰۰ علی ۱۹۲۲ (ایزین Tel: (962-6) 5355000 Fax: (962-6) 5355511 Amman 11942 Jordan E-mail: admin@juedu.jo

From:	Titiana Mola [tmola@KHCC.JO]	Sent:	Sat 18/06/2005 09:18
To:	Diana H Arabiat		
Cc:	Jamal Khatib		
Subject:	IRB Approval		
Attachments:	Approval letter to		

Dear Diana,

Greetings,

Please find attached the approval letter for your study, and note that we are still waiting for the Military services approval.

Best regards

Titiana Mola Institutional Review Board (IRB) Coordinator Senior Administrative Aid for the Associate Director of Medical Affairs King Hussein Cancer Center Tel: + 962 6 5300460 Extn. (1280) Fax: + 962 6 5353001

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THE UNIVERSITY OF HULL

Dr. Mahmoud M. Sarhan, MD Chairman of IRB, KHCC King Hussein Cancer Centre Institutional Review Board (IRB) 21st, February, 2005

Re: PhD Nursing Research Study

Dear Dr. Sarhan,

「③時キア

I appreciate your comment's regarding my initial proposal of "Quality of Life and Psychological distress in Jordanian Oncology pediatric and Chronic Illness, Parental level of Distress and Siblings in Symptoms presentation".

I read with great interest the letter by Mola sent in the 13th, February, 2005, I feel compelled to share some concerns, and clear out several issues relevant to my data collection at the KHCC.

First; who is going to identify patients? To insure consistency in approach, I believe it is better to conduct all interviews my self, I hope with the help of clinic physician and nurses -in charge- I would be able getting an access to the files of children diagnosed with cancer within the last year. Those children who meet the criteria for the study will be recorded, eligible patients at the clinic or currently hospitalised will be approached by a visit to arrange for an appointment for a house interview or at clinic according to family wish and mutual convinces.

Siblings of the children will be excluded from my research activities, I initially wrote my study manuscript including children with cancer and their siblings, a reviewer cited sample heterogeneity as a major limitation. Much of the work studying the psychological functioning of children with cancer or chronic illness has also been criticized for this reason, and advised to split into two manuscripts focusing either on the sick child or the siblings to avoid compromising the quality of the obtained data.

The basis of my study interview will be to interview the child and his mother; permission will be obtained from parent to participate in the study. A brief explanation will be given to the parent, those willing to proceed with the interview will be asked to sign a consent form acknowledging agreement to participate in the study.

Second; the Statistical Package for Social Science (SPSS) will be used to analysis data, this would include:

Two-way analysis of variance (ANOVA).

-Post-hoc test.

-Pearson correlation.

THE UNIVERSITY OF HULL

Third; the DASS-42 scale will be used to measure parental anxiety (mainly the mother). The DASS-42 is a set of three self report scales designed to measure the negative emotional states of depression, anxiety, and stress.

Fourth; regarding the RCMAS and with respect to the few items which meant to be repeated twice in different way, the use of this scale remain a controversial subject, particularly in Jordan, I've done earlier cross-cultural validation over 98 Jordanian children to check the tool reliability. I believe that the critical issue around the use of the RCMAS is not the repeated items. Rather, the law stability of the tool as a reliable measure for the children in Jordan

Finally; involving Dr. AL-Khatib, the director of KHCC Psycho-Oncology program in the research team as to coordinate with other investigators and the PI is always welcomed.

In closing, I would like to reemphasise my appreciation Dr. Sarhan, also I wondered how I might get into contact with Dr. Jamal AL-Khatib for further consultation in the near future.

For any questions about the study, please feel free and do not hesitate to contact me.

Warm regards;

白◎年米

Diana H. Arabiat

Siana Arabio G-7/ Skidby House Taylor Court Salmon Grove HU6 7SW Hull/Yorkshire England

27

Tel: 00441482303053

E-mail: D. Arabiat@2004.hull.ac.uk Diana arab@hotmail.com

From:Titiana Mola [tmola@KHCC.JO]To:diana_arab@yahoo.comCc:Diana H ArabiatSubject:FW: Your proposal

Attachments

Dr. Jamil's Al Khatib email is Jkhatib@khcc.jo

----Original Message----From: Mahmoud Sarhan
Sent: Monday, February 21, 2005 5:47 PM
To: 'Diana'
Cc: Titiana Mola; Jamal Khatib
Subject: Your proposal

Dear Diana:

I have just received your fax re your study proposal. I thank you for taking the time to respond to our concerns we have sighted in our letter to you. As you well aware of, our concern in the IRB is patient safety and convenience, but also we look carefully on the balance between how much work will be done by the investigator and the potential value coming out of the research. We certainly consider those proposals that are part of a thesis, but we believe that this research should be published so that it becomes generalized knowledge.

Sent: Tue 22/02/2005 06:34

I am sending a cc of this email to Dr Khatib; therefore, you will find his email address here.

I appreciate it if you would revise the protocol to include all details in your letter. In addition I would like you to expand on execution plan and the time frame. We would like to know details.

Thanks again. Looking forward to reviewing your revised protocol soon.

Mahmoud M. Sarhan, MD Associate Director for Medical Affairs Professor & Director, Bone Marrow & Stem Cell Transplantation Program King Hussein Cancer Center Amman- Jordan Tel.: +(962-6) 53 00 460 Ext. 1280 Fax: +(962-6) 53 53 001

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 From:
 Titiana Mola [tmola@KHCC.JO]

 To:
 Diana H Arabiat

Sent: Sat 09/04/2005 08:48

Cc: Subject: RE: the ethical permission

Attachments:

Dear Diana, Greetings,

Your changes are in the review process, I will get back to you in this week.

Best regards

----Original Message----From: Diana Arabiat [mailto:D.Arabiat@2004.hull.ac.uk] Sent: Thursday, April 07, 2005 3:40 PM To: Titiana Mola Subject: the ethical permission

Dear Titiana,

With reference to the ethical permission of conducting my study at the KHCC, I hope you had received the granted permission from Jordan University Hospital, and my earlier sent e-mails with attached copies of Arabic translated copy of the consents form.

I admire the effort involved in searching all the ethical dimension of the study, but I intended to have my transfer report of my study early June, and I am in critical need to know where I am going through if I had to do it at Jordan, or exclude my study here at England. I would appreciate any information, even if it is negative. However, the KHCC is the main clinical setting I can refer to get my research sample if i had to do it at Jordan.

Thanks a lot.

Warm regards,

diana

This Email message and its attachments are strictly confidential and may be privileged or otherwise protected from disclosure. It is intended for the individual or entity named above, if you are not the intended recipient, kindly do not read, copy, use, disclose or distribute this communication to others and notify the sender by replying to this message and delete it and all of its attachments (if any) from your system. Thank you for your cooperation.

Titiana Mola [tmola@KHCC.JO] From: Sent: Sat 07/05/2005 08:26 To: Diana H Arabiat Cc: Subject: RE: the ethical permission Attachments: Dear Diana, Greetings, I am writing regarding your study, The IRB at KHCC needs to receive from you 1- The informed consent in Arabic. 2- To determine the primary investigator from KHCC. 3- The approval from other institutions. Once we receive these data, your study will be approved. Best regards Titiana Mola ----Original Message-----From: Diana Arabiat [mailto:D.Arabiat@2004.hull.ac.uk] Sent: Saturday, April 09, 2005 2:04 PM To: Titiana Mola Subject: RE: the ethical permission Dear Titiana, thanks for your e-mail, and i am looking forward to hear from you soon. Regards, Diana H.Arabiat School of Nursing, Applied Health Studies and Social Work. University of HUll. G7/Skidby House Taylor Court Salmon Grove Hull/HU6 7SW Uk **** ****** This Email message and its attachments are strictly confidential and may be privileged or otherwise protected from disclosure. It is intended for the individual or entity named above, if you are not the intended recipient, kindly do not read, copy, use, disclose or distribute this communication to others and notify the sender by replying to this message and delete it and all of its attachments (if any) from your system. Thank you for your cooperation. *******

Appendix B.7.



King Hussein Cancer Center

Institutional Review Board (IRB)

To: Diana Arabiat School of Nursing, Applied Health Studies and Social Work University of Hull

From: Mahmoud M. Sarhan, MD Apellum Chairman of IRB, KHCC

Cc: Samir Khleif, MD Dr. Jamal Al Khatib

Date: June 8, 2005

Ref.: IRB / E/4/05

Subject: Revised version "Quality of life and Psychological Distress in Jordanian oncology pediatric patients or chronic illnesses parental and sibling level of distress"

Dear Ms. Arabiat,

The revised version of the protocol entitled "Quality of life and Psychological Distress in Jordanian oncology pediatric patients or chronic illnesses parental and sibling level of distress" is acceptable to the IRB.

Please inform the IRB office of any unexpected complications related to the study, the date of completion of the study and any publications/ abstracta that may result from this research. And please also note that the IRB is still waiting for the Military Hospital approval.

On behalf of all members of KHCC IRB, I would like to wish you a very successful study.



THE UNIVERSITY OF HULL

Jordan Ministry of Health DIRECTORATE Al-Basheer Hospital Amman- Jordan 3rd, December, 2004

PhD Nursing Research Study

Dear Director of Jordan Ministry of Health

I am a full-time PhD nursing student at the University of Hull Yorkshire, UK. Sponsored by the University of Jordan. Part of my PhD studies include conducting a research study about *Quality of life and Psychological Distress in Jordanian* Oncology Pediatrics or Chronic Illness, Parental Level of Distress and sibling in Symptoms Presentation.

I am presently in the process of seeking permission to conduct my study at Jordan main clinics and hospital wards caring of children with cancer or other chronic medical conditions as(type I diabetes mellitus, end stage renal disease, asthma, etc). This study will be using a random sample of 50 children with cancer, and another 50 child with chronic medical condition, those children will be assessed for Health related quality of life HRQOL using the PedsQL (Varni), and the CDI (Kovacs) with CRMAS (Reynolds&Richmond, 1978) to measure child's level of anxiety and depression. It is planned that data collection will be done between September, 2005 and March, 2006.

I am aware of adhering to ethical issues, as voluntary participation by the informed consent of child's parent, and to maintain confidentiality and anonymity throughout all the research process.

Please find enclosed a brief research proposal summaries my study, your support for this research study is highly appreciated, and I am looking forward to receive a positive reply from you.

Yours' sincerely;

Diana H.Arabiat School of Nursing, Applied Health Studies and Social Work. University of Hull. G7/Skidby House Taylor Court Salmon Grove Hull/HU6 7SW UKE-mail Address: <u>D.Arabiat@2004.hull.ac.uk</u>

Faculty of Health and Social Care

HE HASHEMITE KINGDOM	
OF JORDAN	
MINISTRY OF HEALTH	
Ref No.	

NUL 140.	
Date	

بنسم الله الرخمن الزخيم

المملكة الأردنية الماشمية

وزارة الصحية

1222/ S. D/art _

مدير مستشفى البشير

تحية طيبة وبعد ...

استدعت الي طالبة دكتوراه التمريض في UNIVERSITY of Hull ديانـــا عربيات والذي تطلب فيه الموافقة على السماح لها باجراء بحث التخــرج لأســتكمال متطلبات الحصول على درجة الدكتوراه.

راجيا الاطلاع والسماح لمها بالحصول على المعلومات وحسب ما تســمح بـــه القوانين والانظمة المعمول بها لديكم في هذا المجال.

واقبلوا احترامي ...



عمان - هانف : ۱۳۱۱ ۲۵۵۵ ص.ب : ۸۱ فاکس : ۲۸۸۳۷۳ تلکس : ۱۹۹۵ Amman - Tel.: 5665131 - P.O.Box: 86 Fax: 5688373 Telex: 21595

قرار رتم ۲/۱۱۱ ۲۰۰۲

Appendix B.10.





THE UNIVERSITY OF JORDAN

كلية التمريض Faculty of Nursing

حضرة مدير عام الخدمات الطبية الملكية / المنينة الطبية . تحية طبية وبعد:

النا طالبة دكتوراة من الجامعة الأردنية, أرغب University of Hull/Yorkshire في بريطانيا, وموقدة من الجامعة الأردنية, أرغب في إجراء دراسة استبيانية حول University of Life, and Psychological Distress in Jordanian في إجراء دراسة استبيانية Oncology Pediatrics and Chronic Illness, Parental level of Distress and Siblings in Symptoms Presentation).

أرجو من حضر تكم تسهيل مهمتي بالسماح لي بتوزيع استبيان مقياس الظق(&RMAS, Reynolds). (Richmond) والإكتتاب (CDI, Kovacs) ومقياس نوعية الحياة (PedsQL, Varni). علما" بأن المشاركة اختيارية ولا تتعارض بأى شكل مع آداب وأخلاق البحث العلمي. مرفقا" لحضر تكم موجزاً" من البحث والإستبيان.

هذه الدراسة تعد من الدراسات النادرة في الشرق الأوسط , وستساعد في تشخيص ومساعدة الأطفال الذين. يعانون من اور ام سرطانية أو أمراض مزملة وعاتلاتهم خلال مرحلة العلاج وما بعدها .

وتفضلوا بقبول فانق الاحترام

دباتا هاشم عربيات

أربعون عاماً من التم متحاطية (0 ماه



دي - ۲۰۰۰ (۱۹۲۰) نکس - ۲۰۱۰ (۱۹۲۰) عان ۱۹۹۲ (الأريز) Tel: (962-6) 5355000 Fax: (962-6) 5355511 Ammian 11942 Jordan E-mail: admin@ja.eda.jo

Appendix B.11.



تحيه طيبه وبعد ...

- University of Hull تمت الموافقة على السماح لطالبة الدكتوراه دياتا هاشم عربيات من جامعة University of Hull قي المملكة المتحدة وموقدة عن طريق الجامعة الاردنية بتوزيع استبيان مقياس القلق والاكتتاب عند الاطفال الذين يعانون من اورام سرطانية او امراض مزمنه .
 - ۲. لاجراءاتكم لطفً".



نسخه الى :

- مدينة الحسين الطبية
- المدير الفني والتدريبي
 - رئيس الدائرة المالية
- رئيس شعبة امن الخدمات الطبية ، اشارة لكتابكم رقم ش ١ / ١ / الدريب / ٨٤٠٨ تاريخ ١٨ / ٩ / ١٠٠٧
 - التداول

FAX: 962-6-5347485 TEL: 5804804 EXT: 4312/ 4373 P.O. BOX: 122 Dobyat Al-Amir Rashid, Amman 11831 Jerdan فلكس: ٢٥٣٢ ١٩٣٥ ٦٦ ٢٦٦ تاليون: ٢٨٢ ٩٨٩ فر هي ٢٢٣٢/٢٢٦ ٩ من حب ٢٢ متسلحية الأمير، رائف، عمان ٢٦٨٢٠ الأردن 10:27 AM 18/09/05

ゆの時キア

THE UNIVERSITY OF HULL

Director of Jordan University Hospital Jordan University Hospital PO-BOX 13046 Amman-Jordan

3rd, December, 2004

PhD Nursing Research Study

Dear Director of Jordan University Hospital

I am a full-time PhD nursing student at the University of Hull Yorkshire, UK, Sponsored by the University of Jordan. Part of my PhD studies include conducting a research study about *Quality of life and Psychological Distress in Jordanian* Oncology Pediatrics or Chronic Illness. Parental Level of Distress and sibling in Symptoms Presentation.

I am presently in the process of seeking permission to conduct my study at Jordan main clinics and hospital wards caring of children with cancer or other chronic medical conditions as(type I diabetes mellitus, end stage renal disease, asthma, etc). This study will be using a random sample of 50 children with cancer, and another 50 child with chronic medical condition, those children will be assessed for Health related quality of life HRQOL using the PedsQL (Varni), and the CDI (Kovacs) with CRMAS (Reynolds&Richmond, 1978) to measure child's level of anxiety and depression. It is planned that data collection will be done between September, 2005 and March, 2006.

I am aware of adhering to ethical issues, as voluntary participation by the informed consent of child's parent, and to maintain confidentiality and anonymity throughout all the research process.

Please find enclosed a brief research proposal summaries my study, your support for this research study is highly appreciated, and I am looking forward to receive a positive reply from you.

Yours' sincerely;

Diana H.Arabiat School of Nursing, Applied Health Studies and Social Work. University of Hull. G7/Skidby House Taylor Court Salmon Grove Hull/HU6 7SW UK

Faculty of Health and Social Care

Jordan University Hospital	مستشفى الجامعة الأردنية
Ref.	1. 0. VILY/ ce (1
Date	۲۰۰۰/۲/ ۱۷ خرالتار التاريخ

الفاضله دياتا هاشم عربيات المحترمة

Diana H. Arabiat School of Nursing, Applied Health Studies and Social Work. University of Hull. G7/Skidby House Taylor Court Salmon Grove Hull/HU6 7 SW UK

تحيسة طبيسة ويعد ،،

فأشير الى طلبك توزيع الاستبيان لاجراء بحث بعنوان :-

(Quality of Life and Psychological Distress in Jordanian Oncology Pediatrics or Chronic Illness, Parental level of Distress and billings in Symptoms Presentation).

أعلمك بالموافقة على قيامك بذلك بالتنسيق مع الدكتور رئيس قسم الأطفال .

متمنياً لك التوفيــــق .



121

تلفون ٢٢٥٢٤١٤ - تلكس ٢٢٦٢٩ - فاكس ٢٥٢٢٨٨ - صندوق بريد ٢٠٤٦ - عمان - الأردن Tel. 5353444 - Telex 21629 JU JO-FAX 5353388 - P-O.Box 13046 - Amman - Jordan





THE UNIVERSITY OF JORDAN كلية التمريض Faculty of Nursing

حضر ة و زير التربية والتعليم المحترم. تحية طبية وبعد

النا طالبة دكتور الامن University of Hull/Yorkshire في بريطانيا ، وموقدة من الجامعة الأردنية، ار غب (Quality of Life, and Psychological Distress in Jordanian في إجراء در اسة استبيانية حول Oncology Pediatrics or Chronic Illness, Parental level of Distress and Siblings in Symptoms Presentation).

ارجو من حضر تكم تسهيل مهمتي بالسماح لي بتوزيع استبيان مقباس القاق(&RMAS, Reynolds). عاما" بأن المشاركة Richmond) والإكتتاب (CDI, Kovacs) ومقباس نوعية الحياة (PedsQL, Vami). عاما" بأن المشاركة المتيارية ولا تتعارض بأى شكل مع أداب والخلاق البحث العلمي مرفقا" لحضر تكم موجز ا" من البحث والإستبيان.

هذه الدراسة تعد من الدراسات النادرة في الشرق الأوسط ، وستساعد في تشغيص ومساعدة الأطفال الذين. يعانون من لورام سرطانية أو أمراض مزمنة وعائلاتهم خلال مرحلة العلاج وسا بعدها .

وتقضلوا بقبول فانق الإحترام

ديانا هاشم عزبيات

أربعون عاماً من ال محمدةالجججة أرادة

Diana H. Arabiat School of Nursing, Applied Health Studies, and Social Work University of Hull G7 – Skidby House Taylor Court Salmon Grove Hull/ HU6 7SW UK E-mail Address: D.Arabiat@2004 hull.ac.uk

> . مانگ - ۲۰۰٬۰۰۰ (۱۲۲۰۰) (اکنی - ۲۰۱٬۹۲۰۱) میان ۱۹۲۲ (افرین Tel: (962-6) 5355000 Fax: (962-6) 5355511 Amman 11942 Jordan E-mail: admin tēju edaļo

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	اللوافق / ۲۰۰۰	النام خواط	الرقب ١٠/٣

السبد مدبر التربية والتعليم لمحافظة المنطقة اللواء

الموضوع : البحث التربوي

السلام عليكم ورحمة الدوبركانه،

تقوم الطالبة ديانا هاشم عربيات بإعداد دراسة بعنوان: " Quality of life, and psychological Distrass in University ، وذلك استكمالاً للمصول على درجة التكثوراء في التعريض ، من جامعة University of Hull/Yorkshire في بريطانيا ، ويحتاج ذلك إلى تطبيق ثلاث استيانات على عينة من طلبة المدارس التابعة المديريتكم .

ايرجى تسهيل مهمة الطالبة المذكورة وتقديم المساعدة الممكنة لها.

مع واقر الاحتزام

روند التربية والنطبيم عدد مرة البحث والتطوير بنوينة

نسخة /السيد رئيس قسم البحث التربو ي. نسخة / الملف ١٠/٣

هاتف : ۲۰۷۱۸۱ / ۱۱ فاکس : ۲۲۲٬۱۹ ص.ب (۱۲٤٦)

قرار رقد ۱۱۱ / ۲۰۰۳

Appendix C.1.

sei. نوعية الحياة لدى الأطفال (PedsQL) في المسقحة التالية قائمة بأشواء قد تكون مشكلة بالنسية الك ، رجاءًا" أخبر في ما حجم المشكلة للمري نقضة بالنسبة تك في فترة الشهر الماضي عن طريق وضع دائرة حول: Pines 0 إذا لم تكن مشكلة دياليا" Bernantel 1 تغريبا" لم تكن مشكلة 2 إذا كالت متكلة في بعض الأوقات als wile 3 4 دانما" وفي معظم الأوقات مشكلة لا توجد إجابة مسحبحة أو خاطئة . اذا لم تفهد أي سوال، أرجوك أن تسال لأي مساحدة. غاليا" مشكلة بعض الأوقات تقريبا مشكلة دائما" تواتيا ليمت فيما يتعلق بصحلني 18.2 3Xio 1620 و نشاطی 2 3 يصعب على أن أسير الكثر من مساقة مجمع 0 1 4 2 3 1 0 يصعب على أن أركض 4 بصعب على عمل أي نشاطات رياضية أو تمارين 3 2 1 0 4 يصعب على رقع أي شيء ثقيل 4 3 2 1 0 بصعب على أن أستحم أو الحدّ دوش وحدى 3 2 1 0 4 0 يصعب على أن أعمل أي من الأعمال الروتيتية حول المنزل 3 2 1 4 ل اللم او أتوجع 3 2 1 0 4 مستوى طاقتى متدنى 3 2 1 0 4 يعض الأوقات نقريب مشكلة 15 to " 12 فهاتيا ليس "1" فيما يتعلق بمشاعري (مشائل في) 12:0 18:0 altin تا أشعر بالذوق 4 2 1 0 3 ك أشعر بالعزن 3 2 0 4 1 أنا أشعر بالغضب 0 1 4 3 2 ندى صعوبة في اللوم 3 2 Ü 4 1 أنا قلق مما قد بحصل لي 0 4 3 2 1 بعض الأوقنت غاليا" مشكلة تغريبا مشكلة تهاتيا ليست د لما" كيفيية إنسجامي مع الأخرين (مشاكل في.....) 516.3. alsin 25.34 لدي مشاكل في الإسجام مع الأطقال الأخرين 2 1 0 4 3 الاطفال الأخرون لاير غبوا في أن يكونوا اصدقالي 0 3 2 1 4 الأطفال الأخرون بضايقوني 2 1 0 4 3 الا استطيع عمل اشياء بستطيع عملها أشغال بنفس 0 4 3 2 1 عمرى الا استطيع أن المتابعة هينما ألعب مع الأطفال الأخرين 2 0 4 3 1 تاريبا مشكاة "Leitz غالبا" مشكلة بعض الأوقات نهانيا ليبت فرما بتعلق بالمدرسة (مشاكل في) 215.20 alcie ik: يصعب على الإلتباد في الصف 2 0 3 4 1 ألا أنسى الأشياء 4 3 2 1 0 لدي مسعوبة في متابعة واجباتي المدرسية 3 0 4 2 1 الله القوب عن المكرسة لألنى السعر باللي نست بغير إنه الغربي عن المكرسة لألني اذهب الى الطبيب أو 4 3 2 1 Ũ 4 3 2 1 0 مكتب القد للترجعة القاتونية المعتمدة 5.1

Brind For Authority



قائمة القلق المنقحة للأطفال " بماذا أفكر والشعر "

افر أكل سوال بتمعن ، ضع دائرة هول كلمة "تعم" لأا كلت صحيحة بالتسبة للا ، وضع دائرة هول كلَّمَّ ١٧٢٠ ان كلت تعقد أنها غير صحيحة .

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محمقنيه القوسادة

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F.

عادة ما السعر بالللق من شيء سيئ سيحدث لي

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Translatio

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مقيدس الإكتناب ، القلق ، و الضغوطات

The DASS 42

الأسبوع الماضي

لللم التريحي كالاتى:

لم تنفذق على نهائيا"" انطبقت على لدرجة ما ، أو في بعض الأوقائة انطبقت على بدرجة كابيرة ، أو في عثر فمعقر ، من الوقت انطبقت على كثير ا" أو في معظم الأوقائ.

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كُنْتُ فَرْبِياً" مِنْ لَقَزْعِ وجَنْتُ صَعَوِيَةً هَي أَنَّ أَهَدًا بِعَدَايَ شَيءَ أَرْعَجْنَي كُنْتُ خَانَفًا" مِنْ أَنَّ أَقَحَ فِي مِهمَاتَ تَخْفَهُ لَكَنَ غَيرِ مِحَدَّةً فَحَكَنَ فَقَدِراً" عَلَى عَلَى الأَبْثَرِ حَوْلَ أَي شَيء وَقِدَاتًا هُنِي حَدَّةً مُوقَرَّةٍ وَنَوَتَرَ كُنْتُهُ فِي حَدَّةً مُوقَرَّةٍ وَنَوَتَر

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جمة القانونية المعتمدة

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تعرق بشكل ملحوظ (مثل بداي متعرقة) يقياب اي حرارة علية أو مجهود جسمي

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لدى شعور بالدوخة

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شعرت بدلى كنت سريع الإستياء

شعرت بالكوف يدون أى سيب جود فـ هرت بالكوف يدون أى سيب جود وجدت صعوبة فى الإسترخاء وجدت صعوبة فى الإسترخاء لم استطع الحصول على المنعة من أى شئ كلت أقوم به لم استطع الحصول على المنعة من أى شئ كلت أقوم به

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شمرت يالعزن و الاكتاب أبه نفس أستنظ صبري هون أنافر بأي طريقة (مثل العواصلات، الفقر،الإشارات الضونيه، الانتقار)

اجد نفسي في مواقف نجعاني فلقا" . ولا أنسعر بالراحة الاحين النهائيها انسعر بانه لا بوجد ما تتطنع إليه

ندى إحساس بالإهتراق (مثل حركة قدمي) أجد صعوبة في الإسترخاء لنا أميل الى المبالغة في ردة فعلى للمواقف

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لجد نفسي لنضايق يسهولة اشعر أنني استنفذت كثير ١٠٠ من طاقتي العصبية

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وبندلي)

يظهر في بأني ند لحظى بأي شعور. إيدني على الإطلاق لدى صعوبة في انتنفس (مثل نفس منتابع و سريع ، انقطاع النفس بغرب اي مجهود يظهر فقط أني نم اعد قادرا"، على المتابعة والإستمرار

لجد نفسي منز عجا" لأنفه الأسباب

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3	2 1	0	الم أستطع روبة شيء في المستقبل للتفاول فية	37
3	2 1	0	وجدت المياة بلا مطي	38
3	2 1	0	اجد نفسي مهتاجا"	.39
3	2 1	0	كلت فلقا" من مواقف قد أرتعب فيها وأجعل من نقسي أحمقا"	40
3	2 1	0	ك ي شعور بالإرتعاش (مثلا رجفة اليدين)	41
3	2 1	0	وجدت صعوبة في لغذ المبادر ة لعمل الأشمياء	42

Back translation version of the PedsQL from Arabic into English

On the following page is a list of things that might be a problem for you, please tell me How Much each point have been a problem for you during the last month by circling:

- 0 if it is never a problem
- I almost wasn't a problem
- 2 if it was some times a problem
- 3 usually a problem
- 4 almost always a problem

There is no right or wrong answer.

If you didn't understand any question, please ask for help.

Related my Health and Activities (problems with)	Never a problem	Almost a problem	Some- times a	Usually a problem	Almost always problen
1. It is hard for me to walk more than one block	0	1	2	3	4
2. It is hard for me to run	0	1	2	3	4
3. It is hard for me to do any sport activities or exercise	0	l	2	3	4
4. It is hard for me to lift any things heavy	0	1	2	3	4
5. It is hard for me to take a bath or shower by my own	0	1	2	3	4
6. It is hard for me to do any of the routine works around the house	0	1	2	3	4
7. I have pain or ache	0	1	2	.3	4
8. Thave low energy	0	1	2	3	4

Related my feelings (problems with)	Never a problem	Almost a problem	Some- times a problem	Usually a problem	Almost always probler	
1. I feel afraid	0	1	2	3	4	
2.1 feel sad	0	1	2	3	4	
3. I feel angry	0	1	2	3	4	
4. I have trouble sleeping	0	1	2	3	4	
5. I am worried about what may happen to me.	0	1	2	3	4	

How I get along with others (problems with)	Never a problem	Almost a problem	Some- times a problem	Usually a problem	Almost always problen
1. I have problems getting along with other kids	0	1	2	3	4
2. other kids do not want to be my friends	0	1	2	3	4
3. other kids tease me	0	1	2	3	4
4. I can not do things other kids same age can do	0	1	2	3	4
5. I cant go on while I am playing with other kids	ŭ	I	2	3.48	Ureau

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Related school (problems with)	Never a problem	Almost a problem	Some- times a problem	Usually a problem	Almost always probler	
1. It is hard for me to pay attention in class	Ū.	1	2	3	4	
2. I forget things	0	1	2	3	4	
3. It is hard for me to keep up with my home work	0	1	2	3	4	
4. I miss school because I don't feel well	0	1	2	3	4	
5.1 miss school because I go to the doctor or hospital	0		2	3	4	

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Back translation version of RMAS from Arabic into English

Read each question carefully, put a circle around the word "Yes" if it is true about you, and put a circle around the word "No" if you think it is not true.

1	I find it hard to make up my mind	Yes	No
2	I feel nervous when things do not go the right way for me	Yes	No
3	Others can do things easier than me	Yes	No
4	1 like every one I know	Yes	No
5	Often I find it hard getting my breath	Yes	No
6	I worry a lot of time	Yes	No
7	I am afraid of a lot of things	Yes	No
8	I am always Kind	Yes	No
9	I get angry easily	Yes	No
10	I am worried about what my parent might say to me	Yes	No
11	I feel others doesn't like the way I do things	Yes	No
12	J always have good manners	Yes	No
13	It is hard for me to go to sleep at night	Yes	No
14	I am worried aboat what other people think about me	Yes	No
15	I feel alone even when there are people around me	Yes	No
16	I am always good	Yes	No
17	Often I feel pain in my stomach	Yes	No
18	My feelings get hurt easily	Yes	No
19	My hand always sweaty	Yes	No
20	I am always nice to every one	Yes	No
21	I am tired a lot	Yes	No
22	1 am worried about what is going to happen	Yes	No
23	Other kids are happier than I am	Yes	No
24	I tell the truth every time	Yes	No
25	I have bad dreams	Yes	No
26	My feelings get hurts easily when I am stricken	Yes	No
27	I feel some one will tell me that I am doing things in the wrong way	Yes	No
28	I never get angry	Yes	No
29	I wake up afraid some times	Yes	No
30	I worry when I go to bed at night	Yes	No
31	It is hard for me to keep my mind on my school works	Yes	No
32	I never say things I shouldn't say	Yes	No
33	I move in my seat a lot	Yes	No
34	I am nervous	Ves	No
35	A lot of people are against me	Ves	No
36	1 never lic	Ves	No
37	Often I feel worried about some thing had happening to me	Barning	163

Telefax: 00962.6.5346579 Jordan - Aminan University Str. - KPC Building 3rd Floor - Office # \$93

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Back translation Version of Depression, Anxiety, and Stress Scale (The DASS 42) From Arabic into English language

Please read each statement and circle a round number 0, 1, 2, or 3 which indicates how much the statement applied to you during the last week.

The rating scale as follow:

0 never apply to me

2 For

1 applied to me to some degree, or some times

2 applied to me a considerable degree, or significant time,

3 applied to me very much, or most of the time.

		1 0		-	-
1	I found my self getting upset by quite silly things	0	1	2	3
2	I was aware of my month dryness	0	1	2	3
3	It seems I have not experience any positive feeling at all	0	1	2	3
4	I have difficulty in breathing (e.g. excessive rapid breathing, breathlessness in absent of any physical exertion)	0	1	2	3
5	It seems just that I couldn't keep going	0	1	2	3
6	I tended to over react to situations	0	1	2	3
7	I have a feeling of shakiness (e.g. my legs movement)	0	1	2	3
8	I found it difficult to relax	0	1	2	3
9	I found my self in situations that make me stressed, and I felt just relieved when they ended	0	1	2	3
10	I feel there is nothing to look forward to	0	1	2	3
11	I found my self getting upset easily	0	1	2	3
12	I felt that I had spent a lot of my nervous energy	0	1	2	3
13	I felt sad and depressed	0	1	2	3
14	I found my self getting impatient when I am delayed in any way (e.g. traffics, lifts, traffics light, or waiting)	0	1	2	3
15	I had a feeling of faintness	0	1	2	3
16	I feel I lost interest in every thing around me	0	1	2	3
17	I feel I don't worth much as a person	0	1	2	3
18	I felt I was so touchy	0	1	2	3
19	I perspired noticeably, (e.g. my hands sweaty) with absence of any physical exertion	0	1	2	3
20	I felt afraid with out any good reason	0	1	2	3
21	I felt life is worthless	0	1	2	3
22	I found it hard to relax	0	1	2	3
23	I had difficulty in swallowing	0	1	2	3
24	I was unable to feel enjoyment about any thins I do	0	1	2	3
25	I was aware of my heart action in absent of any physical exertion (e.g. rapid heart rate, missed heart beat)	0	1	2	3
26	I felt blue	0	1	2	3
27	1 was very irritable	0	1	2	3
28	I was close to panic	0	1	2	3
29	I found it difficult to relax after any things upset me	Burg	ar	2	3

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30	I was afraid of being involved in trivial but unfamiliar task	0	1	2	3
31	I was un able to become enthusiastic about any thing	0	1	2	3
32	I was unable to tolerate any interruption for some thing I was doing	0	1	2	3
33	I was in a state of nervousness and tension	0	1	2	3
34	I felt I was worthless	0	1	2	3
35	I was unable to tolerate any thing that keep me away from getting on with what I was doing	0	1	2	3
36	1 felt terrified	0	1	2	3
37	I couldn't see any thing in the future to be hope full about	0	1	2	3
38	I found life meaningless	0	1	2	3
39	I found my self agitated	0	1	2	3
40	I was worried about situations I might panic and make my self like a jerk	0	1	2	3
41	I experience trembling (e.g. shakings of my hand)	0	1	2	3
42	I found it difficult to take the initiative to do things.	0	1	2	3

Appendix D.1.

التاريخ:-----

يسم الله الرحمن الرحيم

عزيزى والد/ والدة الطفل

هذا الإستبيان يبحث في نوعية الحياة لدى الأطفال من منظور صحي, وقد تم تعريب هذا الإستبيان من اللغة الإنجليزية الى العربية لأغراض البحث العلمي, ولدراسة مدى ملائمة هذة الأداة في قياس نوعية الحياة لدى الطفل في المجتمع الأردني أرجو منك تعبنة هذا الاستبيان حول طفلك ثم السماح لطفلك بتعبنة الجزء المتطق به. الطفل في المجتمع الأردني أرجو منك تعبنة هذا الاستبيان حول طفلك ثم السماح لطفلك بتعبنة الجزء المتطق به. إن مشاركة طفلك و رأيه في مدى وضوح هذه الأداة للقياس هامة جدا" وستغني الدراسة من حيث المساعدة في وضع الخطط المستقبلية الجديدة لتحسين أداة تقييم نوعية الحياة للأطفال في المجتمع الأردني من منظور صحي. وضع الخطط المستقبلية الجديدة لتحسين أداة تقييم نوعية الحياة للأطفال في المجتمع الأردني من منظور صحي. وضع الخطط المستقبلية الجديدة لتحسين أداة تقييم نوعية الحياة للأطفال في المجتمع الأردني من منظور صحي. وضع الخطط المستقبلية الجديدة لتحسين أداة تقييم نوعية الحياة للأطفال في المجتمع الأردني من منظور صحي. وضع الخطط المستقبلية الجديدة لتحسين أداة تقييم نوعية الحياة للأطفال في المجتمع الأردني من منظور صحي. وضع الخطط المستقبلية الجديدة للغال من وعية الحياة للأطفال في المجتمع الأردني من منظور صحي. وضع الخطط المستقبلية الجديدة لتحسين أداة تقييم نوعية الحياة الأطفال في المجتمع الأردني من منظور صحي. وضع المع المستقبلية المناء المدراسة فقط وستعامل بسرية تامة, إن مشاركة طفلك في الدراسة ليست إجبارية وفي الإمكان الانسحاب من الدراسة في أى وقت. إذا كان لديك أية أسنلة أو رغبت في معرفة نتائج البحث في وفي الإمكان الانسحاب من الدراسة في أى وقت. إذا كان لديك أية أسنلة أو رغبت في معرفة نتائج البحث في وفي الإمكان الانسحاب من الدراسة في أى وقت. إذا كان لديك أية أسنلة أو رغبت في معرفة نتائج البحث في وفي الإمكان الاسحاب من الدراسة في أى وقت. إذا كان لديك أية أسنلة أو رغبت في معرفة نتائج البحث في وفي الإمكان الاسحاب من الدراسة في أى وقت. إذا كان لديك أية أسنلة أو رغبت في معرفة نتائج البحث في الفي وفي الإمكان الاسحاب من الدراسة في أى وقت. إذا كان لديك أول المنة أو رغبت في معرفة نتائج البحث في الم

مع جزيل الشكر

ديانا عربيات

Appendix D.2.

الرقم #
التاريخ :

PedsQLтм Pediatric Quality of Life Inventory (Arabic)

Version 4.0

) PedsQLنو عية الحياة لدى الأطفال (نموذج الطفل (من عمر 8- 12 سنة)



خلال الشبهر الماضي, كم كانت مشكلة لك

دائما" مشكلة	غالبا" مشكلة	بعض الأوقات مشكلة	تقریبا لم تکن مشکلة	نهائيا ليست مشكلة	فيما يتعلق بصحتي و نشاطي
4	3	2	1	0	يصعب على أن أسير أكثر من مسافة مجمع
4	3	2	1	0	يصعب على أن أركض
4	3	2	1	0	يصعب على عمل أي نشاطات رياضية أو تمارين
4	3	2	1	0	يصعب على رفع أى شيء ثقيل
4	3	2	1	0	يصعب على أن أستحم أو أخذ دوش وحدي
4	3	2	1	0	يصعب على أن أعمل أي من الأعمال الروتينية حول المنزل
4	3	2	1	0	أنا أتالم أو أتوجع
4	3	2	1	0	مستوى طاقتي متدني

دائما" مشکلة	غالبا" مشكلة	بعض الأوقات مشكلة	تقريبا لم تكن مشكلة	نهانيا ليست مشكلة	فيما يتعلق بمشاعري (مشاكل في)
4	3	2	1	0	أنا أشعر بالخوف
4	3	2	1	0	أنا أشعر بالحزن
4	3	2	1	0	أنا أشعر بالغضب
4	3	2	1	0	لدي صعوبة في النوم
4	3	2	1	0	أنا قلق مما قد يحصل لي

دائما" مشكلة	غالبا" مشكلة	بعض الأوقات مشكلة	تقريبا لم تكن مشكلة	نهانيا ليست مشكلة	كيفيية إنسجامي مع الآخرين (مشاكل في)
4	3	2	1	0	لدي مشاكل في الإنسجام مع الأطفال الآخرين
4	3	2	1	0	الأطفال الآخرون لا يرغبوا في أن يكونوا أصدقاني
4	3	2	1	0	الأطفال الآخرون يضايقوني
4	3	2	1	0	أنالا أستطيع عمل أشياء يستطيع عملها أطفال بنفس
					عمري
4	3	2	1	0	أنا لاأستطيع أن المتابعة حينما ألعب مع الأطفال الآخرين

(مشاكل في) نهانيا ليست تقريب مشكلة من	نهائيا ليست مشكلة	تقريبا لم تكن مشكلة	بعض الأوقات مشكلة	غالبا" مشكلة	دائما" مشكلة
في الصف	0	1	2	3	4
0	0	1	2	3	4
عة واجباتي المدرسية 0	0	1	2	3	4
سة لأننى أشعر بأنني لست بخير 0	0	1	2	3	4
سة لأنني أذهب الى الطبيب أو 0	0	1	2	3	4
Appendix D.3. Back translation version of the PedsQLTM from Arabic into English

(Children 8-12 years)

On the following page is a list of things that might be a problem for you, please tell me **How Much** each point have been a problem for you during the last month by circling:

0 if it is never a problem
1 almost wasn't a problem
2 if it was some times a problem
3 often a problem
4 almost always a problem

There is no right or wrong answer. If you didn't understand any question, please ask for help.

Related my Health and Activities (problems with)	Never a problem	Almost a problem	Some- times a problem	Often a problem	Almost always a problem
1. It is hard for me to walk more than one block	0	1	2	3	4
2. It is hard for me to run	0	1	2	3	4
3. It is hard for me to do any sport activities or exercise	0	1	2	3	4
4. It is hard for me to lift any things heavy	0	1	2	3	4
5. It is hard for me to take a bath or shower by my own	0	1	2	3	4
6. It is hard for me to do any of the routine works around the house	0	1	2	3	4
7. I have pain or ache	0	1	2	3	4
8. I have low energy	0	1	2	3	4

Related my feelings (problems with)	Never a problem	Almost a problem	Some- times a problem	Often a problem	Almost always a problem
1. I feel afraid	0	1	2	3	4
2. I feel sad	0	1	2	3	4
3. I feel angry	0	1	2	3	4
4. I have trouble sleeping	0	1	2	3	4
5. I am worried about what may happen to me.	0	1	2	3	4

How I get along with others (problems with)	Never a problem	Almost a problem	Some- times a problem	Often a problem	Almost always a problem
1. I have problems getting along with other kids	0	1	2	3	4
2. other kids do not want to be my friends	0	1	2	3	4
3. other kids tease me	0	1	2	3	4
4. I can not do things other kids same age can do	0	1	2	3	4
5. I cant go on while I am playing with other kids	0	1	2	3	4

Related school (problems with)	Never a problem	Almost a problem	Some- times a problem	Often a problem	Almost always a problet
1. It is hard for me to pay attention in class	0	1	2	3	4
2. I forget things	0	1	2	3	4
3. It is hard for me to keep up with my home work	0	1	2	3	4
4. I miss school because I don't feel well	0	1	2	3	4
5. I miss school because I go to the doctor or hospital	0	1	2	3	4

Appendix D.4.

الرقم #
التاريخ :

PedsQLтм Pediatric Quality of Life Inventory (Arabic)

Version 4.0

)PedsQL نوعية الحياة لدى الأطفال (نموذج المراهقين (من عمر 13- 18 سنة)

ارشادات

في الصفحة التالية قائمة بأشياء قد تكون مشكلة بالنسبة لك , رجاءا" أخبرني ما حجم المشكلة لكل نقطة بالنسبة لك في قترة التشهر الماضي عن طريق وضع دائرة حول:

0 إذا لم تكن مشكلة نهانيا"
1 تقريبا" لم تكن مشكلة
2 إذا كانت مشكلة في بعض الأوقات
3 عادة مشكلة
4 دائما" وفي معظم الأوقات مشكلة
4 توجد إجابة صحيحة أو خاطئة ,
اذا لم تفهم أى سؤال, أرجوك أن تسأل لأى مساعدة.

خلال الشهر الماضي, كم كانت مشكلة لك

دائما" مشكلة	غالبا" مشكلة	بعض الأوقات مشكلة	تقريبا لم تكن مشكلة	نهانيا ليست مشكلة	فيما يتعلق بصحتي و نشاطي
4	3	2	1	0	يصعب على أن أسيرفي الشارع مسافة قصيرة
4	3	2	1	0	يصعب على أن أركض
4	3	2	1	0	يصعب على عمل أي نشاطات رياضية أو تمارين
4	3	2	1	0	يصعب على رفع أى شيء ثقيل
4	3	2	1	0	يصعب على أن أستحم أو أخذ دوش وحدي
4	3	2	1	0	يصعب على أن أعمل أي من الأعمال الروتينية حول المنزل
4	3	2	1	0	انا أتألم أو أتوجع
4	3	2	1	0	مستوى طاقتي متدني

دائما" مشكلة	غالبا" مشكلة	بعض الأوقات مشكلة	تقريبا لم تكن مشكلة	نهانيا ليست مشكلة	فيما يتعلق بمشاعري (مشاكل في)
4	3	2	1	0	أنا أشعر بالخوف
4	3	2	1	0	أنا أشعر بالحزن
4	3	2	1	0	أنا أشعر بالغضب
4	3	2	1	0	لدي صعوبة في النوم
4	3	2	1	0	أنا قلق مما قد يحصل لي

دائما" مشكلة	غالبا" مشكلة	بعض الأوقات مشكلة	تقريبا مشكلة	نهانيا ليست مشكلة	كيفيية إنسجامي مع الأخرين (مشاكل في)
4	3	2	1	0	لدي مشاكل في الإنسجام مع من هم في عمري
4	3	2	1	0	من هم في عمري لا يرغبوا في أن يكونوا أصدقائي
4	3	2	1	0	من هم في عمري يضايقوني
4	3	2	1	0	أنا لا أستطيع عمل أشياء يستطيع عملها من هم بنفس عمري
4	3	2	1	0	أنا لاأستطيع الاستمرار حينما ألعب مع الآخرين

فيما يتعلق بالمدرسة (مشاكل في)	نهانيا ليست مشكلة	تقريبا لم تكن مشكلة	بعض الأوقات مشكلة	غالبا" مشكلة	دائما" مشكلة
يصعب على الإنتباه في الصف	0	1	2	3	4
أنا أنسى الأشياء	0	1	2	3	4
لدي صعوبة في متابعة واجباتي المدرسية	0	1	2	3	4
أنا أتغيب عن المدرسة لأننى أشعر بأننى لست بخير	0	1	2	3	4
أنا أتغيب عن المدرسة لأنني أذهب الى ألطبيب أو المستشفى	0	1	2	3	4

Appendix D.5. Back translation version of the PedsQL from Arabic into English (Children 13- 18 years)

On the following page is a list of things that might be a problem for you, please tell me **How Much** each point have been a problem for you during the last month by circling:

0 if it is never a problem
1 almost wasn't a problem
2 if it was some times a problem
3 often a problem
4 almost always a problem

There is no right or wrong answer. If you didn't understand any question, please ask for help.

Related Health and Activities (problems with)	Never a problem	Almost a problem	Some- times a problem	Often a problem	Almost always problen
1. It is hard for me to walk in the street a short	0	1	2	3	4
distance.					
2. It is hard for me to run.	0	1	2	3	4
3. It is hard for me to do any sport activities or	0	1	2	3	4
exercise					
4. It is hard for me to lift any things heavy.	0	1	2	3	4
5. It is hard for me to take a bath or shower by my	0	1	2	3	4
own.					
6. It is hard for me to do any of the routine works	0	1	2	3	4
around the house.					
7. I have pain or ache	0	1	2	3	4
8. I have low energy	0	1	2	3	4

Related feelings (problems with)	Never a problem	Almost a problem	Some- times a problem	Often a problem	Almost always problen
1. I feel afraid	0	1	2	3	4
2. I feel sad	0	1	2	3	4
3. I feel angry	0	1	2	3	4
4. I have trouble sleeping	0	1	2	3	4
5. I worry about what may happen to him	0	1	2	3	4

How he get along with others (problems with)	Never a problem	Almost a problem	Some- times a problem	Often a problem	Almost always problem
1. I have trouble getting along with others kids	0	1	2	3	4
2. other kids do not want to be my friends	0	1	2	3	4
3. other kids tease me	0	1	2	3	4
4. I can not do things that other kids can do	0	1	2	3	4
5. I cant go on while playing with others	0	1	2	3	4

Related school (problems with)	Never a problem	Almost a problem	Some- times a problem	Often a problem	Almost always problem
1. It is hard to pay attention in class	0	1	2	3	4
2. I forget things	0	1	2	3	4
3.It is hard for me to keep up with home work	0	1	2	3	4
4. I miss school because he don't feel well	0	1	2	3	4
5. I miss school because he go to the doctor or hospital	0	1	2	3	4

Appendix D.6.

	الرقم #
	التاريخ :
10000	

PedsQLтм Pediatric Quality of Life Inventory (Arabic)

Version 4.0

) PedsQL نوعية الحياة لدى الأطفال (نموذج الطفل (من عمر 8- 12 سنة)

ار شادات فى الصفحة التالية قائمة بأشياء قد تكون مشكلة بالنسبة لك, رجاءا" أخبرنى ما حجم المشكلة لكل نقطة بالنسبة لك في فترة الشهر الماضى عن طريق وضع دانرة حول: 0 إذا لم تكن مشكلة نهائيا" 1 تقريبا" لم تكن مشكلة 2 إذا كانت مشكلة في بعض الأوقات 3 عادة مشكلة 4 دائما" وفي معظم الأوقات مشكلة لا توجد إجابة صحيحة أو خاطئة, اذا لم تفهم أى سؤال. أرجوك أن تسأل لأى مساعدة.

خلال الشهر الماضي, كم كانت مشكلة لك

دائما" مشكلة	غالبا" مشكلة	بعض الأوقات مشكلة	تقریبا لم تکن مشکلة	نهائيا ليست مشكلة	فيما يتعلق بصحتي و نشاطي
4	3	2	1	0	يصعب على أن أسير أكثر من مسافة مجمع
4	3	2	1	0	يصعب على أن أركض
4	3	2	1	0	يصعب على عمل أي نشاطات رياضية أو تمارين
4	3	2	1	0	يصعب على رفع أى شيء ثقيل
4	3	2	1	0	يصعب على أن أستحم أو أخذ دوش وحدي
4	3	2	1	0	يصعب على أن أعمل أي من الأعمال الروتينية حول المنزل
4	3	2	1	0	أنا أتألم أو أتوجع
4	3	2	1	0	مستوى طاقتي متدني

دائما" مشكلة	غالبا" مشكلة	بعض الأوقات مشكلة	تقريبا لم تكن مشكلة	نهائيا ليست مشكلة	فيما يتعلق بمشاعري (مشاكل في)
4	3	2	1	0	أنا أشعر بالخوف
4	3	2	1	0	أنا أشعر بالحزن
4	3	2	1	0	أنا أشعر بالغضب
4	3	2	1	0	لدي صعوبة في النوم
4	3	2	1	0	أنا قلق مما قد يحصل لي

ة إنسجامي مع الآخرين (مشاكل في)	نهانيا ليست مشكلة	تقريبا لم تكن مشكلة	بعض الأوقات مشكلة	غالبا" مشكلة	دائما" مشكلة
مشاكل في الإنسجام مع الأطفال الآخرين	0	1	2	3	4
ال الآخرون لا يرغبوا في أن يكونوا أصدقاني	0	1	2	3	4
ال الآخرون يضايقوني	0	1	2	3	4
أستطيع عمل أشياء يستطيع عملها أطفال بنفس	0	1	2	3	4
ي	Section with	Secondaria anda	and the second second	and the second second	
ستطيع أن المتابعة حينما ألعب مع الأطفال الآخرين	0	1	2	3	4

فيما يتعلق بالمدرسة (مشاكل في)	نهانيا ليست مشكلة	تقريبا لم تكن مشكلة	بعض الأوقات مشكلة	غالبا" مشكلة	دائما" مشکلة
يصعب على الإنتباه في الصف	0	1	2	3	4
أنا أنسبى الأشبياء	0	1	2	3	4
لدي صعوبة في متابعة واجباتي المدرسية	0	1	2	3	4
أنا أتغيب عن المدرسة لأنني أشعر بأنني لست بخير	0	1	2	3	4
أنا أتغيب عن المدرسة لأنني أذهب الى الطبيب أو	0	1	2	3	4
المستشفى					111111111

Appendix D.7. Back translation version of the PedsQL from Arabic into English (Parent of Children 8- 12 years)

On the following page is a list of things that might be a problem for your child, please tell me **How Much** each point have been a problem for your child during the last month by circling:

- 0 if it is never a problem1 almost wasn't a problem2 if it was some times a problem
- 3 often a problem
- 4 almost always a problem

There is no right or wrong answer.

If you didn't understand any question, please ask for help.

Related Health and Activities (problems with)	Never a problem	Almost a problem	Some- times a problem	Often a problem	Almost always problem
1. to walk in the street a short distance	0	1	2	3	4
2. to run	0	1	2	3	4
3. to do any sport activities or exercise	0	1	2	3	4
4. to lift any things heavy	0	1	2	3	4
5. to take a bath or shower by my own	0	1	2	3	4
6. to do any of the routine works around the	0	1	2	3	4
house					
7. he have pain or ache	0	1	2	3	4
8. he have low energy	0	1	2	3	4

Related feelings (problems with)	Never a problem	Almost a problem	Some- times a problem	Often a problem	Almost always problen
1. he feel afraid	0	1	2	3	4
2. he feel sad	0	1	2	3	4
3. he feel angry	0	1	2	3	4
4. he have trouble sleeping	0	1	2	3	4
5. he worry about what may happen to him	0	1	2	3	4

How he get along with others (problems with)	Never a problem	Almost a problem	Some- times a problem	Often a problem	Almost always problen
1. getting along with other kids	0	1	2	3	4
2. other kids do not want to be his friend	0	1	2	3	4
3. other kids tease him	0	1	2	3	4
4. can not do things that other kids can do	0	1	2	3	4
5. cant go on while playing with other kids	0	1	2	3	4

Related school (problems with)	Never a problem	Almost a problem	Some- times a problem	Often a problem	Almost always problem
1. to pay attention in class	0	1	2	3	4
2. forget things	0	1	2	3	4
3. to keep up with home work	0	1	2	3	4
4. he miss school because he don't feel well	0	1	2	3	4
5. he miss school because he go to the doctor or hospital	0	1	2	3	4

Appendix E.1.

مطومات عامة حول البحث

ماهو الهدف من هذه الدراسة?

حوادث الحياة لها تأثير كبير على حياة اطفالنا، هذه الدراسة تستقصي تأثير هذه الاحداث على حياة الطفل، وبالتالي على مستوى الضغوطات النفسية للطفل والعائلة الاردنية، نأمل ان ما سيتم جمعه من معلومات في هذا البحث سيؤدي بدورة الى فهم اكبر، وتحسين لمستوى الدعم المقدم لهؤلاء الاطفال وأسر هم في المستقبل. وهي جزء من متطلبات حصولي على درجة الدكتوراة من University of Hull/Yorkshire في بريطانيا.

مالذي يترتب عليه مشاركتي أنا وطفلي في هذه الدراسة?

ما يعنينا في هذه الدراسة هو تأثير الضغوطات النفسية على طفلك، وبالتالي تأثيره على العائلة من خلال اجابة بعض الأسئلة عبر وضع دائرة حول احد الخيارات المرفقة لكل سؤال، او تعليقك حوله.

متى وأين سبيتم اعطائي الاستبيان لتعبنته?

ان قائمة الاستبيانات مرفقة مع ورقة المعلو مات، اذا كنت تسعد لمساعدتنا في هذه الدراسة، رجاءا قم بتوقيع الموافقة الخطية، ثم بامكانك البدء بتعبنة الاستبيان في اى وقت متاح لك سواء في المدرسة أو المنزل، اذا تعذر عليك تعبنته الان، سأكون في غاية الامتنان ان امكنك تعبنة الاستبيان وار فاقة مع الموافقة الخطية في الملف المرفق، علما ان الطوابع البريدية مرفقة مع الطلب.

ماهى المطومات الأخرى التي سبيتم جمعها في هذه الدراسة ?

لا شيّ أخر، ما يعنينا في هذه الدراسة هو الأعراض القلقية و الاكتنابية, ولن نحتاج بأي شكل الي فحص طفلك.

هل ستتأثر علا مات طفلي أو علاقتة بالمدرسة اذا قررت المشاركة في هذه الدراسة?

لا، ان مشاركتك في هذه الدراسة لا تمت بصلة بتحصيل طفلك الدراسي أو علاقته في هذه المدرسة الان او في ا المستقبل.

هل يمكنني الانسداب وعدم المشاركة في البحث متى أردت فلك?

نعم، بامكانك رفض المشاركة في هذه الدراسة، ويمكنك الانسحاب من البحث في اي وقت تختاره، أو الامتناع عن اجابة اي سؤال لا تود اجابته، وسيتلقى طفلك نفس المعاملة بغض النظر عن مشاركتك في هذه الدراسة وعدمها.

هل ستعامل المعلومات بسيرية ?

أى اجابات أو معلومات تقوم بإعطائها ستعامل بسرية تامة، لن يتم ذكر أى أسماء في أى تقرير في هذه الدراسة، وسيؤخذ بعين الاعتبار أن لا يتم التعرف على أى شخص شارك في هذه الدراسة عبر أى من التفاصيل الواردة في تقارير أو نتائج هذه الدراسة.

هل سيتم اخبار أى شخص آخر?

بالاتفاق المسبق معك يمكننا إخبار المرشد الاجتماعي انك تساعدنا في هذا البحث، هو/هي لن يعرف اجابتك أو إجابة طفلك، لكن سيتم ارسال ملخص له حول نتانج هذه الدراسة.

مطومات عامة حول البحث

Appendix E.2.

ماهو الهدف من هذه الدراسة ?

بعض الامراض المزمنة لها تأثير كبير على حياة اطفالنا، هذه الدراسة تستقصي تأثير هذه الأمراض على حياة الطفل، وبالتالي على مستوى الضغوطات النفسية للطفل والعائلة الاردنية، نأمل ان ما سيتم جمعه من معلومات في هذا البحث سيؤدي بدورة الى فهم اكبر، وتحسين لمستوى الدعم المقدم لهؤلاء الاطفال وأسر هم في المستقبل. و هي جزء من متطلبات حصولي على درجة الدكتوراة من University of Hull/Yorkshire في بريطانيا.

مالذي يترتب عليه مشاركتي أنا وطفلي في هذه الدراسة?

ما يعنينا في هذه الدراسة هو تأثير المرض على طفلك، وبالتالي تأثيره على العائلة من خلال اجابة بعض الأسنلة. عبر وضع دائرة حول احد الخيارات المرفقة لكل سؤال، او تعليقك حوله.

متى وأين سيتم اعطائي الاستبيان لتعبَّته ?

ان قائمة الاستبيانات مرفقة مع ورقة المعلومات،اذا كنت تسعد لمساعدتنا في هذه الدراسة، رجاءا قم بتوقيع الموافقة الخطية، ثم بامكانك البدء بتعبنة الاستبيان في اى وقت متاح لك سواء في العيادة المستشفى،أو المنزل، اذا تعذر عليك تعبنته الان، سأكون في غاية الامتنان ان امكنك تعبنة الاستبيان وار فاقة مع الموافقة الخطية في الملف المرفق، علما ان الطوابع البريدية مرفقة مع الطلب.

ماهى المطومات الأخرى التي سبيتم جمعها في هذه الدراسة?

لا شئ آخر، ما يعنينا في هذه الدراسة هو الأعراض القلقية و الاكتنابية, ولن نحتاج بأى شكل الى فحص طفلك، لكن قد نأخذ من ملف طفلك معلومات تتعلق بتشخيصة الطبي، تاريخ تشخيص المرض والعلاجات.

هل سيتأثر علاج طفلي وعلاقتة بالمستشفى اذا قررت المشاركة في هذه الدراسة ?

لا، ان مشاركتك في هذه الدراسة لا تمت بصلة بعلاج طفلك في هذا المستشفى الان او في المستقبل.

هل يمكنني الانسحاب وعدم المشاركة في البحث متى أردت ذلك?

نعم، بامكانك رفض المشاركة في هذه الدراسة، ويمكنك الانسحاب من البحث في اي وقت تختاره، أو الامتناع عن اجابة اى سؤال لا تود اجابته، وسيتلقى طفلك نفس الرعاية الصحية ونوعية العلاج بغض النظر عن مشاركتك في هذه الدراسة وعدمها.

هل ستعامل المعلومات بسيرية?

أى اجابات أو معلومات تقوم بإعطائها ستعامل بسرية تامة، لن يتم ذكر أى أسماء في أى تقرير في هذه الدراسة، وسيؤخذ بعين الاعتبار أن لا يتم التعرف على أى شخص شارك في هذه الدراسة عبر أى من التفاصيل الواردة في تقارير أو نتائج هذه الدراسة.

هل سيتم اخبار أى شخص آخر?

بالاتفاق المسبق معك يمكننا إخبار طبيب طفلك انك تساعدنا في هذا البحث، هو/هي لن يعرف اجابتك أو إجابة طفلك، لكن سيتم ارسال ملخص له حول نتانج هذه الدراسة.

Research consent Form

الموافقة الخطية للمشاركة في البحث

Jordanian Oncology Paedi Remission, Quality of Life presentation of Psychologi distress عربيات.	اسم البحث : atrics in and symptoms cal اسم الباحث: ديانا هاشم	Official code ()
	ذا النموذج بانفسهم	يجب على الاهل تعبنة ه
نعم لا		هل قرأت ورقة المطومات المرفقة عن البحث
نعم لا	بحث	هل تلقيت معلومات كافية حول ماهية موضوع ال
نعم لا	: محاب من الدراسة مستشقى او العاملين فيه	هل انت مدرك ان بامكانك الانسحاب من الدراسة في اى وقت اردت ذلك دونما ابداء اي اسباب لرغبتك في الانس دونما اى تأثير على علاقتك مع هذا اله
نعم لا		هل توافق على المشاركة في هذه الدراسة
نعم لا	ك في هذه الدراسة لبيب طفلك هنا	هل تمانع اخبار الطبيب المعالج عن مشاركة طفلا اذا كانت اجابتك نعم، رجاء ارفق اسم وعنوان ط
		التوقيع الاسم التاريخ

أقر بأنني قد قرأت إ أو ترجمت للمشارك بدقة هذه المعلومات



توقيع الباحث الزنيسي _

Appendix E.4.



King Hussein Cancer Center

Institutional Review Board

عنوان البحث :

Jordanian Oncology Pediatrics in Remission; quality of life and symptoms presentation of psychological distress

الجزء الأول - معلومات للمشارك في البحث:

أ. الغرض من البحث: بعض الامراض المزمنة لها تأثير كبير على حياة اطفالنا، هذه الدراسة تستقصى تأثير هذه الأمراض على حياة الطفل، وبالتالى على مستوى الضغوطات النفسية للطفل والعائلة الاردنية، نأمل ان ما سيتم جمعه من معلومات فى هذا البحث سيؤدى بدورة الى فهم اكبر،وتحسين لمستوى الدعم المقدم لهؤلاء الاطفال وأسرهم فى المستقبل. وهى جزء من متطلبات حصولى على درجة الدكتوراة منUniversity of Hull/Yorkshire فى بريطانيا.

ب. وصف البحث:

تعنى هذه الدراسة بنوعية الحياة وعوارض القلق والأكتئاب للطفل الأردنى بشكل عام ومرضى السرطان بشكل خاص ما يعنينا فى هذه الدراسة هو الأعراض القلقية و الاكتئابية, ولن نحتاج بأى شكل الى فحص طفلك، لكن قد نأخذمن ملف طفلك معلومات تتعلق بتشخيصة الطبى، تاريخ تشخيص المرض والعلاجات. ان قائمة الاستبيانات مرفقة مع ورقة المعلو مات ، اذا كنت تسعد لمساعدتنا فى هذه الدراسة، رجاءا قم بتوقيع الموافقة الخطية، ثم بامكانك البدئ بتعبئة الاستبيان فى اى وقت متاح لك سواء فى العيادة -المسشفى، أو المنزل، (اذا تعذر عليك تعبئته الان، سأكون فى غاية الامتنان ان امكنك عبئة الاستبيان وارفاقة مع الموافقة الخطية فى العيادة -علمان الطوابع البريدية مرفقة مع الطاب).

ج... المخاطر والانز عاجات المحتملة:

لم يورد سابقا اى آثار مزعجة للمشاركة في در اسات مشابهة لهذا البحث في دول من العالم والتي اشتملت في اغلبها على اطفال من الولايات المتحدة و بريطانيا, كما يتوقع ان لا تتسبب مشاركتك بآثار مزعجة.

الفوائد المحتملة:

وجد فائدة مباشرة للمشاركة في هذا البحث، إن مشاركتك في هذ ه	<u>لا ت</u>
اسبة لاتمت بصلة بعلاج طفلك في هذاالمستشفى الان او في المستقبل.	الدر
فاف المسبق معك يمكننا إخبار طبيب طفلك انك تساعدنا في هذا البحث،	بالات
هى لن يعرف اجابتك أو إجابة طفلك، لكن سيتم ارسال ملخص له حول	<u>ھو /</u>
ج هذه الدراسة لاخبارك بالنتائج العامة.	نتاك

<u>لا يوجد.</u>

إنهاء المشاركة (إذا أمكن):

الانسحاب من البحث في	بامكانك رفض المشاركة في هذه الدراسة، ويمكنك
لا تود اجابته، وسيتلقى	اى وقت تختاره، أو الامتناع عن اجابةاي سؤال
النظر عن مشاركتك في	طفلك نفس الرعاية الصحية ونوعية العلاج بغض
	هذه الدراسة أو عدمها.

ح. التعويضات / المعالجات: ا**لتعويضات المادية /المعنوية او المعالجات غير واردة**

ط. المشاركة التطوعية:

المشاركة في هذه الدراسة طوعيه وإذا قررت عدم المشاركة فانك لن تتعرض لأي مضايقات أو لفقدان حقك المشروع في المعالجة ، كما أن قرارك بالانسحاب من الدراسة لن يؤثر علي تلقيك لخدمة علاجية بديلة متوفرة في مركز الحسين للسرطان0 سيتم إبلاغك بأي نتائج هامة جديدة تظهر خلال تطورات البحث مما قد يؤثر بطريقة معقولة على رغبتك في الاستمرار بالمشاركة في هذه الدراسة0

الدكتور 1-ب كما أوافق على أخذ عينات من سوائل أو أنسجة الجسم لأغراض البحث (أنكر الكمية _ أو أحد المشاركين معه بمركز الحسين نعوبلة الجزء الثاني: تفويض من المشارك بالدراسة التي لا يتوقع أن يكون لها فائدة مباشرة 1280 لتوجيه أي أسئلة عامة تتعلَّق بحقوق. وفي حالة وجود أسئلة محدَّدة تتعلَّق في حالة وجود أي استفسار عليك الاتصال على هاتف رقم 5353000 فرعي المنشورات المتعلقة بنتائج الدراسة كما سيبقي رقم سجلك الطبي سري في الحدود كمشارك في هذه الدراسة ستكون هويتك ومحتويات ملفك الطبّي سربة في جميع بهذا البحث أو في حالة حدوث أي إصابات تتصل بالدراسة، نرجو الاتصال على التي يسمح بها القانون ويمكن الإطلاع عليه من قبل المجلس الاستشاري للأبحاث أو بهذا أتطوع للمشاركة في هذا البرنامج البحثي تحت إشراف الوكيل الداعم للدراسة في حدود النظم والقوانين المطبقة بهذا الخصوص0 على هاتف رقم ___ للسرطان والمتضمن هذه الحالات، الأدوية، أو الإجراءات الطبية0 سيتم تزويدك بنسخة موقعة من هذا الإقرار 0 ك. الأشخاص الذين يمكن الاتصال بهم: رقم السجل الطبي أو العنوان : الدكتور ا کو اسم المشارك : للمشارك:

ي. السرية:

وعدد المرات)

2. أقر بأنني قد قرأت – أو شرح لي بلغة مفهومة لدي – هذه المعلومات المتعلقة بمشاركتي في هذا البحث وأن الدكتور / ______ قد أوضح لي طبيعة وأهداف هذه الدراسة ومدي كونها تجريبية (إن كانت كذلك) والآثار الجانبية أو الانز عاجات أو الأعراض أو المخاطر المتوقع حدوثها وجميع المضاعفات الممكنة إن وجدت والناتجة عن أسباب معروفة أو غير معروفة مرتبطة بالدراسة كما أقر بأنه قد أتيحت لي الفرصة لتوجيه جميع الأسئلة المتعلقة بموضوع الدراسة وتلقيت الإجابات الشافية 0

3. أفهم بأن هذه الدراسات ليست لها أي فائدة علاجية مباشرة لي ومع ذلك أتطوع بالمشاركة فيها مع علمي بالمخاطر والانز عاجات الناتجة عنها0

 من المفهوم لدي بأنني استحق استرداد المصروفات التي نتجت عن مشاركتي في هذه الدراسة.

5. كما أفهم بأنه ومن أجل الحصول على المعلومات التي يمكن من خلالها تقييم كفاءة وفعالية هذه الدراسات فان الدكتور: ______ أو أحد المشاركين معه قد يجرون لي بعض الفحوصات التشخيصية الأولية بعد أن يتم شرحها لي تفصيلا0 وأنه إذا وجد بها أي نتائج غير طبيعية فمن الممكن إنهاء مشاركتي بهذه الدراسة0

كما أقر بأنني لا أعاني من أي مشاكل طبية أو نفسية معروفة لدي بحيث يكون من غير الحكمة قبول مشاركتي بهذه الدراسة0

6. 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)0 كما أفهم بأن انسحابي من هذه الدراسة لن يؤثر على حقي في تلقي العناية الطبية اللازمة والتي تمنح للمشاركين بالدراسة أو استحقها في الأحوال العادية0

أوافق على أن يكون هذا الإقرار كمشاركة طوعيه في هذا البحث الطبي

8.كما أؤكد بأنني قد قرأت – أو قرأ لي هذا التفويض وأن كل المعلومات اللازمة قد تمت تعبئتها بدقة قبل توقيعي عليه0

توقيع المريض أو ولي الأمر:
التاريخ :
الاسم :
صلة الفرابة :
 .9 أقر بأنني قد قرأت / أو ترجمت للمشارك بدقة هذه المعلومات
شاهد:
التوقيع الاسم (طباعة):
رقم البطاقة : أقر بأنني قد شرحت للمتطوع/ لقريبه/ أو ولي أمر، المذكور أعلاه بصورة كاملة طبيعة وأهداف مشروع البحث المذكور والمتضمن عدم وجود فائدة مباشرة على المشارك والي أي مدي (إن وجد) هي دراسة تجريبية0 كما قد شرحت المضاعفات المحتمل حدوثها من جراء هذه الدراسة سواء كانت لأسباب معروفة أو غير معروفة0 والعواقب والمخاطر المترتبة (إن وجدت) إذا قرر المتطوع إنهاء مشاركته بالدراسة0 كما إنه من المفهوم لدي بأنه قد فهم طبيعة الدراسة والغرض منها والمخاطر الناتجة عنها وذلك قبل توقيعه على الموافقة بالمشاركة ، ولقد قمت بتوضيح استعدادي للإجابة على أي أسئلة متصلة بهذه الدراسة ، وقمت فعلاً بالإجابة الشافية على جميع أسئلته المتعلقة بالدراسة0

الاسم (طباعة): _____

التاريخ: _____

Appendix E.5. مطومات عامة من ملف الطفل

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	ج- أرمل	 ب- مطلق مانلة	أفراد اله	ا۔ متزوج علاقتك مع ا	فلك على	اجتماعية مرض ط	الحالة الإ كيف أثر	.3 .4
 	ج- أرمل	 ب- مطلق مائلة	أفراد اله	ا۔ متزوج علاقتك مع ا	فلك على	جتماعية مرض ط	الحالة الإ كيف أثر	.3 .4
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	ج- أرمل	 ب- مطلق مائلة	أفراد الع	ا- متزوج علاقتك مع ا	فلك على	جتماعية مرض ط	الحالة الإ	.3 .4
	ج- أرمل	 ب- مطلق مائلة	افراد الم	ا- متزوج علاقتك مع ا	فلك على	جتماعية مرض ط 	الحالة الإ	.3 .4
	ج- أرمل	 ب- مطلق مائلة	افراد الع	ا- متزوج علاقتك مع ا	فلك على	جتماعية مرض ط 	الحالة الإ	.3 .4
	ج- أرمل	ب- مطلق فائلة	افراد الم	ا- متزوج علاقتك مع ا من طفاك	فلك على 	جتماعية مرض ط مرا الذي	الحالة الإ كيف أثر	.3 .4 5
	ج- ارمل	 ب- مطلق مائلة	افراد الع	ا- متزوج علاقتك مع ا من طفلك	فلك على	جتماعية مرض ط ما الذي	الحالة الإ كيف أثر باعتقادك	.3 .4
	ج- ارمل	ب- مطلق	أفراد الم	ا- متزوج علاقتك مع ا من طفلك	فلك على	جتماعية مرض ط ما الذي	الحالة الإ كيف أثر ياعتقادك	.3 .4
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	ج- ارمل	ب- مطلق	افراد الع	ا۔ مترّوج علاقتك مع ا من طفلك	فلك على	جتماعية مرض ط ما الذي	الحالة الإ	.3 .4
	ج- ار مل	ب- مطلق	افراد اله	 أ- متزوج علاقتك مع أ غلقتك غلقتك 	فلك على	جتماعية مرض ط ما الذي	الحالة الإ	.3 .4
	ج- از مل	ب- مطلق	افراد اله	ا- متزوج علاقتك مع ا من طفلك	فلك على	جتماعية مرض ط ما الذي	الحالة الإ	.3 .4
	ج- ار مل	بب- مطلق	افراد اله	ا- متزوج علاقتك مع ا من طفاك	فلك على	جنداعية مرض ط ما الذي	الحالة الإ	.3 .4

7. هل تشعر بالرضى حول مدى حرية ودرجة انفتاحك في مناقشة هذا المرض مع طفلك وعائلتك

- 8. معدل الدخل الشهري
- ا- أقل من 150 دينار
- ب- 150 الى 300 دينار
- ت- 310 الى 500 دينار
- ث- أكثر من 500 دبنار
 - 9. مكان السكن

Appendix E.5. <u>Demographic Data Form for Hospitalised Children with Cancer</u>

A. Personal information from the Child file:
1-Age of the child:
2-Sex: male ()
Female ()
3-Confirmed medical diagnosis
4-Date of diagnosis
5-Type of Treatment
- Chemotherapy ()
- Radiation ()
- Surgery (Specify)
- Medication (Specify)
- Over the counter medication (Specify)
B. General Family Information Sheet
6-Number of the children in family () 7-Family Pedigree (same disease, chronic illness, or any known mental disorders
 8-The social status: -Married () -Divorced () -Widow () 12-"How did your child's illness influence your relation with the family?"
13- "In your opinion, what have caused your child illness?"
14-"Does your child know about his illness, or other siblings, if so, who told then
15-"Do you feel you are openly talking with your child about his disease?"
16-The average income per month -Less than 150 JD () -151-300 JD ()-301-500 JD () More than 500 JD () 17- Place of residence ()

Appendix E.7.

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Version 4.0

CHILD REPORT (ages 8-12)

DIRECTIONS

On the following page is a list of things that might be a problem for you. Please tell us how much of a problem each one has been for you during the past ONE month by circling:

> 0 if it is never a problem 1 if it is almost never a problem 2 if it is sometimes a problem 3 if it is often a problem

4 if it is almost always a problem

There are no right or wrong answers. If you do not understand a question, please ask for help.

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In the past ONE month, how much of a problem has this been for you

ABOUT MY HEALTH AND ACTIVITIES (problems with)	Never	Almost Never	Some- times	Often	Almost Always
1. It is hard for me to walk more than one block	0	1	2	3	4
2. It is hard for me to run	0	1	2	3	4
3. It is hard for me to do sports activity or exercise	0	1	2	3	4
4. It is hard for me to lift something heavy	0	1	2	3	4
5. It is hard for me to take a bath or shower by myself	0	1	2	3	4
6. It is hard for me to do chores around the house	0	1	2	3	4
7. I hurt or ache	0	1	2	3	4
8. I have low energy	0	1	2	3	4

ABOUT MY FEELINGS (problems with)	Never	Almost Never	Some- times	Often	Almost
1. I feel afraid or scared	0	1	2	3	4
2. I feel sad or blue	0	1	2	3	4
3. I feel angry	0	1	2	3	4
4. I have trouble sleeping	0	1	2	3	4
5. I worry about what will happen to me	0	1	2	3	4

How I GET ALONG WITH OTHERS (problems with)		Almost Never	Some- times	Often	Almost
1. I have trouble getting along with other kids	0	1	2	3	4
2. Other kids do not want to be my friend	0	1	2	3	4
3. Other kids tease me	0	1	2	3	4
4. I cannot do things that other kids my age can do	0	1	2	3	4
5. It is hard to keep up when I play with other kids	0	1	2	3	4

A	SOUT SCHOOL (problems with)	Nover	Almost Never	Some- times	Often	Almost
1	It is hard to pay attention in class	0	1	2	3	4
2.	I forget things	0	1	2	3	4
3.	I have trouble keeping up with my schoolwork	0	1	2	3	4
4.	I miss school because of not feeling well	0	1	2	3	4
5.	I miss school to go to the doctor or hospital	0	1	2	3	4

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The Revised Children's Manifest Anxiety Scale

(RCMAS)

"What I think and Feel"

Read each question carefully. Put a circle around the word YES if you think it is true about you. Put a circle around the word NO if you think it is not true about you

1.	I have trouble making up my mind.	Yes / No
2,	l get nervous when things do not go the right way for	me. Yes/No
3.	Others seem to do things easier than I can.	Yes / No
4.	I like everyone I know.	Yes / Nu
5.	Often I have trouble getting my breath.	Yes / No
6.	I worry a lot of the time.	Yes / No
7.	I am attaid of a lot of things.	Yes / No
8.	I am always kind.	Yes / No
9.	I get mad easily.	Yes / No
10,	I worry about what my parents will say to me.	Yes / No
11.	I feel that others do not like the way I do things.	Yes / Nn
12.	I always have good manners.	Yes / No
13.	It is hard for me to get to sleep at night.	Yes / No
14.	l worry about what other people think about me.	Yes / No
15.	I feel alone even when there are people with me.	Yes / No
16.	I am always good.	Yes / No
17.	Often I feel sick in the stomach.	Yes / No
18.	My feelings get hurt easily.	Yes / No
19.	My hands feel sweaty. Leading Bure For Authorized Tra Jordan - Ammai University Bir - KFC B University Bir - KFC B	au Yes / No nstation *46575 Minding *05

20.	1 am always nice to everyone.	Yes / No
21,	I am tired a fot.	Yes / No
22.	I worry about what is going to happen.	Yes / No
23.	Other children are happier than I am.	Yes / No
24.	I tell the truth every single time.	Yes / No
25.	I have bad dreams.	Yes / No
26.	My feelings get hurt easily when I am fussed at.	Yes / No
27.	I feel someone will tell me I do things the wrong way.	Yes / No
28.	I never get angry.	Yes / No
29.	I wake up scared some of the time.	Yes / No
30.	I worry when I go to bed at night.	Yes / No
31.	It is hard for me to keep my mind on my schoolwork.	Yes / No
32.	I never say things that I shouldn't.	Yes / No
33.	I wriggle in my seat a lot.	Yes / No
34.	I am nervous.	Yes / No
35.	A lot of people are against me.	Yes / No
36.	I never lie.	Yes / No
37.	I often worry about something bad happening to me.	Yes / No

For Authorized Transformer Solar Sol

The DASS 42

Please read each statement and circle a number 0, 1, 2, or 3 which indicates how much the statement applied to you over the past week

The rating scale is as follows:

0 Did not apply to me at all

1 Applied to me to some degree, or some of the time.

2 Applied to me a considerable degree, or a good part of the time.

3 Applied to me very much, or most of the time.

 I found myself getting upset by quite trivial things 	0	1	2	3
2. I was aware of dryness of my mouth	0	1	2	3
 I couldn't seem to experience any positive feeling at all 	0	1	2	3
 I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion) 	0	1	2	3
5. I just couldn't seem to get going	0	1	2	3
6. I tended to over-react to situations	0	1	2	3
 I had a feeling of shakiness (e.g., legs going to give way) 	0	1	2	3
8. I found it difficult to relax	0	1	2	3
 I found myself in situations that made me so anxious I was most relieved when they ended 	0	1	2	3
10. I felt that I had nothing to look forward to	0	1	2	3
11. I found myself getting upset rather easily	0	1	2	3
12. I fell that I was using a lot of nervous energy	0	1	2	3
13. I felt sad and depressed	0	1	2	3
 I found myself getting impatient when I was delayed in any way (eg. lifts, traffic lights, being kept waiting) 	0	1	2	3
15. I had a feeling of faintness	0	1	2	3
16. I felt that I had lost interest in just about everything	0	1	2	3
17. I felt I wasn't worth much as a person	0	1	2	3
18. I felt that I was rather touchy	o Fo	Lead r Author Tolofex	rized T	reall ranslation 5.5346575
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 I perspired noticeably (eg, hands sweaty) in the absence of high temperatures or physical exertion 	0	1	2	3
20. I felt scared without any good reason	0	1	2	3
21. I felt that life wasn't worthwhile	0	1	2	3
22. I found it hard to wind down	0	1	2	3
23. I had difficulty in swallowing	0	1	2	3
24. I couldn't seem to get any enjoyment out of the things I did	0	1	2	3
25. I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat)	0	1	2	3
26. I felt down-hearted and blue	0	1	2	3
27. I found that I was very irritable	0	1	2	3
28. I felt I was close to panic	0	1	2	3
29. I found it hard to calm down after something upset me	0	1	2	3
30. I feared that I would be "thrown" by some trivial but unfamiliar task	0	1	2	3
31. I was unable to become enthusiastic about anything	0	1	2	3
32. I found it difficult to tolerate interruptions to what I was doing	0	1	2	3
33. I was in a state of norvous tension	0	1	2	3
34. I felt I was pretty worthless	0	1	2	3
34. I was intolerant of anything that kept me from getting on with what I was doing	0	1	2	3
36. I felt terrified	0	1	2	3
37. I could see nothing in the future to be hopeful about	0	1	2	3
38. I felt that life was meaningless	0	1	2	3
39. I found myself getting agitated	0	1	2	3
40. I was worried about situations in which I might panic and make a fool of myself	0	1	2	3
41. Lexperienced trembling (eg, in the hands)	0	1	2	3
42. I found it difficult to work up the initiative to do things	0	1	2	3

Scoring:

Download the DASS 42 PDF file and the Scoring Template PDF file.

	Depression	Anxiety	Stress
Normal	0 - 9	0 - 7	0-14
Mild	10 - 13	8-9	15 - 18
Moderate	14 - 20	10 - 14	19 - 25
Severe	21 27	15-19	26 - 33
Extremely Severe	28+	20+	34 +

A sum of the scores for each of the seven questions completed by each participant, in each of the sub-scales, are then evaluated as per the severity-rating index below.

Norms: Normative data are available on a number of samples. From a sample of 2914 adults the means (and standard deviations) were 6.34 (6.97), 4.7 (4.91), and 10.11 (7.91) for the depression, anxiety, and stress scales, respectively. A clineical sample reported means (and standard deviations) of 10.65 (9.3), 10.90 (8.12), and 21.1 (11.15) for the three measures.