Psychosocial Predictors of Quality of Life among Jordanian Colorectal Cancer Patients: A Mixed-Method Study

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ABSTRACT

Colorectal Cancer (CRC) is one of the most common forms of cancer worldwide (National Cancer Institute [NCI], 2007); its prevalence is also reflected in the Jordanian population (Jordanian Ministry of Health & Jordan Cancer Registry [MOH & JCR], 2008). It appears that CRC diagnosis and treatment modalities have a negative impact on patients’ physical, social, and emotional well-being and their quality of life (QOL). Alarmingly, up to 35% of CRC patients have clinically significant levels of psychological distress. Accordingly, better understanding of QOL and its psychosocial predictors will assist health professionals, especially oncology nurses, to recognize the effects of CRC and its treatment modalities on patients and to plan appropriate interventions to ameliorate these effects.

This study was conducted in two phases using mixed methods in a sequential-explanatory design to: (1) explore the relationships between hope, coping, psychological distress (depression and anxiety), age, gender, marital status, income, time since diagnosis and QOL among Jordanian CRC patients; (2) identify to what extent hope, coping, psychological distress (depression and anxiety), age, gender, marital status, income and time since diagnosis predicts QOL among Jordanian CRC patients; and (3) describe Jordanian CRC patients’ experiences and perceptions about QOL during their treatment period.

The first phase used a descriptive correlational survey to describe the relationships between the selected independent variables and the dependent variable. In this phase, a sample of 260 Jordanian patients with CRC, from three Jordanian hospitals, completed the study survey. The survey included a number of instruments including:
Functional Assessment of Cancer Therapy-Colorectal (FACT-C), Herth Hope Index (HHI), Jalowiec Coping Scale (JCS) and Hospital Anxiety and Depression Scale (HADS). In addition, the survey included researcher developed questions eliciting demographic and disease-related data. The sample consisted of 142 (54.6%) males and 118 (45.4%) females, with a mean of age 51.9 years (SD 9.48). When the study was conducted 67.7% of the participants had no complications, and 96.9% had no regional metastasis. The majority (98.8%) were treated with a combination of chemotherapy and surgery. Bivariate and multivariate analyses were used. The bivariate analysis indicated significant positive relationships between coping, hope, time since diagnosis and QOL ($r = .55$, $P < .0001$, $r = .57$, and $r = .16$, $P < .0001$ respectively). A significant negative relationship was found between anxiety and depression, gender and QOL ($r = -.76$, $r = -.14$, $P < .0001$). A parsimonious multiple regression analysis indicated that hope, coping, psychological distress and time since diagnosis were predictors of QOL, and explained 66% of the variance in the QOL for this sample.

In phase two, ten participants were purposefully selected to be interviewed about their experiences of CRC and their perceptions about QOL during their illness period. Content analysis revealed two major themes: Participants’ experience of changes during CRC diagnosis and treatment; and Factors influencing QOL. Within the first theme, four categories were identified: Diminishing strength and physical fitness; Cancer as distress; Changing roles; and Changing social life. Within the second theme both extrinsic and intrinsic factors were identified. Extrinsic factors included social support (such as emotional encouragement, practical help, and social engagement) and professional support (such as interpersonal relationships, and patient and family
education). Intrinsic factors reflected internal coping strategies (such as religious faith and attitudes towards prognosis and life).

The results of this study suggest the need to implement education programs to address these distressing experiences and to support those extrinsic and intrinsic factors known to augment Jordanian CRC patients’ QOL.
Statement of Originality

This work has not been submitted previously for a degree or diploma in any university.
To the best of my knowledge and belief, the thesis contains no material previously published or written by another person, except where due reference is made in the thesis itself.

Loai Abu Sharour
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Shoot for the moon. Even if you miss, you’ll land among the stars... (Unknown)

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DEDICATION

I dedicate this thesis to the memory of my mother. Mom, this achievement was always your dream; you were always with me in your soul. Your extraordinary care, integrity, and love fostered my strength and ability to continue. Mom, I miss you very much, everyday and every minute since you went away.

Loai
CHAPTER ONE
INTRODUCTION

Cancer diagnosis is a traumatic event that can have a significant emotional impact on affected patients and their families. Patients undergoing treatment for cancer may experience severe symptoms that affect social and physical functioning, disrupt family life and even lead to depression, all of which may affect quality of life (QOL) (Agarwal, Hamilton, Crandell, & Moore, 2010; Nuamah, Cooley, Fawcett, & McCorkle, 1999). Colorectal cancer (CRC) is the second leading cause of cancer-related mortality, and the fourth most prevalent malignant disease affecting men and women, almost equally (Arndt, Merx, Stegmaier, Ziegler, & Brenner, 2004; Rinaldis, Pakenham, Lynch, & Aitken, 2009). However, CRC and its treatment can have an adverse effect on social functioning, including work and overall life, relationships with friends, relatives and partner, as well as other social activities and interests. In addition, patients may experience a wide range of cancer-related stressors, such as uncertainty about its recurrence and their recovery, and/or the psychological ramifications/consequences (such as depression, anxiety, and stress) related to diagnosis and treatment (Arndt, et al., 2004; Krouse et al., 2009; Rinaldis, et al., 2009). With the development of treatment modalities and medical technologies, cancer has shifted from being fatal, in the short-term, for many sufferers towards often being a chronic disease requiring long-term palliative treatment (Grosv, Dahl, Moum, & Fossa, 2005).

As a result of these complications and reactions to the diagnosis of, and treatment for, cancer patients might experience a diminished QOL in relation to their social, emotional, physical, spiritual and/or psychological well-being (Plummer & Molzahn,
Medical and other health professionals have recognized the importance of measuring QOL as a crucial element in assessing the patient's health, response to treatment and increasing survival role (Akin, Can, Aydiner, Ozdilli, & Durna, 2010; Casso, Buist, & Taplin, 2004; Reeve et al., 2009).

Accordingly, this research aimed to explore the impact of psychosocial variables (including coping, hope, and psychological distress), selected demographical variables (age, gender, marital status, income) and a disease-related variable (time since diagnosis) on QOL among Jordanian CRC patients. It also sought to describe Jordanian CRC patients’ experiences and perceptions about QOL during their diagnosis and treatment period. This chapter includes an overview of the study, background, significance, study purposes, questions, and clarification of terms and structure of the thesis.

OVERVIEW

In order to explain the relationships between hypothesized predictors, and to describe their experiences and perceptions about QOL during their illness period, the study was conducted in two phases using a sequential mixed quantitative – qualitative design, as described by Morgan (1998).

Phase I used a quantitative approach to measure the main variables in the study and to determine their relationship. A total of 260 participants, who met the inclusion criteria, participated in and completed the survey instruments. In Phase II, a sample of 10 patients was purposefully selected from those who had completed the survey. They
were interviewed in order to gain a deeper understanding of the factors relating to their QOL. Their selection reflected the variation in the range of predictors of QOL.

**SUMMARY OF THE KEY FINDINGS**

The majority of the respondents were male, married, educated, and Muslim; did not report having any other chronic illness; did not have complications at the time of participating in the study; had no known regional metastasis of CRC; were treated by chemotherapy and surgery; scored poorly on the physical and emotional well-being dimensions of QOL; scored better on the social/family and functional well-being dimensions of QOL; and, scored in the mild range for depression and anxiety. Evasive, confrontive, and optimistic coping strategies were the most used and effective, while fatalistic and emotive coping strategies were less useful and effective. The results indicated that there were significant positive relationships between hope, coping, time since diagnosis and QOL. Moreover, there was a significant negative relationship between psychological distress (depression and anxiety), gender and QOL. A multiple regression analysis indicated that hope, coping, depression and anxiety and time since diagnosis were predictors of QOL and accounted for 66% of its variance.

The findings from the qualitative phase indicated that CRC diagnosis and treatment: changed participants’ perceptions of QOL; was distressing to themselves and their families; and, impacted upon their family, work and social relationships and roles. Social and professional support, religious faith and attitude towards prognosis and life were important influences on QOL.
BACKGROUND

Global Impact of Cancer

Cancer is a potentially life-threatening disease that engenders considerable distress for patients (Tan, 2007). It is an important public health concern throughout the world (Otto, 2001). The World Health Organization (WHO) (2008) reported that cancer is a leading cause of death worldwide. From a total of 58 million deaths worldwide, in 2005, cancer accounted for 7.6 million (13%) of all deaths. The main types of cancer leading to overall mortality are lung, stomach, liver, colon and breast cancers.

The WHO (2008) report also showed that more than 70% of all cancer deaths in 2005 occurred in low and middle income countries. Further, deaths from cancer, worldwide, are projected to continue rising, with an estimated nine million deaths from cancer in 2015 and 11.4 million in 2030. The most frequent of these cancer types are lung, stomach, liver, colorectal, oesophagus and prostate cancer among men (in order of number of global deaths), and breast, lung, stomach, colorectal and cervical cancer among women (in order of number of global deaths).

Almost one million new cases of CRC are diagnosed, and 25,000 deaths occur, worldwide each year (Ferlay, Bray, Pisani, & Parkin, 2001). However, survival rates have increased throughout the last decade because of earlier diagnosis, improved diagnostic tests, the introduction of adjuvant therapy, and advances in the treatment of metastatic disease (Arndt, Merx, Stegmaier, Ziegler, & Brenner, 2004).

Importantly, CRC affects both genders with a slight increase in the female population. The incidence increases significantly in people over the age of 50, with the mean age at the time of diagnosis being 62 years. The causes of CRC are unknown. However, recent research indicates that diet, genetics and other predisposing factors, such as
bowel disorders and NSAIDS (Non-Steroidal Anti-Inflammatory Drugs) intake, may play an important role in its development. The disease occurs most frequently in the industrialized countries of North America and Northern Europe. For example, in the United States, CRC is the third most common malignant tumour, second only to lung cancer in its incidence and mortality. An estimated 130,500 new cases develop each year, with an annual death rate of 56,300. Mortality rates show a decline in both men and women, and are most likely related to increased diagnosis screening, community awareness, and dietary modification (Otto, 2001). CRC comprises cancers of the colon and rectum, the two main sections of the large bowel. It is the most commonly diagnosed cancer in Australia, after skin cancers. Diagnosis increases progressively with age and is greatest in those over 50 (Australian Institute of Heath and Welfare [AHIW], 2001). The prognosis of CRC depends on the extent of the disease (stage) at the diagnosis time. According to the five-year survival classification, CRC in Australia has approximately 90% survival for patients with a local disease, compared with 7% for patients with metastasis at diagnosis. However, CRC symptoms may not be diagnosed until the advanced stage of the disease (Dunn et al., 2003). For this reason, screening for CRC is recommended for people at risk from the disease, especially starting from the age of 50 years to detect the disease in its early stages, and enhance survival rates. As in the developed countries, CRC is also considered one of the main health concerns and is one of the most common causes of cancer-related deaths in developing countries such as Jordan.

**Cancer in Jordan**

Jordan is located in the Middle East, between latitudes 29-33 North, and between longitudes 35-39 East, extending about 500 kilometres from North to South (MOH & JCR, 2008). It is bounded in the North by Syria, in the East by Iraq and Saudi Arabia,
in the South also by Saudi Arabia, and in the West by the Palestine Authority. The total area is 92 thousand square kilometres. Out of the total area, 75% is desert, mainly along the eastern part of the country. The Dead Sea area is the lowest area in the world, around 407 meters below sea level. Jordan is also divided, from an administrative point of view, into three regions (Central Northern, and Southern) and twelve governorates (MOH & JCR, 2008).

The WHO (2008) report estimated that the population of Jordan in 2008 was 5,350,000; of these, 51.5% were males and 48.5% were females. Approximately 12.8% of the Jordanian population is under 5 years, and 37.4% under 15 years. Only 3.2% of the total population is above the age of 65 years (MOH & JCR, 2008).

In Jordan, the total number of new cancer cases registered by the JCR in 2008 was 6,214; 4,606 (71.1%) cases being among Jordanians, and 1608 (25.9 %) cases being among non-Jordanians. Taking into consideration the population structure of Jordan, and the fact that cancer is primarily a disease of the elderly; the pattern of cancer has some unique characteristics. In 2008, 1,981 (43.1 %) cases of all newly registered cancers occurred in the age group 60 years and above, with 1136 (57.3%) of these cancer cases occurring in men and 845 (42.7%) cases occurring in women. However, 529 (11.6 %) of cases occurred before the age of 30 years (JCR, 2008); the reported cancer cases had been collected from a Population-Based Cancer Registry (JCR) since 1996 (MOH & JCR, 2008).
Distribution of Colorectal Cancer in Jordan

CRC is considered one of the most common cancers among the Jordanian population, as reported by the JMOH, and the JCR, (MOH & JCR, 2008). Table 1.1 presents the colorectal cancer statistics in relation to gender and primary site in Jordan, for the year 2008. Significantly, CRC has the highest incidence rate among Jordanian male cancer patients (14.4%), and is the second most common cancer (11.9%) among Jordanian female cancer patients following breast cancer (MOH & JCR, 2008).

Table 1.1: Numbers of New Cases by Primary Site and Gender (Jordan, 2008)

<table>
<thead>
<tr>
<th>Primary site</th>
<th>Male</th>
<th>Female</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>(%)</td>
<td>N</td>
</tr>
<tr>
<td>Colon</td>
<td>210</td>
<td>9.2%</td>
<td>145</td>
</tr>
<tr>
<td>Rectum</td>
<td>119</td>
<td>5.2%</td>
<td>74</td>
</tr>
<tr>
<td>Total</td>
<td>329</td>
<td>14.4%</td>
<td>219</td>
</tr>
</tbody>
</table>

The JMOH and JCR (2008) reported the percentage of main cancer types in Jordan, according to gender, age, and region. The results showed that CRC is highest (14.5%) among Jordanian male patients across all ages. Indeed, CRC is the second most common type, following lymphoma, in 13% of Jordanian males between the ages of 20-40 years. The highest incidence of CRC (16.7%) is among Jordanian male patients over the age of 50, and is the second most common type (9.4%) after breast cancer among Jordanian female patients across all age groups. Among Jordanian female patients, between 20-40 years, the incidence of CRC is 6.7%, and 12% among females over the age of 50.
According to the distribution of male cancer types by region, in Jordan, colorectal cancer distribution in the central, northern, and southern regions is 14.6%, 14.1%, and 13.1%, respectively (MOH & JCR, 2008). For female cancer types, in Jordan, CRC distribution in the central, northern, and southern regions is 9.8%, 8.3%, and 8.2%, respectively.

**CRC: Diagnosis and Treatment**

When CRC is suspected, the patient may be subjected to a number of diagnostic tests and procedures, such as physical examination and history taking, to check their general signs of health, including signs of disease, such as lumps or anything else that seems unusual. A history of the patient’s health habits, and past illnesses and treatments, are also taken. In addition, a faecal occult blood test, digital rectal exam, barium enema, sigmoidoscopy, colonoscopy, biopsy, and virtual colonoscopy are also undertaken (Otto, 2001). While the number of people diagnosed with cancer at screening time is relatively low, a substantial proportion of people attending screening will experience false positives or be found to have pre-cancerous abnormalities. The psychological distress arising from both false positive and high risk results has been shown to be relatively short-lived. Nevertheless, lingering concerns about the possible psychological sequelae of screening remains. A number of studies have shown that cancer-specific worries may persist for months and even years after screening (Absetz, Aro, & Sutton, 2003; Aro, Pilvikki Absetz, van Elderen, van der Ploeg, & van der Kamp, 2000; Miles & Wardle, 2006). The screening examination itself could generate anxiety, especially the sigmoidoscopy or colonoscopy examinations, which are invasive and uncomfortable procedures, with a risk of bowel perforation (Anderson, Pasha, & Leighton, 2000).
As soon as the diagnosis is confirmed, CRC is treated by one or a combination of the three treatment modalities: surgery, chemotherapy, and radiotherapy. The treatment depends on the staging, the presence of metastases, and the patient’s condition (Otto, 2001). Although cancer therapy modalities have become more powerful and therapeutically more successful over the past 10 years, the cancer-fighting treatments also affect healthy tissue. There are many frequent signs of acute and chronic side effects which can diminish QOL for cancer patients, and negatively affect treatment (Otto, 2001). Some of these side effects include gastrointestinal, haematological, dermatological, gonadal, and oral toxicity (Otto, 2001). In addition, cancer, as a serious illness, affects the patient’s sense of time, priorities, relationships with others, self-confidence, and body image (Ramfelt, Severinsson, & Lutzen, 2002). Eight psychological meanings of cancer and severe illness have been identified, including challenge, enemy, loss, punishment, relief, strategy, value, and weakness. These meanings reflect the patients’ ability to cope, their level of knowledge, cultural support and background, and their beliefs (Lipowski, 1970).

Cancer represents a stressful life event that has wide ranging, physical, psychological, social, financial, and spiritual effects (Yan & Sellick, 2004). In the initial stages of the disease, a diagnosis of cancer imposes an acute crisis for the person. During this period, which occurs within six months, the patient is confronted with not only the illness and its treatment, but also concerns about the meaning of life and death, the future, fear of recurrence, physical disability, and changes to family and social relationships. Although improvements are continually being made, most patients still have a poor prognosis. Those who survive have to contend with a wide array of physical, nutritional, and psychological problems caused by the disease and its
treatment (Yan & Sellick, 2004). Depression and anxiety are the most common types of psychological distress among cancer patients (Teunissen, de Graeff, Voest, & de Haes, 2007). The prevalence of psychological distress described in previous studies varies, depending on patient selection and assessment methods. As a consequence, anxiety and depression incidence among cancer patients is 30% and 39%, respectively.

Recently, medical outcomes have considered the patient’s QOL in addition to survival rate (Matsushita, Matsushima, & Maruyama, 2005). Optimal, intensive patient care has increasingly focused on the psychological, as well as physical, domains (Matsushita, et al., 2005). Many factors, such as disease diagnosis, stage of cancer and treatment modalities affect patients’ psychological state and overall QOL. In addition, the individual’s cognitive ability to cope with this critical condition, and how s/he responds to stressors caused by cancer, was considered as one of the factors that impacted patients’ QOL (Folkman & Lazarus, 1988).

**SIGNIFICANCE OF THE CURRENT STUDY**

The impact of CRC has been extensively investigated in relation to clinical complications, treatment modalities, prognosis and survival. However, while these are extremely important factors, they do not provide or capture the full picture of the impact of diagnosis and treatment on CRC patients’ QOL. Thus, there has been an increasing focus on its assessment as an essential component in evaluating the burden of the disease and treatment.
QOL and its determinants have received growing interest, and physical, mental, and social well-being have, with varying levels of emphasis and in various combinations, been included in the concept (Lehto & Lehtinen, 2005). QOL reflects patients’ satisfaction with their physical, social, spiritual, emotional and functional well-being. Therefore, in order to be truly patient-focused, understanding QOL and its determinants is necessary.

Importantly, the impact of CRC diagnosis and treatment on Jordanian patients’ QOL is still poorly understood because of a lack of research within this culture. Accordingly, the current study responds to the lack of knowledge in understanding QOL and its predictors among Jordanian CRC patients. In the current study, the researcher assumed that QOL in CRC patients was influenced by hypothesized predictors, which include age, gender, income, marital status, time since diagnosis, coping, hope, and psychological distress. This study aimed to describe Jordanian CRC patients’ experiences and perceptions about QOL during their illness period. Therefore, the findings of the current study will assist oncology nurses to better understand the impact of cancer diagnosis and treatment on these patients’ lives and health, and to provide optimal care.

The current study is important because it addresses the shortage in knowledge about the psychosocial predictors of QOL in the Jordanian population. Because the study aimed to identify the most common and useful coping strategies used by CRC patients at the time of diagnosis and during the treatment period, the findings will assist nurses to help their patients better utilize these strategies.
Importantly, by identifying the factors that might influence the patients’ QOL, this study will provide researchers, nurses and other health professionals with needed information that will enable them to develop culturally appropriate interventions that lessen the impact of the most distressing factors while, at the same time, supporting those that promote a better QOL. For example, the results of the current study might be useful for health care professionals such as physicians, care providers, psychosocial therapists in developing communication skills programmes and cognitive behavioural programmes to aid psychosocial adaptation in patients diagnosed with, and under-treatment for, cancer.

Finally, the results of the current study might be utilized by educators to improve undergraduate nursing programs, and specialist postgraduate oncology nursing programs, to better prepare nurses for their role in assessing psychosocial well-being in patients with cancer, in addition to planning appropriate intervention programs for these patients.

**RESEARCH PURPOSES AND QUESTIONS**

The purposes of this two phased study were to:

1. Explore the relationships between hope, coping, psychological distress (depression and anxiety), age, gender, marital status, income time since diagnosis, and QOL among Jordanian CRC patients.

2. Identify to what extent hope, coping, psychological distress (depression and anxiety), age, gender, marital status, income and time since diagnosis predict QOL among Jordanian CRC patients.
3. Describe Jordanian CRC patients’ experiences and perceptions about QOL during their diagnosis and treatment period.

This two phase study addressed the following questions:

1. What is the relationship between coping, hope, psychological distress (depression and anxiety), age, gender, marital status, income, time since diagnosis and the QOL among Jordanian CRC patients?

2. To what extent do coping, hope, and psychological distress (depression and anxiety), age, gender, marital status, income and time since diagnosis predict QOL among Jordanian CRC patients?

3. What are the Jordanian colorectal cancer patients’ experiences and perceptions about their QOL during their diagnosis and treatment period?

**CLARIFICATION OF TERMS**

The following are the theoretical and operational definitions of the terms that are used in this study:

**Cancer**

Cancer is a term for diseases in which abnormal cells divide without control. Cancer cells can invade nearby tissues and spread to other parts of the body through the blood and lymph systems (NCI, 2008). Operationally, CRC patients were identified by medical diagnosis stated in their medical records.

**Colorectal Cancer**

The National Cancer Institute's (2008) theoretical definition of CRC was used in this study, namely, Cancer that develops in the colon (the longest part of the large
intestine) and/or the rectum (the last several inches of the large intestine before the anus.

**Staging of Colorectal Cancer**

The most widely used method for colorectal cancer staging is the Dukes classification, which was developed in 1932 (Otto, 2001). The Dukes system classifies tumours into four major categories, based on the degree and depth of tumour involvement and the presence of lymph nodes. Subcategories were developed by Astler and Collier in 1954 in an attempt to delineate the importance of tumour wall penetration, as follows (Otto, 2001):

- **Stage A:** Carcinoma limited to the mucosa;
- **Stage B1:** Carcinoma invades the muscle but is confined to the bowel wall;
- **Stage B2:** Carcinoma penetrates through the muscularis propria into the serosa and connective tissue;
- **Stage B3:** Same as B2, with adherence or invasion into adjacent organs, but with negative nodes;
- **Stage C1:** Lymph nodes positive for metastatic disease, but main tumour confined to bowel wall;
- **Stage C2:** Lymph nodes positive for metastatic disease and tumor completely penetrates bowel wall;
- **Stage C3:** Same as B3, with positive nodes; and
- **Stage D:** Distant metastasis.

**Quality Of Life (QOL)**

The World Health Organization (WHO, 1995, cited in Ahmedzai et al., 2004, p. 2195) defines QOL as “individuals’ perceptions of their position in life in the context of the
culture and the value system in which they live and in relation to their goals, standards, and concerns”. Six main characteristics of QOL were identified (Ahmedzai et al., 2004):

(1) Subjective or objective (individual perception),
(2) Phenomenological or explanatory (reflects the condition without interpretation),
(3) Multidimensional (includes six dimensions: physical, psychological, level of independence in mobility and work, social relationships, health and social care, spirituality, and personal beliefs),
(4) Evaluative (QOL affected and affected by other variables),
(5) Dynamic (changing over the time depending on the patient’s condition or status),
and,
(6) Quantifiable (QOL assessed and compared in relation to the individual’s status and disease) (Niv & Kreitler, 2001).

THESIS STRUCTURE

Chapter One has provided an overview of the study design and the context in which it is situated. The chapter has also included the importance (significance) of the study, research purposes, clarification of terms, and the research questions of the study.

Chapter Two provides a critical analysis of the literature in relation to QOL, its known predictors and the current state of knowledge about the impact of CRC.

Chapter Three describes the conceptual framework used in this study. In addition, the conceptualization of the variables such as QOL, hope, coping, depression, and anxiety is discussed.
Chapter Four presents the research design, sampling, setting, instrumentation, data collection procedures, ethical considerations, trustworthiness of study, and data analyses methods.

In Chapter Five the results of quantitative phase are presented. This includes overall descriptive and inferential analyses of the hypothesized predictors, and QOL scores. Additionally, it presents the results of the bivariate and multivariate relationships between the variables hope, cope, age, and depression and anxiety, age, gender, marital status, income, and time since diagnosis, and QOL.

Chapter Six presents the findings of the qualitative phase of the study.

Chapter Seven provides a discussion of the findings in relation to the established literature and the research questions, conclusions drawn from the study, and implication of the results or findings in relation to nursing research, practice, and education. The limitations of the study related to methodology are outlined, along with the recommendations for education, future research, and clinical practice.

**SUMMARY**

CRC in Jordan is considered one of the most important health concerns, not only for patients, families, and communities, but also for the health system and health professionals. The general population has been increasing each year in Jordan and the incidence of CRC is also increasing. Treatment of the patients (physically, emotionally, and psychologically) becomes an important goal for medical and nursing staff. Understanding the concept of QOL and its contributing factors will provide a
holistic approach for medical teams, particularly nurses, in focusing on the patients’ needs or domains (physical, psychological, social, spiritual, and sexual) to minimize the effect of disease and the impact of treatment. The following chapter includes relevant literature relating to the main concepts in the current study.
CHAPTER TWO

Literature Review

INTRODUCTION

This chapter presents a review of the literature in relation to the hypothesized predictors of QOL among patients with CRC. In the review, previous studies are analysed and critiqued in terms of what was studied, where the study took place, the methods employed, the results and the implications for nursing. The chapter begins with an overview of the concept of QOL, followed by what is already known about the related QOL factors, and other relevant issues, such as the impact of treatment modalities among CRC patients. Finally, a review of the previously published research relating to coping, hope and psychological distress factors, including anxiety and depression, are examined in the context of QOL.

QUALITY OF LIFE (QOL)

CRC has become one of the most common neoplasms in many developed countries (Tsunoda, Nakao, Hiratsuka, Tsunoda, & Kusano, 2007). While there is a decline in the mortality rates from CRC, many survivors experience physical and psychological sequelae that affect their everyday lives. In addition to being disease-free and the increased overall survival time, QOL is now regarded as an important outcome measure for cancer patients. The assessment of QOL helps to provide a comprehensive and essential understanding of the outcome of cancer treatment modalities. However, QOL is dynamic; little is known about how it changes over time for patients with CRC, especially following medical intervention (Tsunoda, Nakao, Hiratsuka, Tsunoda, & Kusano, 2007).
Indeed, the term QOL is considered a complex, multidimensional concept that is subjective in nature and, therefore, perceived differently by people, depending on how they deal with or react to their different circumstances (Thome & Hallberg 2004). In general terms, health-related quality of life (HR-QOL) is frequently used to focus on the outcomes of clinical treatment, care plans and related practice strategies, for example: physical, emotional and role functioning, physical symptoms and drug toxicity, social well-being, functional ability, life satisfaction, and somatic sensation (Esbensen, Osterlind, Roer, & Hallberg, 2004; Thome & Hallberg, 2004).

However, according to Glise and Wiklund (2002), medical teams have essentially focused on physiological diseases and their treatment modalities. In contrast, patients are concerned with their symptoms, regardless of the presence of physiological or non-physiological disease. To patients, diseases are diagnosed and connected with the presence of symptoms, while clinicians have traditionally concentrated on histological or serological, laboratory findings. Nevertheless, the broad definition of HR-QOL is related to the disease for which the patient is being treated, their morbidity, and other issues related to treatment modalities, such as complications of treatment. Therefore, it is important for broad management plans and treatment strategies to consider physical, emotional, and psychological impacts, as well as overall QOL (Glise & Wiklund, 2002). Moreover, a better understanding of the relationship between psychosocial factors and HR-QOL is essential if an effective and useful interventional program is to be developed, because optimal care addresses both physical and psychological well-being (Mazanec, Daly, Douglas, & Lipson, 2010). Enhancing knowledge of QOL predictors will also improve such understanding, and enable nursing care to be more focused toward the specific needs and demands of the
individual patient, particularly in relation to problems and restrictions they face in daily living (Esbensen, et al., 2004). The following section reviews what is already known of the related factors that influence QOL among cancer patients.

**Factors That Predict QOL in CRC Patients**

The factors that predict QOL are divided into four groups: demographic characteristics, disease-related conditions, treatment-related conditions and patient-related characteristics.

**Demographic Factors**

The existing literature has focused on the effect of demographic variables, such as age, gender, educational level, marital, economic and employment status, on QOL among CRC patients. The following studies have yielded findings related to some, or all, of these variables.

Age is considered one of the factors that contribute to patients’ QOL. A number of studies have assessed QOL among different cancer patients, in different ages; these studies have sought to identify the impact of cancer diagnosis on different age groups. For example, a study by Rustoen, Moum, Wiklund, and Hanestad (1999) was conducted in four different hospitals for cancer treatment in Oslo. Their research found that age was associated with QOL scores amongst breast, prostate, colon and gynaecological cancer patients. Further, the more elderly patients scored better QOL scores in all the subscale domains than did the younger patients. Despite these results, the study did not provide an in-depth explanation of the findings, or explain how the cancer impact varied between the younger and older patients. A year later, Klemm et
al. (2000) postulated that older people might rate their QOL higher than younger people because they do not have high demands in terms of their future, goal achievements, or life’s satisfaction. Their descriptive, comparative study described the most common demands of illness for patients treated for CRC. As part of their research, mailed surveys were sent to a sample of 121 patients. The results showed that the personal meaning of the illness, symptom monitoring, and treatment-related issues were the most common issues identified by the patients.

Supporting these findings was the study conducted by Mkanta, Chumbler, Richardson and Kobb (2007). That study examined the age-related difference in health-related quality of life among newly diagnosed cancer patients receiving chemotherapy. With an acknowledgment of the limitation of the study, including the small sample size (n=34), the results indicated that older patients reported better HR-QOL scores during the treatment period (Mkanta, Chumbler, Richardson, & Kobb, 2007). In the same vein, and aiming to identify the difference in QOL status among different age groups, a cross-sectional study of all patients diagnosed with CRC was conducted at a single hospital in southern England (Simon, Thompson, Flashman, & Wardle, 2008). Significantly, the results from 128 patients showed that married, older and aged patients reported better overall QOL than did those who were widowed or single.

In contrast with the above research findings, the most recent study by Wright and colleagues (2010) examined whether age influences advanced ovarian cancer patients’ prognostics or quality of life at the time of diagnosis. QOL was assessed using EORTC and QOL-V28 in a sample of 64 women patients, aged between 40 and 83 years. The results indicated that there was no difference between the older and
younger women’s self-reported QOL and overall health. Nonetheless, more of the older patients reported that they were cured from the ovarian cancer (reflect their perception) in comparison to the younger patients. However, this difference might relate to several limitations of the study, such as the small sample size (n= 64) and the timing of the study (post the diagnosis); at this time the patients may still have been in shock following the diagnosis (Wright et al., 2010).

In addition to the patient’s age, their financial status (income) was considered as one of the factors that contributed to the QOL of cancer patients. Previous studies indicated that low income patients have reduced overall QOL, compared with patients on higher income levels (Ramsey et al., 2000; Simon, et al., 2008). Further, Ramsey et al. (2000) also reported that higher levels of income were associated with lower levels of depression and higher self-evaluative overall health. Nevertheless, these studies found that patients with lower socioeconomic status (SES) had worse psychosocial outcomes, associated with less satisfaction with the medical treatment and interventions. Those patients also had limited access to medical care services (Ramsey, et al., 2000; Simon, et al., 2008). Confirming these results was the study by Akin et al. (2010). The findings showed that lung cancer patients with low income levels experienced greater symptom distress (physical, emotional and functional), and reported lower overall QOL score than did patients with high income levels (Akin, et al., 2010). Further, this finding highlights the greater need of support, education and assessment (physically and psychologically) required by this group of patients to help minimize the impact of cancer on their QOL.
Another demographical variable identified as a predictor of QOL among cancer patients is gender. Earlier studies (T. Rustoen, Moum, Wiklund, & Hanestad, 1999; Simon, et al., 2008) showed that female patients experienced lower levels of QOL than did the male patients. Indeed, women with cancer were more vulnerable in relation to QOL, their sense of coherence (SOC), perceived economic situation, and social resources (Thome & Hallberg, 2004). Similar findings were reported by Simon et al. (2008). Their study of 128 patients, with advanced stages of cancer, showed that women’s physical well-being was reduced, and more adversely affected, by the colorectal disease than it was for men. In contrast, gender was not found to be associated with QOL in the study by Rustoen, Moum, Wiklund and Hanestad (1999), except in the psychological domain. However, this finding may be unduly influenced by several study limitations, namely: response rate, gender sample bias and heterogeneity bias. The low participant response rate (only 60.4%) may have led to a decline in the level of the representativeness of the sample. Moreover, the majority (76%) of respondents was female. Finally, there was heterogeneity bias of the sample, as the researchers recruited different cancer types, including breast, gynaecological, prostate and colon cancer.

Disease-Related Predictors

The literature review highlighted the many studies that have been conducted to evaluate the impact of CRC disease-related variables, such as the cancer site, stage, type and time since diagnosis on the patients’ QOL.

The first two variables, stage and site of cancer, are logically associated with patients’ QOL status. For example, advanced staged cancer is accompanied by severe physical
complications, as well as a number of psychological problems, for example, distress. As a result, it is not unexpected that such patients reported poor QOL scores (Dunn et al., 2003). This correlation was confirmed by Simon and colleagues (2008) who undertook a cross-sectional study, in England, to determine the association between disease stage and range of psychological outcomes among CRC patients. Two hundred and ninety patients completed the survey. Five scales were used to assess the data: the Center for Epidemiological Studies Depression Scale, the Anxiety scale of HADS, FACT-C, Multidimensional Scale of Perceived Social Support (MSPSS), and Social Difficulties Inventory. The results showed that patients with an advanced disease had poorer QOL scores in the physical, functional and emotional domains, but not in the social/family subscale. Advanced stages of CRC were also associated with severe physical symptoms, such as pain and fatigue which, in turn, affected the psychological well-being of those patients. However, the study’s response rate (60%) and the sample’s lack of ethnic heterogeneity limits the generalizability of the findings.

Nevertheless, the results provide valuable evidence that assessing and improving psychological well-being among CRC patients will increase their QOL (Simon et al., 2008). These findings were supported by a recent study to assess QOL, symptom prevalence, and symptom severity in advanced cancer patients in China (Wang, Shen, & Xu, 2010). A convenience sample of 201 patients, from five community health service centres in Shanghai, China, was recruited. FACT-G was used to measure the patients’ QOL. The results indicated that the patients with advanced cancer had significantly poorer QOL scores; these results were also linked to the number of
symptoms they experienced, such as fatigue, distress, sadness and poor appetite (Wang, et al., 2010).

These quantitative results were further validated by the findings from a qualitative study, centered on patients’ disease stage and location of cancer at diagnosis, conducted in India. Six focus groups, with a total of 38 patients, identified seven areas of morbidity related to CRC: 1) social interaction problems; 2) impaired cognition; 3) fear of cancer recurrence; 4) pain; 5) fatigue; 6) changing bowel habits; and 7) sexual dysfunction (Ness, Holmes, Klein, Greene, & Dittus, 1998). These areas of morbidity affected the patient’s ability to perform daily activities, their role performance, their physical well-being, and their social interaction, which all led to poorer overall QOL.

As the treatment of cancer depends on the location and stage of cancer at diagnosis, patients at an advanced stage require intensive treatment. Consequently, patients might experience a number of complications related to treatment. Furthermore, patients with an advanced stage of cancer reported experiencing more problems related to social interactions, cognition, psychological distress (fear), sexual symptoms and physical symptoms (pain and fatigue while performing daily activities). These stressors appear to be the final step in the decline of the patients’ QOL.

In addition to the disease stage, the time since diagnosis is considered another disease-related predictor of QOL among cancer patients. For example, increasing time since diagnosis with CRC has been found to be associated with better QOL scores, especially in physical and emotional well-being (Ramsey, et al., 2000). This outcome
may be related to the decrease specifically in the disease-related demands experienced, as well as the cancer patient’s adaptation and adjustment to their serious condition (Klemm, Miller, & Fernsler, 2000). In addition, it appears that QOL is improved with the time (Dunn, et al., 2003).

A recent cross-sectional design study, conducted by Safaee and colleagues (2008), assessed the QOL of breast cancer patients undergoing chemotherapy treatment. A sample of 119 patients completed a QOL-C30 questionnaire to measure their QOL score. In this single-centred study, the bivariate and multivariate analyses showed that the duration of disease (time since diagnosis) was positively correlated with the global QOL score. Thus, the patients with a duration of disease less than four months reported lower QOL scores (Safaee, Moghimi-Dehkordi, Zeighami, Tabatabaee, & Pourhoseingholi, 2008). However, a careful interpretation of the results is required due to the limitations of the study, namely: the small sample size and the cross-sectional design which cannot identify any changes over time, thus, no cause and effect relationship can be established (Denise Polit & Beck, 2009).

**Treatment-Related Predictors**

The CRC treatment modalities, including chemotherapy, radiotherapy and surgery, have been investigated many times in relation to their impact on patients’ QOL. The treatment modality chosen for the patient depends on the cancer site and stage.

Surgical treatment is the first choice for most of that cancer types especially CRC (Otto, 2001). The two surgical options are the formation of a stoma or anastomosis. The formation of a permanent or temporary intestinal stoma is usually essential after
colorectal cancer resection surgery (Ma, Harvey, Stewart, Andrews, & Hill, 2007). The literature review highlighted that the stoma negatively affects CRC patients’ QOL, especially with respect to physical symptoms (GI disturbance), emotional, functional (daily activity demand), and social aspects. This outcome may relate to dissatisfaction with their preoperative preparation for surgery, their postoperative physical symptomatology, stoma-related complications or the presence of negative stoma-related thoughts and beliefs (Ma, et al., 2007). In spite of a new surgical technique in stoma formation, CRC patients still report a number of complications related to the stoma such as diarrhoea, odour and abdominal distension and infection, all of which impact their QOL (Graham, 2009). According to the International Ostomy Association (IOA, 2010) CRC patients with stomas report and experience numbers of physical and psychosocial complications that negatively affect their QOL.

Both anastomosis and colostomy have an adverse impact on the patients’ QOL and can lead to a number of complications that reduce the patients’ health status and, finally, their QOL. Indeed, the literature review reveals that patients experience a wide range of surgical complications, such as dehydration secondary to excessive ileostomy output, colitis, wound infection, urinary retention, prolonged ileus, esophagitis, GI bleeding and pneumonia. All complications significantly lower the HR-QOL scores (Anthony, Hynan, et al., 2003). In addition to the physical, psychological, social, and emotional distress, postoperative complications can also occur, such as bowel habit changes, urinary problems and a decrease in functional, physical ability (Sailer, Fuchs, Fein, & Thiede, 2002).
While the literature review identified that some patients with stoma report having lower QOL, particularly in relation to social engagement, and performing physical activities; there is no clear evidence regarding QOL status in stoma and non-stoma patients. To gain a better understanding of this area, a longitudinal, single-centre study was carried out in Germany to investigate HR-QOL, as a primary endpoint for patients undergoing sphincter-saving rectal resection (Sailer, et al., 2002). A total of 64 patients were studied during the three phase research project: 1) preoperative phase; 2) at the time of the stoma reversal phase; and, 3) at 3-month intervals for one year thereafter phase. Additionally the patients’ QOL was assessed using three instruments: the Gastrointestinal Quality of Life Index (GIQLI), the European Organization for Research and Treatment of Cancer (EORTCQOL-C30), and the European Organization for Research and Treatment of Cancer colorectal module EORTC QOL-CR38) (Sailer, et al., 2002). Thirty-nine patients completed the survey; the overall findings showed that patients, who had undergone a colonic pouch, had a better QOL than those who had a straight anastomosis (Sailer, et al., 2002). Further, the results showed that patients with CRC experienced a range of physical, psychosocial, and emotional problems related to postoperative complications. However, due to a number of limitations with the study, a careful interpretation of the results should be considered. These limitations include small sample size (39 patients), a focus on patients from a single centre (which lacks regional and cultural influences), and attrition from the longitudinal study.

In contrast, Camilleri-Brennan and Steele (2001) carried out a prospective study to determine QOL over time among CRC patients who had undergone surgery. The 65 patients, from Ninewells hospital, Dundee, the United Kingdom, were followed up for
one year post surgery; their QOL was measured using three validated assessment tools (the QLQ-CR38 questionnaire, the European Organization for the Research and Treatment of Cancer (EORTC) QLQC30, and the Medical Outcomes Study Short-Form 36 version 2 (SF36v2). The results showed that the patients’ QOL improved over time, improving significantly after six months. Further, the patients reported that their bowel function returned to normal over the one year period. However, they did not qualify their meaning of ‘normal’ (Camilleri-Brennan & Steele, 2001). Of relevance to the current study, the generic instrument used, may not be sensitive enough to measure or reflect the overall QOL for colorectal cancer patients. Additionally, the sampling method (sample size) may not allow the findings to be generalised; accordingly, careful interpretation of the results is required.

In the treatment of CRC, after surgical intervention chemotherapy and/or radiotherapy treatments are the second choice (Blazeby, Sanford, Falk, Alderson, & Donovan, 2005). Such adjuvant therapies have an impact upon the cancer patient’s QOL. They experience a number of complications related to these modalities, such as GI symptoms, haematological disorders and pain (Allal et al., 2005). The research examined the effect of preoperative chemotherapy and/or chemo-radiotherapy on the QOL of 103 patients with cancer in the USA; the assessment tool was EORTC QLQ-OES18 (oesophageal site-specific module) and EORTC QLQ-C30 (Blazeby, et al., 2005). The study showed deterioration in most aspects of HR-QOL during preoperative chemotherapy. In addition, patients proceeding to concomitant radiotherapy deteriorated further; they also reported experiencing specific problems with reflux symptoms, role and social functioning. After the neoadjuvant treatment, but before the surgery, their HR-QOL returned to baseline levels. However, six weeks
after surgery, the patients once again reported a marked reduction in their physical, role and social functioning, while they also experienced increased fatigue, nausea and emesis, pain, dyspnoea, appetite loss and coughing (Blazeby, et al., 2005).

A recent systematic review of the relevant articles, focusing only on one cancer type (esophagogastric cancer) and on one treatment modality (chemotherapy), was undertaken by AL-Batran and colleagues (2010). The study assessed the effects of chemotherapy on the HR-QOL of patients with metastatic or local advanced cancer. The literature review was conducted using PubMed and was limited to clinical studies published between 1998 and 2008, in the English language. Despite these limitations, 41 publications were examined. Nevertheless, the results of this intensive review are a valuable contribution to the field, as well as confirming previous studies regarding the side effects of chemotherapy and its impact of the patients’ QOL. Importantly, the systematic review concluded that the decision for treatment should take into account the patients’ HR-QOL, and the efficacy of the therapeutic regimen (Al-Batran & Ajani, 2010).

As can be seen from the above overview, as a result of using different treatment modalities, or combinations of multi-model therapy, patients might experience a range and intensity of physical complications. As a consequence, their period of hospitalization (length of stay) could increase. Thus, the patients might experience a range of psychosocial problems, such as stress, in addition to physical complications, such as hospital acquired infection. All these experiences could lead to a decline in patients’ QOL.
For this reason, hospitalization time (length of stay) is also considered one of the disease-related factors that have a negative effect on QOL among CRC patients. Indeed, patients with longer stays in hospital account for a significant expenditure of hospital resources (Sharma, Sharp, Walker, & Monson, 2008). Hence, in the UK, there is considerable emphasis on reducing postoperative stay, and then utilizing those savings to improve other services in the NHS (National Health Service). In addition to surgical complications being linked with increased postoperative stay and hospital expenditure, other factors also increase length of stay (LOS), namely: age, type of operation and the classification of the patient’s condition. According to Sharma et al. (2008), postoperative LOS was considered an important outcome after CRC surgery, as well as being correlated with QOL domains. In their research, 110 eligible CRC patients were studied to evaluate the effects of personality, mood, coping and QOL on LOS. A positive affect relates to the predisposition of the patient to experience positive mood states and reflects the patient’s state of energy, excitement and enthusiasm. Positive affectivity was found, by Sharma et al. (2008), to be associated positively with the patient’s level of social activity and physical exercise. High scores for the functional well-being scale of FACT were also found to be correlated with a shorter postoperative stay (Sharma, et al., 2008). Indeed, the QOL domains, including the functional wellbeing (FW), physical wellbeing (PW) and additional concern (AC) items were found to be significantly associated with postoperative LOS for colorectal cancer patients (Sharma, Sharp, Walker, & Monson, 2007; Sharma, et al., 2008). Additionally, the results also showed a significant association among the pre-treatment FACT-C social well-being (SW), emotional well-being (EW) and FW scales, and the FACT-C total score, as well as the presence of postoperative complications in CRC patients.
Similarly, a recent publication by Laky and colleagues (2010) confirms the findings, from the previous studies, that there is a correlation between the length of stay (hospitalization) and the patient’s QOL. The FACT-G was used to measure the QOL of 157 patients with gynaecological cancer. The results showed that LOS was associated with a higher risk of infections, hospital acquired disease, malnutrition and overall QOL, in addition to greater costs. No matter what the cancer type, these studies strongly support the need for sharing and the importance of pre-treatment management and assessment of the patient’s condition (nutrition, risk for postoperative complication and baseline QOL) (Laky, Janda, Kondalsamy-Chennakesavan, Cleghorn, & Obermair, 2010; Sharma, Sharp, et al., 2007; Sharma, et al., 2008).

Patient-Related Predictors

A cancer diagnosis is a stressful life event that may affect patients’ physical, psychological, social, economic, sexual and spiritual aspects of QOL (Yan & Sellick, 2004). The first stage of a cancer diagnosis imposes a particular crisis for the patient and may result in shock, denial or rejection of the presence of the disease. Patients then have to confront the illness and its treatment modalities. According to Svedlund, Sullivan, Sjodin, Liedman and Lundell (1996), patients with gastrointestinal tract (GIT) cancer appear to have more complaints, such as decreased libido, insomnia, loss of appetite and mood changes, compared with other types of cancer patients. Furthermore, as a result of the diagnosis and treatment for cancer, patients experience a wide range of psychological and physical symptoms that impact negatively with their life, health and QOL (Svedlund, Sullivan, Sjodin, Liedman, & Lundell, 1996). A recent comprehensive study by Akin et al. (2010) showed that lung cancer patients,
who had experienced physical symptoms, including lack of energy, coughing, pain, lack of appetite, nausea and psychological symptoms (such as feeling nervous, sad and worried), reported lower QOL scores.

Thus, it can be seen that QOL is a multifactorial and dimensional concept that includes the affect of the disease, the treatment, and the patients’ reactions (Plummer & Molzahn, 2009). How patients react or behave to their new situation, and identifying which factors might contribute to their reaction, has become of great interest to health professionals. Of particular importance, as identified by the literature review, is the finding that perceived social support and the meaning of their illness plays an important contribution to the patients’ health and QOL.

According to Sammarco (2001), social support is “a perception that leads individuals to believe that they are cared for and loved, esteemed and valued, and that they belong to a network of communication and mutual obligation” (p.213). Such a perception is considered one of the most important domains of psychological functioning during cancer diagnosis and treatment (Clarke, Booth, Velikova, & Hewison, 2006). Further, it is considered a valuable and important resource for psychosocial adaptation and adjustment for cancer patients and for improving QOL (Wortman, 1984). This background was the basis for Sammarco’s (2001) investigation into the relationship between perceived social support, uncertainty, and QOL among younger cancer survivors. A sample of 101 patients, aged less than 50 years, completed the study questionnaires. The results showed a positive correlation between perceived social support and QOL, while a significant negative correlation was found between
uncertainty and QOL. Additionally, a significant positive correlation was found between network size and the socioeconomic subscale of QOL.

Similar findings were found from a Chinese study, namely, that a lack of social support correlated with depression and then with poor HRQOL in newly diagnosed cancer patients (Yan & Sellick, 2004). The study also revealed that perceived financial difficulty and symptom distress had a significant effect on QOL. Moreover, the numbers of symptoms, such as fatigue, pain, weight loss, dry mouth and loss of appetite, also influenced QOL.

Earlier, Chang, Hwang, Feuerman and Kasimis (2000) had undertaken a study to assess symptom prevalence and intensity, and their relation to QOL in medical oncology patients, at a Veteran Affairs medical centre in the USA. Two hundred and forty inpatients and outpatients reported that pain, lack of energy or poor performance status, dry mouth, shortness of breath, difficulty in sleeping, and lack of appetite were correlated with diminished QOL. The findings also identified that family was the major source of emotional support, followed by practical support, while health professionals were the primary source of informative support.

In addition to perceived social support, the meaning of illness is considered another factor that plays a valuable role in enhancing cancer patients’ ability to overcome their situation. It appears that the meaning of illness is shaped by an individual’s experience of life and the impact of cultural, spiritual, biological, psychological and economic factors (Downe-Wamboldt, Butler, & Coulter, 2006). Hence, social support not only provides assistance and protection among cancer patients, it is also an
emotional, informational, and tangible support (Tan, 2007). Patients with inadequate or unsatisfying social support (from family, friends, peers, and the community) have negative outcomes, such as psychosocial distress, relational strain and poor communication (Due, Holstein, Lund, Modvig, & Avlund, 1999). In contrast, factors improving cancer patients’ positive coping abilities include social support, marital status, religion and the ability to solve social problems (Tan, 2007).

These results confirm those obtained by Downe-Wamboldt, Butler and Coulter (2006). They explored the relationship between the meaning of illness, perceived social support resources, coping strategies used, and QOL among cancer patients and their families. Eighty-five patients and 85 family members completed the study questionnaires. The results showed that both patients and family members reported high levels of perceived social support. Coping strategies used by both the patients and their families reflected that optimistic coping was the most used strategy by both groups. Self-reliant, supportive, and confrontative coping strategies were also used. Such levels of social support and coping strategies positively affected the patients’ QOL. In a more recent study by Lim, Yi and Zebrack (2008), social support was linked to patients’ QOL; thus, the higher the level of social support (larger network size, diversity, and closer social ties) the lower the depressive symptoms, which, in turn, contribute to better QOL (Lim, Yi, & Zebrack, 2008).

**QOL Issues in CRC Patients**

Emotional and interactional perspectives of the meaning of illness by patients with CRC have been explored by a number of researchers. A qualitative study, involved interviewing 52 patients using open-ended questions at the time of diagnosis, as well
as three and 12 months after the diagnosis (Ramfelt et al. 2002). The main theme to emerge related to finding the meaning of illness to achieve emotional coherence. The themes were divided into two dimensions: (1) unified embodiment, which refers to gratefulness, confidence in oneself and others, and looking forward to creating a new future; and, (2) dichotomised embodiment, which refers to altered self-value, loss of temporality, and infringement of body integrity. To guide the interviews, the meaning of illness was divided into eight categories (challenge, enemy, loss, punishment, relief, strategy, vague, and weakness).

These meaning categories were derived from Lipowski (1970) to reflect a patient’s knowledge, beliefs, attitudes, and experience about chronic disease. The researcher presented these categories to the patients, who chose the most relevant, as well as those that reflected their meaning of illness. However, one limitation of the study is that it did not explain how these themes affected the patients’ lives, their general health, or the outcome of their chronic illness. Further, the study did not highlight or address what the patients were doing to control and overcome this critical condition in their lives.

Decades later, a number of studies have sought to explain patients’ and families’ concerns and experiences after a CRC diagnosis. For example, Northouse, Schafer, Tipton and Metivier’s (1999) qualitative study used semi-structured interviews with thirty colon cancer patients and their spouses, over a period of two to 36 months, after diagnosis. The study specifically targeted their reaction to the cancer diagnosis, the colostomy, their change in life style, and satisfaction with received information. The findings indicated that spouses were more negatively affected by the diagnosis, and
that fear of recurrence was their greatest concern. However, both patients and their spouses worried about the changes in their life style, but it was the spouses who were more concerned about the roles and relationships changing (Northouse, Schafer, Tipton, & Metivier, 1999). Nevertheless, both patients and their spouses were satisfied with the information they received in relation to their treatment. A limitation of this study was that, while the patients’ and spouses’ concerns were presented, no explanation was given as to how these factors might affect their QOL. Further, the researchers did not address factors related to the CRC diagnosis and treatment impact on the patients and their spouses, such as coping, hope, and the level of psychological distress.

In a Swedish study of patients’ and families’ experience after a colostomy, Persson and Hellström (2002), using a qualitative approach, found similar results. They identified better outcomes when patients shared their concerns regarding altered body image, influences on sexual life, uncertainty, influences on social life, influences on sports, and leisure activities, and physical activity. The researchers enhanced and clarified the importance of preoperative teaching related to the management of a colostomy. However, they ignored other relevant aspects, such as physical, emotional and psychological complications, as well as pharmacology.

Significantly, the study did not discuss the psychological impact of colostomy surgery, especially as it affected the patient’s body image, and social and sexual functioning. This omission occurred, in spite of previous studies showing that a colostomy has a harmful effect on the QOL of patients with CRC. The finding may be related to the interview questions developed by the researchers who were more
concerned about the patients’ feelings, attitudes, and life experiences, changes in social life and body appearance, and future expectations. While numerous studies highlight the impact of having a stoma on a patient’s health, little attention is paid to how the patients deal with, control, and interact with this issue. Thus, there is a need to investigate how this treatment modality (stoma) affects a patient’s level of hope, anxiety and depression.

Identifying predictors of HR-QOL is becoming an area of interest to health researchers, particularly oncology nursing researchers. Most research has involved quantitative methods, with a limited number being qualitative studies; different instruments have also been used to measure QOL (mostly generic instruments). One such study identified factors that were associated with poor HR-QOL in patients with CRC, including: (1) reduced postoperative performance status; (2) stoma surgery; (3) diarrhoea; (4) constipation; and (5) age, younger than aged 65 years (Wilson, Alexander, & Kind, 2006). These findings supported an earlier qualitative USA study, that found several emerging themes from the data, namely: body image, social-well being, and physical well-being concerns (Blair et al., 2003). The patients reported the need to limit their leisure activities, with some having to discontinue any strenuous physical activities. Additionally, the treatment had a negative impact on the patients’ body image (for example, their appearance, and the necessity to wear looser clothing). Furthermore, they reflected upon their loss of anonymity and intrusive thoughts about their relationships with others (which limited their engagement in social activities).

Another USA study also identified the factors that were associated with post-treatment HR-QOL (Anthony, Long, et al., 2003). Seventy-one patients with CRC
completed a FACT-C survey to assess their HR-QOL. Univariate and multivariate analyses were undertaken to assess the relationships between the patient demographics, tumor site, and treatment-related variables, with a 12-month FACT-C follow-up. The results indicated that only preoperative complications were negatively associated with HR-QOL among CRC patients. Interestingly, no relationships were found between patients’ demographic variables and treatment-related factors. These results are in contrast to the later studies. Perhaps the small sample size was the reason for this difference in the results with other studies.

While the findings from these studies were interesting, it needs to be remembered that they focused on the demographic, treatment-related and disease-related variables, in addition to physical performance, without highlighting the psychological predictors. Moreover, the previous studies also failed to address cultural influences on the patients’ experiences and desires, and so careful interpretation and implications of these findings are required.

Nevertheless, the study by Sharma, Sharp, Walker, and Monson (2007) identified the factors that influenced early postoperative QOL after elective resection for CRC. The study involved a series of questionnaires (HADS, FACT-C, the positive and negative affects schedule (PANAS), mood rating scale (MRS), and the EuroQOL (EQ-5D), which were completed by 104 patients, with CRC, seven days before their surgery and six weeks after the surgery. The results indicated that patient characteristics, such as age, affected FACT-C emotional wellbeing; the tumour stage positively affected HADS, and the FACT-C functional wellbeing; chemotherapy and radiotherapy were not associated with postoperative QOL; and, postoperative morbidity (particular chest
infection, wound infection) negatively affected postoperative HADS, FACT-C functional wellbeing and PANAS. Moreover, the results showed that postoperative QOL was correlated with the preoperative level of QOL; while preoperative social support was correlated with postoperative anxiety and depression levels; and, postoperative morbidity (complications) predicted anxiety, depression, QOL, mood and PANAS. Finally, the presence of stoma predicted postoperative QOL.

Lundh Hagelin and his colleagues (2006) undertook a cross-sectional study in Sweden of 278 patients with advanced cancer. The study explored a number of factors, including the experience of diagnosis, physical symptoms, aspects of QOL, and period of survival. The results from the EORTC QLO-C30 instrument indicated that the period of survival, from initial assessment to death, which ranged from less than 15 days to more than 120 days, was associated positively with QOL scores (a longer survival time was correlated with an increase in QOL scores). Moreover, older patients coped well, adapting to their terminal condition and returning to their functions faster than the younger patients. In contrast to previous results, married/cohabiting patients reported a poorer QOL. The researchers concluded that this score was low because they were unable to participate in social and community activities. However, these findings are consistent with other studies, where, for instance, patients with physical symptoms, such as constipation, fatigue, loss of appetite, diarrhoea and dyspnoea, reported lower levels of QOL (Lundh Hagelin, Seiger, & Furst, 2006).

Dunn et al. (2003, 2006) undertook two intensive literature reviews to identify what was known about QOL for CRC patients. Four electronic databases were selected
(Medline, Psycho Info, CINAHL, and Sociological Abstract) for the years 1979 to 2001. Forty-one articles were reviewed, with more than half of the studies being conducted in the USA, followed by other western countries, such as the Netherlands, the UK, Australia, Canada, and Sweden. The analysis showed three main areas of study: definitions and measurement of QOL; predictors of QOL; and the relationship of QOL to the period of survival.

In relation to the definition and measurement of QOL, Dunn et al.’s (2003, 2006) results indicated that QOL is a basic, subjective term with no particular or universal definition. Indeed, QOL reflects the patient’s perception of their physical, functional, emotional, sexual, spiritual, and social states. Further, the measurement of QOL appeared to serve three purposes: medical evaluation of treatment outcomes, such as tumour response and survival rate; outcomes of palliative care; and, evaluation of the impact of the disease on survivors. The review also identified that two main types of instruments were used to measure QOL among CRC patients: generic, and disease-specific (with the latter having higher internal validity than the former) (Aaronson, 1991; Aaronson et al., 1991).

The factors associated with QOL were grouped into five broad categories, including: demographic characteristic, such as age, gender, educational, and economic status; disease descriptors, such as tumour site and stage; time since diagnosis; social support; and, life style factors, such as exercise and leisure time (Dunn, et al., 2003). Male patients with CRC showed better QOL adjustments than did female patients, while low income patients reported reduced QOL due to an inability to achieve basic demands (Dunn, et al., 2003; Ramsey, et al., 2000). The CRC stage and site were
significantly associated with the patient’s overall QOL, as they reflected different treatment modalities, symptom severity, and prognosis.

Dunn et al.’s (2003) literature review also indicated that the patient’s QOL improved with time, as the patient adjusted and adapted to their new life experiences. Further, previous studies examined both the positive impact of social support on the patient’s QOL, and the need for an assessment of the potential negative impacts of social support (Dunn, et al., 2003). Unequivocally, social support from patients’ families, partners, relatives, peers, the community and health care professionals appears to improve overall QOL.

In their later literature review, Dunn et al (2006) assessed a number of qualitative studies using the same databases and publication interval. Only seven studies were identified by the search. The analysis showed brief insights into the experiences of patients with CRC. Once again several themes emerged, namely: the meaning of being given a diagnosis of CRC; changing outlook on life, self and others; living with cancer; hope; social interaction; cognition; fears; physical symptoms long-term management; and body image. While the reviewed studies agree in relation to the importance of QOL and the patient’s concerns related to the outcome, no clear in-depth or consistent themes emerged.

In response to this lack of data, Dunn et al. (2006) conducted an Australian qualitative study, using in-depth interviews to gain an understanding of CRC patients’ experiences and QOL. Two researchers conducted 15 audio-taped individual and group interviews using open-ended questions and note taking. Six themes emerged,
namely: satisfaction with the process of diagnosis and treatment; support, including perceived information, QOL; benefits of the diagnosis; making sense; and coping strategies. The participants stated that being given the opportunity to talk freely about the disease, treatment and side effects had helped to decrease the pressure and enabled them to better cope with the disease.

The study (Dunn et al., 2006) added important knowledge to the qualitative aspects of QOL, despite the limitations of the research, such as: the non-inclusion criteria of patients experiencing significant side effects of treatment; the majority of patients being recruited from the same public hospital; and the small number of patients in the focus group. Further, the study reported that coping was considered one of the predictors of QOL; however, it did not identify what strategies were used by patients to deal with or manage their critical condition.

Recently, two systematic reviews were conducted in order to explain QOL among CRC patients. Jansen and colleagues (2010) undertook an intensive literature review to investigate CRC patients’ QOL and to identify the impact of chronic and late effect of the disease and treatment on their QOL. After examining the potential eligible articles, 14 articles were included in the review. The results suggested that, in general, participants were reported to have good to excellent overall QOL in four studies. However, despite high psychological QOL, depression and anxiety were more prevalent among CRC survivors than the general population of similar age because of the fear of recurrence or metastases and distress regarding future diagnostic tests. Furthermore, the review aimed to identify the determinants of their QOL. The findings showed that there are four types of determinants of QOL among patients with
CRC including (1) general determinants (age, gender, ethnicity, education level, large social network, (2) health-related determinants including body mass index (BMI), (3) cancer-related factors (stoma, radiotherapy, recurrence of cancer) and (4) further determinants including smoking, alcohol intake, hospital visits, sexual life, travel and employment status (Jansen, Koch, Brenner, & Arndt, 2010).

In terms of exploring and comparing the experience and coping behaviours of men and women with CRC after chemotherapy treatment, McCaughen and colleagues (2010) conducted a qualitative study involving 38 patients with CRC (24 men and 14 women) in Northern Ireland. Semi-structured interviews were conducted to achieve the research aims. Three themes emerged from the interviews including new normal as they experienced new side effects of the treatment including incontinence, tiredness and bowel problems. The second theme was living with uncertainty; the participants experienced uncertainty about their future, survival and recurrence of cancer. The participants shared the need for social support during their illness period and explained how important this was during this crucial time. However, the study did not identify what kinds of social support were important for the participants.

In summary, this literature review showed that a large number of studies have assessed QOL among cancer patients. Importantly, a range of factors were identified as predictors of QOL among patients with cancer. As mentioned above, these studies had focused mainly on demographic factors, such as: age, gender, marital status, and SES. In addition, disease-related factors (including stage, site, and time since diagnosis) were linked to QOL, while treatment-related factors (including surgical intervention (stoma and anastomosis), chemotherapy and radiotherapy, and length of hospitalization were broadly investigated in relation to QOL. Finally, patient-related
factors (namely, perceived social support, and meaning of illness) were also investigated and linked in relation to QOL.

However, most of these studies were undertaken with other cancer types (mostly breast cancer); only a few studies investigated QOL for CRC patients, especially during the illness/treatment period. Moreover, these previous studies were concerned mainly with the impact of treatment modalities on the patients’ lives, health and QOL. In any study, therefore, QOL must be seen as a multidimensional concept that includes physical, emotional, social, spiritual, satisfaction and psychological domains. Thus, it is becoming clear and essential to focus on the psychosocial predictors of QOL.

As cancer is considered a chronic disease, the aim of health professionals is to provide a better quality of medical care, through a better understanding of QOL in CRC patients during their treatment, as well as identifying and learning about the predictors of their QOL. Both are critical steps in the development of an effective care plan, in assisting nurses to identify risk groups, in formalising goals, in developing specific strategies to enhance the patients’ QOL, and in mitigating the problems of the treatment and disease itself.

To extend the background information for the current study, the literature review related to hope, coping, and psychological distress, including anxiety and depression, among CRC patients is discussed in the following section.
Coping, Hope, Psychological Distress (Depression and Anxiety)

Patients with CRC have reported a number of factors as being associated with the nature and degree of their QOL, namely: coping, hope, social support, and psychological distress (including depression and anxiety). The following section addresses these hypothesized psychosocial predictors in relation to QOL.

Coping

The diagnosis of, and treatment for, CRC is considered a stressful and challenging situation for the patients. As such, patients are faced with a wide range of psychosocial, physical, and emotional problems (Rinaldis, et al., 2009).

Generally, however, the psychological determination of QOL is dependent on the manner in which the patient accepts, deals with, and recognises their disease status, treatment, and disease-related complications, and on how they cope with this critical condition (Matsushita, et al., 2005). Thus, coping is considered an important factor in stressful, physical, and psychosocial adaptation (Nordin & Glimelius, 1997). Indeed, coping has been defined as “changing cognitive and behavioural efforts to change external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (Lazarus & Folkman, 1984, p. 141). Two coping strategies employed to confront and seek solutions to the situation are: problem-focused strategies, and emotion-focused strategies. These strategies do not focus on the event, but centre on ameliorating the associated level of emotional distress. Importantly, the coping model, developed by Lazarus and Folkman (1984), has been used in studies exploring how patients cope with different diseases, including cancer (Tan, 2007).
Within the literature, a number of studies have identified the factors that predict and enhance the use of coping strategies by cancer patients. One of the most important factors is social support because it makes a significant contribution to the patient’s level of coping (Tan, 2007; Tan & Karabulutlu, 2005; Zaza, Sellick, & Hillier, 2005). For example, in Turkey, a cross-sectional descriptive correlational study of cancer patients (the majority being females, with breast cancer) showed that significant correlations existed between the social support strategies and coping strategies. However, a negative correlation was identified between the social support strategies and emotion-focused coping strategies (Tan, 2007).

One possible explanation might be the Turkish cultural context, the patients’ religious beliefs, and how the patients and their families are affected by this stressful situation (Tan, 2007). Nevertheless, there was a positive correlation between the social support strategies and the problem-focused coping strategies, such as confident and optimistic approaches, as well as seeking social support. In addition, a significant relationship was found between the duration of the illness, seeking social support, and the use of coping strategies. In this context, the family was the main source of support; they have an important role in enhancing coping among patients with cancer and should, therefore, be educated and supported by health care professionals in their support and coping approaches (Devine, Parker, Fouladi, & Cohen, 2003; Tan, 2007; Tan & Karabulutlu, 2005).

Recently, oncology nursing researchers have conducted a number of studies to identify the most common coping strategies used by cancer patients. For example, Deimling and his colleagues (2006) carried out a study in Ireland to identify coping
behaviours and strategies of older adult long term cancer survivors. The researchers also identified personal and illness/treatment characteristics that were associated with the use of particular types of coping strategies, such as: planning, acceptance, venting, denial, and seeking social support. More recently, additional coping strategies were identified by Agarwal and colleagues (2010). The most common coping strategies used by African-American patients, with head and neck cancer, were: having emotional support, being strong and self-reliant, and engaging in distracting activities (Agarwal, Hamilton, Crandell, et al., 2010). Further, these studies showed that using these coping strategies was highly associated with better QOL and well-being (Agarwal, Hamilton, Crandell, et al., 2010; Deimling et al., 2006).

A recent study by Smith et al., (2010), that assessed the relationship between improving coping strategies and QOL, among patients with breast cancer, also identified similar findings. The research involved a prospective, single-arm, pilot study, enrolling a convenience sample of 44 eligible patients at Duke University medical centre. The results showed that improving patients’ coping skills, self-efficacy, and spiritual meaning/peace significantly correlated with a decrease in despair, and correlated with an increase in overall QOL (S. K. Smith et al., 2010). As noted earlier, limitations related to the previous studies surrounded their focus mainly on breast cancer, head and neck cancer, surviving cancer patients, sample size, and research design. The difficulties arise because the studies were mostly cross-sectional, with an inability to make any causal connections. Nevertheless, the results are considered useful and helpful in developing an interventional program to improve the patients’ QOL, through the enhanced use of appropriate and effective coping strategies.
Further, the previous studies recommended that more research be undertaken using: a larger sample size, different cancer types, and different assessment tools (to identify other coping strategies used by cancer patients in order to develop an interventional program to enhance the patients’ QOL during their cancer journey) (Agarwal, Hamilton, Crandell, et al., 2010). Thus, coping strategies are seen as essential tools to improve cancer patients’ QOL. This outcome would include: decreasing the impact of psychological distress and enhancing the fighting spirit. For example, Moorey and colleagues (2003) used the Cancer Coping Questionnaire (CCQ) to assess three samples of cancer patients/survivors in the UK. A positive correlation was found between CCQ and the fighting spirit; CCQ was negatively correlated to hopelessness/helplessness. The overall coping score, as measured by the CCQ, was negatively correlated with depression, but not with anxiety (Moorey, Frampton, & Greer, 2003). In an earlier USA study, coping style was found to be highly correlated with emotional distress and QOL in breast cancer patients (R. Schnoll, Harlow, Brandt, & Stolbach, 1998).

Matsushita et al. (2005) confirmed these results in a Japanese study to assess the relationships between psychological characteristics (such as anxiety and depression), QOL, and coping style, among patients with gastrointestinal cancer. Eighty-five inpatients, in a single hospital site, completed the research questionnaires on three occasions: before surgery, before discharge, and six months after discharge. The results showed that patients’ depression levels were higher before discharge, than before surgery, as well as six months after their discharge. One possible reason for this outcome relates to their physical status not returning to normal, as they had wished. In contrast, no significant differences were found in their anxiety levels on
any of the three occasions. However, some methodological limitations were identified; namely: small sample size (that was not appropriate, or large enough to run multiple regression analyses), and the single site for the study. Hence, it is questionable whether the results are generalisable.

To sum up, the literature review highlights that patients living with cancer do suffer from different types of psychological distress and physical symptoms, related to both the diagnosis of the cancer, and the treatment complications, which affect their over QOL. Thus, coping was considered a predictor and critical factor for improving a patient’s QOL, as well as for minimizing the impact of psychological distress (Vachon, 2006). Nevertheless, there are several limitations to most of the studies. Firstly, the majority of these studies were concerned with, and focused on, identifying the coping strategies used by women with breast cancer, followed by oral and neck cancer. Few studies investigated coping strategies used by both men and women diagnosed with CRC. Secondly, not all coping strategies are either effective or useful for all cancer patients. Indeed, there is little information about which coping strategies are used by cancer patients, in general, and which are used by patients with CRC in particular (Rinaldis, et al., 2009; Zaza, et al., 2005). To address these limitations and to extend the existing knowledge, the current study used a well developed scale to measure the eight identified coping strategies. This approach sought to fully evaluate the diversity of coping strategies that are used by Jordanian CRC patients.

The following section discusses the notion of hope and the impact of psychological distress, including depression and anxiety, to identify their influence upon cancer patients.
Hope

Hope is considered one of the most important variables in healing, coping and enhancing QOL during periods of stress and loss. In addition, the presence of hope has been shown to improve the patient’s physical and mental well-being (Felder, 2004). Further, hope has been studied in relationship to patient characteristics, and different types of acute and chronic diseases, mostly in cancer patients (Ballard, Green, McCaa, & Logsdon, 1997; Herth, 2000).

Indeed, several studies have identified hope as an antecedent to, and essential in, coping and perceived control over illness. In the USA, Felder (2004) addressed how the patients cope with a cancer diagnosis; they investigated the relationship between hope and coping among 204 patients with various cancer types. A significant positive relationship was found to exist between the level of hope, as measured by the Herth Hope Scale (HHS), and coping, as measured by the Jalowiec Coping Scale (JCS) (Brockopp, Hayko, Davenport, & Winscott, 1989; Felder, 2004; Herth, 1989).

Moreover, it was found that the patients used different coping strategies, regardless of the cancer diagnosis. These strategies included: the optimistic coping style (positive outlook); the confrontive coping style (exhibiting constructive problem solving); and the evasive coping style (indulging in avoidance behaviours). In addition, the strength of religious convictions, and the performance of family role responsibilities, were significantly related to the variables of hope and coping (Herth, 1989). Furthermore, according to Brockopp et al. (1989), relationships were shown to exist between the levels of perceived personal control, and the need for hope and information for 56 adult cancer patients.
Other studies have examined the relationships between hope and the symptoms of cancer. Vellone and his colleagues (2006) found that hope was negatively correlated with anxiety, depression and boredom during hospitalization. Indeed, higher levels of hope were correlated with lower levels of psychological distress, reduced cancer-related physical symptoms or pain, increased ability to carry out daily activities, and higher global QOL scores. Similar results were reported by Lin, Lai and Ward (2003). Their comparative study showed that cancer patients, with pain, had significantly lower levels of performance status, lower levels of hope, and higher levels of total mood disturbance than cancer patients without pain (Lin, Lai, & Ward, 2003). Thus, boredom during hospitalization was negatively correlated with the level of hope among cancer patients. Further, boredom was also associated with psychological distress, such as anxiety and depression (Vellone et al., 2004). These findings suggest that medical staff, and nurses in particular, could reduce the effects of boredom among cancer patients by sharing, with them, planned activities and programs to enhance hope (Vellone at al.,2006).

These results were confirmed by a recent study (Rustoen, Cooper, & Miaskowski, 2010), conducted to evaluate the relationships between demographic and clinical characteristics, health status, hope, psychological distress, and life satisfaction, and to evaluate whether hope mediated the relationship between psychological distress and life satisfaction. The results indicated that hope played a key role as mediator for improving the sample of 194 cancer patients’ psychological status, life satisfaction, and an improvement to their QOL. Additionally, the researchers highlighted the need to further investigate hope in relation to QOL among cancer patients, as these variables had not been investigated in-depth.
The recent study by Mazanec et al. (2010) was conducted to understand the role of hope in improving HR-QOL for newly diagnosed adult cancer patients. This relationship was considered a critical step in developing effective screening tools and targeted interventions for psychosocial care. Thus, a cross-sectional, predictive correlational design was used. The results showed that a positive relationship between hope, spirituality, and HRQOL existed. In addition, a negative relationship was found between the level of hope and psychological distress (depression and anxiety) (Mazanec, et al., 2010). While the study’s limitations rested on a restricted sample of white people whose data were collected as part of a psychosocial registry, this study highlighted the need to identify the psychosocial predictors of HR-QOL at the time of the diagnosis, and during the treatment/illness period. Consistent with these findings, hope has also been shown to be important in patients’ psychological adjustment to illness for various cancer types (mainly breast cancer) (Vellone, Rega, Galletti, & Cohen, 2006). Further, according to Lee (2001), hope has a profound buffering mechanism in terms of the psychological adjustment-related factors of fatigue, and among women with breast cancer receiving postsurgical follow-up treatment (E. H. Lee, 2001).

The 2010 study by Berendes and colleagues (2010) highlights the relationship between hope and adjustment. The researchers hypothesized that higher levels of hope would be related to lower levels of pain, as well as other lung cancer symptoms (i.e. fatigue and coughing), and lower psychological distress (i.e. depression) (Berendes et al., 2010). Despite the small sample size (n= 51), the results showed that a high level of hope was significantly associated with lower levels of major physiological symptoms of lung cancer (such as pain, fatigue, cough) and psychological symptoms
(depression). Also, these results indicate that hope plays a valuable role in improving the patient’s adjustment to the diagnosis of cancer.

Arguments abound in the literature about the significant role that hope plays for cancer patients. Hence, it is becoming an important for health professionals to identify the strategies that are commonly used to maintain hope in cancer patients. A phenomenological study, by Bulsara, Ward and Joske (2004), identified the core strategies used by haematological cancer patients in Australia. Seven commonly used strategies that patients use to maintain their hope were identified from in-depth interviews, namely: fighting spirit; acceptance and finding a balance; changing and re-evaluating life’s priorities; the importance of support from significant others, such as family and friends; health care providers’ support and positive attitude; ability to rely on short-term goals and planning for long-term goals; and, the desire to help other patients cope with their cancer experience.

It is clear that patients, who have the ability to fight against their diagnosis, accept and learn how to live with their new condition, and modify their goals and priorities, will be able to control and cope with their condition and master their illness. Moreover, the findings showed that hope was an important and essential factor influencing psychological modification. Additionally, patients and their families spoke of the hope for new cures, and the possibility of more effective treatments being available in the future. They believed that this area of cancer research was progressing rapidly. Having and maintaining optimal health, hope and the ability to cope with their critical condition, were important factors in fighting the cancer (Bulsara, Ward, & Joske, 2004).
In addition to the previous strategies, spirituality and/or religious practice and beliefs appear to enhance adjustment; they do this through their ability to provide actual meaning, and by promoting hope through an explanation for the experience of illness and suffering in life, and the meaning of death (Moadel et al., 1999). Consistently, most studies posit that improving and enhancing religiosity correlates with increased hope among cancer patients (Weaver & Flannelly, 2004). Additionally, spirituality is also linked to better QOL. For example, a recent comprehensive study (Assimakopoulos et al., 2009) evaluated the role of spirituality in improving the QOL for 118 cancer patients receiving chemotherapy treatment. This single-centre observational study found that a positive relationship existed among spirituality, having spiritual support from the surrounding community, and the patients’ scores of QOL. However, the study did not explain how spirituality enhanced the patients’ QOL status, or what kind of religious practices were used by the participants to give them hope.

Further, hope has been investigated in relation to the diagnostic disclosure of cancer. According to Lin and Tsay (2005), a patient informed of a diagnosis of cancer suffers from emotional distress, such as fear, anxiety, depression and shock. However, cancer patients informed about their diagnosis have significantly higher levels of hope than those who were not informed (Degi, 2009; Faridhosseini, 2010; Lin, Lai, et al., 2003; Lin et al., 2003; Lin & Tsay, 2005). Thus it appears that patients who lack information about their diagnosis are at a greater risk from increased levels of anxiety, distress, uncertainty, fear and dissatisfaction (Lin, Tsai, et al., 2003). Moreover, the results showed a negative correlation between time since diagnosis and level of hope. This outcome is related to treatment modalities and treatment-related complications,
prognosis and outcomes of the cancer. The result is, nevertheless, inconsistent with other studies that showed no relationship between time since diagnosis and level of hope (Greene, O'Mahony & Rungasamy, 1982; Herth, 1989).

In summary, hope can be considered as a personal element that is associated with psychological well-being and health outcomes in healthy individuals, as well as in patients with acute and chronic illness. There is a crucial need to explain, in-depth, the role of this key element in relation to the patients’ QOL. Such knowledge will increase the health professionals’ understanding, and provide data that can assist the development of effective intervention programs for cancer patients (Mazanec, et al., 2010). In addition, in spite of the large numbers of studies that have been conducted to assess the sense of hope in cancer patients, there is still a gap in that knowledge, possibly the result of researchers having limited information about how patients’ level of hope varies by cancer type, stage or complications (Chi, 2007). Furthermore, few studies have investigated the relationship between hope and QOL among CRC patients. The studies that have been undertaken, in the main, have addressed this link in women with breast cancer.

Psychological Distress (Depression and Anxiety)

The diagnosis of, and treatment for, cancer can cause psychological distress, specifically depression and anxiety (Nordin, Berglund, Glimelius, & Sjoden, 2001). Depending on the study, the prevalence of depression and anxiety in patients with cancer appears to range from 0 to 49% (van't Spijker, Trijsburg, & Duivenvoorden, 1997). This variation in the findings may be related to the different types of cancer and the different treatment modalities under investigation (Nordin, et al., 2001).
According to Weisman (1976), the risk factors that increased the level of depression among cancer patients included: social isolation, feelings of loss, pain, and socio-economic pressure. The study assessed the impact on 163 patients of being newly diagnosed with cancer (i.e., breast, colon, lung, melanoma or Hodgkin’s disease) and to find significant clues for later emotional distress. The more vulnerable patients were identified as having more symptoms when first diagnosed, and that the systemic symptoms were more significant than was expected for the type of cancer or the staging. Further, these highly vulnerable patients were generally pessimistic, anticipated little recovery, and had practically no support from significant others. Also, they had more marital problems, tended to suppress their feelings, and had a history of depression (Weisman, 1976). However, the denial in itself did not mean vulnerability. Most patients showed little denial throughout the period of observation, but the more vulnerable patients tended to vacillate between denial and acceptance. What was more indicative of future emotional problems related to indecision about the treatment and regrets about the past (Passik et al., 1998).

Similar findings were identified in a recent study to discover the predictors and risk factors for depression among African American cancer patients (Agarwal, Hamilton, Moore, & Crandell, 2010). The results of this single-centre study showed a prevalence of depression of 27.2% among the 283 patients in the sample. The risk factors included: age (younger patients were most likely to experience depression); economic and social problems (their inability to find a job); symptoms and adverse effects of treatment; and living with the family (family support worked as a protective element from depression) (Agarwal, Hamilton, Moore, et al., 2010).
Additionally, depressive symptoms have been found to adversely impact upon cancer patients by interfering with: their treatment; increasing the length of hospitalization; reducing overall survival time; diminishing the effectiveness of the immune system; and reducing QOL (McDaniel, Musselman, Porter, Reed, & Nemeroff, 1995). Further, as the human body responds to stress through the autonomic nervous system, hypothalamic-pituitary-adrenocortical axis and the cardiovascular system, these systems can be damaged by prolonged stress (McEwen, 1998). Moreover, a patient’s QOL can be diminished because of the impairment of physical and work activities, social isolation, deterioration in family relationships, financial problems and a decrease in sexual activity (Gilbar, 1991; Newell, Sanson, Girgis, & Ackland, 1999).

A recent meta-analysis review has provided support for the findings from previous studies, namely, that psychological distress (i.e. depression) is associated with, and considered a significant predictor of, mortality in cancer patients. These researchers recommended studying psychological distress among specific cancer types, with large sample sizes (Satin, Linden, & Phillips, 2009).

Anxiety and depression are also associated with the severity of symptoms, chronic treatment, social isolation, suicidal ideation, and prognosis of the disease (Zhou et al., 2005). To date, however, few studies have examined the correlation between comorbid anxiety and depression effects, or the impact on patients with digestive cancers, such as colorectal, oesophagus, liver and gastric cancers (Zhou, et al., 2005). One such study addressed anxiety associated with medical situations in a heterogeneous sample of 320 adult cancer patients. The patients completed the Cancer Inventory of Problem Situations, which identifies anxiety in a variety of medical
situations. On average, 44% of the patients reported some anxiety in medical situations, and 23% reported significant anxiety (Schag & Heinrich, 1989). Moreover, such anxiety was somewhat situation and gender dependent. Females were more likely to report anxiety, with greater intensity, than males, while watching other patients receive treatments, waiting to see the doctor, waiting to find out the results of tests, going to the hospital, and receiving chemotherapy (Schag & Heinrich, 1989). Multiple regression analysis were used to identify the correlates of the anxiety, with 57% of the variance accounting for by age, sex, problems communicating with the health team, and global adjustment to the illness.

Furthermore, for patients with advanced cancer in hospice care, psychological distress (depression and anxiety) was associated with illness severity, pain score, and impairment in the emotional and physical aspects of QOL (E. M. Smith, Gomm, & Dickens, 2003). Similar results were reported by Payne (1992), who explored social roles, relationships and perceptions of treatment. In that study, QOL was operationalized as a measurement of anxiety, depression, and self-esteem, health locus of control, physical performance and symptoms. Fifty-three patients with advanced breast cancer or ovarian cancer under palliative treatment were studied, prospectively, for six months to assess whether the site of the cancer and the method of chemotherapy administration influenced their QOL. The regression analysis indicated that anxiety and depression accounted for most of the variance in quality of life (Payne, 1992). The depressed patients’ QOL was more affected than was the QOL for non-depressed patients in the social, emotional, cognitive and physical domains (Grassi et al., 1996). These results support the importance of assessing and evaluating depression and anxiety in relation to QOL in patients with cancer. In particular, there
is the need to use a large sample size, and undertake the study in different health institutions.

Traditionally, health professionals have focused on the response of the tumour, and the disease-related physical complications and reactions, more so than for the psychological outcomes (Agarwal, Hamilton, Moore, et al., 2010; Hassanein, Musgrove, & Bradbury, 2005; Mazanec, et al., 2010). However, Hassanein and colleagues (2005) cross-sectional descriptive study in the UK investigated the psychological outcomes, and their relationship to 68 patients’ QOL (mainly functional well-being), and coping strategies, following treatment of oral cancer. The researchers used HADS, EORETC, UW-QOL, and MAC-Q in their assessments. They found that the incidence of depression and anxiety was 25%, with a strong negative correlation between psychological distress (namely depression and anxiety) and the patients’ QOL and coping. Nevertheless, the researchers recommended that future research use a larger sample size and disease-specific instruments to measure QOL (Hassanein, et al., 2005). Consistent with these findings, newly diagnosed Swedish patients with breast, colorectal, gastric or prostate cancer experienced higher levels of depression than did non-advanced disease patients (Nordin, et al., 2001).

Another important factor in psychological adjustment to cancer was social support (Helgeson & Cohen, 1996). Helgeson and Cohen’s (1996) literature review highlighted the association of emotional, informational and instrumental social support with psychological adjustment to cancer. Three main types of social support were identified: emotional support involving the verbal and non-verbal communication of caring and concern, such as active listening, reassuring and
comforting; informational support, which enhanced the patient’s sense of control, management of their illness, and level of hope; and instrumental support, including transportation, money and household help. Of the three, emotional support was determined, by the patients, as the most important type of support. Such correlational studies investigating social support and adjustment to cancer measured the perceptions of patients’ behaviours, rather than the actual behaviours (Helgeson & Cohen, 1996).

**SUMMARY**

To date, numerous researches have assessed the factors contributing to QOL among cancer patients and, in particular, CRC patients, concentrating on four main areas. First, the studies have assessed the impact of demographic variables, such as: age, gender, marital status, educational level, and income (Klemm, et al., 2000; Ramsey, et al., 2000; Rustoen, et al., 1999; Simon, et al., 2008; Thome & Hallberg, 2004). Second, the researchers have explored the impact of the disease (cancer), and the treatment-related factors, such as: the stage and site of the disease, the time since diagnosis, the presence of metastases, the type of surgery, chemotherapy and/or radiotherapy regimes, and the treatment complications (e.g. dyspnoea, fatigue, GI disturbance and chest infection) on the patient’s QOL (Anthony, Hynan, et al., 2003; Blazeby, et al., 2005; Camilleri-Brennan & Steele, 2001; Ma, et al., 2007; Sailer, et al., 2002; Sharma, Sharp, et al., 2007). The third area of research has focused on the patient-related factors, such as: received social support from family, peers and spouse, as well as physical symptoms and financial support (Chang, Hwang, Feuerman, & Kasimis, 2000; Clarke, et al., 2006; Downe-Wamboldt, et al., 2006; Due, et al., 1999; Sammarco, 2001; Tan, 2007; Yan & Sellick, 2004). Fourth, other studies have focused on the meaning of the illness, the outcomes, and the concerns of CRC patients.
related to QOL. The studies also identified the patients’ and their families’ concerns about the cancer diagnosis, colostomy, impact of lifestyle changes, and satisfaction with the medical care system. Most of these studies assessed QOL in the postoperative phase.

This current literature review (see Appendix K for summary) has highlighted the difficulty of integrating known predictors (such as demographics, disease and treatment-related factors and physical factors) into a framework because of the methodological limitations and the unclear or absent theoretical basis for the modeling of QOL predictors in CRC patients (Dunn, et al., 2003). Also, difficulties arise with the generalisability of findings for the majority of the studies about predictors of QOL. The problem occurs because of the concentration on patients in the USA or other Western countries. The lack of cross-cultural data reduces the applicability of the findings to Arabic cancer patients, particularly CRC. This outcome is regrettable as CRC is the most common cancer type among Jordanian cancer patients.

In addition, there have been no studies demonstrating any relationships between the psychological aspects (depression and anxiety), hope, and coping strategies and QOL among Jordanian CRC patients. Indeed, little is known about how Jordanian CRC patients rate their overall QOL, as well as their level of hope, depression and anxiety. Moreover, there is limited knowledge about what coping strategies they use to deal with, control, and face their life-threatening condition. Thus, the current study is significant because of the dearth of evidence in relation to Jordanian CRC patients’ experiences, perceptions and concerns regarding QOL issues.
The following chapter (Chapter 3) presents a discussion on the conceptual framework and conceptualization of the main variables (coping, hope, QOL and psychological distress, (anxiety and depression).
CHAPTER THREE

Conceptual Framework

INTRODUCTION

This chapter presents the conceptual framework based on the literature review. This framework was used to guide the study, reflect study hypotheses and questions, and describe the variables in relation to their potential contribution to QOL in CRC patients. Moreover, this chapter addresses the conceptual and operational definitions of the hypothesised predictors of QOL, including hope, coping, psychological distress (depression and anxiety), in addition to the selected demographic and treatment-related variables.

CONCEPTUAL MODEL

The following figure illustrates the proposed conceptual framework that was developed, based on the review of QOL literature among CRC patients. The following sections address the conceptual and operational definitions of the main variables under-study.
Quality of Life

A noticeable change in health patterns in developed countries was identified during the twentieth century, with a decrease in communicable diseases and an increase in chronic conditions (Velikova, Stark, & Selby, 1999). This change has led to greater attention being given to the importance of QOL as a positive physical, emotional, spiritual, and mental well-being (Velikova, et al., 1999). Indeed, QOL has become a critical concept in the care of chronic disease, particularly cancer (Tanaka & Gotay, 1998).

QOL as a concept has been recognized and discussed for decades (Gerth van Wijk, 2005). Researchers have addressed the concept as a philosophical and socio-political
phenomenon (Petterson & Bredow, 2004). However, recently, QOL has been
developed into a theory, particularly in response to the growing interest in QOL as
expressed by health care professionals (Patterson & Bredow, 2004). Furthermore,
there is increased interest in QOL, as an important domain in health care for patients
with chronic disease, particularly cancer patients. Regrettably, many definitions of
QOL exist. The following section addresses the most common definitions of QOL.
Despite these definitions, there is a lack precision and consistency, specifically in the
definition of QOL (Padilla, Grant, & Ferrell, 1992; Plummer & Molzahn, 2009).
Thus, the following section addresses the definition of QOL as a concept used in
health science research.

**Definition of QOL**

There is no universal definition of QOL (Jocham, Dassen, Widdershoven, & Halfens,
2006; King & Hinds, 1998). However, Ferrans (1990) categorized QOL as a term
concerned with happiness/ satisfaction, goal achievement, natural capacity and social
activity, and which includes four main domains: health/functional domain,
social/economic domain, psychological /spiritual domain, and family domain
(Ferrans, 1990).

defines QOL as “individuals’ perceptions of their position in life in the context of the
culture and the value system in which they live and in relation to their goals,
standards, and concerns”. Six main characteristics of QOL were identified (Ahmedzai,
et al., 2004):

(1) Subjective or objective (individual perception),
(2) Phenomenological or explanatory (reflects the condition without interpretation),

(3) Multidimensional (includes six dimensions: physical, psychological, level of independence in mobility and work, social relationships, health and social care, spirituality, and personal beliefs),

(4) Evaluative (QOL affected and affected by other variables),

(5) Dynamic (changing over the time depending on the patient’s condition or status),

and,

(6) Quantifiable (QOL assessed and compared in relation to the individual’s status and disease) (Niv & Kreitler, 2001).

In the current study, each of these characteristics has a critical implication on the measurement of QOL. For example, ‘subjective’ refers to the patients reporting their QOL by using a self-report scale (in the current study; FACT-C). In addition, multidimensional features, as mentioned above, refers to a number of domains that reflect the patient’s overall QOL (in the present study FACT-C composed of family, physical, sexual, functional well-being/domains of QOL, and other concerns to reflect specific symptoms related to CRC patients). In a recent study, dynamic characteristics refer to QOL at the time of diagnosis and during the illness period. In fact the current study is cross-sectional, but it captures the QOL status at the time of diagnosis and during illness period). This study aimed to explain the impact of hypothesized predictors on the QOL, thus, it reflects the evaluative characteristic of QOL. Finally, quantifiable characteristics of QOL refer to assessing it in relation to specific conditions/diseases, specifically among patients with CRC only. Phase II of the current study explains the patients QOL, including the impact of the diagnosis and
treatment, and determining the influencing factors that had contributed to the participants’ QOL.

Three categories of QOL definition were identified by Peterson and Bredow (2004) to clarify the meanings and definitions of QOL, namely: global, component, and focused.

**Global**: This definition refers to satisfaction/dissatisfaction, a cognitive experience, happiness/unhappiness and affective realization. Both internal (feeling, thoughts) and external (activities, socialization) stimuli are included.

**Component**: This definition addresses the objective (functional ability, socioeconomic status) and subjective (self-esteem, personality) dimensions of QOL. This is the most popular and useful definition because it is easier to be operationalized (Patterson & Bredow, 2004).

**Focused**: This definition includes both the explicit (for example with a focus on HR-QOL or a microeconomic QOL), and the implicit (for example a focus on a limited number of components, yet referring to the more general term, QOL) (Patterson & Bredow, 2004, p. 276).

In the present study, the component category was utilized, as the study measured QOL in CRC patients, specifically, and used a disease-specific instrument (FACT-C) that reflected the main component/domains of QOL, such as social, functional and physical well-being. In the development FACT-C, both subjective and objective dimensions of QOL were addressed, as both patients and health professionals were interviewed in order to develop this instrument (Ward et al., 1999).
Despite the challenge related to defining QOL, there are areas of conceptual agreement among researchers and experts (Grant, Padilla, Ferrell, & Rhiner, 1990; King & Hinds, 1998). Most would agree that QOL is comprised of both positive and negative facets of life and is a multidimensional concept.

There is a general agreement between researchers in relation to using HR-QOL and QOL terms in health research. Thus, the term QOL reflects all domains of a patient’s well-being, including physical, social, emotional, sexual, spiritual, and functional. Additionally, it includes the effect of living standards, desire, and environmental factors, such as socialization, ability to cope, and family support (Glise & Wiklund, 2002; Mandzuk & McMillan, 2005; Schalock, 2004; Velikova, et al., 1999). On the other hand, the term HR-QOL is used specifically in relation to the patient’s treatment and is considered alongside morbidity and other issues of treatment, such as complications, hospitalization and examination procedures (Glise & Wiklund, 2002; Padilla, et al., 1992; Petterson & Bredow, 2004; Schalock, 2004). Therefore, the term QOL is more accepted, popular, and widely used in oncology literature than the term HR-QOL or subjective health status (Glise & Wiklund, 2002).

In the current study, the researcher aimed to explore the QOL predictors, including age, gender, marital status, income, time since diagnosis, hope, how they cope and what strategies they use and psychological distress (depression and anxiety) in Phase I. In Phase II, the Jordanian patients’ perceptions and experiences about QOL during their illness are explained. Thus, the need seems clear for a broad definition of QOL to reflect all aspects of patients’ health status. Therefore, the researcher used QOL terms in order to reflect CRC patient’s well-being. WHO’s (1993) theoretical
definition of QOL was used in measuring health status. Further, QOL was defined as individuals’ perceptions of their position in their life, within the context of the culture and value system in relation to their goals, standards and concerns.

**Dimensions of QOL**

In the current study, the researcher focused on assessing demographic, time since diagnosis, and psychosocial factors, as hypothesised predictors of QOL among Jordanian CRC patients. This approach was taken because 35% of CRC patients have clinically significant levels of depression and psychological distress (Sharma, Walker, Sharp, Monson, & Walker, 2007). In addition, psychological status for the patients, including depression, anxiety, level of hope, and ability to cope with the serious and crucial problem, are considered essential principles and indicators for social and medical treatment. Many previous studies have focused on the physical well-being among CRC patients, including pain, appetite, GI disturbance and physical functioning such as mobility. Accordingly there is now a need to focus on psychological well-being, particularly in relation to QOL among CRC patients. There is a clear need for further studies to explore relationships between psychosocial factors and QOL. The following section describes the main domains of QOL, including physical, psychological, social, and spiritual-wellbeing.

*The Physical domain* of QOL is considered as one of the most common dimensions that have been traditionally described and studied. It refers to the patients’ ability to perform daily activity, and their strength, power and energy (King & Hinds, 1998; Petterson & Bredow, 2004).
The Psychological well-being domain refers to many variables, such as the patient’s control, anxiety, depression, enjoyment, fear of recurrence, cognition and attention, and distress of diagnosis and treatment control (King & Hinds, 1998; Petterson & Bredow, 2004).

The Social domain concerns how the patients interact and engage with the community and surrounding environment. Additionally, it measures the patients’ ability to carry on relationships with family, friends and work colleagues (King & Hinds, 1998; Petterson & Bredow, 2004).

The Spiritual well-being domain of QOL refers to the patient’s perceptions of the meaning of life and death, faith in God, and performing religious rituals. Moreover, spiritual domain refers to factors such as the meaning of illness, religiosity, transcendence, hope, uncertainty, inner strength and self-sufficiency (King & Hinds, 1998; Petterson & Bredow, 2004).

Overall QOL has been defined as the patient’s subjective evaluation and perception of their life as a whole (Velikova, et al., 1999). It refers to an individual’s appraisal of, and satisfaction and happiness with their current level of performance and functional ability (Patterson & Bredow, 2004; Velikova, et al., 1999). Further, it reflects the results of all the domains, such as physical, psychological, spiritual, social and emotional (Niv & Kreitler, 2001).

A number of variables have been found to correlate with and predict the level of QOL among patients with chronic illness, particularly for CRC patients. The following
section addresses the concepts of hope, coping, psychological distress (depression and anxiety), selected demographic and time since diagnosis, as the main hypothesized predictors of QOL among CRC patients.

Demographics and Time since Diagnosis

In the current study, selected demographic variables, including age, gender, marital status, income, and treatment-related factors (time since diagnosis), were included in the hypothesized model of QOL predictors. These variables were derived from the literature as the most common variables that might have an impact on the patients’ QOL when diagnosed with, and treated for, CRC.

Hypothesized Psychosocial Predictors of QOL

The following sections address the three main hypothesized psychosocial predictors of QOL: hope, coping, and psychological distress.

Hope

In this study, hope is hypothesised as a psychosocial predictor of QOL and is described in the literature as complex, multidimensional, and dynamic (Herth & Cutcliffe, 2002a). Kubler-Ross (1969, 1975), a recognized pioneer in the care of the dying, believed that the terminally ill person must maintain hope. She stated that the coping mechanisms of denial, anger, bargaining, and depression came and went, but in most of the 200 patients she studied, hope persisted. Indeed, Kubler-Ross (1975) describes hope as serving to nourish people psychologically in difficult times. From her study of critically ill patients, Miller (1989) concluded that hope was an important strategy that enabled patients to control and counter their condition during a period of
critical illness. It not only reinforced physiological defences, but also helped patients emotionally to endure crises (Herth & Cutcliffe, 2002a; Miller, 1989).

Dufault and Martocchio (1985) proposed a model of hope that delineates two different types of hope (particularized and generalized) that may coexist in the final stages of life. Particularized hope is associated with specific goals or objects, and generalized hope is the intangible inner experience of hope that is not connected to any specific goals or object (Dufault & Martocchio, 1985; Herth & Cutcliffe, 2002a).

Miller (1985) described three levels of hope. The most elementary level of hope includes superficial desires, such as basic materials and goods, followed by the next level of hope, which includes a focus on personal accomplishments and relationships. The third level of hope is the most intense and powerful, as it requires finding meaning in loss or suffering (Herth & Cutcliffe, 2002b; Miller, 1985).

**Definition of Hope**

In the current study, the definition offered by Dufault and Martocchio (1985) was used. Thus, within this context hope is defined as “a multidimensional dynamic life force characterized by a confident yet uncertain expectation of achieving good, which, to the hoping person, is realistically possible and personally significant” (p. 380). Dufault and Martacchio’s (1985) definition also served as the conceptual basis for the Herth Hope Index (HHI) instrument used to measure hope (Herth, 2000).
Coping

The second hypothesised predictor of QOL, coping, is defined in the literature as a process that unfolds in the context of a situation or condition that is appraised as personally significant and as taxing or exceeding the individual’s resources for coping (R. Lazarus & Folkman, 1984). The coping process is initiated in response to the individual’s appraisal that important goals have been harmed, lost, or threatened (Folkman & Moskowitz, 2004).

In the years since the early 1980s, coping has been defined as a complex, multidimensional process that is sensitive both to the environment, and its demands and resources, and to personality dispositions that influence the appraisal of stress and the resources for coping (Folkman & Moskowitz, 2004). Indeed, coping is strongly associated with the regulation of emotion, especially distress, throughout the stress process. Certain kinds of escapist coping strategies are consistently associated with poor mental health outcomes, while other kinds of coping, such as the seeking of social support or instrumental, problem-focused forms of coping. These forms are sometimes associated with negative outcomes, sometimes with positive ones, and sometimes with neither, usually depending on the characteristics of the appraised stressful encounter (Folkman & Moskowitz, 2004).

Lazarus and Folkman (1980, 1984) defined coping as thoughts and behaviours that people use to manage the internal and external demands of situations that are appraised as stressful. This definition has become widely accepted (Folkman & Moskowitz, 2004; Tennen, Affleck, Armeli, & Carney, 2000).
**Multidimensional Nature of Coping**

Coping has different functions, namely: management of the problem (problem-focused coping) and emotion regulation (emotion-focused coping), in addition to several broad categories, such as situation modification, control distress emotion, and response adaptation to distress emotion (Cummings, Greene, & Karraker, 1988). Folkman and Lazarus (1988) stated that coping consists of both cognitive and behavioural strategies to control and manage the internal and external stimuli or demands. These efforts or strategies change, depending on the relationship between the person and their environment (Folkman, Lazarus, Gruen, & DeLongis, 1986). Folkman et al. (1986) also identified eight types of coping: intrapersonal processes, such as problem solving and regulation of emotion (distance, self-control, positive re-appraisal, and escape-avoidance), interpersonal problem-focused processes (confrontation), and emotion focused processes (the seeking of informational and emotional support).

Folkman and Lazarus' (1984) definition of coping was used in this study to guide the measurement and assessment of coping among Jordanian CRC patients. Coping is defined as patient’s behaviours and thoughts that are used to control and regulate the critical events and painful emotions. Accordingly, Jalowiec Coping Scale (JCS) was used to measure coping as a concept among target patients. JCS reflects the strategies that are used by the patients, provided from families, to cope and manage the difficult circumstances. This scale reflects eight coping styles: confrontive, evasive, optimistic, fatalistic, emotive, palliative, supportive and self-reliant coping strategies (Frank-Stromborg & Olsen, 2004).
Psychological Distress (depression and anxiety)

Psychological distress is considered the third hypothesised predictor of QOL in this study and has been conceptualized in relation to two domains; anxiety and depression.

**Anxiety**

Anxiety is defined as “an unpleasant subjective experience associated with the perception of real or imagined threat”, or, more comprehensively, “an emotion that signifies the presence of danger that cannot be identified, or if identified, is not sufficiently threatening to justify the intensity of the emotion” (Frank-Stromborg & Olsen, 2004, p. 362). Anxiety plays a central role in the functioning of personality. All individuals experience some degree of anxiety to foster creativity and face daily challenges; however, anxiety can also impair cognitive and intellectual functioning as well as interfere with effective problem solving (Frank-Stromborg & Olsen, 2004).

**Depression**

Depression is a disorder in which mood and vitality are lowered to the point of despair (Bottomley, 1998). Patients report that life is meaningless, and experience feelings of misery and hopelessness (Hughes, 1985). When cancer patients experience depression, it becomes apparent that it is one of the most critical and crucial psychological problems to identify (Massie & Holland, 1990).

In this study, depression is defined as “a common disorder that presents with depressed mood, loss of interest or pleasure, feelings of guilt or self-worth, disturbed sleep or appetite, low energy, and poor concentration” (van der Wal, van Voorst, & Jaarsma, 2005, p. 99). The diagnosis of life threatening disease, particularly cancer,
causes psychological distress (mainly depression and anxiety) and stress for cancer patients (Hung-Ru Lin, 2003; van der Wal, van Voorst, & Jaarsma, 2005). Improving psychological well-being influences positive self image among cancer patients, including their awareness, coping and ability to adjust (Hung-Ru Lin, 2003). Unfortunately, around 25-35% of cancer patients suffer from psychological distress during their treatment time (Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001). In the current study, the researcher aimed to detect the level of depression and anxiety, among Jordanian cancer patients, and how these factors predict QOL level among them.

**SUMMARY**

QOL is a subjective multidimensional concept that is increasingly being used as a clinical outcome in chronic illness patients, and in cancer patients particularly. Recently, medical teams have attempted to evaluate cancer patients’ QOL during daily interventions, and utilize these evaluations when making decisions about patient care. QOL has become a critical measure of CRC treatment effect and disease-related distress. Many factors are related to QOL in CRC patient within the treatment time, such as hope, coping, and psychological distress (depression and anxiety). Understanding these concepts and their dimensions will improve the determination of the relationships between QOL and these concepts, to provide optimal medical and nursing care to CRC cancer patients.

The following chapter discusses the methodological aspects of the current study.
CHAPTER FOUR
Research Methodology

INTRODUCTION
This chapter presents the research methods, as well as the assumptions upon which this mixed methods study is based. The study is underpinned by the pragmatic paradigm of inquiry and uses a priority sequence model of QUANTITATIVE → qualitative design (Morgan, 1998). In this chapter, the study design is discussed in relation to the contribution of each method. The research hypotheses, setting, sampling and recruitment procedures, data collection methods, survey instruments, data analyses methods, and methods to enhance the trustworthiness of the study are also explained. Finally, issues related to ethical considerations are addressed within the context of this study.

PARADIGM OF INQUIRY
Paradigms are defined as “patterns of beliefs and practices that regulate inquiry within a discipline by providing lenses, frames and processes through which investigation is accomplished” (Weaver & Olsen, 2006, p. 460). Paradigms have also been described as ‘world views’ that include ontological (nature of reality), and epistemological (nature of knowledge) perspectives (Creswell, 2009). Creswell (2009) asserts that there are three major worldviews–postpositivism, constructivism and pragmatism. When considering research in the domain of social science, the postpositivist worldview has been defined as “a direction in the philosophy of social science that aims to find general laws and regularities based on observation and experiment” (Holloway & Wheeler, 2006, p. 287), and hence it is linked to quantitative research methodologies (Creswell, 2009; K. Weaver & Olson, 2006). The second paradigm is
constructivism, which is based on the idea that the social world cannot exist independently of human beings. People, therefore, construct their social reality in the context of interaction (Creswell, 2009). In terms of research, this means that “participants and the researcher construct meaning together” usually by qualitative methodologies (Holloway & Wheeler, 2006, p. 285).

Finally, the third paradigm, pragmatism, is concerned with actions, situations, and consequences of events. Accordingly, the researcher identifies the research problems and employs any appropriate approaches to achieve an understanding of the phenomena (Creswell, 2009). The pragmatic researcher chooses the methods and strategies that best achieve the purposes of the study (Doyle, Brady, & Byrne, 2009). Pragmatists do not believe that there is a single worldview; rather, there is flexibility to collect the data by using different approaches. Thus, a mixed–method approach will often provide the best understanding of the research problem.

Paradigm purists believe that mixed-methods researchers need to justify and explain the rationale for using two different approaches in one study (Creswell, 2009; David Morgan, 2007). In the current study, the researcher believed that a quantitative approach alone could determine the degree of relationship between the variables (hope, coping, psychological distress, and QOL), but it would be unable to generate understanding of how these variables impact QOL (Greene, Caracelli, & Graham, 1989). Accordingly, a follow-up qualitative phase was planned to provide that understanding.
In the current study, a conceptual framework was derived from the literature, and the study design was developed to guide the process of undertaking two different, but linked, approaches to the research. The researcher started with a quantitative phase in order to test the hypothesis that psychosocial variables predict QOL, in addition to identifying the relationships between these hypothesized factors. Accordingly, in Phase I, quantitative data were collected using several scales that measured the variables under study: hope, coping, psychological distress and QOL. The data were collected and analysed using statistical procedures to test the hypotheses.

In order to provide a better understanding and to explain the variations in results from the quantitative phase, a follow-up qualitative phase was undertaken using a purposeful sample of participants. In Phase II, the qualitative study, the researcher aimed to gain an in-depth understanding of the complexity of the phenomena (QOL and its hypothesized predictors) using semi-structured interviews to illuminate participants’ perspectives.

**Strategy of Inquiry**

There are two types of mixed-method designs; concurrent, when both quantitative and qualitative are used in parallel, and sequential, when one method is followed by the other (Morgan, 1998). A sequential design can be further described as exploratory, embedded or explanatory (Bergman, 2008). Exploratory designs begin exploring the problem/issue with qualitative methods and then proceed to test or generalise these findings by quantitative methods. An embedded design usually involves collecting qualitative data before or after an intervention (Bergman, 2008).
A sequential explanatory mixed methods study design was utilised to answer the proposed research questions. In this design, an initial quantitative phase is followed by qualitative methods of inquiry to help explain the quantitative results (Bergman, 2008). Morgan (1998) has termed this study design qualitative follow-up (QUANTITATIVE → qualitative) within a Priority-Sequence Model, which seeks to integrate the complementary strengths of different methods through a division of labour. This outcome is achieved through two basic decisions: a priority decision that pairs a principal method with a complementary method, and a sequence decision that determines whether the complementary method precedes or follows the principal method. The qualitative follow-up design employs a small descriptive study to explain, enhance and/or corroborate the findings from a principal quantitative study (Morgan, 1998).

In the first phase of the current study, quantitative methods were employed to measure hope, coping, psychological distress depression and anxiety, and QOL levels among Jordanian CRC participants, in addition to questions eliciting their socio-demographic data and disease-related conditions. A follow-up qualitative phase was used to illustrate, clarify, and better understand the results from the quantitative phase, including perceived psychosocial factors and treatments that impacted on the phenomena under study. The following section describes the methods of data collection and analyses for Phases I and II of this study.
PHASE I: QUANTITATIVE RESEARCH METHOD

Phase I was conducted to: (1) to explain the relationships between hope, coping, depression and anxiety, age, gender, marital status, income, and time since diagnosis and QOL; and (2) to explore to what extent psychosocial factors hope, coping, and psychological distress, age, gender, marital status, income and time since diagnosis predict QOL among Jordanian CRC patients. The following section details the research hypotheses, design, setting, sampling and recruitment of participants, data collection instruments, and data analyses methods.

Research Hypotheses

In Phase I the following hypotheses were generated from the literature review:

1. There is a relationship between coping, hope, psychological distress (depression and anxiety), age, gender, marital status, income, time since diagnosis and QOL among Jordanian CRC patients.

2. Hope, coping, and psychological distress (depression and anxiety), age, gender, marital status, income and time since diagnosis predict QOL among Jordanian CRC patients.

Design

A predictive correlational design was used in Phase I to describe the interrelationships of hope, coping, psychological distress, age, gender, marital status, income, time since diagnosis and QOL among Jordanian CRC patients. This design allowed a description of the association between two or more variables, including coping, hope, psychological distress, age, gender, marital status, income and time since diagnosis, and QOL. It aimed to describe the relationship of naturally occurring phenomena.
This study is descriptive, not experimental, and so there is no control of the independent variable; thus a cause and effect relationship cannot be established (Polit & Beck, 2004). A predictive correlational design is frequently used when there is little knowledge about the topic of interest or, in the case of the current study, to describe the relationships among the psychosocial factors, age, gender, marital status, income, time since diagnosis, and QOL. A predictive correlational design provides a better understanding of the complexity of the phenomena under study, as the hypothesized predictors may make a unique contribution to QOL among CRC patients.

**Setting**

The study was conducted in three hospitals in Jordan: King Abdullah University Hospital (KAUH), Jordan University Hospital (JUH), and AL-Bashir hospital. These hospitals are located in different geographical regions and specialise in cancer treatment, hence the majority of cancer patients are referred to one of these hospitals for treatment and follow up.

**King Abdullah University Hospital (KAUH)**

As a general hospital, KAUH provides various clinical and referral health care services to other health care sectors in Jordan. It is within the Jordan University of Science and Technology (JUST) campus, which is located in the north of Jordan. The hospital provides primary, secondary, and tertiary health care services to more than one million inhabitants of Irbid, Ajloun, Jarash and Mafraq governorates, and to all the Hashemite Kingdom of Jordan population in general. The hospital capacity is 683 beds, which can be increased to 800 beds in emergency situations. Currently there are around 450 nurses working in the hospital in different wards, units and clinics.
Jordan University Hospital (JUH)

Jordan University Hospital (JUH) was established in 1971 and was originally named the Amman Grand Hospital, being renamed JUH in 1975 after it affiliated with Jordan University and its medical school. With over 531 beds, it is one of the most specialized and high-teaching medical centres in the public sector, along with the King Hussein Medical Center and the King Abdullah Hospital. JUH patients are referred from the Jordanian Ministry of Health (JMOH), are employees of Jordan University and their dependents, or employees of private firms with whom JUH has contractual agreements, as well as some independent private patients.

Al-Bashir hospital

The Al-Bashir hospital is located in Amman City, the capital of Jordan. It is a public hospital with a 600-bed capacity operated by the JMOH. Al-Bashir hospital is a teaching hospital offering clinical training for medical, nursing, and other health-related disciplines. It has one of the only two specialized and well-established high technological radiotherapy units in the country. Currently, 815 nurses work in this hospital.

Sample Selection and Recruitment

The recruitment of patients to participate in this study involved two major tasks: identifying eligible candidates and gaining the cooperation of the individual who had been deemed eligible for the study (Polit & Beck, 2004). The following recruitment strategies were used in this study. First, the researcher conducted a presentation for medical and nursing staff, in each hospital setting, to provide an overview of the study purposes, methods and its significance. In order to identify eligible participants, a
detailed explanation was provided to oncology clinical nurse specialists (CNS) and the charge nurses of each oncology ward and unit. They then identified patients who met the eligibility criteria and agreed to participate. Following this, the researcher approached, in person, potential participants, obtained their permission to participate, and subsequently gained access to their contact details, files and medical records on computer, in order to collect information related to their age, marital status, gender, educational level, annual income, and religion. Data about their regional metastasis, time since diagnosis, treatment modalities, presence of chronic diseases and complications were also collected.

A package comprising an information sheet, consent form, and survey instrument was given to each eligible patient. Consenting participants were asked to complete the questionnaire which was coded to enable the researcher to identify potential participants for Phase II of the study. When participants completed the questionnaires, the researcher reviewed the medical chart to extract the relevant disease-related conditions. Patients’ approval was obtained to participate, access files and to contact them in the second phase of the study, if this was required. Contact details, including their full name, address, mail box, and telephone or cell phone numbers, were collected from eligible participants so that they could be contacted for Phase II. The researcher used a code to match a patient’s ID and contact details.

**Inclusion criteria**

The following inclusion criteria were set for the proposed sample:

- Jordanian patients;
- Over 18 years of age, male and female;
- Diagnosed with colorectal cancer (as primary or secondary);
• Treated for CRC cancer (surgery, chemotherapy, radiotherapy or combination); and

Exclusion criteria

The following exclusion criteria were set:

• Diagnosed with another type of cancer;
• Unaware of diagnosis;
• Diagnosed with mental or psychiatric disorders (pre-cancer diagnosis);
• Mute patients, or patients with hearing and/or vision problems; and,
• Terminally ill patients (patients under palliative care/treatment).

Participation in a research project aims to elicit information, experiences and thoughts, and to discuss the main issues under study; thus, some physical disabilities are considered barriers to effective and useful communication between the researcher and the participants (Parka & Song, 2005). For this reason, mute patients or patients with hearing/vision problems were excluded from the study, as they may have had difficulty communicating and relating their experiences, hearing or responding to the researcher’s questions. Additionally, terminally ill patients, under palliative care, were excluded from participation as the research aimed to assess patients who were receiving active treatment.

Sample Size Calculation

Cohen’s formula (1988) was used to estimate the required sample size for the quantitative phase of the current study. Cohen (1998) identified three levels of effect of sample size: small effect 0.20, medium effect 0.50, and large effect 0.80. Based on this classification, a medium effect of correlations between coping, hope, depression
and anxiety, age, gender, marital status, income, time since diagnosis and QOL was used to guide the sample size calculation because “most nursing studies cannot expect the effect size in excess of .50; those in the range of 0.20 - 0.40 are the most common” (Polit & Beck, 2009, p. 497). A sample of 280 participants was estimated to achieve 80% power to detect an R-squared of 0.05 attributed to five independent variables by using Power Analysis and Sample Size software (PASS, 2009). Another popular method to estimate sample size to test/run multiple regression analysis is that the sample must include at least 15 participants per predictor variable (Reinard, 2006).

**Limitations to the Sample**

Convenience sampling refers to the use of participants who are easily accessible to the study. The advantages of using a convenience sample include the ease of conducting the research, access to large samples, cost effectiveness and time saving (Talbot, 1995). However, convenience sampling has a risk of selection bias that is greater than other quantitative sampling methods (Denise. Polit & Beck 2004). Since the sample may not represent the population, the findings are limited to the specific group of people in the sample and may not be generalised beyond this point, that is, there is limited external validity. To minimise these limitations, the researcher recruited the sample from three different hospitals to ensure a wide cross section of participants. In addition, using well-developed and clear inclusion and exclusion criteria contributed to sample homogeneity.

**Data Collection Methods**

The data were collected via a self-report questionnaire comprising demographic data questions, including age, marital status, gender, educational level, annual income,
number of family members, religion, and four previously validated instruments. In addition, disease-related data, including regional metastasis, time since diagnosis, treatment modalities, presence of chronic diseases and complications, were extracted by the researcher from the patients’ medical records. The following scales were used to measure the main variables in Phase I.

1. Functional Assessment of Cancer Therapy-Colorectal (FACT-C)

The Arabic version of the Functional Assessment of Cancer Therapy-Colorectal (FACT-C) was used after being translated from the original English language to Arabic to measure health-related QOL among Jordanian CRC patients. This instrument was originally developed by the Functional Assessment of Chronic Illness Therapy (FACIT) measurement system. The FACT-C is a specific-disease instrument to measure HR-QOL among CRC patients. It consists of 36-items divided into two parts: Part One contains 27 items divided into four primary QOL domains: (1) physical well-being, (2) social/family well-being, (3) emotional well-being, and (4) functional well-being. Part Two of the FACT-C consists of nine items related to the general symptoms of colorectal cancer (e.g. appetite, digestion, control of bowels, difficulties with ostomy, body appearance). Each item has a 5-point Likert scale ranging from 0 “not at all” to 4 “very much”. The average time to complete the 27-item FACT-C is 10 minutes (Frank-Stromborg & Olsen, 2004). The possible score of FACT-C ranges from 0 to 144. Higher FACT-C scores indicate good QOL, whereas low scores indicate poor QOL. In this study, subscale and total scores of QOL were analysed to understand which domains are affected by the predictors. The FACT-C subscales include: physical well-being (7 items, score range 0-28), social/family well-being (7 items, score range 0-28), emotional well-being (6 items, score range 0-24),
functional well-being (7 items, score range 0-28), and colorectal concerns (9 items, score range 0-36) (FACT C items are presented in Appendix D).

In order to assess the reliability and validity of FACT-C, Ward et al. (1999) used three separate and distinct validation samples with different ethnic and stage of disease compositions. The results suggested that the FACT-C is a reliable and valid measure in both its English and Spanish language versions. Thus it was expected that it would also work well in Arabic. Specifically, the FACT-C evidenced good internal consistency reliability (Cronbach’s alpha = 0.85) and concurrent validity, as well as an ability to distinguish between groups based on functional status and extent of disease. The FACT-C was also found to be sensitive to changes in functional status (Ward, et al., 1999). The colorectal cancer-specific items for the Colorectal Cancer Subscale (CCS) were found to have adequate convergent and divergent validity. Its internal consistency was adequate in most samples.

2. Herth Hope Index (HHI)

The HHI was used in the current study to measure the level of hope among Jordanian CRC patients during their illness. Herth (1992) developed and evaluated HHI to measure hope with a scale that has 12 items, using a 4-point Likert response with no items requiring reverse scoring. The total score ranges from 12 to 48, where the higher scores indicate a great level of hope (HHI items are presented in Appendix E).

A study to evaluate the psychometric properties of the HHI involved 172 adults from diverse settings, illness status, and backgrounds (Herth, 1992). Validating instruments included the HHI, the Existential Well-Being Scale (EWS), the Nowotny Hope Scale
(NHS) for concurrent criterion-related validity, and the Hopelessness Scale (HS) to assess divergent validity. Factor analysis confirmed the original conceptualization represented by the three subscales (Frank-Stromborg & Olsen, 2004). High correlations were obtained between the HHI and the entire criterion measures, HHI and the HHS ($r = 0.92$), the EWS ($r = 0.84$), and the NHS ($r = 0.81$). The correlation between the HHI and the HS was inverse ($r = -0.73$). This suggests that the HHI is a comprehensive and reliable measure and that the HHI is measuring essentially the same dimensions as the HHS. In addition, the correlation between the HHI and the NHS ($r=0.81$) indicates that the HHI is measuring hope, but is slightly different conceptually from the NHS (Herth, 1992). Construct validity was achieved through the factorial isolation of three elements: (1) temporality and future; (2) positive readiness and expectancy; and (3) interconnectedness (Herth, 1992). All the instruments attained acceptable Cronbach’s alpha, including 0.97 for the HHI (Frank-Stromborg & Olsen, 2004).

3. Jalowiec Coping Scale (JCS)
The Jalowiec Coping Scale (JCS) is a 60-item; self-report instrument developed in 1977 by a group of nurse researchers (Jalowiec, Murphy, & Powers, 1984). The respondent rates or scores how often each of the coping strategies is used on a four-point (0-3) rating scale. The JCS has two parts: use of coping styles (strategies), and effectiveness of these strategies. In Part A, respondents rate how much they have used each coping strategy to overcome or manage the stressor. The degree of use and effectiveness of coping strategies is rated on a four-point (0-3) Likert scale. The overall score ranges from 0-180, where a higher score indicates a greater use of coping styles and a greater effectiveness of these strategies. Additionally, there is
space at the beginning of the questionnaire to list which stressor or stressful event is under investigation. This permits the examination and comparison of situation-specific coping. Eight coping styles are identified: (1) confrontive, (2) evasive, (3) optimistic, (4) fatalistic, (5) emotive, (6) palliative, (7) supportant, and (8) self-reliant (see below). The subscales were derived by thematic clustering.

1. Confrontive: constructive problem-solving, facing up to and confronting the problem or situation (10 items);
2. Evasive: doing things to avoid confronting the problem (13 items);
3. Optimistic: positive thinking or positive attitudes about the problem or situation (9 items);
4. Emotive: expressing or releasing emotions (4 items);
5. Fatalistic: pessimistic thinking or pessimistic attitudes toward the problem or situation (5 items);
6. Palliative: doing things to make yourself feel better (7 items);
7. Supportant: using support systems (including a religious support system) (5 items); and
8. Self-Reliant: depending on your self to deal with the situation, rather than on others (7 items).

Adequate psychometric properties have been established and demonstrated in multiple populations (Jalowiec, Grady, & White-Williams, 2007). The test-retest reliability is 0.79 for total coping scores, and the alpha reliability for the total effectiveness was 0.92 (Jalowiec et al, 2007). A result for the two factor solutions that were used to evaluate the construct validity of the scale, which showed that 80% (141) of the problem items loaded on factor I and 56% of the effective items loaded on factor II (Jalowiec, et al., 1984) (JCS items are presented in Appendix C).
4. Hospital Anxiety and Depression Scale (HADS)

In order to assess depression and anxiety as major psychological distresses among cancer patients, the Hospital Anxiety and Depression Scale (HADS) was used in this study. The HADS is a brief, self-administered rating scale designed to detect anxiety and depression among individuals with medical illnesses (Frank-Stromborg & Olsen, 2004). It is intended to screen for clinically significant depression among medically ill patients and to measure and monitor the severity of depression through repeated administration. The HADS focuses on the psychological rather than somatic manifestations of depression, excluding items that are characteristic of both depression and medical illness, such as appetite and sleep disturbance. The HADS contains 14 items with a 4-point Likert scale, seven pertaining to depression and seven to anxiety. Each subscale (anxiety and depression) is treated separately. The anxiety level is rated from 0-28, where a higher score indicates a higher level of anxiety among patients. This is similar to the depression scores, which range from 0-28, with higher scores indicating greater levels of depression.

The construct validity of the HADS was examined using an exploratory factor analysis in a sample of 568 cancer patients (Zung, Broadhead, & Roth, 1993). The internal consistency of the two subscales using coefficient alphas was high (anxiety and depression Cronbach’s alpha = 0.93, and 0.90 respectively) (Frank-Stromborg & Olsen, 2004). The HADS items are presented in Appendix F. The following individual questions were developed from the literature in order to describe the demographic characteristics of the sample.
5. Individual Items—Demographical Data and Disease-Related Conditions

The demographic data questions were developed based on the literature, to elicit background information about the participants in Phase I. A standard set of seven questions were included, and related to the patient’s age, marital status, gender, educational level, annual income and religion. For this survey, demographic questions preceded the scales (Appendix B).

Disease-related questions were developed from an extensive review of the literature to provide appropriate information about the patients’ disease conditions. They consisted of questions related to the regional metastasis, time since diagnosis, treatment modalities, presence of chronic diseases and complications. The researcher obtained this information from the patients’ medical records and files. The most common demographical variables (including age, gender, marital status, income), and disease-related variables (time since diagnosis) were included in the bivariate and multivariate analyses. However, the researcher collected other variables to describe the sample characteristics because they may affect the patient’s experience and perspectives in relation to QOL, which were explored during the qualitative phase.

Reversing Items in the Survey

In some of the survey instruments used in this study, response codes to certain items needed to be reversed. For example, FACT-C has many different items (including Physical well-being GPI to GP7, Social/Family well-being GS1-GS7, Functional well-being GF1-GF7, Emotional well-being GE1, 3, 4, 5, 6, and GE2) that needed reverse scoring. Reversing guidelines were used to manage the response revised questions. Moreover, the same revision process with specific items of HADS was
employed. The following section describes the process used to translate the scales from English to Arabic.

**Instrument Translation Processes**

Brislin’s (1986) model of translation is recommended as the most reliable method for developing an equivalent translated instrument (Yu, Lee, & Woo, 2004). This method was used for the translation of the survey instruments into Arabic. The strength of this model lies in the step back translation, through which translation errors can be effectively identified. This translation process involved five important steps.

Step 1: Forward translation: English to Arabic language by three native speakers of the Arabic language (two living in Jordan and one living in the United States). All translators were highly qualified in medical and/or health concepts and all possessed a PhD degree in nursing.

Step 2: Reconciliation of forward translations by one native Arabic language speaker, who was familiar with medical and/or health concepts, and not involved in the forward translation, and was PhD qualified.

Step 3: Back translation of reconciled version from Arabic to the English language by a native English speaker, fluent in Arabic, not involved in the previous steps, knowledgeable with medical and/or health concepts, and PhD qualified.

Step 4: Comparison of the translated version with the original English language version.

Step 5: Preliminary analysis, as described below, conducted to measure validity and reliability of the translated instruments, to assess the time needed to complete the
translated instruments, and comparing with the original language, in addition to clarity and consistency of the language.

**Preliminary Analysis and Results**

Pre-analysis was conducted in order to examine the reliability of the translated scales used in this study. A sample of the first 40 respondents’ completed surveys was used as pilot data to check the internal consistency of the study’s scales (HHI, JCS, HADS, and FACT-C). In this study the internal consistency of each scale was measured using Cronbach’s alpha. Estimates of 0.90 and above are considered highly reliable, 0.80-0.89 indicates good reliability, and 0.70-0.79 indicates acceptable reliability for scales. Cronbach’s alpha is also used to determine whether scale items reflect a single variable or dimension (Gliner, Morgan, & Harmon, 2001; Reinard, 2006).

A pilot study of a small sample of respondents is suggested so that the scale can be assessed in relation to clarity and consistency of item wording, and to establish the approximate time participants require completing the scale (Polit & Beck, 2009). Conducting a pilot study increases the applicability of the main study by identifying the reliability and applicability of the instruments before conducting the main study (Thabane et al., 2010). In addition, it gives the researcher the opportunity to modify the scales based on the respondents’ suggestions.

However, a critical concern relates to including the pilot sample in the main study sample (Teijling & Hundley, 2002; Thabane, et al., 2010). In the current study, the pilot sample was added to the main study sample, as no changes were made to any of the wording of the scales used, and the participants reported that the survey questions
were clear and easy to understand (Teijlingen & Hundley, 2002; Thabane, et al., 2010). On average, the respondents reported that the survey took approximately 25 to 30 minutes to complete. A preliminary analysis of these first 40 surveys showed an acceptable reliability of these translated surveys; thus no modifications were made to the original surveys. Consequently, the pilot sample was added to the final sample to increase the sample size (Teijlingen & Hundley, 2002; Thabane, et al., 2010). Table 4.1 presents the reliabilities for each of the translated instruments. The results indicated acceptable internal consistency for this sub-sample and were similar to the original instruments.

Table 4.1: Reliability of the Translated Instruments ($N=40$)

<table>
<thead>
<tr>
<th>Scale</th>
<th>Number of Items</th>
<th>Cronbach’s Alpha (Arabic version)</th>
<th>Cronbach’s Alpha (original version)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jalowiec Coping Scale (using of coping strategies, Part A)</td>
<td>60</td>
<td>0.88</td>
<td>0.79</td>
</tr>
<tr>
<td>Jalowiec Coping scale (effectiveness of using coping strategies, Part B)</td>
<td>60</td>
<td>0.90</td>
<td>0.92</td>
</tr>
<tr>
<td>Herth Hope Index (HHI)</td>
<td>12</td>
<td>0.84</td>
<td>0.97</td>
</tr>
<tr>
<td>Hospital Anxiety and Depression Scale (HADS)</td>
<td>14</td>
<td>0.93</td>
<td>0.91</td>
</tr>
<tr>
<td>Functional Assessment of Cancer Therapy- Colorectal (FACT-C)</td>
<td>36</td>
<td>0.87</td>
<td>0.85</td>
</tr>
</tbody>
</table>

**Data Analysis**

In this study, several steps were carried out for the quantitative data analysis, including data cleaning and verification, and descriptive and inferential analyses. The following section describes these steps.
Data Cleaning and Verification

Data entry is a tedious and error-prone task, and so it is necessary to verify the entries and correct any mistakes. Several methods of verification were employed in the current study. The first was to visually compare the numbers printed on a printout of a data file with codes on the original sources. The second method was to enter all the data twice and compare the two sets of records visually and by computer. The data cleaning involved two types of checks; the first was to check for outliers and out-of-range codes. Outliers can be found by inspecting frequency distributions, paying special attention to the lowest and highest values. In this study, the outliers at the univariate and bivariate levels were evaluated. The researcher examined the distribution of observations, selecting as outliers those cases that fell at the outer ranges of the distribution. The pairs of variables were assessed jointly through scatter plots. The second data-cleaning procedure involved consistency checks, which focused on internal data consistency (Denise. Polit & Beck 2004). In this task, the researcher checked for errors by testing whether data for different variables were compatible. Outliers at the multivariate level were detected by using Mahalanobis Distances (MD) (Baxter, 1999; Rousseeuw & Zomeren, 1990). In the current study, based on the number of the independent variables, the critical value at level 0.001 was 29.59, and so any MD score above that critical value was deemed an outlier. Finally, the data transformation, through performing item reversal, was checked. The researcher used JCS, and FACT-C–scoring guidelines to recode item responses in SPSS (version 14.0).
Descriptive Analyses

Descriptive statistics, including frequencies and percentages, were used to describe the sample characteristics in terms of demographics (age, marital status, gender, educational level, religion) and disease-related conditions (regional metastasis, treatment modalities, presence of chronic diseases and complications). Descriptive statistics using means and standard deviations were employed to describe age, annual income, number of family members and time since diagnosis, and the JCS, FACT-C, HHI, and HADS scales.

Inferential Analyses

Inferential statistics, which are based on the laws of probability, provide a means for drawing information about a population from a sample (Denise, Polit & Beck 2004). In addition, it assists the researcher to do the following (Talbot, 1995):

- Estimate or predict a population parameter from sample statistics;
- Generalise to the population; and,
- Hypothesis testing.

Bivariate Analysis

Pearson’s product-moment correlation coefficient (Pearson’s r) was used to identify correlations between each of the independent variables, including hope, coping, psychological distress (depression and anxiety), age, gender, marital status, income, time since diagnosis, and the dependent variable (QOL).
Multivariate Analysis

Multiple regression ($R^2$) analysis using a model-building approach, as described by Hair et al. (2006), was undertaken to identify the predictors of QOL. The dependent variable, QOL was measured as a single continuous variable, while the independent variables (hope, coping, psychological distress (depression and anxiety)) were also measured as continuous variables. The major goals of multiple regression analyses are to predict changes in the dependent variable from changes in the independent variables to determine which of the independent variables are useful predictors of the dependent variable, and to ascertain the proportion of change in the dependent variables attributable to each independent variable (Talbot, 1995). A standard multiple regression ($R^2$) using a model-building approach (Hair, Anderson, Tathan, & Black, 2006) was employed to predict the relationships between hope, coping, psychological distress (depression and anxiety), age, gender, marital status, income, time since diagnosis, and QOL among Jordanian CRC patients. The following steps in the model-building approach were employed as follows:

At the beginning of the analysis, the aspects of normality, linearity, and heteroscedascity of residuals were assessed. Normality refers to the assumption that each variable is normally distributed. Linearity assumes that there is a straight-line relationship between two variables. Finally, heteroscedascity assumes that the variability in the scores for one continuous variable is the same at all values, and is related to the normal distribution of the sample.

In the first steps of model-building, bivariate analysis was performed to explain the relationship between independent variables, including hope, coping, psychological
distress (depression and anxiety), age, gender, marital status, income, time since diagnosis, and the dependent variable (QOL).

- In theory, variables that were significantly correlated to QOL in the first step of the model-building approach were included and entered in the standard regression analysis. Consequently those independent variables, which did not significantly correlate to the dependent variable, were excluded from the next step of the model building approach (Hair et al., 2006).

- Based on the results of the initial regression model analysis of the independent variables, the variables that showed no correlation with the dependent variables were excluded from the regression model. Thus, parsimonious model regression was performed again, including only the variables that had a correlation with the dependent variable on the initial regression analysis (Hair et al., 2006).

The regression variate was assessed using a number of steps in relation to multicollinearity. First, a check of the correlation matrix for all independent variables (hope, coping, depression and anxiety, age, gender, marital status, income, time since diagnosis) was undertaken to assess correlations between these variables. In theory, if the independent variables are highly correlated (0.90 and above) with each other it will be difficult and inappropriate to use the regression model (Hair et al., 2006). Next, multicollinearity among hypothesized predictors was checked through an examination of the tolerance and variance inflation factor (VIF, as recommended by Hair et al (2006). Theoretically, tolerance refers to the assumption that the variability of one independent variable is not explained by another, and tolerance close to zero
reveals a problem with multicollinearity. A standard cut-off point is a tolerance value of 0.10 and for VIF, if the value is above 10. In the current study, the tolerance value for each independent variable was above the ceiling tolerance value of .10, and the VIF results were less than 10. For all inferential statistics, a $p$ value of 0.05 or less was used to identify the statistical significance, and the confidence intervals (CI) were set at 95%.

**PHASE II: RESEARCH METHODS**

This section describes the research methods employed in Phase II, the qualitative phase of the study.

**Sample Selection**

Qualitative research approaches tend to utilize small samples and emphasize depth rather than breadth (Talbot, 1995). The researcher attempts to attain an understanding through an in-depth and detailed exploration of the phenomenon, group or person. In this study, a sample of 10 participants was chosen purposefully. The selection of the participants for the individual interviews was guided by the need for a better understanding of how the variables of interest (hope, coping, psychological distress) impacted upon QOL, and to identify the participants’ perspectives of the influences. To this end, participants were selected to represent both commonality and uniqueness of the survey’s results.

**Purposeful Sample**

Since the aim of conducting a qualitative follow-up phase was to enrich and enhance the understanding of the survey results, the researcher selected the participants purposefully to represent a maximum variation (Polit & Beck, 2009). The researcher
used a maximum variation sampling method to classify the participants, according to their results in the quantitative phase, into three groups, to better understand the phenomena from different perspectives (patients with different scores and levels of QOL, coping, hope, and psychological distress).

- Group A: represented patients with high scores of hope, coping, QOL and low scores of psychological distress.
- Group B: represented patients with average scores of the main variables under study.
- Group C: represented patients with low scores of hope, coping, QOL, and high levels of psychological distress.

Table 4.2 displays the score ranges for each of the variables measured in Phase I across the three groups of participants who were purposively selected to be interviewed.

<table>
<thead>
<tr>
<th>Group</th>
<th>Participant Survey #.</th>
<th>QOL Range (0-144)</th>
<th>Coping Range (0-180)</th>
<th>Hope Range (12-48)</th>
<th>Psychological Distress Range (0-56)</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>83</td>
<td>120</td>
<td>103</td>
<td>42</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>84</td>
<td>120</td>
<td>102</td>
<td>42</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>108</td>
<td>119</td>
<td>115</td>
<td>42</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>240</td>
<td>117</td>
<td>100</td>
<td>46</td>
<td>8</td>
</tr>
<tr>
<td>B</td>
<td>7</td>
<td>98</td>
<td>88</td>
<td>42</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>11</td>
<td>95</td>
<td>94</td>
<td>35</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td>6</td>
<td>95</td>
<td>122</td>
<td>37</td>
<td>21</td>
</tr>
<tr>
<td>C</td>
<td>146</td>
<td>73</td>
<td>66</td>
<td>31</td>
<td>19</td>
</tr>
<tr>
<td></td>
<td>28</td>
<td>59</td>
<td>70</td>
<td>28</td>
<td>29</td>
</tr>
<tr>
<td></td>
<td>157</td>
<td>47</td>
<td>85</td>
<td>35</td>
<td>25</td>
</tr>
</tbody>
</table>
Recruitment of Patients

In order to address the purpose of Phase II, that is, to illustrate and obtain a deeper understanding of the quantitative results, the researcher provided all the participants with an information sheet that explained the two study phases, as well as the possibility that some would be selected to participate in the second phase. For this reason, the researcher asked participants to write down their contact details in the survey and assured them that all these addresses and contact details would be treated confidentially. Once the participants were selected for participation in this phase, the researcher contacted him/her to arrange an appointment, based on their health, and availability. Eleven participants were contacted, and interviewed, although one participant withdrew and requested that his data not be used, as he only wished to talk about his feelings and express his emotions. The participant was advised to consult a counsellor, however he did not perceive that there was a need for this as he thought he could manage his own condition. However, the researcher provided him with the contact details of the counsellor for future consultation if this should be needed. Thus, only the data from 10 interviews were analysed.

Data Collection Methods

Audio-taped semi-structured interviews were conducted to elicit the participants’ perceptions and experiences related to their quality of life and its predictors (such as coping, hope, and psychological distress). The researcher conducted all of the interviews in the participants’ private rooms, at each of the three hospitals, to ensure privacy and a comfortable environment. Each interview lasted for approximately 30 minutes and was conducted in Arabic. The purpose of this phase was explained to participants prior to beginning the interview. A semi-structured interview approach
was used because this ensured that the same topic areas were covered with all participants. However, it also encouraged patients to talk freely about various issues in relation to their QOL, and to describe and reflect on their experiences. In addition, participants had the freedom to respond in their own words, and provide as much or as little detail as they desired (Polit & Beck, 2004). During interviews, the researcher was sensitive, thoughtful, and empathic to the participant’s tone of voice, facial expressions, gestures and reactions, and modified the process (for example, short breaks) if required. The researcher stopped when no new information emerged during the interview.

Because the qualitative data collection and analysis were undertaken simultaneously, the researcher re-interviewed selected participants to gain a more in-depth understanding, re-clarification, and explanation of their ideas and thoughts, as expressed in the first interview. Three participants were re-interviewed, for example, the researcher re-interviewed participant number 83 for more information in relation to the chemotherapy side-effects which affected his QOL, in addition, to a description of the role of the nurses in managing these problems.

**Interview Data Translation Process**

Conducting a study in one language and reporting the results and outcomes in another language is increasing in the social sciences because of the need for assessment and understanding of cross-cultural and social perspectives of the phenomenon (Birbilli, 2000). However, the issues related to the translation process from one language into another are complicated because of differences in meaning and connotation (Marshall & Rossman, 2006). The quality of the translation process is dependent on numerous
factors, including the autobiography of the researcher–translator; the researcher’s level of knowledge of the language, and of the culture of the target sample under study.

The current study was conducted in an Arabic country and in the Arabic language, yet the results are being presented in the English language. To eliminate the problems related to the translation process, the researcher employed back translation, consultation, and collaboration with an official translator, who was native speaker of the Arabic language, and fluent in English, to achieve a maximum level of accuracy. The process of obtaining comparability of meanings was greatly facilitated and achieved by the researcher and the official translator because they had a perfect understanding of the language and an extensive knowledge of the culture and use of linguistic nuances. Consequently, a “literal” translation process was undertaken. A literal translation process involved translating word-by-word (Birbili, 2000; Temple & Young, 2004).

**Data Analyses**

At the completion of each audio-taped interview, the recording was translated into English after careful and repeated listening, and the data were transferred to computer CDs for better volume and sound quality. Following this, the contextual data were analysed using a directed content analysis approach in order to identify subcategories, categories, and domains.
Content Analysis Approach

Recently, content analysis has become a research method which is widely used in health science research (Hsieh & Shannon, 2005). It is defined as “a research method for the subjective interpretation of the content of the text data through the systematic classification process of coding and identifying themes or patterns” (Hsieh & Shannon, 2005, p. 1278). In order to analyse the textual data the researcher has to select one of the three main approaches to qualitative content analysis: conventional, directed, and summative. Essentially, the major differences among these approaches are coding, origins of codes, and challenges regarding the trustworthiness of data, in addition to the purpose and questions of the study (Hsieh & Shannon, 2005). The following table presents a summary of the differences between these three approaches.

Table 4.3: Differences among Content Analysis Approaches

<table>
<thead>
<tr>
<th>Approach</th>
<th>Rationale</th>
<th>Analysis process</th>
<th>Emergent Codes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Conventional</td>
<td>Limited literature or existing theory about the phenomena.</td>
<td>Ongoing analysis as subcategories and categories are identified during the analysis.</td>
<td>Codes emerge from the data.</td>
</tr>
<tr>
<td>Directed</td>
<td>To support/extend the existing theory or theoretical conceptual framework.</td>
<td>Subcategories/cATEGORIES are predetermined before data collection; the researcher asks question related to these categories.</td>
<td>Codes are already developed based on the prior literature/theory.</td>
</tr>
<tr>
<td>Summative</td>
<td>To understand and explain the phenomena under study through identifying the meaning and counting of words with the context.</td>
<td>Findings emerge through the analysis, and prior literature supported.</td>
<td>Codes are identified during/before the analysis of the textual data.</td>
</tr>
</tbody>
</table>
In this study, the semi-structured interview guide questions (Appendix H) were developed from the review of the literature and to illustrate and explain the results from the quantitative phase. Thus, use of a directed approach enabled further description of the impact of the CRC diagnosis and different treatment modalities on the patients’ QOL, in addition to exploring their perceptions of what influenced their QOL. The researcher developed the interview guide/questions to focus on the known dimensions of QOL, including physical, psychological, social and spiritual well-being, as well as somatic/disease and treatment-related symptoms (King & Hinds, 1998). The following provides examples of the interview questions:

- How has your quality of life changed since your diagnosis with Colorectal Cancer including:
  - Physical Well-being (weight changes, bowel control, sleeping pattern, pain)
  - Social/family life
  - Emotional well-being
  - Functional well-being (daily activity, employment)
  - Sexual life
  - Spiritual and religious life

Consistent with the purpose of the qualitative phase of the current study, “to understand the quantitative results and the variations of the participants’ scores of the QOL and related predictors”, the researcher developed a number of questions to identify the factors that influenced their results, for example:

- Where does your hope come from? And how do you maintain this level of hope?
- What situations/events make you feel anxious and/or depressed?
- What kinds of things have you found yourself thinking about since your diagnosis?
What are you doing to overcome or manage your feeling of depression and anxiety?

What are the factors that have influenced your QOL at the time of diagnosis and during treatment period?

There are limited standard guidelines for performing content analysis. The development of a high-quality categorization scheme involves a careful reading of the data, with an eye to identify underlying concepts and clusters of concepts. However, generally, researchers use the following three steps, during content analysis, to convert the data to smaller, more manageable units that can be retrieved and reviewed. The following steps describe how this process was enacted in this phase of the study.

Step one: Identifying a meaning unit

A meaning unit refers to the content unit, idea, thoughts, words, a textual unit, phrase, and sentence or paragraphs that reflects a specific meaning within the contextual data (Elo & Kyngas, 2008; Graneheim & Lundman, 2004). Thus, in the current study, the interviews were read several times to obtain the meaning and identify common experiences, as well as different perspectives among the participants. Following this, the textual data about the participants’ experiences of having CRC were extracted and entered into a table which represented the code or verbatim of analysis. These meaning units (verbatim) were abstracted and condensed into the sub-categories.

Step two: Generating Sub-categories and Categories

A category is defined as a collection of ideas, thoughts or content that shares a common experience, or meaning, and reflects one point within the text data (Downe-Wamboldt, 1992; Graneheim & Lundman, 2004). Thus, the data were abstracted and
condensed into the sub-categories and then grouped into various sub-categories labelled and constituted together to form larger units called categories. Table 4.3 presents an example of the analysis process.

Table 4.4: Example of Verbatim, Sub-Categories, and Categories from Content Analysis.

<table>
<thead>
<tr>
<th>Category</th>
<th>Sub-category</th>
<th>Exemplar of Participants’ Verbatim</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer As Distress</td>
<td>Experiencing a Range of Emotions</td>
<td><em>It was really a shock for me to know that I have a cancer in my colon, and I never imagined that I would be diagnosed with cancer in my colon.</em></td>
</tr>
<tr>
<td></td>
<td>Changing Perceptions of the Future</td>
<td><em>I know cancer is not easy and so difficult to cure and it takes time; many bad ideas, thinking what will happen to me? Will I survive or not? What will happen to my family and people I love? How can I take chemotherapy? What things will happen to me? Will I lose my hair or not? It is like walking in a dark area; you know nothing about this, what will you do? How will you arrange everything?</em></td>
</tr>
<tr>
<td></td>
<td>Losing Self-Confidence</td>
<td><em>It [colostomy bag] limits my activity, in addition decrease my self-confidence because of its smell and it is very hard to choose my clothes. All these things affect my life and decrease my QOL also.</em></td>
</tr>
</tbody>
</table>

Careful attention to the text, and in-depth discussion with the participants, helped to identify the sub-categories, which reflected the participants’ experiences and feelings they expressed. For example, the participants faced and experienced a range of psychological feelings and emotions, such as *shock, denial, anxiety, fear, and worry*, as a result of their CRC diagnosis, as well as receiving aggressive treatment modalities, including chemotherapy, surgery, and radiotherapy. Thus these feelings (codes) were grouped into one sub-category under the title of *Experiencing a Range of*
Emotions. A similar process was employed to identify the other sub-categories in this qualitative phase.

The abstraction process was continued to group these sub-categories together as one category to reflect and describe the meaning of these sub-categories. A process of interpretation and discussion were performed with experts to extract the categories. For example, the sub-categories mentioned above reflected the impact of a CRC diagnosis and treatment on the participants’ psychological status and explained the range of distress that CRC caused them. Thus, a category Cancer as Distress was used to reflect these emotions. The rationale behind using the word Distress refers to the broad definition of distress as a word; it covers the emotional and cognitive responses to a stressful state. Consequently, participants faced varied emotional and cognitive responses to being diagnosed with CRC, which ranged from psychological emotions to losing self esteem.

Step three: Emerging Domains

The categories were linked together and discussed in relation to shared experiences and commonalities that would capture the categories as a meaningful whole (Polit & Beck, 2004). This analysis is called a domain analysis. For example, four categories were linked together to form the first domain in the current study, as illustrated below.
The process of linking the categories together was based on the interaction between these categories. Similarly, the second domain in the present study was generated to reflect the factors that influenced the participants’ QOL.

**Trustworthiness of the Study**

Qualitative researchers have traditionally used terms such as establishing truth value, fittingness, consistency and neutrality when describing the processes used to enhance the rigour and trustworthiness of the study (Appleton, 1995; Sandelowski, 1986). These concepts will be described in terms of their application to this study.
Truth Value

Guba and Lincoln (1981) suggest that the truth value of a qualitative study should be evaluated by its credibility. They stated that the determination of credibility can be accomplished only by taking data and interpretations to the sources from which they were drawn and asking participants whether they believe or find the results plausible (Guba & Lincoln, 1981). A qualitative study is thus deemed credible if it reveals accurate descriptions of the experience that participants would immediately recognise, from those descriptions or interpretations, as their own (Sandelowski, 1986). Consequently, in the current study, the researcher provided the participants with the written draft about their interview once he transferred the data from the record. In addition, the researcher asked and repeated the audio-tape after the interview finished to confirm that he faithfully represented their stories.

Trustworthiness of the qualitative phase was also facilitated through careful engagement with participants during the interviews in respect to their health condition and status (interviews lasted approximately 30 minutes because of the patients’ fragile health). The short time frame may have created a limitation to the study, but it was considered important to gain participants’ perspectives. Because of the short interview times, a number of participants were re-interviewed to gain an in-depth understanding of the phenomena, to verify their perceptions, and to ensure useful and rich information was obtained.

Fittingness

Applicability in qualitative research is somewhat similar to external validity in quantitative research (Appleton, 1995). Although qualitative researchers agree that
general ideas can be found in particular cases, they also argue that generalisability is something of an illusion since every research situation is ultimately about a particular researcher’s interaction with particular subjects in a particular context (Sandelowski, 1986). Generalisability reflects the degree to which the research findings are applicable to other populations or samples (Polit & Beck, 2009). Guba and Lincoln (1985) suggest that the idea of fittingness is more appropriate and should replace the term generalisability when evaluating qualitative research. Participants are initially selected because they can illuminate the phenomenon being studied so participant selection contributes to fittingness. In qualitative research, representativeness frequently refers to the data rather than to the participants or settings. Specifically, the researcher must establish the typicality of the observed events, behaviours, or responses in the lives of the participants (Sandelowski, 1986).

In the current study, the data might not reflect or represent all patients with CRC, but the generalisability can be achieved by replicating the study across several population groups by using the same methods. This process was explained in-depth in relation to the methods that were undertaken in this project, such as sampling, recruitment, and the analysis process. In addition, the researcher explained the characteristics of the participants, selection process “purposeful sampling” and purpose behind this, to facilitate transferability. Thus, in Phase II, the qualitative study, fittingness was obtained by purposefully selecting the participants to represent both commonality and uniqueness of the sample from the Phase I findings, based on the maximum variation to reflect and discuss the variables from different perspectives. Therefore, the researcher explained each step undertaken, starting from the sampling strategies, and analysis process to provide the reader with an audit trail from which the methods
might be used in different settings or replicated in different countries (Malterud, 2001). To enhance confidence, the analysis process was undertaken under the supervision of the researcher’s supervisors so as to compare, discuss and advise the researcher and ensure fittingness.

Consistency

Guba and Lincoln (1981) propose that the concept of auditability be the measure of the consistency in qualitative research studies. A study and its results are auditable when other investigators are able to follow the decision and processes used by the investigator. The objective of ensuring auditability is to ensure that other researchers could arrive at the same or comparable, but not contradictory, conclusions, given the researcher's data, perspective and situations that emerged in the original study.

In this study, the researcher carried out two pilot interviews to develop his interviewing skills. The researcher used a standardized interview guide to increase the consistency of the data collected. An audio-tape recorder was used to record all interviews for later transcription, to increase the fidelity and veracity of interpretation of the textual data. Moreover, in some cases, the participants were re-interviewed for greater explanation and increased understanding of some points that were presented in the first interview.

Neutrality

Neutrality refers to freedom from bias in the research process and product (Sandelowski, 1986). Guba and Lincoln (1981) suggest that confirmability be the criterion of neutrality in qualitative research. Qualitative research emphasizes the
meaningfulness of the findings, achieved by reducing the distance between the investigator and the subject, and by eliminating artificial lines between the subjective and objective reality (Sandelowski, 1986). Qualitative research values subjectivity rather than objectivity in two ways: the subjective involvement of investigators with their participants, and the emphasis on subjective reality or the meanings subjects give to, and derive from, their life experience (Sandelowski, 1986). In the current study, the researcher clearly described each stage of the research process, starting from identifying the research question, the data collection processes, the data analysis, and the justification of the steps taken.

**Ethical Considerations**

Permissions were granted to undertake the study from the Griffith University Human Research Ethics Committee, as well as the Ministry of Health–Hashemite Kingdom of Jordan (MOH), King Abdullah University Hospital (KAUH), Al-Bashir Hospital, and Jordan University Hospital (JUH). Once participants were identified, written consent was obtained, after explaining the purpose of the study (Appendix A). In addition, the participants were assured that the information obtained would be treated confidentially and for research purposes only. During the data collection, patients’ identification details were treated confidentially and only the researcher had access to the participants’ details to ensure privacy and confidentiality of the information. The questionnaires were coded as study numbers only to allow for follow-up of the non-responders and for selection of participants for Phase II of the study.

During the qualitative phase, interviews were conducted in a private room, and the purpose and the methods of the study were explained to participants. None of the
participant’s name or any other identification details were mentioned during the audio-taped interviews. Moreover, because of the participants’ fragile health, the researcher explained that the interviews could be conducted at the participants’ convenience, and based on their ability to participate. Finally, the participants were assured that they were free to withdraw at any time without prejudice, and that participation was voluntary. The study was underpinned by the following fundamental ethical principles:

*Beneficence:* the individual acts to prevent harm, remove harmful conditions, and promote positive benefits for others (Talbot, 1995). Levine (1981) has classified these risks into four categories: (a) physical: adverse reaction to an experimental drugs or treatment protocol; (b) psychological: an increase in anxiety secondary to being a research participants, fear, and stress; (c) social: participation in a sensitive topic study (e.g. alcohol or HIV), which could result in labelling or loss of privacy for the participants; and (d) economic: financial threats, such as loss of a job, money, or health insurance, if participation in the study becomes (R. J. Levine, 1981). In addition, freedom from exploitation should be maintained during the study. Thus, study participants enter into a special relationship with researchers, and it is crucial that this relationship not be exploited. Exploitation may be overt and malicious (e.g. sexual relationships, use of subjects' identifying information to create a mailing list, and use of donated blood for the development of a commercial product) (Polit & Beck, 2004).

In the current study, the research methods did not include any harmful effects, such as physical, economic, or social threats. Moreover, participants were not involved in any experimental trials. The researcher provided participants with an information sheet
that contained the background of the study, research purposes, and potential benefits of the participation and results (Appendix A). This approach ensured that the consent would be informed. However, participation may cause emotional distress to the participants as a result of their being asked to recall details of their experiences having, or being diagnosed with, CRC. Thus, two supervisors monitored the conduct of the research in both phases to advise the researcher in case of sensitive issues and hazards that might have an impact on the participants. As a contingency in the management of potential psychological distress, the researcher asked three counsellors, one from each hospital, to consult with participants in the event that they become distressed or if they appeared to be depressed or anxious during the interviews.

The principles of respect for human dignity were obtained through self-determination. That is, participants have the right to decide voluntarily whether to participate in a study based on the truthfulness and accuracy of the information given; and thus the right to full-disclosure. The researcher fully described the nature of the study, the person's right to refuse participation, the researcher's responsibilities, and the likely risks and benefits (Denise. Polit & Beck 2004). As a consequence, patients were asked to sign the consent form after an overview explaining the study’s purposes and methods. Patients were assured that participation was voluntary, and that they had the right to withdraw any time during the study, without prejudice or penalty. The researcher explained to participants that there may be no direct benefits for them, but the results of the study may potentially help in improving the patient care through identifying the factors that predict the QOL.
The third broad principle, articulated in the Belmont report (1979), concerns *justice*. The justice principle includes participants’ right to fair treatment (such as fair and non-discriminatory selection of participants, respect for culture and other forms of human diversity, and non prejudicial treatment of those who decline to participate or withdraw), and the right to privacy through maintaining confidentiality. In addition, the participants’ rights to decline or withdraw from participating without prejudice. The researcher used the following steps to ensure confidentiality: (a) assigned an identification number to each participant; (b) all of the data obtained were stored in a locked file (using password known only to the researcher); (c) computer/files access was restricted to the researcher; (d) all of the surveys will be stored in a locked cupboard in a controlled access room at the Griffith University (for a period of 7 years) as per the NHMRC Guidelines (Ref No: NRS/29/08/HREC); and (e) the research data were aggregated in the quantitative study, and reporting a specific case was presented without identifying patient identification details (such as name, family name). Pseudonyms were used for hospitals and participants in the qualitative study.

**SUMMARY**

The use of the mixed-method design is increasingly being used in nursing research. In this study, a priority sequence model, using a sequential explanatory mixed method design, was used to explain the phenomena under study (QOL and its hypothesized psychosocial predictors), to provide more in-depth understanding of the situation, and to explain significant quantitative results. In this study, the utility of using the mixed-method design with oncology patients offered a versatile approach to in-depth understanding and to explaining a complex concept (QOL) and its predictors. In addition, it captured the complexity and diversity of the patients’ values, perceptions
and experiences during their cancer treatment journey. The following chapter presents the results of Phase I, the quantitative survey.
CHAPTER FIVE
Phase I- Quantitative Survey Results

INTRODUCTION
This study sought to describe the predictors of quality of life (QOL) in patients with colorectal cancer (CRC). To this end, this quantitative phase aimed to describe the relationships between coping, hope, psychological distress (depression and anxiety), age, gender, marital status, income, time since diagnosis, and QOL among Jordanian CRC patients. This chapter presents the descriptive and inferential results of this phase. It presents the analysis of data in relation to the response rates, sample characteristics, and scale frequencies and reliabilities. Bivariate relationships among the variables are reported, and the predictors of QOL identified through the use of a standard multiple regression model.

CHARACTERISTICS OF THE SAMPLE
A total of 320 patients, who were diagnosed with CRC across three Jordanian hospitals, were invited to participate. Of these, 260 patients completed the survey forms, for a response rate of 81.25%. The sample was drawn from three different medical institutions in Jordan, which represented the three main regions of Jordan. Table 5.1 presents these data.

Table 5.1: Distributions of the Sample (N = 260)

<table>
<thead>
<tr>
<th>Hospital Name</th>
<th>Number (n)</th>
<th>Frequencies (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>AL-Bashir hospital</td>
<td>160</td>
<td>61.5</td>
</tr>
<tr>
<td>Jordan University (JUH)</td>
<td>30</td>
<td>11.5</td>
</tr>
<tr>
<td>King Abdullah University Hospital (KAUH)</td>
<td>70</td>
<td>27.0</td>
</tr>
</tbody>
</table>
The demographic data were collected to describe the participants in this study; the data included educational level, marital status, and religion. The participants’ educational level varied from primary to postgraduate certification. The majority of the participants were married (89.5%) and Muslim (98.5%). Table 5.2 displays these results.

Table 5.2: Selected Demographical Characteristics of the Participants \((N = 260)\)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Number (n)</th>
<th>Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>142</td>
<td>54.6</td>
</tr>
<tr>
<td>Female</td>
<td>118</td>
<td>45.4</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>9</td>
<td>3.5</td>
</tr>
<tr>
<td>Married</td>
<td>233</td>
<td>89.5</td>
</tr>
<tr>
<td>Widow</td>
<td>16</td>
<td>6.2</td>
</tr>
<tr>
<td>Divorce</td>
<td>2</td>
<td>0.8</td>
</tr>
<tr>
<td><strong>Education Level</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary</td>
<td>50</td>
<td>19.2</td>
</tr>
<tr>
<td>Secondary</td>
<td>81</td>
<td>31.2</td>
</tr>
<tr>
<td>Diploma</td>
<td>62</td>
<td>23.8</td>
</tr>
<tr>
<td>Bachelor</td>
<td>53</td>
<td>20.4</td>
</tr>
<tr>
<td>Postgraduate</td>
<td>14</td>
<td>5.4</td>
</tr>
<tr>
<td><strong>Religion</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Muslim</td>
<td>256</td>
<td>98.5</td>
</tr>
<tr>
<td>Christian</td>
<td>3</td>
<td>1.2</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>0.3</td>
</tr>
</tbody>
</table>

In the current study, data related to the presence of complications and chronic disease were collected, in addition to time since diagnosis and treatment modalities. The participants’ ages ranged from 23 to 76 years, with a mean age of 51.9 years (SD 9.48); and, time since diagnosis ranged from 2 to 24 months, with a mean of 11.69 (SD 4.80). With respect to education, 20% of the participants had a primary school education, however, the researcher and panel translated the surveys into language that
was comprehensible for all education levels. In addition, 65.4 % of the participants had no complications at the time of the data collection, and 96.9% of participants had no regional metastasis. The great majority (98.8%) were treated with different treatment modalities (a combination of chemotherapy and surgery). Table (5. 3) displays these results.

Table 5.3: Disease-Related Characteristics of the Participants (N = 260)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Number</th>
<th>Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Present Chronic Illness</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>84</td>
<td>32.3</td>
</tr>
<tr>
<td>No</td>
<td>176</td>
<td>67.7</td>
</tr>
<tr>
<td>Complications</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>90</td>
<td>34.6</td>
</tr>
<tr>
<td>No</td>
<td>170</td>
<td>65.4</td>
</tr>
<tr>
<td>Complication Type:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gastrointestinal</td>
<td>86</td>
<td>33.1</td>
</tr>
<tr>
<td>Neurological</td>
<td>2</td>
<td>0.8</td>
</tr>
<tr>
<td>Genitourinary</td>
<td>2</td>
<td>0.8</td>
</tr>
<tr>
<td>Regional Metastasis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>8</td>
<td>3.1</td>
</tr>
<tr>
<td>No</td>
<td>252</td>
<td>96.9</td>
</tr>
<tr>
<td>Treatment modalities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>3</td>
<td>1.2</td>
</tr>
<tr>
<td>Combined (Chemotherapy, and Surgery)</td>
<td>257</td>
<td>98.8</td>
</tr>
</tbody>
</table>

SCALES RESULTS

A total of four scales were used in this study to address the research question, namely: Herth Hope Index (HHI) (Herth, 1992), Jalowiec Coping Scale (JCS) (Jalowiec, et al., 1984), Hospital Anxiety and Depression Scale (HADS) (Frank-Stromborg & Olsen,
2004), and Functional Assessment of Cancer Therapy- Colorectal (FACT-C) (Ward, et al., 1999). The following section details the reliability of the translated scales, and the descriptive results in relation to each of the scales.

**Reliability of the Translated Scales**

In the current study, the four scales (HHI, JCS, HADS, and FACT-C) were translated from English into Arabic using Brislin’s (1986) model of translation. Cronbach’s alpha was used to assess the internal consistency of the translated scales. The results indicated acceptable reliability coefficients for each of the four scales. Table 5.4 details these results.

Table 5.4: Cronbach’s Alpha for the Translated Scales Used in the Study (N=260)

<table>
<thead>
<tr>
<th>Scale</th>
<th>Number of Items</th>
<th>Cronbach’s Alpha (Arabic version)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jalowiec Coping Scale (JCS)</td>
<td>60</td>
<td>0.84</td>
</tr>
<tr>
<td>Herth Hope Index (HHI)</td>
<td>12</td>
<td>0.75</td>
</tr>
<tr>
<td>Hospital Anxiety and Depression Scale (HADS)</td>
<td>14</td>
<td>0.92</td>
</tr>
<tr>
<td>Functional Assessment of Cancer Therapy- Colorectal (FACT-C)</td>
<td>36</td>
<td>0.92</td>
</tr>
</tbody>
</table>

**Scales’ Descriptive Results**

As previously mentioned, four scales were employed to measure Jordanian participants’ level of hope, coping, psychological distress (depression and anxiety), and QOL. The following section details the descriptive results, including absolute (n) and relative (%) frequencies for each of the scales (HHI, JCS, HADS, and FACT-C).
Hope

To measure the level of hope, participants were asked to describe their level of hope using HHI (Herth, 1992), which contains 12 items. The results indicated that participants’ total of hope level ranged from 24 to 46, with a mean of 37.5 (SD 3.9), with the higher scores indicating a greater level of hope. The highest percentage of participants agreed that they had a positive outlook toward life (80.4%), and 81.5% of the participants could see possibilities in the midst of difficulties. The majority of the participants (60.4%) had a faith that gave them comfort, and nearly 60% could recall happy/joyful times. Nearly 70% of participants strongly agreed that their life had value and worth. Over half (57.7%) of the participants believed that each day had potential. Table 5.5 presents these results.

Table 5.5: Frequency and Percentage of HHI Scale Items (N=260)

<table>
<thead>
<tr>
<th>Scale item</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have a positive outlook toward life</td>
<td>1 (0.4)</td>
<td>12 (4.6)</td>
<td>209 (80.4)</td>
<td>38 (14.6)</td>
</tr>
<tr>
<td>I have short and/or long range goals</td>
<td>2 (0.8)</td>
<td>32 (12.3)</td>
<td>133 (51.2)</td>
<td>93 (35.8)</td>
</tr>
<tr>
<td>I feel all alone</td>
<td>93 (35.8)</td>
<td>133 (51.2)</td>
<td>25 (9.6)</td>
<td>8 (3.1)</td>
</tr>
<tr>
<td>I can see possibilities in the midst of difficulties</td>
<td>3 (1.2)</td>
<td>22 (8.5)</td>
<td>212 (81.5)</td>
<td>23 (8.8)</td>
</tr>
<tr>
<td>I have a faith that gives me comfort</td>
<td>0 (0.0)</td>
<td>6 (2.3)</td>
<td>157 (60.4)</td>
<td>97 (37.3)</td>
</tr>
<tr>
<td>I feel scared about my future</td>
<td>5 (1.9)</td>
<td>59 (22.7)</td>
<td>98 (37.7)</td>
<td>98 (37.7)</td>
</tr>
<tr>
<td>I can recall happy/joyful times</td>
<td>5 (1.9)</td>
<td>19 (7.3)</td>
<td>151 (58.1)</td>
<td>85 (32.7)</td>
</tr>
<tr>
<td>I have deep inner strength</td>
<td>2 (0.8)</td>
<td>22 (8.5)</td>
<td>147 (56.6)</td>
<td>88 (33.8)</td>
</tr>
<tr>
<td>I am able to give and receive caring/love</td>
<td>3 (1.2)</td>
<td>23 (8.8)</td>
<td>147 (56.6)</td>
<td>87 (33.5)</td>
</tr>
</tbody>
</table>
I have a sense of direction
I believe that each day has potential
I feel my life has value and worth

<table>
<thead>
<tr>
<th>I have a sense of direction</th>
<th>2 (0.8)</th>
<th>55 (21.2)</th>
<th>134 (51.5)</th>
<th>69 (26.5)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I believe that each day has potential</td>
<td>3 (1.2)</td>
<td>6 (2.3)</td>
<td>101 (38.3)</td>
<td>150 (57.7)</td>
</tr>
<tr>
<td>I feel my life has value and worth</td>
<td>0 (0.0)</td>
<td>2 (0.8)</td>
<td>78 (30.0)</td>
<td>180 (69.2)</td>
</tr>
</tbody>
</table>

Coping

In the current study, coping was measured by the JCS (Jalowiec, et al., 1984) which consists of 60 items that reflect the eight different coping strategies. Participants were asked to answer the two parts of this scale; Part A relates to the use of coping strategies and how often the patients used these strategies, and Part B reflects how useful these strategies were for patients.

*Use of Eight Coping Strategies (Part A)*

The descriptive results indicated that participants’ use of coping strategies ranged from 47 to 135, with a mean 99.3 (SD 13.03). The higher scores indicated a greater level of coping. The results indicated that *Evasive* coping strategies were used predominantly between the participants, with a mean 21.4 (SD 3.8), followed by *Confrontive* coping strategies, with a mean 18.5 (SD 3.3), and *Optimistic* coping strategies, with a mean 17.8 (SD 3.1). In contrast, *Fatalistic* and *Emotive* coping strategies had the lowest scores between the other coping strategies, with means of 3.7 (SD1.6) and 3.3 (SD 1.8), respectively (Refer to Table 5.6). The JCS has 60 items which measure eight coping strategies.
Table 5.6: Part A Use of Eight Coping Strategies (N=260)

<table>
<thead>
<tr>
<th>Coping strategy</th>
<th>Minimum</th>
<th>Maximum</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Confrontive</td>
<td>7.00</td>
<td>28.00</td>
<td>18.45</td>
<td>3.33</td>
</tr>
<tr>
<td>Evasive</td>
<td>9.00</td>
<td>31.00</td>
<td>21.35</td>
<td>3.78</td>
</tr>
<tr>
<td>Optimistic</td>
<td>6.00</td>
<td>25.00</td>
<td>17.82</td>
<td>3.10</td>
</tr>
<tr>
<td>Fatalistic</td>
<td>0.00</td>
<td>09.00</td>
<td>03.75</td>
<td>1.58</td>
</tr>
<tr>
<td>Emotive</td>
<td>0.00</td>
<td>09.00</td>
<td>03.28</td>
<td>1.84</td>
</tr>
<tr>
<td>Palliative</td>
<td>3.00</td>
<td>17.00</td>
<td>12.82</td>
<td>2.63</td>
</tr>
<tr>
<td>Supportant</td>
<td>7.00</td>
<td>14.00</td>
<td>10.97</td>
<td>1.55</td>
</tr>
<tr>
<td>Self- Reliant</td>
<td>4.00</td>
<td>18.00</td>
<td>11.24</td>
<td>2.55</td>
</tr>
<tr>
<td>Total of coping strategies that are used to handle stressful situation</td>
<td>47.00</td>
<td>135</td>
<td>99.31</td>
<td>13.03</td>
</tr>
</tbody>
</table>

*Effectiveness of Coping Strategies (Part B)*

The second part of the JCS reflects the effectiveness of different coping strategies used by the patients to manage difficult situations. The results indicate that the total scores for the effectiveness of coping strategies ranged from 42 to 143, with a mean 93.5 (SD 13.67); the higher scores reflected a greater effectiveness for the coping strategies. In addition, the results indicated that *Evasive* coping strategies were the most effective style of coping, with a mean 19.8 (SD 3.8), followed by *Confrontive* coping strategies, 17.6 (SD 3.7), and *Optimistic* coping strategies, with a mean 14.9 (SD 2.8). Moreover, and consistent with the results of coping strategies, *Fatalistic* and *Emotive* coping strategies had the lowest scores, with means of 3.6 (SD1.6) and 3.0 (SD 2.2), respectively (Refer to Table 5.7).
Table 5.7: Part B: Effectiveness of Coping Strategies (N=260)

<table>
<thead>
<tr>
<th>Coping strategy</th>
<th>Minimum</th>
<th>Maximum</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Confrontive</td>
<td>7</td>
<td>41</td>
<td>17.62</td>
<td>3.69</td>
</tr>
<tr>
<td>Evasive</td>
<td>9</td>
<td>31</td>
<td>19.78</td>
<td>3.79</td>
</tr>
<tr>
<td>Optimistic</td>
<td>5</td>
<td>21</td>
<td>14.86</td>
<td>2.78</td>
</tr>
<tr>
<td>Fatalistic</td>
<td>0</td>
<td>10</td>
<td>3.58</td>
<td>1.59</td>
</tr>
<tr>
<td>Emotive</td>
<td>0</td>
<td>10</td>
<td>2.96</td>
<td>2.18</td>
</tr>
<tr>
<td>Palliative</td>
<td>3</td>
<td>19</td>
<td>11.95</td>
<td>2.71</td>
</tr>
<tr>
<td>Supportant</td>
<td>6</td>
<td>33</td>
<td>10.64</td>
<td>2.03</td>
</tr>
<tr>
<td>Self- Reliant</td>
<td>3</td>
<td>18</td>
<td>10.42</td>
<td>2.26</td>
</tr>
<tr>
<td>Total of how much these strategies are useful</td>
<td>42</td>
<td>143</td>
<td>93.45</td>
<td>13.67</td>
</tr>
</tbody>
</table>

**Psychological Distress**

The Hospital Anxiety and Depression Scale (HADS) (Frank-Stromborg & Olsen, 2004) was used in this study in order to assess psychological distress within this Jordanian sample. The HADS consists of 14 items (7 items were used to measure depression, and 7 items were used to measure anxiety among the participants). The descriptive statistics included absolute (n) and relative (%), frequencies, means and standard deviations. The higher scores reflected greater depression and anxiety. The results indicated that participants had mild depression, with a mean of 6.3 (SD 3.3), and mild anxiety, with a mean of 7.9 (SD 3.0); the total score of HADS ranged from 0 to 30, with a mean of 14.2 (SD 5.8). The score of 0 to 7 for either subscale could be regarded as being in the normal range, a score of 8 to 10 moderate, and a score of 11 or higher indicating a severe disorder (Snaith, 2003). The results also indicted that 83.1% of the participants no longer enjoyed the things as much as they used to enjoy them, while 13.5 % of the participants reported that they enjoyed the things they used to enjoy, but only a little. In addition, 1.9 % of the participants had definitely lost their interest in their appearance, and only 15.8 % did not care so much as they should.
about their appearance. Moreover, 83.5% of the participants were not able to laugh and see the funny side of things, while 13.5% reported that they could definitely laugh and see the funny side, but not as much as previously. Furthermore, a minority of the participants had sudden feelings of panic (0.8%), and 14.6% of them, quite often, having sudden feelings of panic. Finally, 33.8% of the participants could sit at ease and feel relaxed. Table 5.8 summarizes these results.

Table 5.8: Frequency and Percentage of HADS Scale ‘Items (N=260)

<table>
<thead>
<tr>
<th>Item</th>
<th>Number N</th>
<th>Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel tense or ‘wound up’</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Most of the time</td>
<td>10</td>
<td>3.8</td>
</tr>
<tr>
<td>A lot of the time</td>
<td>23</td>
<td>8.8</td>
</tr>
<tr>
<td>From time to time/occasionally</td>
<td>213</td>
<td>81.9</td>
</tr>
<tr>
<td>Not at all</td>
<td>14</td>
<td>5.4</td>
</tr>
<tr>
<td>I feel as if I have slowed down</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nearly all the time</td>
<td>2</td>
<td>0.8</td>
</tr>
<tr>
<td>Very often</td>
<td>24</td>
<td>9.2</td>
</tr>
<tr>
<td>Sometimes</td>
<td>121</td>
<td>46.5</td>
</tr>
<tr>
<td>Not at all</td>
<td>113</td>
<td>43.5</td>
</tr>
<tr>
<td>I still enjoy the things I used to enjoy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Definitely as much</td>
<td>5</td>
<td>1.9</td>
</tr>
<tr>
<td>Not quite so much</td>
<td>216</td>
<td>83.1</td>
</tr>
<tr>
<td>Only a little</td>
<td>35</td>
<td>13.5</td>
</tr>
<tr>
<td>Hardly at all</td>
<td>4</td>
<td>1.5</td>
</tr>
<tr>
<td>I get a sort of frightened feeling like ‘butterflies’ in the stomach</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not at all</td>
<td>123</td>
<td>47.3</td>
</tr>
<tr>
<td>Occasionally</td>
<td>106</td>
<td>40.8</td>
</tr>
<tr>
<td>Quite often</td>
<td>26</td>
<td>10.0</td>
</tr>
<tr>
<td>Very often</td>
<td>5</td>
<td>1.9</td>
</tr>
<tr>
<td>I get a sort of frightened feeling as if something awful is about to happen</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very definitely and quite badly</td>
<td>12</td>
<td>4.6</td>
</tr>
<tr>
<td>Statement</td>
<td>Count</td>
<td>Percentage</td>
</tr>
<tr>
<td>--------------------------------------------------------------------------</td>
<td>-------</td>
<td>------------</td>
</tr>
<tr>
<td>Yes, but not too badly</td>
<td>85</td>
<td>32.7</td>
</tr>
<tr>
<td>A little, but it doesn’t worry me</td>
<td>153</td>
<td>58.8</td>
</tr>
<tr>
<td>Not at all</td>
<td>10</td>
<td>3.8</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I have lost interest in my appearance</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Definitely</td>
<td>5</td>
<td>1.9</td>
</tr>
<tr>
<td>I don’t take as much care as I should</td>
<td>41</td>
<td>15.8</td>
</tr>
<tr>
<td>I may not take quite as much care</td>
<td>115</td>
<td>44.2</td>
</tr>
<tr>
<td>I take just as much care as ever</td>
<td>99</td>
<td>38.1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I can laugh and see the funny side of things</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>As much as I always could</td>
<td>5</td>
<td>1.9</td>
</tr>
<tr>
<td>Not quite so much now</td>
<td>217</td>
<td>83.5</td>
</tr>
<tr>
<td>Definitely not so much now</td>
<td>36</td>
<td>13.8</td>
</tr>
<tr>
<td>Not at all</td>
<td>2</td>
<td>0.8</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I feel restless as if I have to be on the move</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Very much indeed</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Quite a lot</td>
<td>29</td>
<td>11.2</td>
</tr>
<tr>
<td>Not very much</td>
<td>197</td>
<td>75.8</td>
</tr>
<tr>
<td>Not at all</td>
<td>34</td>
<td>13.1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Worrying thoughts go through my mind</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>A great deal of the time</td>
<td>4</td>
<td>1.5</td>
</tr>
<tr>
<td>A lot of the time</td>
<td>37</td>
<td>14.2</td>
</tr>
<tr>
<td>Not too often</td>
<td>78</td>
<td>30.0</td>
</tr>
<tr>
<td>Very little</td>
<td>141</td>
<td>54.2</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I look forward with enjoyment to things</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>As much as I ever did</td>
<td>2</td>
<td>0.8</td>
</tr>
<tr>
<td>Rather less than I used to</td>
<td>211</td>
<td>81.2</td>
</tr>
<tr>
<td>Definitely less than I used to</td>
<td>43</td>
<td>16.5</td>
</tr>
<tr>
<td>Hardly at all</td>
<td>4</td>
<td>1.5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I feel cheerful</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>1</td>
<td>0.4</td>
</tr>
<tr>
<td>Not often</td>
<td>49</td>
<td>18.8</td>
</tr>
<tr>
<td>Sometimes</td>
<td>202</td>
<td>77.7</td>
</tr>
<tr>
<td>Most of the time</td>
<td>8</td>
<td>3.1</td>
</tr>
</tbody>
</table>

| I get sudden feelings of panic                                           |       |            |
Quality of Life (QOL)

In this study, QOL was measured with a disease-specific instrument, the Functional Assessment of Cancer Therapy-Colorectal (FACT-C) (Ward, et al., 1999). The participants were asked to answer the 36 questions scale in order to assess their QOL during cancer treatment. The higher results reflect a greater QOL. The scale is divided into two parts. Part One contains 27 items divided into four primary QOL domains: (1) physical well-being (possible score from 0 to 28), (2) social/family well being (possible score from 0 to 28), (3) emotional well-being (scores range from 0 to 24), and (4) functional well-being (scores range from 0 to 28). Part Two of the FACT-C consists of nine items related to general symptoms of colorectal cancer (e.g. appetite, digestion, control of bowels, difficulties with ostomy, body appearance). The results indicated that over 75% of the participants experienced various physical symptoms, such as nausea, pain, feeling ill, forced to spend time in bed, and bothered by side effect of treatment. According to the social and family well-being factors, the results indicated that the participants satisfied and received incredible emotional and social
support from their families and friends (98.2, and 91.2%, respectively). In addition 91.1 % of the patients’ families accepted the diagnosis of cancer, and 78.1 % of the participants were satisfied with their families’ communication about their illness. Moreover, 60% of the participants were feeling sad since being diagnosed with CRC, feeling nervous (66.5%), with the majority of them worried about dying and their condition (71.9, and 61.5 %, respectively). In relation to functional well-being, 84.2% of participants accepted their illness, and were able to work (including working at home), with 85.8% and 77.7 % enjoying the things they usually did for fun. Furthermore, 83.5% had control over their bowel, and had a good appetite (83.5%), with 76.5% of the participants liking their body’s appearance. Finally, 55 participants had a colostomy bag (21.2%). The majority of the participants, who had a colostomy bag, reported feeling embarrassed by the colostomy appliance (18.5 %), or found that the caring of the colostomy was difficult (27.7%). Table 5.9 details the relative and absolute frequencies of the FACT-C Scale ‘items.
Table 5.9: Frequency and Percentage of FACT-C Scale ‘Items (N=260)

<table>
<thead>
<tr>
<th>QOL’ Domains</th>
<th>Not at all N (%)</th>
<th>A little bit N (%)</th>
<th>Somewhat N (%)</th>
<th>Quite a bit N (%)</th>
<th>Very much N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>PHYSICAL WELL-BEING</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have a lack of energy</td>
<td>13 (5.0)</td>
<td>36 (13.8)</td>
<td>38 (14.6)</td>
<td>97 (37.3)</td>
<td>76 (29.2)</td>
</tr>
<tr>
<td>I have nausea</td>
<td>19 (7.3)</td>
<td>16 (6.2)</td>
<td>25 (9.6)</td>
<td>62 (23.8)</td>
<td>138 (53.1)</td>
</tr>
<tr>
<td>Because of my physical condition, I have trouble meeting the needs of my family</td>
<td>13 (5.0)</td>
<td>19 (7.3)</td>
<td>33 (12.7)</td>
<td>98 (37.7)</td>
<td>97 (37.3)</td>
</tr>
<tr>
<td>I have pain</td>
<td>19 (7.3)</td>
<td>14 (5.4)</td>
<td>37 (14.2)</td>
<td>115 (44.2)</td>
<td>75 (28.8)</td>
</tr>
<tr>
<td>I am bothered by side effects of the treatment</td>
<td>33 (12.7)</td>
<td>43 (16.5)</td>
<td>48 (18.5)</td>
<td>122 (46.9)</td>
<td>14 (5.4)</td>
</tr>
<tr>
<td>I feel ill</td>
<td>14 (5.4)</td>
<td>29 (11.2)</td>
<td>35 (13.5)</td>
<td>118 (45.4)</td>
<td>64 (24.6)</td>
</tr>
<tr>
<td>I am forced to spend time in bed</td>
<td>3 (1.2)</td>
<td>29 (11.2)</td>
<td>39 (15.0)</td>
<td>127 (48.8)</td>
<td>62 (23.8)</td>
</tr>
<tr>
<td><strong>SOCIAL/FAMILY WELL-BEING</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel close to my friends</td>
<td>00 (0.0)</td>
<td>9 (3.5)</td>
<td>19 (7.3)</td>
<td>125 (48.1)</td>
<td>107 (41.2)</td>
</tr>
<tr>
<td>I get emotional support from my family</td>
<td>00 (0.0)</td>
<td>2 (0.8)</td>
<td>2 (0.8)</td>
<td>66 (25.1)</td>
<td>190 (73.1)</td>
</tr>
<tr>
<td>I get support from my friends</td>
<td>00 (0.0)</td>
<td>6 (2.3)</td>
<td>17 (6.5)</td>
<td>90 (34.6)</td>
<td>147 (56.6)</td>
</tr>
<tr>
<td>My family has accepted my illness</td>
<td>01 (0.4)</td>
<td>11 (4.2)</td>
<td>11 (4.2)</td>
<td>58 (22.3)</td>
<td>179 (68.8)</td>
</tr>
<tr>
<td>I am satisfied with family communication about my illness</td>
<td>00 (0.0)</td>
<td>2 (0.8)</td>
<td>6 (2.3)</td>
<td>49 (18.8)</td>
<td>203 (78.1)</td>
</tr>
<tr>
<td>I feel close to my partner (or the person who is my main support)</td>
<td>13 (5.0)</td>
<td>7 (2.7)</td>
<td>6 (2.3)</td>
<td>50 (19.2)</td>
<td>184 (70.8)</td>
</tr>
<tr>
<td>I am satisfied with my sex life</td>
<td>15 (5.8)</td>
<td>30 (11.5)</td>
<td>106 (40.8)</td>
<td>99 (38.1)</td>
<td>10 (3.8)</td>
</tr>
<tr>
<td><strong>EMOTIONAL WELL-BEING</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel sad</td>
<td>20 (7.7)</td>
<td>36 (13.8)</td>
<td>48 (18.5)</td>
<td>132 (50.8)</td>
<td>24 (9.2)</td>
</tr>
<tr>
<td>I am satisfied with how I am coping with my illness</td>
<td>02 (0.8)</td>
<td>10 (3.8)</td>
<td>27 (10.4)</td>
<td>101 (38.8)</td>
<td>120 (46.2)</td>
</tr>
<tr>
<td>I am losing hope in the fight against my illness</td>
<td>04 (1.5)</td>
<td>18 (6.9)</td>
<td>38 (14.6)</td>
<td>137 (52.7)</td>
<td>63 (24.2)</td>
</tr>
<tr>
<td>I feel nervous</td>
<td>21 (8.1)</td>
<td>29 (11.2)</td>
<td>37 (14.2)</td>
<td>167 (64.2)</td>
<td>6 (2.3)</td>
</tr>
<tr>
<td>I worry about dying</td>
<td>08 (3.1)</td>
<td>21 (8.1)</td>
<td>44 (16.9)</td>
<td>135 (51.9)</td>
<td>52 (20.0)</td>
</tr>
<tr>
<td>I worry that my condition will get worse</td>
<td>15 (5.8)</td>
<td>24 (9.2)</td>
<td>52 (20.00)</td>
<td>160 (61.5)</td>
<td>9 (3.50)</td>
</tr>
</tbody>
</table>
**FUNCTIONAL WELL-BEING**

<table>
<thead>
<tr>
<th>Description</th>
<th>Count (Percentage)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am able to work (include working at home)</td>
<td>1 (0.4) 8 (3.1) 28 (10.8) 117 (45.0) 106 (40.8)</td>
</tr>
<tr>
<td>My work (include working at home) is fulfilling</td>
<td>4 (1.5) 7 (2.7) 32 (12.3) 110 (42.3) 107 (41.2)</td>
</tr>
<tr>
<td>I am able to enjoy life</td>
<td>00 (0.0) 7 (2.7) 34 (13.1) 122 (46.9) 97 (37.3)</td>
</tr>
<tr>
<td>I have accepted my illness</td>
<td>5 (1.9) 2 (0.8) 29 (11.2) 110 (42.3) 114 (43.8)</td>
</tr>
<tr>
<td>I am sleeping well</td>
<td>00 (0.0) 9 (3.5) 25 (9.6) 94 (36.2) 132 (50.8)</td>
</tr>
<tr>
<td>I am enjoying the things I usually do for fun</td>
<td>1 (0.4) 5 (1.9) 52 (20.0) 161 (61.9) 41 (15.8)</td>
</tr>
<tr>
<td>I am content with the quality of my life right now</td>
<td>3 (1.2) 6 (2.3) 49 (18.8) 164 (63.1) 38 (14.6)</td>
</tr>
</tbody>
</table>

**ADDITIONAL CONCERNS**

<table>
<thead>
<tr>
<th>Description</th>
<th>Count (Percentage)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have swelling or cramps in my stomach area</td>
<td>36 (13.8) 109 (41.9) 56 (21.5) 36 (13.8) 23 (8.8)</td>
</tr>
<tr>
<td>I am losing weight</td>
<td>173 (66.5) 31 (11.9) 21 (8.1) 19 (7.3) 16 (6.2)</td>
</tr>
<tr>
<td>I have control of my bowels</td>
<td>10 (3.8) 14 (5.4) 19 (7.3) 27 (10.4) 190 (73.1)</td>
</tr>
<tr>
<td>I can digest my food well</td>
<td>4 (1.5) 12 (4.6) 15 (5.8) 69 (26.5) 160 (61.5)</td>
</tr>
<tr>
<td>I have diarrhoea</td>
<td>81 (31.2) 117 (45.0) 29 (11.2) 23 (8.8) 10 (3.8)</td>
</tr>
<tr>
<td>I have a good appetite</td>
<td>3 (1.2) 24 (9.2) 16 (6.2) 139 (53.5) 78 (30.0)</td>
</tr>
<tr>
<td>I like the appearance of my body</td>
<td>12 (4.6) 27 (10.4) 22 (8.5) 124 (47.7) 75 (28.8)</td>
</tr>
</tbody>
</table>

Do you have an ostomy appliance? *(Check one box)*

- ☐ Yes 55 (21.2)
- ☐ No 205 (78.8)

*If yes, please answer the next two items:*

<table>
<thead>
<tr>
<th>Description</th>
<th>Count (Percentage)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am embarrassed by my ostomy appliance</td>
<td>00 (0.0) 2 (0.8) 5 (1.9) 14 (5.4) 34 (13.1)</td>
</tr>
<tr>
<td>Caring for my ostomy appliance is difficult</td>
<td>00 (0.0) 1 (0.4) 2 (0.8) 18 (6.9) 33 (20.8)</td>
</tr>
</tbody>
</table>
The following results are presented in relation to the total scale score and scores within each domain of the FACT-C. Using a sample of 260, the total of the QOL score mean was 100.39 (SD 16.3). For this Jordanian sample, the results indicated that social/family well-being of QOL had the highest score (mean 23.4; SD 3.8), while emotional well-being of QOL had the lowest score (mean 16.2; SD 4.5). Table 5.10 details these results.

Table 5.10: Range, Mean and Standard Deviation of the FACT-C Domains ($N=260$)

<table>
<thead>
<tr>
<th>FACT-C Domains</th>
<th>Minimum</th>
<th>Maximum</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical well-being of QOL</td>
<td>1</td>
<td>28</td>
<td>19.30</td>
<td>6.43</td>
</tr>
<tr>
<td>Emotional well-being of QOL</td>
<td>5</td>
<td>24</td>
<td>16.24</td>
<td>4.50</td>
</tr>
<tr>
<td>Functional well-being of QOL</td>
<td>3</td>
<td>28</td>
<td>21.98</td>
<td>4.62</td>
</tr>
<tr>
<td>Social/family well-being of QOL</td>
<td>6</td>
<td>28</td>
<td>23.43</td>
<td>3.78</td>
</tr>
<tr>
<td>Additional concern of QOL</td>
<td>11</td>
<td>30</td>
<td>19.44</td>
<td>3.42</td>
</tr>
<tr>
<td><strong>Total FACT-C score</strong></td>
<td>47</td>
<td>123</td>
<td>100.39</td>
<td>16.29</td>
</tr>
</tbody>
</table>
RELATIONSHIPS BETWEEN PREDICTORS AND QOL

The first research question in this study was, “What is the relationship between coping, hope, psychological distress (depression and anxiety), age, gender, marital status, income, and time since diagnosis and QOL among Jordanian colorectal cancer patients?” A series of product moment correlations, using Pearson’s $r$ were conducted to test the associations for hope, coping, psychological distress, age, gender, marital status, income, and time since diagnosis with QOL. The underlying statistical assumptions were examined and found to be met. The scatter plots indicated that there was a linear relationship between QOL and JCS, the HHI and HADS scores, gender, and time since diagnosis, with the scores clustered around the regression line.

The results demonstrated significant positive relationships between hope, time since diagnosis, coping, and QOL. There was a significant negative relationship between psychological distress (as measured by HADS), and total of QOL, which accounted for 57.0% of the variance shared between these two variables. Moreover, there was no significant relationship between age, marital status, income, and QOL, finally a significant negative relationship was found between the gender and QOL. Table 5.11 details the results of the correlations.
Table 5.11: Correlational Analysis between Hope, Coping, Psychological Distress (Depression and Anxiety), Time Since Diagnosis, Age, Gender, Marital Status, Income and QOL (N=260)

<table>
<thead>
<tr>
<th>Independent Variable</th>
<th>r</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coping (JCS)</td>
<td>0.55</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td>Hope (HHI)</td>
<td>0.57</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td>Psychological distress (depression and anxiety) (HADS)</td>
<td>-0.76</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td>Time since diagnosis</td>
<td>0.16</td>
<td>0.009</td>
</tr>
<tr>
<td>Age</td>
<td>0.33</td>
<td>0.600</td>
</tr>
<tr>
<td>Gender</td>
<td>-0.14</td>
<td>0.030</td>
</tr>
<tr>
<td>Marital Status</td>
<td>-0.04</td>
<td>0.57</td>
</tr>
<tr>
<td>Income</td>
<td>0.05</td>
<td>0.48</td>
</tr>
</tbody>
</table>

MULTIVARIATE ANALYSIS

The second research question asked, “To what extend are hope, coping, psychological distress (depression and anxiety), age, gender, marital status, income, and time since diagnosis predictive of QOL among Jordanian CRC patients?” A standard multiple regression ($R^2$) analysis was used to establish the relative contribution of the hypothesized predictors (hope, coping, and psychological distress (depression and anxiety), age, gender, marital status, income and time since diagnosis to QOL). A model-building approach was used to describe the relationships between the independent variables and QOL in the multiple regression analysis (Hair et al., 2006).

A structured three-phased approach was used to achieve a parsimonious regression model for this sample. First, statistical assumptions in relation to normality, linearity, heteroscedascity and independence of residuals were assessed. Second, the independent variables, where there were significant correlations with QOL, were entered into an initial regression model. Third, the variables that were correlated in the initial regression model were only entered into the parsimonious regression model.
This regression analysis was conducted to determine the magnitude of the interactions of independent variables in relation to the correlation matrix, Beta weights and their significance level (t-statistic and p-value) (Hair et al., 2006). The independent variables, correlated with QOL in the bivariate analyses (coping, hope, psychological distress (depression and anxiety), gender, and time since diagnosis) were included in the initial regression model.

In the current study, a preliminary regression analysis was undertaken; all the independent variables that were correlated with QOL in the bivariate level were entered in this model. Table 5.13 displays the standardized regression coefficient ($\beta$), and standard error (SE). The initial model for QOL accounted for 66.3% of the variance, with $R^2 = 0.663$, adjusted $R^2 = 0.656$, $F (99.98, p < .0001)$. The results indicated that there were positive relationships between coping, hope, time since diagnosis and QOL ($b = 0.30, 0.70$, and $0.27$, respectively), and a negative relationship between psychological distress (depression and anxiety) and QOL ($b = -1.58$). An assessment of the standardized beta coefficients within this model suggests that coping has slightly more impact in the model. Table 5.13 displays the results of this model.
The initial model showed that coping, hope, psychological distress (depression and anxiety), and time since diagnosis predicted QOL among Jordanian CRC patients. In addition, the results showed that coping had the most impact on the model; in contrast, gender had the least impact. However, an examination of the regression analysis showed that gender was not one of the predictors of QOL ($p=0.62$). Therefore, it was important to reassess and run the regression analysis in relation to the predictors that were significantly correlated with QOL. Consequently another regression analysis was undertaken to achieve model parsimony, as recommended by Hair et al. (2006). The following table (5.14) represents the parsimonious regression model.
Table 5.1: Parsimonious Regression Model for QOL Predictors ($N=260$).

<table>
<thead>
<tr>
<th>Predictor</th>
<th>Standardized Coefficients</th>
<th>SE</th>
<th>B</th>
<th>P</th>
<th>95.0 % CI Interval from Lower Bound</th>
<th>Upper Bound</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coping (JCS)</td>
<td>.24</td>
<td>.05</td>
<td>.30</td>
<td>.001</td>
<td>0.20</td>
<td>0.40</td>
</tr>
<tr>
<td>Hope (HHI)</td>
<td>.17</td>
<td>.18</td>
<td>.70</td>
<td>.001</td>
<td>0.34</td>
<td>1.06</td>
</tr>
<tr>
<td>Psychological distress (depression and anxiety), (HADS)</td>
<td>-.56</td>
<td>.12</td>
<td>-1.58</td>
<td>.001</td>
<td>-1.82</td>
<td>-1.34</td>
</tr>
<tr>
<td>Time Since diagnosis</td>
<td>0.08</td>
<td>0.10</td>
<td>0.27</td>
<td>0.03</td>
<td>0.03</td>
<td>0.52</td>
</tr>
</tbody>
</table>

Total $R^2$ 0.66

Note: Dependent Variable - QOL (FACT-C)

The results from the parsimonious regression model indicated that coping, hope, psychological distress (depression and anxiety), and time since diagnosis predicted QOL. The results showed that $R^2 = .663$ (adjusted $R^2 = .65$), $F (125.27, p < .0001)$. In this model, coping had the most to contribute; in contrast, HADS had the least impact. Finally, the above mentioned independent variables accounted 66.3% of the variance in QOL.

Multicollinearity Checks

In the current study, the regression variate was assessed in relation to multicollinearity. First, the correlation matrix for all independent variables was examined to identify multicollinearity (Appendix J). All correlations were within a range of $-0.43$ to $0.43$, and so were not highly correlated with each other, and were less than the suggested 0.90, which may indicate multicollinearity (Hair et al, 2006). However, a lack of any high correlations does not guarantee a lack of collinearity. Hair et al (2006) recommended assessing the tolerance and variance inflation factor (VIF). Tolerance
refers to the assumption of the variability in one independent variable not explained by the other independent variables. The VIF reveals much of the same information as the tolerance factor. Multicollinearity would be indicated in a tolerance level of less than .10 or a VIF value of above 10 (Hair et al., 2006). The tolerance value for each independent variable was above the ceiling tolerance value of .10, consistent with the absence of serious levels of multicollinearity. This judgment was further supported by a VIF value for each independent variable below the threshold tolerance value of 2.0. Table 5.15 displays the results of the collinearity diagnostics matrix.

**Table 5.15: Collinearity Diagnostics Matrix (N=260).**

<table>
<thead>
<tr>
<th>Independent Variable</th>
<th>Correlations</th>
<th>Collinearity Statistics</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Part</td>
<td>Partial</td>
</tr>
<tr>
<td>Coping (JCS)</td>
<td>0.34</td>
<td>0.21</td>
</tr>
<tr>
<td>Hope (HHI)</td>
<td>0.23</td>
<td>0.14</td>
</tr>
<tr>
<td>Psychological Distress (HADS)</td>
<td>-0.62</td>
<td>-0.46</td>
</tr>
<tr>
<td>Time since diagnosis</td>
<td>0.14</td>
<td>0.08</td>
</tr>
</tbody>
</table>

Assessment of the Part correlation coefficients displayed in Table 5.15 indicated the strength of the relationship between QOL, and each separate independent variable, when the predictive effects of the other independent variables in the regression model were removed (Hair et al., 2006). The partial correlations indicate the incremental predictive effect of each predictor variable. The total $R^2$ for the model does not equal all of the squared part correlation values because the part correlations represent only the unique contribution of each variable, with any overlap or equal variance removed or partialled out (Hair et al., 2006).
Model Evaluation

Figure 5.1 summarises the multivariate results between the independent variables, including hope, coping, psychological distress (depression and anxiety), and time since diagnosis, and the dependent variable QOL in the multiple regression model.

Three criteria was used to evaluate the fitness of the hypothesized model: (1) sample size, (2) the statistical significance of the $p$-value ($< 0.05$), and (3) the difference between R squared and adjusted R squared (Hair et al., 2006). With a standard multiple regression, the sample size should be 10-20 participants per each variable (Tabachnick & Fidell, 2001). In the current study, a sample size was calculated carefully in order to support a standard multiple regression analysis. In addition, a smaller difference between R squared and adjusted R squared ($R^2 = 0.66$, adjusted $R^2 = 0.65$) was found, which reflected a better fit of the model. Finally, the significant $p$-value for each variable was checked.
A sample of 260 patients was recruited with a response rate of 81.25%. The sample consisted of 142 (45.6) male, and 118 (45.4) female, participants, with a mean of age 51.9 (SD 9.48). At the time of the research being conducting, 67.7% of the participants had no complications, and 96.9 % of them had no regional metastasis. The majority (98.8%) were treated with a combination of chemotherapy and surgery. Bivariate and multivariate analyses were used to assess and predict the relationship between hope, coping, and psychological distress (depression and anxiety), age, gender, marital status, income, and time since diagnosis as independent variables, and QOL as a dependent variable. The results indicated that there were significant positive relationships between coping, hope, time since diagnosis and QOL. In addition, a significant negative relationship was found between anxiety and depression, gender
and QOL. The parsimonious multiple regression model results indicated that hope, coping, depression and anxiety, and time since diagnosis were predictors of QOL among Jordanian CRC patients. The regression model accounted for 66.3% of the variance in QOL. The following chapter addresses Phase II of the study, the qualitative findings.
CHAPTER SIX

Phase II – Qualitative Findings

INTRODUCTION

This chapter presents the findings from the qualitative data analysis of Phase Two. The aim of this phase was to provide deeper understanding of the impact of CRC on the participants’ QOL and the factors that influenced their level of QOL, hope, coping and psychological distress. Ten semi-structured interviews were undertaken with a purposeful sample to illustrate, explain and gain a deeper understanding of the results of Phase I, the survey. A content analysis approach was undertaken, as described in chapter four. The findings detailed in this chapter are presented under the following headings: Participants’ experience of changes during CRC diagnosis and treatment, and factors influencing QOL.

CHARACTERISTICS OF THE PARTICIPANTS

To further explain the impact of physical and psychological factors on CRC patients’ QOL, semi structured interviews were conducted with 10 patients who participated in Phase One of this study. The age of the participants ranged from 40 to 66 with a mean age of 51.2 years (SD = 9.47). Of the 10 participants interviewed, nine were male. The majority of them were married and Muslim and, at the time of interview, all participants reported having had bowel surgery, with five resulting in permanent colostomies. Time since diagnosis ranged from 4 to 24 months. Table 6.1 presents the characteristics of the selected participants.
<table>
<thead>
<tr>
<th>Group</th>
<th>Participant Survey #</th>
<th>Gender</th>
<th>Age</th>
<th>Married Yes/No</th>
<th>Time Since diagnosis (Month)</th>
<th>Colostomy Yes/No</th>
<th>Treatment modalities</th>
<th>Regional metastasis Yes/No</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>109</td>
<td>M</td>
<td>40</td>
<td>Yes</td>
<td>7</td>
<td>No</td>
<td>Chemo &amp; Surgery</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>83</td>
<td>M</td>
<td>66</td>
<td>No</td>
<td>13</td>
<td>Yes</td>
<td>Chemo &amp; Surgery</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>84</td>
<td>M</td>
<td>45</td>
<td>Yes</td>
<td>11</td>
<td>No</td>
<td>Chemo &amp; Surgery</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>240</td>
<td>M</td>
<td>43</td>
<td>Yes</td>
<td>24</td>
<td>No</td>
<td>Chemo &amp; Surgery</td>
<td>No</td>
</tr>
<tr>
<td>B</td>
<td>6</td>
<td>M</td>
<td>63</td>
<td>Yes</td>
<td>6</td>
<td>No</td>
<td>Chemo &amp; Surgery</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>7</td>
<td>M</td>
<td>47</td>
<td>Yes</td>
<td>15</td>
<td>Yes</td>
<td>Chemo &amp; Surgery</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>11</td>
<td>F</td>
<td>60</td>
<td>Yes</td>
<td>4</td>
<td>Yes</td>
<td>Chemo &amp; Surgery</td>
<td>No</td>
</tr>
<tr>
<td>C</td>
<td>146</td>
<td>M</td>
<td>58</td>
<td>No</td>
<td>12</td>
<td>Yes</td>
<td>Chemo &amp; Surgery</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>28</td>
<td>M</td>
<td>45</td>
<td>Yes</td>
<td>11</td>
<td>No</td>
<td>Chemo &amp; Surgery</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>157</td>
<td>M</td>
<td>45</td>
<td>Yes</td>
<td>10</td>
<td>Yes</td>
<td>Chemo &amp; Surgery</td>
<td>No</td>
</tr>
</tbody>
</table>
PARTICIPANTS’ EXPERIENCE OF CHANGES DURING CRC DIAGNOSIS AND TREATMENT

The participants were selected to illustrate the maximum variation in scores measuring hope, coping, psychological distress, and QOL. That is, participants were selected from three groupings: high hope, coping, and QOL scores with low anxiety and depression (Group A), average scores across all scales (Group B), and low hope, coping, and QOL scores with high anxiety and depression (Group C).

The data are presented under the following two headings: Participants’ experience of change during CRC diagnosis and treatment, and Factors influencing QOL. The following section presents the findings associated with the participants’ experience of CRC diagnosis and treatment, including their perceptions of QOL, distress, changing in their roles, and changing in their social life. Table 6.2 summarises these findings into categories and sub-categories of QOL.

Table 6.2: Impact of CRC on Jordanian Patients’ QOL

<table>
<thead>
<tr>
<th>Categories</th>
<th>Sub-categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perception of QOL</td>
<td>Diminishing strength and physical fitness</td>
</tr>
<tr>
<td></td>
<td>Side effects of treatment</td>
</tr>
<tr>
<td>Cancer as Distress</td>
<td>Experiencing a range of emotions</td>
</tr>
<tr>
<td></td>
<td>Changing perceptions of the future</td>
</tr>
<tr>
<td></td>
<td>Losing self-confidence</td>
</tr>
<tr>
<td>Changing Roles</td>
<td>Changing role responsibilities</td>
</tr>
</tbody>
</table>
A diagnosis of colorectal cancer and the subsequent treatment modalities had a negative and adverse impact on the participants’ QOL (as well as the families’ functioning), physical, psychological and social functioning (including work life). Furthermore, it affected their relationships with friends, relatives, and partners, as well as having further effects on other social activities and interests. The participants with CRC, both with stoma and non-stoma, were afflicted with complications, such as frequent or irregular bowel movements, diarrhoea, flatulence, and fatigue; also they often had to follow dietary restrictions, all of which affected their QOL.

In the current study, there was a universal agreement among the participants, regardless of age, treatment modalities, time since diagnosis, educational level, marital status, presence of colostomy bag or financial status, in respect to the negative impact of CRC treatment on every dimension of their QOL. The findings illustrated that there were no variations between the participants from the three different groups in the physical impact of CRC on their QOL.

The QOL, coping, hope, and psychological distress (depression and anxiety) scores were influenced by a variety of factors that contributed to the participants’ conditions and status during the treatment period. These factors are discussed later in the chapter. The following section describes and explains how a diagnosis of, and treatment for, CRC impacted upon their QOL.
Perception of QOL

Their perception of QOL was the first category reported upon by the participants. They told of the importance of their physical ability as being related to their perception of overall QOL and perceived health. The diagnosis and treatment of CRC affected the participants’ physical well-being and, consequently, impaired their ability to participate in and attend social and community activities. The participants agreed that physical (dis)ability affected their perceptions of their whole life and health. The following sub-categories were identified from the data: Diminishing strength and physical fitness, and side effects of treatment. The following section presents these sub-categories.

Diminishing Strength and Physical Fitness

The participants explained how their perception of QOL had been altered and how it related to the changes in their physical ability prior to and since the diagnosis of, and treatment for, CRC. They determined what QOL meant to them in relation to their ability to carry out their daily activities of living, which also related to having the necessary strength and fitness to undertake their usual duties properly. For many, their ability to carry out even the simplest activities, such as showering was, at times, an almost insurmountable task. One patient with an average score of QOL stated:

For me I see QOL as optimal health and the ability to carry out daily affairs. Once I am feeling there is nothing affecting my ability and I have full freedom to do what I like to do without worrying or caution of my health at that time I have better QOL (Male # 6).

Another male participant, with average scores, acknowledged the importance of health in his life and identified health as the most important and essential aspect of his
QOL. Moreover, he defined QOL as living without pain and suffering, and with the physical capability to perform and undertake daily duties. He said:

*To be free of suffering and away from any problem means I have a good QOL. Someone said "health is a crown on the head of healthy people". Nothing in this world equals good health and the ability to do what you like to do without cautions (Male # 7).*

Despite high scores of QOL, hope and coping; this sub-group of participants also complained about the impact of the diagnosis and treatment for CRC. These participants typically compared their health and status before and after the diagnosis of cancer, and they defined their health through their ability to live as previously. They perceived a good QOL as the ability to do all of their daily activities, such as shopping, driving children to school, sharing in the home’s organising and related duties, and with the physical capacity to share and participate in social activities and be active in the community. For example; a male participant from group A (high scores) said:

*Quality of life means to me my ability to live as previous. It means my ability to do the daily activity, and routine daily events with my family and friends without effect on my health (Male # 109).*

The majority of participants shared similar perspectives and described the ways in which their physical ability had changed drastically after the diagnosis of cancer. They complained about a decline in their energy and fitness, how they slept much of the time, and were unable to perform basic activities like shopping and engaging in social activities, such as attending community meetings, participating in celebrations like weddings and parties, and visiting friends. Participants unanimously agreed that the impact of treatment, such as surgery and chemotherapy, and other different
procedures, such as x-rays, CT-Scans, and blood tests, and long and frequent hospitalizations, diminished their ability to carry out the most basic tasks. One patient who had a lower score of QOL reported:

*It affects my life totally, everything is changed now, I am unable to do my job, I am feeling tired and exhausted all the time, it so hard and difficult, this disease differs from any other disease. It damages my whole life, see what happened to me, different procedures, treatments, seriously, after I finish the chemotherapy cycle, I can’t walk, I am feeling tired and sick (Male # 146).*

There appeared to be little difference in the impact of CRC on physical well-being, regardless of the variations in the QOL score and status; both high and low score participants reported that they faced and experienced a decline in their physical ability.

As mentioned previously, QOL has been defined as a multidimensional concept wherein one dimension has an effect on others. The participants explained how their physical ability affected the other dimensions, such as their roles. In the following quotes, two participants explained how their physical ability had changed after their diagnosis of CRC, and how their lack of energy and strength disrupted their role in life by limiting their ability to effectively handle their job or career. In this context, the decline in physical ability was considered an essential element in negatively affecting the participants’ health and QOL. In spite of their high scores of QOL the following quotes demonstrate that physical inability had a consequent adverse effect on the participants’ functional and social well-being. One participant said:

*I see my ability to do my job and other activities, shopping, exercise, social activities less than previous and sometimes I am feeling I have less energy*
and power specially the three days after the chemotherapy course (Male # 109).

Another participant related the same experience insofar as their physical inability having a negative impact on their functional well-being. He said:

My whole life has changed since the diagnosis and discovery of cancer starting with my ability to do the daily routine activities including my job and basic things in my life. At the beginning I was unable to take care of myself even in simple things like bathing (Male # 84).

A decline in physical ability was considered as one of the complications or outcomes associated with CRC treatment modalities by all the participants during their illness period.

Side Effects of Treatment

The sub-category, side effects of treatment, encompassed a number of descriptions related to the side effects caused by different treatment modalities, including chemotherapy and surgery. Many participants reported on the numerous physical complications or side effects they suffered during the cancer treatment period, including pain, loss of appetite, vomiting, diarrhea and infection. The participants described the magnitude of their suffering in relation to the symptoms and complications during their illness, and how much these affected their QOL. One male participant, who reported having a high QOL, stated:

I have severe pain after the surgery and [it] drains in my body, that in addition to a loss in my weight, loss of appetite (Male # 109).
Participants with advanced colorectal disease are likely to receive aggressive therapy and frequently report many side effects. However, regardless of the disparity in their QOL scores, and the related predictor status, two male participants related similar experiences of their affliction from the complications of treatment. They described how much they suffered from these complications of treatment; they reported upon the many GI complications they suffered during the treatment period, such as loss of appetite and increased pain. They stated:

I didn’t have any appetite and I was on fluids for some time, that’s additional to diarrhoea after the surgery, frequent pain before and after the surgery. And at the beginning of the disease I lost around 10 kilograms (Male # 240).

I had a feeling of pain and suffering from diarrhoea, particularly after the surgery...At the beginning and after the surgery, because of the infection I had to stay in the ICU for two weeks....The only things making me feel very bad and reduce my QOL is the complications or side effects of the treatment chemotherapy. It is very bad medicine; it causes many problems, particularly vomiting and diarrhoea...(Male # 6).

As a result of the experienced complications of treatment, the participants’ hospitalization period increased. During such hospitalization they underwent further assessment, management, and treatment, which further disrupted the participants’ lives in relation to work, physical fitness and emotional well-being. A male participant described his frustration as a result of the frequent hospitalizations and side effects of chemotherapy. He stated:

I must come to the hospital frequently for chemotherapy and suffering from its complications such as diarrhoea, oral infection, I am feeling tired after the course and unable to handle my life as previous (Male # 83).
Cancer as Distress
The second category that was analysed in the textual data was cancer as distress. The term refers to the participants’ psychological status, feelings, and reactions at the time of the CRC diagnosis and during the treatment period. Being diagnosed with CRC changed the participants’ and families’ perceptions of their lives and their current and future plans. Cancer, in general, and CRC in particular, was spoken of as a stressful and painful experience, associated with distressing feelings and thoughts, and diminished self confidence, which varied with the disease prognosis and related to the conditions, symptoms, and general health status. Regardless of the improvement in the CRC screening and detection procedures, treatment modalities and increasing survival rates, CRC continues to be a serious and life-threatening disease. The participants were concerned with, and thought about, their life and death after diagnosis.

The diagnosis of CRC and its consequent treatment created major problems that were perceived as a disaster and crisis for the participants and their families. Many of the participants experienced distressing feelings and thoughts, which left them with little confidence in their appearance and their ability to manage their altered bodily functions. In spite of the variation in their QOL, hope, coping, and psychological distress scores, they all described similar psychological feelings they were experiencing. The majority of the participants identified and reported that the cancer diagnosis and treatment was a source of distress, diminishing self-confidence, and a death sentence. Three psychological sub-categories were identified, including: experiencing a range of emotions, changing perceptions of the future, and losing self-confidence. The following sections present the findings in these sub-categories.
Experiencing a Range of Emotions

The first sub-category highlighted the patients, with CRC, experiences over a range of emotions. They experienced challenges and psychological distress during the treatment and illness period. Despite of the development of technology, and being the recipients of advanced treatment modalities, participants viewed the diagnosis of cancer as a sentence of painful and impending death; this outcome caused a great psychological impact. The responses they experienced included shock, denial, fear, anxiety, and apprehension, which negatively impacted upon the participants’ QOL. The following sections present these feelings and thoughts.

Feeling shocked is often the first reaction when CRC is diagnosed. The participants felt numb and did not believe what was happening. The findings of this study indicated that, while shock and denial may be universal experiences during a personal crisis, they are also unique and individualized. All participants described experiencing a painful feeling of shock at the time of diagnosis, but some found it difficult to express any emotion immediately following the diagnosis. They stated that they were watching things in their life happen as if they were happening to someone else the situation seemed to be so unreal. The diagnosis of CRC was accompanied by shock and disbelief related to debilitated health, and intrusive thoughts of death and suffering. For example, regardless of his high score of QOL, a male participant reported the impact of CRC diagnosis on his psychological well-being as:

*It was really a shock for me to know that I have a cancer in my colon, and I never imagined that I would be diagnosed with cancer in my colon (Male, #109).*
The diagnosis of CRC is a shock and is painful for the participants’ families also. The family starts thinking about the patient’s condition, and how they will behave and manage this stressful situation. A male participant from a different group (group B) shared a similar experience:

> When the cancer was discovered and my doctor told me about this I felt I am alone, and I refused this fact, as I know the cancer is difficult to treat and it takes a long time to treatment, so I asked myself what will happen to me, it was a shock for my family, [and] friends also. No one believes in this, they asked the doctor to repeat the tests again (Male, #7).

As illustrated above, *denial* and the idea of “this is not true” are often the initial thoughts and responses of the participants at the time of the diagnosis. The participants thought, "This can’t be happening to me" and sometimes they thought “Why Me?” They had a sense of disbelief or unreality, and they did not understand what was happening. They described feeling like an outsider, looking at a scene that seemed surreal. For example, a male participant discussed his inability to face the reality of CRC diagnosis. He said:

> I never thought of this disease at all, I was healthy and was never admitted to the hospital before, and when he told me that I have cancer I said why? What did I do to have cancer? I spent two days refusing to talk to anyone, just thinking that I have a couple of months before dying (Male# 83).

Denial was initially used by the participants as a coping strategy by refusing to acknowledge their diagnosis with CRC. Indeed, denial can protect and minimize the participants’ feelings of anxiety, shock, despair and tension at the time of diagnosis, but it can also impair communication between patients, families, care givers, and
medical professionals, especially about the seriousness and severity of the condition and the treatment required.

The following participant expressed feelings of denial and rejection of the truth regarding the diagnosis of CRC. He described his feelings when he was informed about the diagnosis of cancer, and how he rejected the whole idea and asked for a repeat of the diagnosis tests. He said:

*When the specialist at hospital said that I have colon cancer, it was like someone shot me, it was very hard, at beginning I didn’t trust him and I said that we have to repeat the diagnosis procedures again to make sure, I started crying* (Male, #157).

There are no direct causes for CRC but there are a number of risk factors that might contribute to the development of CRC. The participants could not believe the fact that a ‘healthy’ person might be diagnosed with CRC and not necessarily have other medical problems. One participant who was diagnosed with CRC, although he had never had any medical problems or been admitted to hospital before, wondered how he had acquired the disease, in spite of having a previously healthy life. He believed that the disease was part of the ageing process and should be secondary to other medical problems. He said:

*I am so young to have a cancer; I was healthy and strong, working hard in this life to make my family’s life easier for them* (Male, #157)

A CRC diagnosis causes fear and worry. The participants fear the cancer itself, its prognosis, and complications, and whether it is curable or not, and what will happen in the future. In addition, they fear for the recurrence of the disease. Fear of cancer
was considered a terrifying experience and an emotional roller-coaster for the participants. The participants were afraid and worried about a number of factors, such as physical suffering, complications, prognosis of the disease and the development of metastasis. They expressed concern about their families’ future and how they will manage this health crisis, and how well their families would cope emotionally and financially should they pass away. A male participant explained his emotional reaction at the time of diagnosis:

*When the cancer was discovered and the doctor told me about this I felt I am alone, and I refused this fact, as I know the cancer is difficult to treat and it takes long time of treatment, so I asked myself what will happen to me, it was a shock for my family, and friends also…*(Male # 7).

The participants experienced anxiety when they were diagnosed with a life-threatening disease because of its threat to their lives, survival and future. Anxiety was reported when the participants received the diagnosis of cancer, undergoing surgical treatment, as a result of aggressive treatment complications, and when waiting for test results and diagnosis. One male participant explored his feelings:

*My whole life is changed, I am becoming more anxious and sensitive and worry about my future and asking myself what will happen to my family if I passed away* (Male, #157).

**Changing Perceptions of the Future**

The initial diagnosis of CRC is considered one of the most painful, stressful, and emotional stages for the participants, as well as for their families. The participants often experienced uncertainties and unpredictable feelings about their future, their condition, and their survival, as well as about their families’ future. Participants
expressed feelings of anxiety and apprehension; they became increasingly sensitive and uncomfortable when communicating with people or facing events because of changes in their body, appearance, and physical problems related to the stoma, such as flatulence and odour. Such factors generated feelings of embarrassment around people, increased their reluctance to engage in any social life, and caused them to reflect upon their changed perception of the future. One participant said:

*My life is different and became worse; I am becoming more sensitive and anxious* (Male, #28).

Another participant experienced the same feelings of anxiety and distress related to the CRC diagnosis, in general, and particularly related to being left with a stoma. The presence of a stoma negatively impacted the participant’s QOL and generated feelings of anxiety and apprehension about interacting with people. This reaction related to a number of problems, such as lack of control over bowel habits, discomfort and embarrassment when changing or emptying the bag in a public area and fear of spillage from the bag. Hence, participants’ lives were changed, and they became more anxious and hypersensitive. A male participant said:

*Our life was changed, and I am becoming more angry and anxious, and more sensitive to everything, particularly after the surgery and presence of this bag in my abdomen* (Male, #7).

Psychological responses were influenced by a number of factors, such as prognosis of the disease, complications, fear of recurrence, the level of information that was provided, and social support. The participants’ psychological feelings fluctuated, becoming more apprehensive when they experienced more complications. A male participant said:
I was very anxious and apprehensive with this problem, I am feeling that people are looking at me and they know that I have cancer; I can read their feeling of sorrow for my condition in their eyes (Male, #83).

Additionally, severe anxiety interfered with cancer treatment and the participants’ level of communication and social functioning, which led to social isolation and avoiding interaction with others. One participant said:

I am feeling I am stressed and anxious, I don’t like to talk with others and I'd like to stay alone (Male, #6).

Being diagnosed with a serious disease such as CRC generated a wide range of emotional and cognitive thoughts for the participants and their families. The diagnosis of cancer was feared as a fatal and incurable disease, with unexplained causes or aetiology, and was associated with distressing thoughts and perceptions. The participants shared their intrusive thoughts during the illness period, such as suffering an uncertain future, worrying about the family, a poor prognosis and permanent disability, and the recurrence or spread of the disease. A male participant stated:

I know cancer is not easy and so difficult to cure and it takes time; many bad ideas, thinking what will happen to me? Will I survive or not? What will happen to my family and the people I love? How can I take chemotherapy? What things will happen to me? Will I lose my hair or not? It is like walking in a dark area; you know nothing about this, what will you do? How will you arrange everything? (Male, #240).

Participants also highlighted the idea of death as inevitable and an obvious end to the cancer, as one participant said:

I thought I will not survive from this, particularly after the surgery (Male, Formal interview, #6).
Another male participant shared his fear of death and explained his worry about his family’s future, in addition to his worry about the recurrence of cancer.

*The idea of death, what will happen to my family, the cancer will come back or not (Male, #240).*

Moreover, two of the participants appeared to want to rationalise the diagnosis of CRC. They blamed themselves for contracting cancer and reasoned that the cancer was a result of their mistakes. They expressed guilt toward their families and they found it difficult to tell them about the disease because they were worried about the family’s response and feelings. They stated:

*Many bad thoughts came to my mind at the moment, I said I will die; it is a matter of time, maybe days or months, no one can cure me of this disease, and what will I say to my family (Male, #157).*

*I never think of this disease at all, I was healthy and never admitted to the hospital before, and when he told me that I have cancer I said why? What did I do to have cancer? (Male, #83).*

**Losing Self-Confidence**

The CRC treatment modalities vary between surgery and chemotherapy, or both. Three major surgical procedures can be performed, depending on the disease stage and conditions, including colon resection with re-anastomosis, colostomy (temporary or permanent), and abdomino-perineal resection. Regardless of the effectiveness and advantages of surgical treatments; the participants experienced a number of physical complications postoperatively, such as pain, infection, and GI disturbance.
Furthermore, being left with a stoma had a psychological impact on the participants’ well-being. Losing self-confidence was conveyed by the participants when describing the impact of the stoma on their image and interactions with their community, which limited their movement and ability to be an active member of the society.

Losing self-confidence was implied by the participants in relation to their physical function, appearance, outlook, body integrity and maintenance. Stoma surgery had a great impact on the participants’ daily life, such as travelling, daily care and job performance. The presence of a stoma had a negative impact on the participants’ appearance, ability to meet other people, and to continue outdoor activities, especially because of their fears of incontinence or flatus which limited their self-confidence. A male participant stated:

*It (stoma) has bad smell, and sometime it opens suddenly and damages my clothes and put me in very bad situation (Male, #146).*

This reaction was not a unique feeling in relation to suffering associated with the stoma appliance; rather the impact of stoma was a universal feeling shared among the participants with stoma, as indicated in the following excerpt:

*It limits my activity, in addition decreases my self-confidence because of its smell and it is very hard to choose my clothes. All these things affect my life and decrease my QOL also (Male, #7).*

The same problem was mentioned by a female participant, as she shared her emotional distress caused by having a stoma. She preferred to be alone and avoided social participation or interacting with others. The participant explained:
Having a bag like this one is a disaster and very bad. I asked the doctor if this device is essential and he said it will be for the rest of my life. I am feeling very bad because of this, I don’t know how to care with it, it needs special technique for changing, beside its smell, I am feeling shame to go out and visit my friends (Female, #11).

Having a stoma was problematic for the participants because it needed specialised attentive care and management. The participants complained about the daily skin care, changing of the appliance, and dietary restrictions associated with the stoma, which disrupted their lives, decreased their self-confidence and reduced their QOL. One male participant said:

*Especially this bag, it very bad, it needs special care, and it causes me a lot of problems, it must be changed frequently* (Male, #157).

In addition to the physical and psychological impact of CRC on the participants, the following section addresses the functional impact of CRC that they also faced.

**Changing Roles**

The category changing roles reflects the participants’ ability to undertake their usual family and employment roles. A CRC diagnosis and the treatment generated a wide range of impairments, disabilities, limitations, and malfunction for the participants, caused by localized, obvious, and visible problems (including the stoma appliance) and generalized problems (such as the physical symptoms of weakness, pain, and GI disturbances). These factors contributed to the participants’ inability to meet family and employment expectations and, occasionally, led to unemployment, or the inability
to get a new job. Two sub-categories emerged from the data including \textit{changing role responsibilities} and \textit{becoming dependent on others}.

Regardless of their variation in QOL status; seven participants reported a reduction in their functional ability; they also had difficulty in maintaining their family responsibilities and employment because of the effects of the CRC treatment. The following sections highlight the participants’ experiences and stories of how the diagnosis of, and treatment for, CRC negatively impacted their functional well-being.

\textbf{Changing Role Responsibilities}

This sub-category describes the participants’ roles and responsibilities within their families and at work, and outlines how these roles and responsibilities changed after the diagnosis of CRC and during the treatment period.

In most cultures, the parents’ role in their families includes responsibility to preside over, provide for, and protect the family. For the male participants diagnosed with CRC, the inability to fulfill their roles as father, provider and protector was a source of stress and frustration. Jordanian men are responsible for providing and meeting the family members’ needs (including school fees, feeding small children, and making major family decisions), while the mother’s primary responsibility is to nurture the children. Following a diagnosis of CRC, and during the treatment period, participants’ roles in their families had drastically changed. Often, the participant’s responsibilities and roles within a family shifted to the other parent due to a lack of physical ability to manage and provide family care. This feeling of uselessness and the inability to manage the role effectively, and the need to hand over the family responsibilities, created a sense of helplessness, powerlessness and incapacity, which also contributed
to a decline in the participant’s QOL. One male participant stated how his role had changed through the stages of the illness and treatment:

*I am never feeling like this before; it’s a new feeling to me and for my family also. I am always working and take care of my family, supporting them and do everything to make our life better. The responsibility shifted to my family because I don’t have the ability to manage their life, but now I am the leader again and sharing them in everything related to our life, I am working and supporting them, they see me strong and have ability again to solve all problems* (Male, #83).

The CRC diagnosis and treatment had an effect and impact on the participants in terms of their role responsibility; it negatively affected both male and female participants. A female participant shared similar thoughts to the male participants when she said:

*My life is totally different, I used to take care of my house, I was responsible for everything at my home, doing shopping, joining my family in our activities, but now it is becoming different, my married daughters come frequently to my home to do everything: cleaning, washing, cooking, I am feeling I am not helpful anymore. They ask me to take care of myself only and don’t worry about anything else* (Female #11).

As a result of the CRC treatment complications, participants reported suffering from a lack of strength and physical fitness, which affected their capability to perform their roles and continue to take on responsibilities in their family. Under these circumstances the participants perceived that they had little choice but to relinquish their responsibilities to their partners, or children, etc. It is usual for the parents to feel obliged to help one another with these responsibilities, as equal partners, in rearing their children. This strengthens the family bond, and provides the parents with
feelings of support and enables them to feel relaxed and secure about the family, especially during the hospitalization and treatment period. However, the participants were concerned about their family members during their hospitalization; how to meet their needs and provide comfort. Three participants felt confident that everything within the family was under control and that their life was returning to normal; they felt happier and less worried, as indicated in the following statement:

*When my wife took full responsibility for my family while I was at the hospital. I was feeling that my family was okay and my kids were under observation and the responsibility of my wife. She showed me how much she is strong and I must fight this disease not only for me but to be with my wife again at least to say thanks for her for everything she is doing for me and for our family. My kids keep their life on routine, going to the school and success, help their mother in the home activities. This makes me feel relaxed and feel comfortable about them and less worried about them (Male # 109).*

Being diagnosed with CRC also generated a negative impact on the participants’ employment and productivity at work. The CRC diagnosis and treatment disrupted the participants’ work time because of the suffering they underwent from the complications of treatment, frequent hospitalization and clinic visits. In addition, they suffered mood and emotional disturbances, which ultimately robbed participants of time from work, and prevented or limited their ability to manage, supervise, and continue their work. One male participant with a high QOL stated:

*I spent some time after the surgery to go back to my normal life and able to handle my job, I took a leave for two months after the surgery, and sometimes I am feeling tired in my job because of treatment and conditions (Male, # 240).*
Another participant shared the same feelings and experienced similar difficulties. His disease and treatment-related factors, such as hospitalization and complications, affected his ability to perform his job. He said:

*My disease affected my whole life, my ability and my social life also, I was busy in the treatment and I have to stay at the hospital for couples of days every month, this affected my job and my ability also* (Male, #109).

Living with the effects of the CRC treatment resulted in some participants’ having to change their work situation. The majority of the participants were unable to work, or worked shorter hours, or had to find alternative employment that accommodated their reduced ability to fulfil the hours and duties required. One male participant said:

*I am unable to do my job properly and as expected. I am working as a school manager and I have a lot of experience in this, but now I have asked the director to change my duties to a job which needs less effort and strength. As I said I changed my job to be suitable for me, I know this job is below my expectation but this is something out of my hands* (Male, #28).

Another of the participants decided to terminate his job and look for another that was better suited to his reduced functional ability. He said.

*I resigned from my job for many things, I am tired and feeling sick all the time, I came to hospital for several days each month for chemotherapy, and the manager of stores asked me to leave my job* (Male, 146).

During the illness period, the participants who had their own businesses searched for support from the closest people around them specifically their family. Their family had to supervise and manage their job during their hospitalization period. However, due to the situation many participants found themselves in, they were forced to close
their business for a short time, which disrupted their life and financial status, and ultimately lead to a decline in their QOL. A male participant said:

This is the first time for me to stay at the hospital for a long time way from my family and my life. I closed my store because no one can manage this (Male, #6).

Many participants described their perceptions of their employers’ attitudes to them in relation to treating them as handicapped or disabled, and unable to manage their duties, and fulfil their position description. Some participants were unsuccessful in gaining employment because of the perceived stigma associated with their medical condition. For one participant, who was forced to resign from his previous job, gaining employment elsewhere was difficult, due to his medical condition. He stated:

This surgery and the opening I have [colostomy] I left my job, and unable to find another one. Yes, but they refused my application for the job, because of my health, they said they can't give the job for the person with cancer, and some of them they are so gentle they said you need special care and now focus on your health. (Male, #146).

Becoming Dependent on Others

The second sub-category, becoming dependent on others, described the participants’ dependency on those around them to meet and perform their daily activities. Some of the participants described their physical function in relation to dependence on others. In many instances they relied on their families and other care providers to perform their basic caring and to manage the ravages of their physical symptoms while they were under treatment. They reported an inability to manage personal activities of daily living, and they frequently asked for help from their families, which caused disruption
to the other family members. The crisis of a cancer diagnosis can shatter patients’ families, leaving them suffering from this new experience, and disrupting their life routines and responsibilities, for example, changing roles and duties and handling new tasks, such as frequent hospital visiting, and financial management. This situation led to the participants feeling upset and useless, which negatively affected their QOL. A participant from group A described his experiences:

*This disease made my life worse at the beginning, there was poor life without any quality because I am sick and all the time I need help in my fundamental activities. know when you are all the time working and healthy and suddenly you are sick and asking people for help in basic things, it is really difficult and hard for me, I am always taking care of my family and now I am fully dependent on others (Male # 240).*

As the disease progressed, the participants experienced and suffered from a number of complications, such as pain, diarrhoea and vomiting, which increased their functional dependence on others. As a result of these changes they became fully dependent on caregivers in basic activities, such as obtaining medications, managing finances, job supervision, home care, transportation and errands. In spite of their differences in QOL level, the following participants’ quotes indicate that physical dependency was a shared phenomenon between the participants. They stated:

*I have a bad feeling after the diagnosis and surgery; I was feeling like a disabled or handicapped person, this is [a] difficult and hard feeling for me when I am asking someone for help or assistance in basic things (Male #84).*

*I lost my power and my ability to handle basic things in my life; I am dependent on my family now (Male #157).*

CRC also had an impact on the participants’ social wellbeing, which is described in the next section.
**Changing Social Life**

Living with CRC not only impinged on the participants’ physical, functional and psychological well-being, but also affected their social lives as well. QOL was defined by participants’ as the ability to participate in social life through engaging in significant family events, being with friends, and being an active member in the community. Two sub-categories were identified in this domain: *becoming socially isolated* and *disrupting family life*. One male defined QOL as follows:

> Quality of life means living happy in a warm, close family environment, and being close to my friends, in addition to doing the same activities that I did before the diagnosis of this bad disease (Male, # 109).

**Becoming Socially Isolated**

Participants experienced changes in their body, functions, roles, employment, and future plans that resulted from the diagnosis of and treatment for CRC. As mentioned before, the participants suffered from a number of physical symptoms and complications, such as pain, GI symptoms and fatigue, as well as a number of psychological problems, such as anxiety, fear, and shock. All these factors affected the participants’ ability to take part in social activities. For example, one of the male participants mentioned how the diagnosis of CRC, and the complications of treatment limited, his ability to enjoy being with people:

> It [CRC diagnosis and complications] affected my social life also; I was sensitive to be with people, they are asking too much, I know they would like to make sure that I am good but really I was very anxious and prefer to be alone (Male, # 83).
Another participant mentioned how his life had altered since he was diagnosed with CRC and how much he had suffered from the crisis, particularly at the time of diagnosis and following the treatment period. CRC had a negative impact on his social life; this was perceived as being difficult and negatively affected his QOL. However, he was given a good prognosis and, consequently, was able to participate socially, which meant that his QOL improved. He said:

_I am becoming more socially active also, attending social activities like weddings parties, visiting friends and doing some social events (Male, #240)._ 

Many of the participants with colostomies mentioned the impact of the colostomy appliance on their social life. For instance, a male participant explained how his stoma appliance limited his ability to actively participate. He said:

_Also it [stoma] prevents and limits my movements, participating in social life, and I have to wash and take shower many times a day to prepare myself for prayer. It tears suddenly also, so I have to take care of my activity (Male, #7)._ 

These factors impacted upon daily functioning and led to negative effects on the participants’ self-care capabilities and desire to interact socially. In some cases, the participants failed to maintain their relationships with families, friends, and work colleagues. One participant stated:

_So this limits my social activities, I didn’t go for visit because of this; I am feeling sensitive when I am visiting my friends because I am going to the toilet frequently (Male, #83)._
The findings indicated that the diagnosis and treatment for CRC was a threat to the participants’ families and had a negative impact on their structures, roles, bonds and lives. The illness of a single family member impacted upon the stability and structure of the whole family. The illness period for the participant was considered as a crucial and difficult time, not only for the participants, but also for their families, resulting in disrupted family life.

Disrupting Family Life

A diagnosis of an aggressive disease, such as colorectal cancer, impacted not only upon the participants, but it adversely affected their families. The participants’ families experienced existential concerns that forced them to modify their lives, goals, priorities, and relations. These changes were related to disrupted family schedules, finance problems and changing roles.

As with the participants, the first emotion experienced by the families was shock; no one was ready to hear that their father/mother/sister/brother had cancer. They were afraid for their family member, but also for the impact on their own lives. For many of them, the diagnosis of cancer was reported by the participants as an overwhelming existential concern which the family could not understand and found difficult to discuss. One of the participants described his family’s feelings at the time of diagnosis. He said:

*It was difficult time for me and I am sure for my family also. After two days they came to the hospital and I saw them, we didn’t talk, we cry only; I thought I will not see them again (Male, # 83).*
The family perceived the diagnosis of cancer as the end of life and could not see a cure or treatment for this disease. A male participant explained his family’s feelings and reactions at the time of breaking the bad news. He stated:

_This disease affected me and my family also, they are shocked about the diagnosis, crying and shouting, waiting for the results of surgery and worrying about. It [Diagnosis of Cancer] was[a] shock to me and my family also (Male, # 240)._ 

These feelings affected the participants; they felt guilty that they were responsible for what was happening to their families. One participant said:

_My family’s attitude toward this disease at the first month after my diagnosis… my family refused this and this makes me feel stressed (Male, # 7)._ 

Families’ lives were changed fundamentally as a result of the cancer diagnosis and the treatment schedules, which forced the participants to stay at hospital, and the families to take on additional responsibilities. A male participant explained that:

_They visited me all the time, at the beginning of the diagnosis when I had the surgery. My brothers scheduled sleeping with me in the hospital to help me. They helped my family in everything and they stayed with them during this bad time. They donated blood for me before the surgery, in addition; my brothers looked after my stores when I was at the hospital (Male, #109)._ 

Such family life disruption generated feelings of distress for the participants and they felt guilty because of that; they thought they were responsible for these changes in their families’ lives.
My family life was disrupted because of my health. They used to come to the hospital every day, and I see how much they worry; my wife becoming more nervous and stressed, she is responsible for everything at that time. Our life is totally changed and it is becoming worse (Male, # 6).

Because of the negative and harmful impact of the cancer on the participants’ families, the participants worried about their families’ future and how they would manage. One male participant was relieved because he did not have a family to worry about him. He said:

Do you know I am so lucky that I don’t have a family, I am single and I can take responsibility of myself but what will happen if I have a family, wife, kids—what will happen to them?, who will look after them? (Male, # 146).

SUMMARY

Content analysis was undertaken to analyze the qualitative data from the ten participants in the current study. A directed content analysis approach was utilized to identify the categories and sub-categories. The participants reported a negative impact of CRC diagnosis and treatment on their health, including their perceptions of QOL, distress, changing social life, and changing roles in their life. However, the results of the quantitative phase indicated there were variations in the participants’ scores of QOL, hope, coping and psychological distress. Consequently, Phase II was undertaken to understand and identify the influencing factors behind these variations. Various influencing factors were reported by the participants during the interviews. The following section represents the influencing factors that contributed to the participants’ QOL.

The study’s findings thus far have described the participants’ experience of being diagnosed with, and their treatment for, CRC, including their perceptions of QOL,
distress, and changes in their social life and their roles. The participants unanimously reported that they were negatively affected by the diagnosis and treatment for CRC. However, there was some variation among the participants’ scores of QOL and related psychosocial variables, including level of hope, coping and psychological distress (depression and anxiety). For this reason, Phase II of the study was undertaken to identify and better understand some of the factors that influenced these variables. Importantly, both extrinsic and intrinsic factors have been identified as being influencing factors. The following section presents the factors that enhanced or diminished the participants’ QOL, as well as their levels of hope, coping and psychological distress; as summarised in (Table 6.3).

Table 6.3: Influencing Factors of QOL

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<thead>
<tr>
<th>Influencing Factors</th>
<th>Categories</th>
<th>Sub-categories</th>
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<td>Extrinsic Factors</td>
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<td>Professional Support</td>
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<td>Intrinsic Factors</td>
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<td>Attitude Towards Prognosis and Life</td>
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EXTRINSIC FACTORS

In the context of this study, extrinsic factors could be categorised into two groupings: social support and professional support. Each category and their sub-categories are presented and described in the following sections.

Social Support

Social support was the first category that emerged and was considered one of the most important mediating factors on the participants’ QOL at the time of diagnosis and during the treatment period. Social support was described, by the participants, as having a supportive network of family, friends and work colleagues who provided a variety of supports, including emotional encouragement, practical help and social engagement.

Emotional Encouragement

The diagnosis of CRC generated distressing feelings for the participant, such as fear, anxiety, denial and shock. Consequently, ongoing emotional support was required and essential for the participants to help them overcome this crisis, as well as manage the actual and potential problems related to the treatment.

Participants with high scores in QOL, hope and coping reported receiving a lot of emotional encouragement from their families, which enhanced their ability to face their problems and to feel secure and supported. Emotional support was identified by the participants as empathy, concern, affection and acceptance by their loved ones. This perception of support enhanced their QOL and provided them with incredible strength to face and fight the diagnosis of CRC, and to cope with the physical effects
and complications related to the various adjuvant treatments. A male participant with a high score of QOL stated how much his family helped him to manage his condition:

To be with your family is something very important for me. I have a wonderful family, specially my wife; I have an amazing wife... She helps me all the time, making everything easy for me..... At the beginning she accepted my diagnosis and said to me this disease is like any other disease and by treatment and following the doctor’s plans I will survive. These words gave me hope and power to fight this disease. (Male, # 109).

Another male participant, with average scores shared similar experiences and described the ways in which friends supported and assisted him during the treatment period. He explained how much their genuine concern encouraged and increased his resolve to overcome his condition and made him believe that there were people who cared about him:

In addition, support from my friends, colleagues making me feel that I am not alone in this life and I have people who love me (Male, #7).

However, participants with lower scores presented a different perspective as highlighted by one male participant with no family commented:

I said to you that I thank God that I don’t have a family, wife and kids, because I would be scared for their future but seriously I wished that I had a family when I saw the other patients’ families visiting them and supporting them I felt really lonely (Male, #146).

Practical Help

CRC can become a chronic disease that demands long-term treatment that may last for several years. The care of the patients is then shifted from the hospital to the home, which increases the burden on the patients’ families, friends, work colleagues and other care providers. In this study context, the sub-category, practical help, was given from hospital admission to long after discharge, and took many forms, including
assistance with activities of daily living and physical care, and support to sustain or find employment. Such support enhanced participants’ ability to manage their condition and increased their optimism. A male participant from group B stated:

*My family support, they do everything to make this disease easy, they provide care for me all the time and support me, they take care of my food, drinks, everything...etc.* (Male, #6).

In addition to his family’s emotional support, a male participant described how much his family members, including siblings, assisted him. Such support changed his perspective and increased his ability to cope with the disease as there were people around him who were willing to make his life easier, and ready to cover in his absence and manage his business:

*Assistance and support from my family, but not only from my wife but also from my brothers and sisters, they do many things for me; they help my family in everything and they stay with them during this bad time. They donate blood for me before the surgery. In addition, my brothers managed my stores when I was at the hospital. This is really helpful when you feel that there are some people who can take care of you and help you when you ask them for help.* (Male, #109).

In contrast, the male participant who commented on his loneliness, because he did not have a wife and children to support him, described a situation in which his siblings were unable or unwilling to provide any practical help:

*Yes, but they [brothers and sisters] said they don’t have the ability to help me because they have other responsibilities and they are busy. Do you know, I didn’t see them for 6 months* (Male, #146).

Creating a supportive climate was not only mediated by family and relatives, but also by friends and work colleagues. For the participants, friends played a key role in enhancing the participants’ feeling of support because they provided them with
ongoing emotional, practical and informational assistance. This support made a difference for five participants (from groups A and B) by helping them deal with the physical, psychological, and functional problems that emerged from the diagnosis of, and treatment for, CRC. A male participant with a high QOL score stated:

My colleagues in my job, they are ready to provide me with assistance all the time, sometimes when I am feeling tired or unable to do some job, they do this job instead of me and advise me to take a rest or go home if I need to (Male, # 240).

Another participant explained how much his family’s and friends’ support increased and fostered his level of hope to fight his condition:

Support from my friends and colleagues at job also helped me a lot (Male, #83).

Social Engagement

Social engagement was described by the participants as the ability to participate and share in family and community activities, enjoy free time with close friends, and become engaged in meaningful work. It also reflected the quality of the relationships participants had with significant individuals.

Participation in social activities alleviated stress and decreased the impact of CRC on the participants’ psychological status by increasing their hope and general feelings of enjoyment, thus reducing participants’ propensity to ruminate over their condition. A female participant explained how much her involvement in social life and activities allowed her to enjoy her life in spite of her condition:

I am always catching up with my neighbours; we go shopping, drinking coffee together, attending birthday parties. Last week we went to my neighbour’s daughter’s wedding; it was great to be with people and have fun with them. I
feel that I still have many things to do in this life when I am joining my friends and families. These things make me feel happy and this maximizes my hope in the future days (Female, #11).

Social engagement was also an important factor in providing opportunities to share knowledge and experiences with others, which also decreased participants’ stress and tension. Three participants with high scores reported that participation in their social community allowed them to continue to play an active role in the community, which in turn increased their confidence and resolve to recover from this life-threatening illness. A male participant said:

In addition, my friends provide me with help and assistance; they ask about my health and condition and my response to the treatment... I’m enjoying my life with my friends; we go to coffee shops together, picnics and BBQ also. They are real friends, and we know our friends in difficult times (Male, #109).

Being married, having close friends and work colleagues, interacting with neighbours and participating in social activities appeared to improve participants’ QOL, level of hope and coping abilities.

In contrast, three participants with low scores in QOL, hope and coping, and high scores in psychological distress were dissatisfied with the perceived lack of support given by their social network at the time of their diagnosis and during their illness period. They identified unhelpful and unsupportive family members, employers and community assistance. One of them explained the lack of support from his family, and how this increased his difficulties, changed his life perspective, and decreased his hope for the future:

There is no meaning of brotherhood in this life.... Of course, to feel that you are alone facing this problem is so hard (Male #146).
Another male participant, who found it difficult to maintain employment because of his decline in health, expressed his feelings of emotional distress in relation to others’ judgments of his work abilities because of having cancer. This participant believed that employers assumed he would not be able to manage his professional role and responsibilities:

*I lost my job; I am without any stable financial support, to be dependent on the charity this is a bad feeling (Male, #157).*

**Professional Support**

The second extrinsic factor that mediated the participants’ QOL was the quality of professional support they received while being treated; the support encompassed the sub-categories of *interpersonal relationships* and *patient and family education*. The following section describes these sub-categories.

**Interpersonal Relationships**

A positive relationship between the clinical staff, particularly nurses, and the patients and their families was identified as essential to a good outcome from the treatment plan for the patients. Clinical staff challenged the participants directly and indirectly to manage their situation and maintain hope for the future through speaking words of support and motivation, as illustrated by a male participant from group A, when asked what had assisted him in the hospital:

*Giving the patient hope of survival; for me my doctor and the nursing staff giving me the assurance that I am progressing very well (Male, #109).*

Other participants with high and average scores of QOL, hope, and coping also acknowledged how much communication styles, either verbal or non-verbal,
enhanced their ability to manage the problems associated with CRC diagnosis and treatment.

.... when they give me assurance and I see how much they care about my health... (Male, #6).

The way of talking from the hospital staff gives you hope; they smile all the time, making you feel relaxed and they provide me with assurance that everything will be good in time (Male, #240).

Nurses’ interactions with participants were described in terms of encouraging them to re-start their lives and adapt to the situation through engaging in informative, constructive and friendly chatting with participants to discuss their feelings and difficulties. The concern expressed by nursing staff was important for participants. A male participant who had a high QOL score said:

Support and great assistance from the staff here, they are really great, they are well trained and have a good experience to deal with us. They are patient and provide support for us all the time; they push us to restart our life again through participating in the social life and through the assurance about my case, this gives us time to talk about our feelings (Male, #83).

For the same participant, support rendered by nurses was extended directly through providing care and encouraging participants to express their feelings. This care, and willingness to help, enhanced participants’ QOL as they felt that staff genuinely cared about them:

Their (nurses) behaviours with me starting from the admission to leaving the hospital...asking about what happened to me at home; if I have any problems at home, if there is anything making me feeling bad, if I have any questions about my health.. The idea of support and making me feeling that I am not alone and there is people taking care of my health and really concerned about my status (Male, #83).

The importance of appropriate communication between nurses and participants was regarded as an integral part of the treatment plan. It established a trusting relationship
and provided participants with assurance that they were involved in every step of the treatment plan’s potential outcomes.

I believe their [nurses] role is essential because they are the only staffs who spend time with the patients starting from entry to hospital to discharge; the staffs here always smile and make jokes to encourage me. Sometime when they have time we talk about different things in life, in addition, they explain every procedure for me, which makes me feel I am part of the treatment and decision making, they deal with me as a friend more than a patient (Male, #84).

Another male participant acknowledged the concerns and helpful communication provided by both medical and nursing staff:

I have a helpful doctor who came daily to my room, to check and I see him ready to answer any question I have, sometime I called him at night if I have an emergency, he answering me, same thing for the nurses here, and they are helpful and show support all the time... (Male, #84).

The same participant explained his satisfaction about the nursing care and communication, and how much their attitudes and behaviours played a key role in building a trusting relationship.

I spent a long time at hospital, starting from my diagnosis and surgery, and I went every three weeks for chemotherapy. I know everyone at this wing of hospital. I mean if you trust their work you feel relaxed and confident about the treatment and the plan they have, moreover, how they deal and communicate with me makes me feel satisfied (Male, #84).

However, participants from group C (low QOL status) explained the negative impact on QOL as a result of the profound lack of support and inappropriate communication styles from some of the nurses and doctors which led to emotional distress. Communication difficulties were perceived to result in inadequate care and an inability to converse properly:

Do you know some of them they come to my room to measure blood pressure, temperature, they didn’t talk at all, they do their job and leave. I complained many times but no one listened (Male, #146).
Inadequate communication extended to attending specialist who was perceived by one of the participants as lacking in supervision of other staff:

> And my doctor he doesn’t respond to my call. His fellow [registrar] said that he is busy and he will come after few days and I don’t need to be worry about this because he is doing and treating me as the specialist plan and he is doing everything that my specialist ordered... I don’t trust them (Male, #157).

Another participant from the same group shared a similar experience. Some participants worried about their condition and believed their condition required professionals with experience in order to manage and follow the care plan, and apply the interventional programs. They objected to their follow-up being handed over to other professionals:

> There is one thing I am not happy with "my doctor" I didn’t see him for a long time, his team said he was busy and that they were following his plan in the treatment, I know they are good but not like the specialist (Male, #28).

Patient and Family Education

A good understanding of the disease, treatments and side effects appeared to impact positively on the participants’ QOL and ability to cope. One participant explained that he needed to know more about CRC in respect to its causes, management options and complications, and how to manage and overcome the potential problems.

> I am reading a lot about colon cancer in the pamphlets and papers that nurses have given to me about the treatment, side effect of chemotherapy, and how to deal with this, about the diet and what food is allowed and what must be avoided, so I am feeling really I know everything about my disease. This helps me a lot (Male, #109).

Patient teaching and nurses’ actions in providing them with adequate and meaningful information related to their condition were considered essential. Teaching and involving participants and their families in the care plan enhanced the quality of care.
provided. Participants described their satisfaction and improved QOL with regards to the medical staff teaching.

You know I am sure the ways of giving information by the doctor and nurses are very important for the patients. The staff here (doctor and nurse) they gave me a full picture about my disease and the plan of treatment; this really helped me a lot when you find the doctor and nurse who are ready to listen to you and show how much they take care of you, that gives you a feeling of being satisfied and comfortable. You feel supported and assisted by them (Male, #109).

Another participant supported this view, perceiving that this information improved his ability to minimize the effects of the complications, as well as to manage his side effects and the complications associated with his condition.

They provided me with enough information about the cancer, what the causes are, how to manage the chemotherapy complications, giving us time to talk about our feelings and sharing everything with us. They taught about the potential complications and what I need to do to overcome and manage this, for example they teach me about certain types of food that causes vomiting and is difficult to digest particularly in the first couple of months after the surgery, e.g. meat, garlic, spices. And I have to increase the food that contains fibres and fluid (Male, #83).

The nurses used different strategies to teach participants and their families about their condition and how to care for the most common complications related to the different treatment modalities. The pivotal role of nurses was emphasized by the majority of the participants; it also decreased their fear and anxiety as they felt they were supported by the professionals in managing their condition. A male participant, who had a high QOL score said:

The nurses are so cooperative; they answer all questions that I and my family have especially according to the care at home. They run like a lesson for the patient's family, teaching those who take care, including type of food, changing of the abdominal opening...oral care, I remember when I had infection in my mouth, the nurses taught me how to do oral care and what type of mouth wash I should use (Male, #84).

Similarly, two participants with average scores commented:
And they teach my family how to do this and what other things that they need to do including type of food and it must be soft, no spices, free of oil, and how I know when it is becoming infected. They gave me a pamphlet about this also (Male, #7).

Talking about the main complications and how we can prevent and minimize its effects, they gave us a information papers for this and next week they will do the same lesson but for our families. They asked me to choose one person from my family to attend and to teach him how to take care of me. At least I know more about the disease and how to manage it. To know more about our problem that gives me a way to expect what will happen and to be ready for any possibilities (Male, #6).

However, one participant complained of inadequate teaching regarding the management of the colostomy post-operatively and how much this affected him:

No one [the nurses] did that for me; the other patients taught me this. The nurses asked me to change it when I was in the hospital and they gave me the equipment and asked me to do that. Before three months I was admitted to the hospital because of infection in the site of this colostomy (Male, #146).

**INTRINSTIC FACTORS**

Intrinsic factors refer to the elements that activate behaviours, feelings and the internal state of the participants towards their new condition. In the current study, internal coping strategies were identified as internal elements that influenced the participants’ responses, coping, and the handling of their new situations. The two intrinsic factors that played a role in mediating the participants’ status during their illness period were: 

*Religious faith* and *Attitude towards prognosis and life*

**Internal Coping Strategies**

Two internal strategies were used by the participants at the time of diagnosis and during the treatment/illness period: religious faith and attitude towards prognosis and life; these strategies are described below
Religious Faith

Six participants discussed going back to their God and practising religious activities after facing the life crisis of CRC diagnosis. Religious faith provided meaning and purpose to life and helped them face many challenges during the treatment period. Moreover, religious faith answered the participants’ questions and queries related to the meaning of illness, life, death and health. In the current study, two participants believed that being diagnosed with CRC was a test from their God for their patience and that they should be thankful.

Beliefs and religion, once you believe that everything that happens is already planned from God. In our holy book the Qur’an, it says everything that happens is from God and we must accept this because this is a trial of your patience. For me I am happy that my God selected me for this trial and I am sure he will help me during this, he will help me by giving me extra power and energy and facilitate my life (Male, # 109).

Religious faith appeared as a growing experience and changed over time. It was described as being relatively static before, however, it changed rapidly when the participants faced and experienced challenges associated with the diagnosis of CRC. Consequently, this change provided the opportunity for spiritual growth through the use of prayer and reading the holy books.

Participants described a positive relationship with their God that helped them with the acceptance of the diagnosis and feeling supported by Knowing that God will help them through this disaster. A male participant believed that religion was most important in helping him during the illness period.

The most important is one’s beliefs and religion. I have the hope if I thank God for this; he will help to overcome and manage my problem. I am sure this is a test for my patience and I must succeed not only to be cured from
Another participant who had a strong belief in God fervently believed that everything served a divine purpose. However, it was not always possible to know the wisdom of these decisions and choices:

*My strong beliefs and religion that my God is choosing the better things for us but sometimes we don’t understand the purpose of this* (Male, #84).

The spiritual dimension influenced participants’ perspectives and how they defined the illness, and being diagnosed with CRC. Four participants stated how they used religion as a coping strategy to face existing problems and adjust to this situation.

*I am sure my God will help me to pass this distress properly. God never leaves his people without help. This problem is only a test for me; he tests me to see how much I am patient and thankful also. Praying also and reading the Qur’an help me a lot* (Male, #7).

All participants reported their belief in God, and their faith, as being crucial during the cancer treatment journey. Practising their religion shaped participants’ perspective of life and enhanced their ability to overcome new situations. Religious faith provided the chance to review their lives and actions. The following quote from a participant of group A explains how religion changed his life view:

*But in another site, I recognized the importance of beliefs and religion in this and how the life has two faces bad and good one. And returning back to the God "Allah" by practicing the religious rituals, in addition, I am more concentrated in my behaviours and action* (Male, #109).

The experience of having cancer strengthened the relationship between participants and their God. This relationship continued to be one of the main sources of strength; a place for reviewing their life and praying. During the cancer treatment participants
sought assistance from the religious community and this led to increased feelings of tranquillity. A male participant explained how much his religious faith helped relieve his anxiety:

*I am more religious now and I am feeling more need for God, praying and reading a holy book Qur’an frequently, I am feeling less stressed and anxious while I am doing this* (Male, #28).

The practising of religious activities was significant in participants’ lives especially during the diagnosis of CRC. This practice enabled them to cope on a more conscious level with life and cancer; and also helped them restore their lives through fostering acceptance of the disease and trying to rationalise their situation. The deep relationship between participants and God increased their beliefs in His ability to help and cure them. Two participants described how their religious faith fostered hope and improved their QOL:

*Everything around me maximizes my level of hope, my beliefs and religion; I am sure my God will help me to pass this distress properly. God never leaves his people without help, this problem is only a test for me, he tests me to see how much I am patient and thankful also* (Male, #7).

**Attitude Towards Prognosis and Life**

Patients’ perceptions that their disease is curable and their belief that everything will be under control enabled them to cope with the disease and manage its complications, while increasing their optimism. One of the male participants who had a high QOL explained:

*My desire to fight this disease, it’s a battle between me and cancer and I must win this war, my doctor said to me "we are going for battle for two years, are you ready to fight?" I said to him:” yes I will do my best in this, I will use all my weapons, and hope of survival and fight the disease is one of these weapons”* (Male, #109).
Another participant shared the same idea and acknowledged the importance of being optimistic about his prognosis and life ahead:

*I am sure the coming days or the future will be good, we just need to prepare for this future by working hard, these days of sickness are transitional and one day it will be finished and I am sure that I will be good. Still there are many things to do in this life for my family (Male, #240).*

The meaning of life was an important element for the participants in giving them the sense of worth through setting their goals, planning for the future, and granting them the power and ability to finish the journey of treatment peacefully. A male participant explained his ability to set goals and plan for the future, and how helpful this was during the illness period:

*Keep my goals between my eyes ...I have a nice dream for me and my family to be together in the future; this is giving me a huge power to continue and complete this treatment...(Male, #7).*

A positive attitude towards restoring their lives was highly important in enhancing the participants’ QOL, regardless of the crisis of a cancer diagnosis:

*I am trying to live a normal life as before the diagnosis...this is working, I am telling myself that I can manage and find a solution for this problem. I must be strong and give my family power; if they feel I am weak and unable to cope they will fall down and their life will be difficult for this I must keep my feet on solid land during this. I forget that I have cancer and life will continue if we are feeling good or bad, so I will keep my internal power at the maximum and if I will die I will die with smile on my face (Male, # 240).*

In comparison to these expressed positive attitudes, another participant from the low score group expressed a fatalistic attitude towards his future:

*It is out of my hands, what I can do, this is not my choice to have cancer... (Male, # 157).*
SUMMARY

Clearly, the diagnosis of, and treatment for, CRC had harmful and adverse effects on the participants and their families, including their perceptions of QOL, distress, change in social life, and change in their roles in life. Regardless of this, a wide range of variation was found in the participants’ scores of QOL and its’ psychosocial predictors. These related to a number of influencing factors that created differences in the way the participants’ QOL was affected. The factors were divided into extrinsic factors, including social support (emotional encouragement, practical help, and social engagement), and professional support (interpersonal relationship, and patients/families teaching), as well as intrinsic factors that reflect internal coping strategies, including spirituality (faith), and attitude towards prognosis and life. The following chapter presents a discussion of the results, recommendations, limitations, and conclusions.
CHAPTER SEVEN
Discussion and Conclusions

INTRODUCTION

The purpose of this study was to gain a better understanding of how a patient’s quality of life (QOL) is impacted by colorectal cancer (CRC). To this end a mixed-method study of Jordanian patients, diagnosed and treated for CRC, was conducted to:

1. Describe the relationships between hope, coping, psychological distress (depression and anxiety), age, gender, marital status, income, time since diagnosis, and their QOL;

2. Determine to what extent hope, coping, and psychological distress (depression and anxiety), age, gender, marital status, income, and time since diagnosis predicted their QOL; and,

3. Describe their experiences and perceptions about their QOL, during their period of illness.

The study was conducted in two phases: a quantitative survey (comprising several previously developed instruments) of patients from three different hospitals, followed by semi-structured interviews of a purposefully selected sample of patients representing diversity in QOL scores. The quantitative data of Phase I were analysed using a model-building approach (Hair et al, 2006), while in Phase II, content analysis, using a directed approach, was utilized to analyse the textual data. The employment of multiple data sources and methods made it possible to cross check and validate the findings, whistle ensuring that the information generated was comprehensive.
This chapter provides a critical discussion of the key findings in the context of what is already known from the literature, as well as in relation to the research questions. Based on the conclusions drawn from this study, a discussion of the important contributions of this research to academic knowledge and education, clinical practice, and future research is presented. Finally, the limitations of the study are identified and discussed, along with recommendations for future research.

**KEY FINDINGS**

In this study, undertaking a mixed method approach facilitated the breadth and depth of understanding about the QOL of patients with CRC, particularly in relation to the psychosocial impact. The following seven points present a summary of the key findings of the study.

1. The majority of the respondents:
   - were male, married, educated, and Muslim;
   - did not report having any other chronic illness;
   - did not have complications at the time of participating in the study;
   - had no known regional metastasis of CRC;
   - were treated by chemotherapy and surgery;
   - scored poorly on the physical and emotional well-being dimensions of QOL;
   - scored better on the social/family and functional well-being dimensions of QOL; and
   - scored in the mild range for depression and anxiety.
2. Evasive, confrontive, and optimistic coping strategies were the most used and effective, while fatalistic and emotive coping strategies were less useful and effective.

3. There were significant positive relationships between hope, coping, time since diagnosis, and QOL.

4. There was a significant negative relationship between psychological distress (depression and anxiety), gender and QOL.

5. Hope, coping, depression and anxiety, and time since diagnosis were predictors of QOL and accounted for 66% of the variance in QOL.

6. CRC diagnosis and treatment: changed participants’ perceptions of QOL; was distressing to themselves and their families; and impacted upon their family, work and social relationships and roles.

7. Social and professional support, religious faith and attitude towards prognosis and life were important influences on QOL.

DISCUSSION

Sample Representativeness

A comparison of this study’s sample, with data reported by the Jordanian Cancer Registry (JCR, 2008), indicates that it is reasonably representative of the Jordanian population with CRC. Thus, the sample enhances the generalisability of the findings. For example, in the current study, the sample was predominantly male (54.6 %) and had a mean age of 51.9 years. The JCR (2008) reported a median age at diagnosis of 61 years (for both genders), with CRC being most common in the over 50 years age group. In relation to gender, the JCR (2008) reported that CRC was the most common cancer type among male patients, and the second most common cancer type among
female patients, with a ratio of 1.2 male to 1.0 female. The same ratio was found in the current study’s sample. Finally, the JCR reported that the incidence of cancer, in 2008 in Amman, was just over three times that of such incidences in Irbid. The present study’s sample was taken from three general hospitals, KAUH, JUH, and Al-Bashir, located in these two governorates. The results reflected similar outcomes to those found in the JCR sample. In summary, the characteristics identified by the participants in this study concur with the national sample of Jordanian patients, diagnosed with CRC, which described only the percentage and targeted individuals only. Additionally, as with the data from the present study, the JRC data were collected from three regional hospitals to maximize the generalisation of the results.

**QOL and Colorectal Cancer**

In the present study, QOL was measured using a disease-specific instrument (FACT-C), which consists of four primary QOL domains: physical, social/family, functional and emotional well-being (Frank-Stromborg & Olsen, 2004). The following sections discuss these domains.

**Physical Well-Being**

In terms of physical well-being, the participants scored poorly on the physical dimension of QOL, describing numerous debilitating effects from the illness and its treatment. These findings are not surprising considering that all participants were recruited while they were undertaking treatment. Indeed, the treatment is known to cause a wide range of physical complications, including, but not limited to, pain, vomiting, nausea, constipation and diarrhoea (Wilson, et al., 2006). These results support previous work undertaken by Wilson et al. (2006), who found that poor bowel
function, such as constipation or diarrhoea, after the surgical treatment, was highly correlated with the patients’ QOL.

These physically debilitating conditions are also known to limit the patients’ involvement in social activity (Camilleri-Brennan & Steele, 1998; Solomon & Cherny, 2006). Similar findings were also reported by this study’s participants when they described how the embarrassment and unpredictability of their altered bowel function stopped them from returning to work or engaging in family and community social events.

As with the current study’s results, another study by Anthony and colleagues (2003) found that patients experiencing surgical complications had significantly lower HR-QOL scores. These results were also consistent with the research by Sailer and colleagues (2002), whose study described QOL among cancer patients who had undergone a surgical intervention. The results of this longitudinal, single-centre study showed that patients experienced a range of physical complications (changes in bowel habits and urinary problems), and social and psychological problems which negatively affected their QOL.

The impact of a cancer diagnosis on HR-QOL is poorly and incompletely understood because of the current focus on the risk of recurrence, chance of remission and survival (Reeve, et al., 2009), as well as the limited studies into the psychosocial aspects. However, a large, longitudinal population-based study was conducted in the USA to examine the impact of a new cancer diagnosis on HR-QOL among older Americans before and after the diagnosis (Reeve, et al., 2009). A sample of 1432
patients with all cancer types was selected; their HRQOL was assessed using Short
Form-36 survey. The results of this study indicated a decrease in the patients’ physical
well-being compared to the score before the diagnosis. These results seem reasonable,
as the patients experienced a range of side effects from the treatment modalities
(surgery, chemotherapy, radiotherapy). In addition to this, the study also explored
how the respondents’ activities of daily living were affected. Patients with CRC had
difficulty in bathing, dressing, eating, and getting out of chairs (Reeve, et al., 2009).
Importantly, these results enrich our understanding of changes in the HR-QOL before
and after the treatment. Nonetheless, using one research method only (namely the
quantitative method) has a limitation as it restricts the data obtained (Greene, et al.,
1989).

In the current study, using mixed-methods had an advantage over the previous studies,
as it captured both the respondents’ QOL scores and provided an in-depth explanation
of these results. These qualitative findings support the results of the quantitative phase
by describing how the diagnosis of, and treatment for, CRC affected the participants’
physical well-being. Consequently, it was found that these problems impacted upon
their ability to carry out their job and household duties, thereby further diminishing
their QOL. Importantly, 21% of the participants wore a colostomy appliance, which
also compromised their physical fitness; especially as such appliances cause a range
of physical symptoms, including pain, infection and GI disorders. These results
support previous research findings (Carlsson, Berglund, & Nordgren, 2001; Jenks,
Morin, & Tomaselli, 1997; Persson & Hellström, 2002) that having a colostomy bag
caused physical discomfort and infection, in addition to psychological problems, such
as a change in body image.
Previous studies, relating to cancer diagnosis and the use of different treatment modalities, have investigated their relationship to the physical well-being dimension of QOL (Carlsson, et al., 2001; Persson & Hellström, 2002). Despite a number of limitations, such as reduced sample size, research methodology, or limited geographical and cultural representation, these studies have showed that treatment for cancer can have a detrimental effect on patients’ QOL, particularly in regard to physical well-being. Some of these negative symptoms included changes in bowel habits, urinary problems, prolonged ileus, dehydration, GI bleeding and pain (Anthony, Long, et al., 2003; Ma, et al., 2007; Sailer, et al., 2002; Simon, et al., 2008).

Social/Family Well-Being of QOL

In contrast to poor physical well-being, indicated by the scoring and description by the participants in the current study, the areas of social/family well-being scored quite highly, with the participants reporting good social/family circumstances. These findings could be related to the fact that a large family or social network surrounded most of the participants at the time of the diagnosis and during the treatment period. Importantly, during the interviews, participants acknowledged the benefits of receiving all types of social support, including emotional, practical, and social engagement. This finding concurs with previous findings by Sammarco (2001), who found positive correlations between perceived social support and QOL, and network size and QOL in young cancer survivor patients. However, the results from the current study contradict Reeve and colleagues’ (2009) results; they reported that their participants had a decline in their social well-being, this might be related to limited physical well-being, number of physical limitations and symptoms, in addition to,
lack of social support due to different cultural norms, and perceived social support. The current study had an advantage by explaining in-depth the impact of a CRC diagnosis on the participants’ QOL dimensions, and importantly, identified the influencing factors that affected their QOL status.

The qualitative findings of the present study indicated that an encouraging and supportive network, whether it is social or family based, is a positive influence on QOL. Moreover, as the majority of participants were married, this finding may suggest that their spouses' willingness to offer a high degree of support, during the stages of diagnosis and illness, directly influenced the participants’ positive sense of well-being. In conclusion, the study highlighted the importance of social support; indeed, the participants acknowledged social support as one of the most positively influential factors that improved their QOL during this period. The implications of social support on the participants’ QOL will be discussed in greater depth later in this chapter.

An earlier study, conducted by Due and colleagues (1999), also found that patients with inadequate or unsatisfying social support (family, relatives, community) had negative outcomes, such as psychological distress. These outcomes then led to poor communication and isolation, which diminished the patients’ QOL even further. Importantly, the findings from the present study also agree with these results, with the participants having too little or no helpful social support (from family, friends, and work-colleagues) reporting psychosocial problems, such as social isolation.
A number of researchers have identified that social support is one of the most important factors that improve positive coping of patients with cancer (Tan, 2007). Similarly, social support was found to be one of the important domains of psychological functioning, being a resource for psychological adaptation and adjustment, and improved patient QOL (Clarke, et al., 2006; Sammarco, 2001; Wortman, 1984).

**Functional Well-Being**

It is generally agreed that cancer diagnosis and treatment causes a range of emotional distress for patients. As QOL domains have a catalytic effect on one another, experiencing physical symptoms and emotional distress might affect the other QOL dimensions. However, the results from Phase I of the current study have indicated that the participants had an overall high functional well-being. These results suggest that respondents may have the capability to function on a limited scale, and that they have adapted, previously, to functioning at a lower capacity. Indeed, it could also be that older patients’ pre-set ideologies, in relation to their life goals, and what they have achieved to date, allow their demands to be less focused on more stringent life expectations (Lundh Hagelin, et al., 2006). Similarly, Rustoen et al. (1999) found that elderly patients attain better QOL scores in all subscales (dimensions) than do the younger patients (Rustoen, et al., 1999). Klemm, Miller and Fernsler (2000) identified that younger patients have more demands than do older patients with respect to their future, goals achievements and life’s satisfaction.

However, a study by Chen and colleagues (2003) found that their participants demonstrated a significant decline in their QOL domains, including physical, and
functional, in addition to their daily living activities (ADL). The differences in the study results between Chen and colleagues (2003) and the present study might be related to the age of the participants. In contrast to the current study, Chen and colleagues recruited and focused on patients over 70 years of age. These researchers also assessed participants’ QOL among different types of cancers (which can each have different prognosis complications and impacts) (Chen et al., 2003). It is for this reason that the current study calls for the importance and need to conduct a further age-appropriate comparative study to assess and compare QOL among different groups of patients based on their age.

**Emotional Well-Being**

The quantitative results for the last domain of QOL, emotional well-being, indicated that the participants scored poorly at the time of diagnosis and during the treatment period. These results are both feasible, and not surprising, as the diagnosis of CRC can cause considerable emotional and psychosocial distress, while also disrupting the patients’ normal lives (Sharma, Walker, et al., 2007). Despite any differences in cancer type, the results of the current study are supported by Trask’s (2004) previous study, which assessed QOL and emotional distress experienced by patients with advanced prostate cancer. That study showed that the treatment of cancer (chemotherapy) affected the patients’ QOL, in relation to their emotional well-being (Trask, 2004).

The findings from the qualitative phase of the present study highlighted that a CRC diagnosis, and the resultant treatment, affected the lives of the patients, especially their psychological and emotional well-being. Three sub-categories emerged from the
qualitative data, namely: experiencing a range of emotions, such as fear, shock, and denial; changing perceptions of the future; and losing self-confidence. These emotional reactions are considered normal after a patient has been diagnosed with cancer (Honda, Goodwin, & Neugut, 2005). Such a reaction is not surprising as cancer is a life-threatening disease that affects both the lives of the patients and their families. Its diagnosis thus generates a large range of emotional feelings (Honda, et al., 2005; Peck, 1972). Similar results were reported by Penner (2009). His study assessed the QOL of patients with head and neck cancer, and found that patients experienced a range of psychological and emotional feelings following their diagnosis with cancer, or because of complications arising from the treatment modalities (Penner, 2009). The current and previous studies have confirmed that cancer (regardless of the type) causes patients to exhibit a wide range of negative psychological feelings with harmful outcomes on their QOL.

Significantly, the qualitative results from the current study expand the knowledge of the relationship between emotional status and social well-being among CRC patients. These negative changes have ramifications for the community as a whole, and the patient and their family, namely, their isolation from community and social activities, their loss of self-confidence and interruptions to their functional life, such as their job or employment performance. Other studies have indicated that emotional and well-being status of patients, and their lower QOL, are linked to increasing hospitalization periods, reducing compliance to the cancer treatment, and increasing the number of negative biological impacts (Bonacchi et al., 2010; DiMatteo, 2004; Skarstein, Aass, Fossa, Skovlund, & Dahl, 2000). Examples from the current study, supporting the above findings, include the results showing that participants with a stoma appliance
can have poor emotional well-being, while participants with no stoma can also suffer emotionally from a cancer diagnosis. Thus, patients with CRC experience a range of emotional distress and feelings.

In summary, CRC diagnosis and treatment have a negative impact on the respondents’ lives, their emotions and QOL. However, a number of predictors and factors were identified in the quantitative and qualitative phases of the current study as essential elements that directly and positively, or negatively, influence QOL status. The following sections present a discussion of these factors (especially in relation to previous studies) and how they impact the participants’ QOL.

PREDICTORS OF QOL IN CRC PATIENTS

The following sections discuss and critique the relationship between the hypothesized predictors and QOL among Jordanian CRC patients:

Selected Demographic and Disease-Related Predictors

In the current study selected demographic variables, including age, gender, marital status, income and disease-related variable (time since diagnosis) were included in the analysis as the most common variables that predict QOL in cancer patients generally.

The bivariate results showed that there is no relationship between the respondents’ age and QOL. This result contradicts previous work that identified a strong relationship between these two variables, as the existing literature identified that older patients have a better QOL than younger patients, which are related to their demands (Klemm, et al., 2000; Mkanta, et al., 2007; Rustoen, et al., 1999). One explanation for
this contradiction is related to the age of the current sample, as the respondents’ mean age was 51.9, and there was a lack of variance in the age group. These data are in contrast with the previous studies, where participants were recruited from different age groups.

The current study identified no relationships between marital status and income and QOL among Jordanian CRC patients. This result is also contradictory to the results from the literature (Mkanta, et al., 2007; Ramsey, et al., 2000; Simon, et al., 2008). One possible reason for this contradiction could relate to the lack of variation in the current sample (90% of the respondents were married, and more than half of the respondents had similar incomes).

Gender was correlated with QOL in the bivariate analysis; however, the results of the multiple regression analysis indicated that gender was not one of the predictors of QOL among Jordanian CRC patients. This result might be related to the way the sample was split, as around half of the participants were male and the other half were female. These results contradict the data in previous literature that indicated gender as one of the demographic predictors of QOL among cancer patients (Dunn, et al., 2003; Rustoen, et al., 1999; Simon, et al., 2008).

Finally, time of diagnosis was correlated with and predicted the participants’ QOL. These findings are consistent with, and are supported by the previous literature (Klemm, et al., 2000; Rustoen, et al., 1999; Safae, et al., 2008; Simon, et al., 2008). Over time, the cancer patients started adapting to their new situation and the demands related to being diagnosed with cancer and, therefore, this adaptation decreased their
psychological distress and improved their QOL. However, these results contradict Rustoen and colleagues’ (1999) results as they found no correlation between the time since diagnosis and the patients’ QOL scores. This difference may be related to the lack of variation in the sample as the majority of the participants had been diagnosed within the six months prior to the study.

Psychosocial Predictors of QOL

The following sections discuss the psychosocial predictors of QOL, including hope, coping, and psychological distress.

Hope and Quality of Life

The relationship between hope and QOL has not been well studied or examined in relation to the various population types (Rustoen, 1995; Rustoen, et al., 1999). The results of these studies showed a significant positive relationship between hope and HR-QOL. They also appear to present a realistic picture of the patients’ QOL. This is especially so as hope is considered a key contributing factor to improving the patients’ QOL, indirectly, by enhancing and improving their ability to adjust to the disease, as well as their ability to adapt to the loss of their former life and abilities and to their uncertain future (Herth & Cutcliffe, 2002b). Additionally, hope increased their level of perceived control over the crisis, and their ability to handle this new and difficult situation (Chi, 2007). Further, hope is also related to reducing the length of hospitalization, and decreasing the time between diagnosis and disclosure (Lin, Lai, et al., 2003), and promoting psychological well-being (Mei-Ling, 2003). Hope allows the patients to live and die in a more dignified and accepting way, as it fosters their
ability to continue looking to the future, and to the belief that they can beat the disease, thus, fostering the patients’ QOL.

Put succinctly, hope is an important factor for survival, healing, recovery and the improvement of quality of life among the majority of cancer patients, regardless of the type of cancer (Vellone, et al., 2006). Hope is an essential component in a patient’s ability to cope, to perceive control over their critical condition, and to improve their psychological adjustment to a serious illness, such as colorectal cancer. Importantly, hope appears to improve the physical and mental well-being of cancer patients (Felder, 2004).

Hope is also considered a powerful force for a belief in a future life, even though it may be filled with difficulties and limitations (Miller, 2007). Keeping their spirits high and their positive beliefs about the future are important factors for patients with CRC to have a worthwhile life. This approach is necessary as CRC is a threat to their lives (both present and future), especially when they are uncertain about their future, and what will be at the end of their treatment journey. Consequently, having a high level of hope motivates and increases the patients’ possibilities in relation to them achieving their goals, to their continuing treatment and to fighting the challenges that arise as they develop their plans and perform the required tasks, such as follow-up treatment, clinic visits and maintaining life as usual.

The findings from the current study indicate that hope plays an essential role in improving the patients’ QOL. In addition, both QOL and hope share key elements, such as multidimensionality, time and concern about interpersonal relationships
Accordingly, in nursing research, hope and QOL are seen as valuable concepts. Indeed, hope is considered an inner resource that strengthens the participants to help them cope with their cancer, achieve their goals, and continue their treatment.

In the current study, two types of hope were identified and enhanced the participants’ QOL: particularized hope (which is associated with the participants’ willingness to continue their treatment, pass the period of illness/treatment and obtain a cure for this disease), and generalized hope (that reflects their wishes to restore their life, having a happy and healthy future with their families, and the ability to restart their life with a new beginning). These findings support the results obtained by Duggleby and colleagues (2007). Their research used an interventional program, called “Living with hope Program” (LWHP), with a sample of 60 terminally ill cancer patients; the results identified that an improvement in the patients’ level of hope increased their QOL (Duggleby et al., 2007). The results provide valuable knowledge with respect to the difference in the population between the present study and Duggleby et al.’s study.

Coping and Quality of Life

The results of the current study highlight the importance of using coping strategies when facing and managing the difficulties and complications associated with a CRC diagnosis. In addition, the ‘evasive’ and ‘optimistic’ coping strategies were identified as the most commonly used and effective strategies for the respondents. These styles were used most often by the patients to cope with their diagnosis and during their treatment. Similar findings were obtained by Halstead and Fernsler (1994), who reported that the optimistic coping strategy was the most effective coping style used.
by surviving cancer patients. The participants in the current study chose similar coping strategies. Interestingly, ‘emotive’ and ‘fatalistic’ coping strategies had the lowest use, possibly indicating that they did not help patients adapt or cope with their new difficulties. The current findings reinforce the results by Halstead and Fernsler (1994), namely, that ‘emotive’ and ‘fatalistic’ coping strategies are the potential cause for guilt feelings. Additionally, the current findings showed that the participants’ chosen coping strategies were often highly effective in reducing their psychological distress (depression and anxiety) and improving their QOL (Halstead & Fernsler, 1994).

According to several studies over the last decade (Mullens, 2004; Deimling, et al., 2006; Lazarus, 1993; Mullens, McCaul, Erickson, & Sandgren, 2004; Schnoll, Harlow, Stolbach, & Brandt, 1998), effective coping strategies enhance psychological adjustment among cancer patients, while fostering and increasing their fighting spirit, and decreasing their feelings of hopelessness, anxiety, and depression. The outcome is improved and increased patient QOL levels. Consistent with this outcome, the participants from the present study faced the challenge of living with CRC. Undeniably, the diagnosis of such a life-threatening disease is considered a disaster because of the related complications, the possibility of death and the long term treatments. These challenges require great adaptability from those patients to carry on with their life. The findings from the qualitative phase showed that the participants, who developed such an adaptive mechanism, and used all effective and useful strategies to face the diagnosis of cancer and live with it, reported more life satisfaction, less psychological/emotional problems and more power/spirit to manage their life under the new circumstances.
Lazarus and Folkman (1984) identified coping as “a process of 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. 14). This definition reflects the interaction between patients and their cancer diagnosis; it is also relevant to how they handle and live with their cancer. Thus, a diagnosis of cancer changes the patients’ needs, causes additional stress and threatens their previous way of life. Consequently, cancer patients start their journey using coping strategies, such as seeking social support, and cognitive and behavioural adaption, to enable them to handle, manage and overcome the associated problems and changes they face after their diagnosis of cancer. The use of coping styles varies between patients, tending to revolve around a number of factors, such as disease condition, social support, age and general health status (Mullens, et al., 2004). For example, coping has been found to be highly associated with age, with older people using more coping strategies and having a higher level adaptive system when confronting a new situations (Schnoll, et al., 1998). This ability was also seen in the current study where coping strategies were used by the majority of the participants; importantly the majority of participants were older than 50 years. Further, as the descriptive results indicate, the participants had a reasonable level of coping that they used to face the challenge of being diagnosed with cancer.

The importance of using effective and powerful coping strategies was identified by Andersen, Kiecolt-Glaser and Glasers (1994), especially in association/relation to the bio-behavioural response of the patients. They found that patients who were unable to cope, or had adjustment difficulties to their new circumstances, experienced psychological problems (such as depression), in addition to some biological
(physiological) problems (such as respiratory infections, decline in their immune system) and a deterioration in their QOL scores. Supporting these results were the findings of Rosech and others (2005). Their meta-analysis review assessed the relationship between coping categories and indices of adjustment in men with prostate cancer. They concluded that stress, related to being diagnosed with cancer, was negatively associated with QOL. Further, this relationship appeared in the patients’ bio-behavioural responses. For example, patients with high QOL had a good appetite, had fewer sleep problems and were more compliant with their medical plan. In summary, the ability of the cancer patients to cope and manage their new situation affected their QOL, disease prognosis and response to the treatment plan (Roesch et al., 2005). Thus, it is apparent how necessary it is to understand patients’ ability to cope and to identify the kinds of strategies that they are applying / utilizing as they face their problems.

The use of a mixed-method approach has provided a holistic view and expanded our understanding of the variables under study. The findings from the qualitative phase have identified further coping strategies that influence the participants’ QOL (namely, spirituality and attitude towards prognosis and life). These strategies were not included in the quantitative survey that was used in the current study (namely, JCS); thus, the current study’s findings expand our knowledge regarding the coping strategies used by the cancer patients (specifically CRC), and identified that spirituality and attitude towards life and prognosis were also useful coping strategies that were used by the participants.
Psychological Distress (Depression and Anxiety) and Quality of Life

An individual, who faces a stressful situation, or a tough time, such as receiving the diagnosis of cancer, manifest a number of psychological responses, reactions and feelings, including depression, anxiety, demotivation, aggressiveness and self-depreciation (Abeloff, Armitage, Niederhuber, & Lichter, 2000; Masse, 2000). Indeed, depression and anxiety were identified as the most common types of psychological distress associated with cancer (Teunissen, et al., 2007).

In the current study, the Phase 1 results showed that participants reported feeling mild depression and anxiety. Zobora et al. (2001) had found similar results in their review of 9000 profiles to determine the prevalence of psychological distress among different cancer patients, and to examine the difference in psychological distress between the different types of cancer in the United States (USA). Their results indicated an overall prevalence of psychological distress ranging from 29.6% to 43.4%, depending on the cancer type (Zabora, et al., 2001). However, while the current study focused exclusively on patients with CRC, both studies indicate that cancer patients face a range of psychological distress/emotions at the time of diagnosis and during the illness period.

The results from both studies are supported by the findings of Tsunoda et al. (2005), especially in relation to the prevalence of psychological distress among CRC patients. Their cross-sectional study, conducted in Japan, analysed a sample of 140 patients with CRC, using HADS, to identify and measure the participants’ levels of anxiety and depression. The results showed that 7.8% of the participants had anxiety, and 36.7% suffered from depression. Furthermore, a negative relationship was found
between emotional function (EF) of QOL and depression and anxiety, as measured by HADS (Tsunoda et al., 2005). The results from the current study extend and support the results obtained by Tsunoda et al.’s study (2005), which focused only on the emotional function of QOL. As QOL is a multidimensional concept, the current study sought to assess the relationship between HR-QOL as a total (including the four main dimensions), along with depression and anxiety. Consistent with these results, similar results were obtained in a recent study conducted to assess the relationship between depression and anxiety, and QOL among Turkish cancer patients (Alacacioglu, Yavuzsen, Dirioz, & Yilmaz, 2009, 2010). The results from the current study concur with Alacaciolu and colleagues’ findings in determining that patients with psychological distress (namely depression and anxiety) experienced and reported lower scores of QOL.

Similar findings were also found by Skarstein and colleagues’ (2000) cross-sectional study. They used HADS and EORETC to determine the impact of anxiety and depression with 586 cancer patients’ QOL dimensions. Statistically significant negative relationships were identified between depression and anxiety, and QOL dimensions, particularly the emotional dimension (EF). While Skarstein and colleagues linked depression and anxiety to the emotional well-being of mainly breast and gynecological cancer patients, each type of cancer has specific impacts because of the prognosis, severity, and related problems that it might cause. QOL is a multidimensional concept that includes not only emotional well-being, but also, physical, functional, social/family and sexual well-being. The current study findings extend our knowledge regarding the impact of psychological distress on cancer
patients (focusing on colorectal cancer patients), as it has definitively shown that depression and anxiety had an adverse impact in all QOL dimensions.

Importantly, it appears that cancer patients, in general, and CRC patients, in particular, are faced with, and experience psychologically distressing feelings, resulting in depression and anxiety. Further, these reactions and feelings may have a negative outcome by delaying: treatment plans and strategies; the treatment itself; the decision-making process; the patient’s response to the treatment or complications; and finally, the patients’ overall QOL domains (physical, emotional, social, sexual and psychological) (McDaniel, et al., 1995; McEwen, 1998; Newell, et al., 1999; Uchitomi et al., 2003). The effects on the patients’ QOL from psychological distress (depression and anxiety) can lead to a decline in cancer patients’ QOL at the time of the diagnosis and during the treatment/illness period (Montazeri, Milroy, Hole, McEwen, & Gillis, 1998). According to Tiernan (1998), these symptoms can persist and lead to the disruption of the treatment plan and the general management of the disease and related symptoms (Tiernan, 1998). These results were confirmed by the qualitative findings of the present study, where the participants with a poor QOL score had a range of negative psychological feelings, such as denial, shock, fear and worry.

Psychological distress has a wide range of impacts on patients with cancer, as other studies have linked psychological distress/emotions to increased hospitalization periods and length of stay, or they decreased the effective response to the treatment and compliance with the treatment strategies (Hopwood & Stephens, 2000; McDaniel, et al., 1995). Such psychological distress can be related to physiological dysfunction

As the previous studies have limitations related to a single design (quantitative), they have limited explanations of how the psychological distress interferes with the patients’ lives and QOL. The current study’s qualitative results supported these findings and provided an in-depth explanation of how the diagnosis of cancer, and the consequent emotional problems, interfered negatively with the patients’ lives. For example, some participants had suffered from distressing psychological feelings, and so they reported difficulties with their employment and their ability to run or follow their routine/daily activity; and possibly, through their poor health, they were unable to work. At the same time their medical expenses increased, as a result of their illness; their illness sometimes became such a problem that they had to resign from their jobs. The end result was a decline in their functional dimension of QOL. Further, in other studies, depression and anxiety has been found to disrupt the patients’ sleep patterns and increase sleep disturbance (Davidson, MacLean, Brundage, & Schulze, 2002; Mystakidou et al., 2005).

In addition to the above predictors, a number of factors were identified from the second phase of the current study, as key elements that contributed to the participants’ QOL. The following section discusses these factors.
EXTRINSIC FACTORS

Social Support and QOL

For any patient, the diagnosis of cancer is considered a painful, stressful and life-threatening experience that affects them and their family. The psychological impact of a CRC diagnosis usually involves mental and emotional stress, which can become apparent at any time during the illness period. Further, the patient’s psychological distress can be negatively impacted by any further deterioration in their physical condition (Clarke, et al., 2006; Sammarco, 2001). The qualitative findings, from the current study, confirm that social support, particularly by the immediate family, is the major influencing factor that positively affects the patient’s health status, QOL and psychological condition. Regardless of the cancer type, these results concur with the previous work by Sammarco (2001), namely, that social support was a vital component that fosters the cancer patient’s belief that they are lovingly surrounded by concerned people, who are willing to assist them in managing their cancer condition. Furthermore, a strong network provides verification to the patient that they are supported and valued by their immediate family and friends.

In the current study the participants received different types of social support from different sources; the following section discusses the importance of these support resources.

The Sources of Support

As noted above, the qualitative results of this study and others (Devine, et al., 2003) have identified the importance of the participants’ social support (i.e. family and friends) in increasing their coping mechanisms, thereby directly ensuring that they
have a higher level of QOL. Such a support network provides the strength, hope, ability and spirit that the participants needed to enable them to face their diagnosis and continue their treatment. The outcome was a belief in their personal capacity to overcome a difficult situation with the ultimate ending being a cure.

This outcome is unsurprising considering that social support: can be a buffering effect among women with metastatic or recurrent breast cancer (Koopman et al., 1998); is associated with less mood disturbance and less stress (Koopman, Hermanson, Diamond, Angell & Spiegel, 1998); and can be an adaptive cognitive processing response (Lepore & Helgeson, 1998; Lepore, Silver, Wortman, & Wayment, 1996). Lepore (1996) and Lepore and Helgeson (1998) developed a social-cognitive processing model to integrate findings related to intrusive thoughts, avoidance, social support and adjustment to cancer. Importantly, the current study showed that participants with little social support scored lower in terms of psychological distress (depression and anxiety), QOL and an ability to manage their condition. Consequently, participants endured higher psychological distress and exhibited various negative thoughts, including a heightened sense and feeling of loneliness and distress. These findings have expanded our understanding of the importance of family support mechanisms to improve cancer patients’ QOL.

Previous studies (Ell, 1996; Sammarco, 2001; Tan, 2007; Tan & Karabulutlu, 2005) have given only cursory attention to the interpersonal relations between the patient and their family, and the mechanism of support such as the kind of support, family supportive behaviours, and how the patients perceived these behaviours. In contrast, the findings from the current study outline, in detail, the social support mechanism
available to the patients and their surrounding social network (families, relatives, friends, and work-colleagues), their psychological situation and the daily supportive activities on offer to the patients during their illness period. Such understanding can only enhance our knowledge of the importance of the social support mechanisms in terms of caring for cancer patients.

Indeed, the results from the current study closely fit the results from previous research, namely: that a strong social network is associated with better psychological adjustment, outlook, and improved health status (Manne & Glassman, 2000; Tan, 2007; Tan & Karabulutlu, 2005) and that patients who received social support (particularly married participants) have less stress, anxiety and better QOL (Parker, Baile, de Moor, & Cohen, 2003).

Furthermore, a high level of social support can act as a coping mechanism by assisting the patients in the identification and provision of their basic needs, and by providing them with the emotional support needed to adapt to new and challenging situations. Family support can be instrumental in enabling the patient to maintain a higher level of control during their illness period (Manne & Glassman, 2000; Tan, 2007; Tan & Karabulutlu, 2005). Regardless of the differences in the methodology (e.g. quantitative or qualitative), population, culture (e.g. western or Eastern), or type of cancer (CRC or breast cancer), the results from the current study support the findings of similar previous studies (Sammarco, 2001; Tan & Karabulutlu, 2005). These studies showed that patient family support was essential for, and associated with, high levels of hope among cancer patients.
Components of Social Support

The three most integral social support components were identified, by the participants in the qualitative phase of the current study, as emotional, practical and social engagement. These elements had a positive effect on their health status, particularly in the areas of accepting and facing the diagnosis of CRC, and coping with the subsequent complications associated with the disease or the treatment regime.

The participants acknowledged that *emotional support* (such as empathy, concern about their health, affection and acceptance of the diagnosis) were paramount when dealing with family and friends. As the majority of the participants were male, the results contradict the findings of Clarke et al. (2006). These researchers had postulated that male patients were less likely to seek, or be concerned about obtaining, emotional support. Indeed, they found that informational support was a first priority for males, and that emotional encouragement was deemed as inappropriate. However, this result may be biased due to the participants’ culture, and the type and severity of cancer. The differences in findings, however, could be that they conducted their study on breast cancer and melanoma patients. Nevertheless, there is a close fit with the results of the current study and the findings of earlier research (Aymanns, Filipp, & Klauer, 1995; Hilton, 1996; Krongrad et al., 1997; Nichols, 1995; Tan & Karabulutlu, 2005). The latter findings identified that emotional support, provided by the family, plays a vital role in alleviating depressive symptoms, improving positive thinking and helping patients to cope with the stress resulting from the disease and treatment.

*Practical help* is another social support component that is provided by participants’ families, with practical help being seen as “instrumental” in improving the patients’
status. This improvement is achieved by assisting and aiding the patients to: minimise the impact of the cancer diagnosis and treatment; reduce psychological distress; and improve their coping mechanisms. In addition, such support appears to positively enhance their QOL (DiMatteo, 2004; Krishnasamy, 1996; Manne & Glassman, 2000). Specifically, practical support also refers to the provision of information, knowledge, and advice that assists patients to understand their disease/treatment plan (DiMatteo, 2004). As a consequence, they could set about developing their own plans and coping strategies to better handle the CRC diagnosis, as well as to make realistic and appropriate decisions. Such social support also appeared to reduce the participants’ confusion, increased their awareness of their disease, enhanced their ability to make the right decision and provided them with the confidence to follow their treatment plan. Tan’s (2005) study also identified the importance of both sharing and providing the patients with enough information related to their condition and management. Thus, having relevant and reliable information about their condition improved their QOL, making them feel more satisfied, supported, and in control (Tan, 2007; Tan & Karabulutlu, 2005).

The current findings are significant as they link “practical” social support and the behavioural outcome. Indeed, the results from the qualitative phase indicate positive contributions and changes on the participant’s behaviours toward life and socialization. Thus, by receiving social support, the participants became more active, more willing to participate, have more hope and show more ability to manage their situation. These findings also indicate that the social support experienced by the participants has a documented salutary effect when there is support present and available. In contrast, there is a negative/harmful impact when the needed support
is absent, or when potential supporters (family, relatives, and friends) are unavailable.

The third component of social support was *social engagement*. It reflects the degree to which the participants interact with, or engage in, community activities. This enables the participants to practice and play their new role in the community, as well as between family members. The result was feelings of enjoyment and happiness, and their sense of responsibility, while at the same time they experienced a decrease in tension and stress through sharing their stories and information. Finally, social engagement provided the participants with the knowledge that they could still be active members of the community. These outcomes led to an improvement in their QOL, their ability to cope and the strengthening of their internal drive to continue the treatment, fight the cancer and overcome associated difficulties. Similar findings have helped to explain the role of social integration in patients’ health, such as: (1) patients with high social engagement have better physical and psychological well-being (Smith, Fernengel, Holcroft, & Gerald, 1994); (2) large groups of people help to provide the patients with all types of necessary support (Helgeson & Cohen, 1996; Helgeson, Cohen, Schulz, & Yasko, 2000); and, (3) the patients’ ability to adjust to, and live with, illness is increased (Helgeson, et al., 2000). Importantly, the results from the current study identified social engagement as an important role in helping participants to share their experiences and relieve stress. Further, it was considered one of the coping strategies that helped the participants face their new situations. In spite of the importance of social support in improving the patients’ conditions, health, QOL and ability to cope with the critical conditions, an early study conducted in the UK indicated that social support caused additional stress for the
patients with cancer, as cancer can generate a wide range of physical limitations and avoidance behaviours (Krishnasamy, 1996).

**Professional Support and QOL**

As well as support from significant others, the participants also identified professional support through staff-patient communication and relationships and the teaching and imparting of knowledge to themselves and their families. The following section discusses the study’s results in relation to these two areas.

**Staff-Patients Communication/Relationship**

Researchers (Fleischer, Berg, Zimmermann, Wüste, & Behrens, 2009) have defined communication as “a dynamic, complex and context-related ongoing multivariate process in which the experiences of the participants are shared” (p. 342). In the current study, the participants identified that effective communication required the existence of a good relationship between the clinical staff, particularly the nurse, the patients and their families. The study highlighted the two main types of communication used between the professionals and the patients, namely: verbal and non-verbal communication.

Nursing communication/interaction played a key role in enhancing the participants’ mindfulness, while utilizing different coping strategies, such as re-starting their life again, by engaging in a variety of activities, and becoming an active member of their family and community. Different styles of communication were used, including: careful listening, frequent enquiring, and encouraging the participants to express their feelings. These strategies were seen as most helpful and useful, and lead to the
maintenance and improvement of the participants’ psychological well-being. Importantly, the participants felt that they were cared about and treated nicely by another. These results point to the need to use a communication enhanced model, incorporating different styles of communication, such as: listening, conservations that will foster the patients’ abilities to manage their sensitive situations, talking about their feelings, and, finally, those that will enable the nurse to identify the patients’ needs (K. Williams, Kemper, & Hummert, 2005). Thus effective, patient/family-centred communication and interactions procedure will facilitate many valuable and meaningful health outcomes, namely: symptoms control, pain control, resolution of physical and functional symptoms, and improvements to psychological functioning of patients (Fallowfield & Jenkins, 1999; Stewart, 1995). In contrast, ineffective communication between the professionals and patients will only lead to dissatisfaction, improper care and a rise in the number of emotional problems, such as anxiety (Stewart, 1995). Consistent with these results, the results of the current qualitative study showed that the participants, who had received inappropriate/ineffective communication from the professionals (nurse and doctors) had emotional problems (such as distress), in addition to inadequate care. Furthermore, the findings indicated suboptimal and lack of helpful communication in regard to information sharing, while interpersonal relationships caused a wide range of psychological problems and affected the emotional, social, and psychological well-being, and culminated in poor QOL status for the participants.

On the other hand, a valuable interpersonal communication procedure enhanced the participants’ QOL through fostering their satisfaction with the care they were receiving and increasing their positive engagement in their treatment plan.
Additionally, effective communication between the nurses and their patients enables the nurse to assess and evaluate the patients’ health status, obtain an accurate physical and psychosocial assessment and evaluate their responses to the treatment and therapeutic interventions (Williams & Gossett, 2001). The current findings are in agreement with previous work on the importance of communication between health professionals and the patients (Fleischer, et al., 2009; Shattell, 2004; Williams & Gossett, 2001; Williams, et al., 2005; Williams, Ilten, & Bower, 2005). Consequently, effective and positive communication is a vital part of quality nursing care, constructively influencing the patients’ satisfaction, and improving the patients’ psychological status, particularly through giving them the opportunity to express their feelings and emotions. Undoubtedly, this communications approach will enhance the patients’ QOL during their treatment/illness period. These results parallel the previous studies conducted in the past decades, namely, that the patients/families reported dissatisfaction with the hospital staff communication behaviours (Bond, 1982; Davis, Kristjanson, & Blight, 2003; Seale & Kelly, 1997). Consistent with these findings, Williams (1998) indicated that non-professional caring/communication behaviours (emotional distancing, negative verbal/nonverbal body language) caused patients to feel helpless, have emotional problems, low self esteem, and decrease their sense of control (Williams, 1998).

The results appeared to show that the communicative behaviours of the professionals (and nurses in particular) play an important role in meeting the participants’ requests (emotionally and physically). To date, most of the earlier studies have focused on the communication between the patients and professionals in relation to only the giving of bad news (e.g. a cancer diagnosis) (Hagerty et al., 2004; Hagerty, Butow, Ellis,
Dimitry, & Tattersall, 2005; Hagerty et al., 2005). Thus, there is a lack of understanding of the value of interpersonal communication between the cancer patients and the professional to achieve an improvement in the patients’ QOL, especially during their illness period. The current study resulted from the need to explore this aspect of QOL further. The present study has, therefore, addressed and discussed, in detail, the role of effective communication in fostering the patients’ satisfaction, increasing coping skills and strategies, optimising hope, and finally improving QOL.

**Patient/Family Teaching**

In the current study, participants identified that how they and their families were taught about their illness, most often by the nurses, was very important in preparing them to manage and cope with the diagnosis of cancer. In addition, they reported that such learning increased their knowledge about the disease, the complications that can arise and the strategies needed to manage their condition. This knowledge and understanding enhanced their satisfaction and increased their involvement in the treatment plan, becoming an important member of the decision making team. These results parallel Fawzy’s (1999) literature review findings that patients receiving educational intervention showed a significant improvement in their anxiety level and a reduction in their treatment-related problems (Fawzy, 1999). Several European and USA studies have indicated that the patients with cancer, who had a desire and willingness to know about their disease (cure, side-effects of treatment) (Cassileth, Zupkis, Sutton-Smith, & March, 1980; Davidson & Mills, 2005; Meredith et al., 1996) reported a high level of satisfaction and less psychosocial problems. These findings were supported by the current study. Indeed, the importance of sharing
knowledge about their cancer with other patients and their families was said to be essential. The understanding gained from this process helped to ensure optimal care. The findings also confirm the earlier findings of Fosbinder (1994), who developed a theory of “interpersonal competence” that identified the elements of interpersonal relationships between the health professional and the patients (Fosbinder, 1994). While the cancer type was different, both studies identified that sharing information (explaining, instructing, and teaching) is an essential aspect of effective nursing care. Indeed, a number of studies (Given, Given, & Kozachik, 2001; Williams & Gossett, 2001) have shown that increasing the patients’/families’ awareness of the disease, through providing appropriate, relevant and adequate information, ensured that they were willing to participate in enhancing their health outcomes. They were especially willing to improve their ability to follow-up the treatment plan, follow instructions and develop their ability to minimise or prevent expected complications. Thus, the current study and previous studies were in agreement about the role professions needed to play in teaching the patients and families to improve their QOL.

In addition to the above extrinsic factors, the following sections discuss the impact of intrinsic factors on participants’ QOL.

**INTRINSIC FACTORS**

**Spirituality and QOL**

Spirituality has been found to be an important influencing factor to a patient’s QOL when diagnosed with cancer (Mueller, Plevak, & Rummans, 2001). Indeed, it appears to provide patients, at that crucial period in their lives, with structure and meaning in relation to their life’s values, behaviours, events, and experiences.
Definition of Spirituality

In the current study, the participants described spirituality as: (1) religious activities, including the participants’ religious practices, such as praying, reading holy books, and visiting holy places; and, (2) a way to find the meaning of disease, death and life, with participants defining disease as a test from God in terms of their patience and ability to continue with their life. These definitions reflect the importance of spirituality in the participants’ lives, as it gave them a framework for finding the meaning of their illness. It also provided them with a sense of control over their current problem/s; they believed that they had a great source of support from their God. This definition concurs with the findings from previous studies. For example; 23 African-American patients, with various types of cancer, defined spirituality as having faith, religious practice, treating others well and their relationship with a higher power (Schulz et al., 2008).

Role of Spirituality in Cancer

Importantly, in the present study, spirituality enhanced the participants’ coping, increased their QOL and fostered their acceptance. These findings seem to have a universal component, as regardless of the study population, their ethnic grouping, or their religion, similar results are found (e.g. Walton and colleagues, 2004). Their qualitative study (Walton & Sullivan, 2004) contributed to the theory development and understanding of what spirituality means to men with prostate cancer, as well as how their spirituality influenced their treatment. The results showed that prayer was an important and vital element in improving QOL, providing them with assurance and comfort (emotionally) and increasing their inner strength.
For the participants in the current study, spirituality provided a sense of reality that helped them to face their problem/s; they also identified the wisdom of being diagnosed with cancer “as a test from the God”. The latter knowing increased their ability to see the problem more clearly and find a range of solutions to these difficulties. Similar findings were found by Mattis (2002), who examined the role of spirituality in African-American women with breast cancer. The study found that spirituality played a role in enhancing the participants’ ability to accept the disease, learn life’s lessons, trust in a higher power and see the purpose behind their situation (Mattis, 2002).

Spirituality also helped the participants to manage their disease through receiving support from their God, that is, their knowing that God would help them through this disaster. These and the findings from the current study are also congruent with Levine et al.’s (2007) results, namely, that African-American women with breast cancer engaged in spiritual activities, had faith and appreciated life. Additionally, they had a strong belief in God’s help and assistance during their illness period (Levine, Yoo, Aviv, Ewing, & Au, 2007). Importantly, the qualitative results of the current study showed that a participant’s spirituality enabled them to absorb the shock of being diagnosed with cancer through their ability to go to their God and ask for help in managing the crisis. Thus, spirituality was found to be an essential factor in positive psychological adjustment to the diagnosis of CRC; this finding is congruent with other studies (Laubmeier, Zakowski, & Bair, 2004; Romero et al., 2006; Schnoll, Harlow, & Brower, 2000), especially that by Lee and colleagues (2000). Their study on breast cancer survivors, within the San Francisco Bay area, found that spirituality and praying were important and valuable factors in the healing and recovery process.
In addition, they believed that their “God” would support them in any circumstance (Lee, Lin, Wrensch, Adler, & Eisenberg, 2000).

In summary, it can be clearly asserted that, regardless of the participant’s type of cancer, culture, religion or ethnic group, spirituality positively enhances the participants’ psychological adjustment to their cancer. Finally, while the role of nurses in this area of patient spirituality is limited, they can, however, provide basic spiritual information in relation to facilitating the practice of religious rituals or provide contacts with religious mentors.

This current study also highlights the impact of “Islamic” religion on the participants’ QOL, with the study sample representing a new cultural perspective, namely “Arabic” (previous studies having focused on Western culture). In general, Arabic-Muslims believe that everything related to their health is controlled and created by the God “Allah”. It is stated in the holy book “Qur’an” that Muslims should encourage health promotion and disease prevention and seek health care in sickness (Yosef, 2008). This study thus fills some knowledge gaps and improves upon the understanding identified by Levine and colleagues (2007), with spirituality as an important component in improving the QOL of cancer patients. These authors called for the need to assess the role of spirituality among different ethnic groups in order to gain a full picture about the role of spirituality “in general” in managing the cancer patients’ condition. In summary, the results from the current study confirm that spirituality is a key factor/element in fostering the patient’s own management of their condition through increasing their acceptance of the diagnosis, and increasing their spirit to fight this life-threatening disease.
As the study was conducted in a specific culture (Arabic, mainly Islamic patients), it should be acknowledged that the characteristics of that culture influences and impacts the patient’s and family’s values, attitudes, behaviours, health practices and health-related decisions. In Arabic countries, the family is considered the strongest unit in the community. Structurally, it is considered patriarchal, patrilocal (wife is expected to live with/near the husband’s parents), patrilineal (descent through the male line) and extended. Within the family, functional roles depend on gender and age; the father is considered the head of the family and the decision maker. In addition, he is responsible for providing the family with all essential needs. The mother’s role is to nurture, build and ensure that children are raised according to Muslim cultural and traditional values. Finally, the role of children (both male and female) is to obey, respect parents, assist them in the daily activities, respect elderly people with the community and to behave according to cultural and traditional norms and values (Zahr & Hattar-Pollara, 1998). In Jordanian society, family members play a crucial role in the treatment plan for cancer patients because of their cultural expectations and obligations.

The emerging themes, categories and subcategories of the current study concur with the results of the previous studies conducted in different cultures (Manne & Glassman, 2000; Tan, 2007; Tan & Karabulutlu, 2005), with more in-depth explanation about the role of the family members. However, the results of the current study highlights how the diagnosis of cancer of one the family members can significantly and negatively affect and disrupt the other members’ lives.
Furthermore, the results of the current study are consistent with previous studies conducted in different cultures in terms of the importance of spirituality in enhancing the patients’ level of hope and in enhancing their level of coping (Mattis, 2002; Walton & Sullivan, 2004). The participants believed that being diagnosed with cancer is like a trial from their God to test their ability, patience and thankfulness. This is related to the cultural and religious beliefs and values of the Arabic-Muslim patients.

Finally, this study’s findings explained how spirituality influenced the participants’ QOL, and how they used spirituality as a coping mechanism following their diagnosis of cancer. While the qualitative results of the current study addressed the role of spirituality in improving QOL among CRC participants, the findings are generalisable in attempts to improve the QOL among patients with other cancer types (Marie Elena, Barbara, & Mark, 1998; Rippentrop, Altmaier, Chen, Found, & Keffala, 2005).

**Attitude towards Prognosis and Life**

In the second phase of the current study, participants’ perceptions and attitudes about their condition, the positive meaning they attach to life and how they see their prognosis, contributed positively to their QOL. This outcome was attained through enhancing their ability to manage their problem, and increase their level of hope (through their belief in a good future, which also gave them the chance to think about their future), and thus set plans with achievable goals.

These qualitative results support previous quantitative research undertaken by Schnoll et al. (2002), who recruited a sample of 700 participants to identify the predictors of positive psychological adjustment for cancer patient survivors. Their results indicated
that possessing a positive meaning of life, and optimism, were important factors in predicting the participants’ positive adjustment to the cancer (Schnoll, Knowles, & Harlow, 2002). Similar results were reported by Vickberg and colleagues (2000), who concluded that positive meaning and perception were important contributing elements in improving psychological well-being by decreasing intrusive thoughts and psychological distress (Vickberg, Bovbjerg, DuHamel, Currie, & Redd, 2000). These results present a logical explanation for why and how positive perceptions, and the attachment of positive meanings, can work as a protective mechanism or coping strategy against the impact of psychological, physical, or social problems/difficulties (Schnoll, et al., 2002; Vickberg, et al., 2000). In this study, the results indicated that patients’ ability to cope and to find the meaning of life, despite being diagnosed with a life threatening disease like cancer, was an important and crucial element in improving the QOL. Moreover, adopting a positive outlook enabled them to cope with their new situation.

**LIMITATIONS**

The following section presents the limitations of the present study in relation to the two phases. In Phase I, the quantitative survey, the discussion focuses on the study design, sampling, data collection, and measurement. The limitations for Phase II, the qualitative interviews, focus on the data collection technique and the data analysis approach.

**Phase I**

*Study Design*
In the present study, the quantitative approach used a cross-sectional, correlational design. This approach could be seen as a limitation in terms of the research outcomes, especially as the study did not focus on the causal effects of the relationships between hope, coping, psychological distress, and QOL. Thus, it was not possible to evaluate the causal relationship between the independent variables and the dependent variable. However, the researcher sought to provide an initial understanding of the explanatory variables that contribute to QOL in Jordanian CRC patients. As this study is non-experimental, using multiple regression analysis involves ambiguity about the direction of causal relationships. Nevertheless, it did provide the ability to assess the degree of the relationship and the interaction between the dependent and independent variables (though not the cause or effect of the relationships, as found in experimental studies), and have greater statistical control.

**Sampling**

A second limitation of Phase I of the current study is the use of convenience sampling. As a consequence, the study suffered from the risk of selection bias, which is greater than in other quantitative sampling methods (Polit & Beck 2004). As a result, the sample may not represent the population; thus, the findings are limited and related specifically to the sample itself. Nevertheless, the study allowed access to large samples, making it cost effective, and permitted the time constraints to be addressed (Talbot, 1995). Importantly, the participants were recruited from three cancer, geographically different, treatment hospitals and, thus, the sample population contained a wide cross section of participants. In addition, the well-developed and clear inclusion and exclusion criteria were used and contributed to the sample’s homogeneity.
A third limitation involved the way the study focused on one type of cancer, “colorectal cancer” (CRC). Consequently, the results may be unique and specific to this group of patients, and so may not be generalisable to other cancer groups. However, CRC is considered the most common type of cancer among Jordanian cancer patients (JMOH & JCR, 2008); in addition, it is often complicated and can result in wide range of problems (such as physical, emotional, sexual, and social) that contributed negatively to the patients’ QOL. Moreover, the creation of a stoma for many patients with CRC has a significant and negative influence on the patient’s QOL domains (particularly psychosocial) (Dunn, et al., 2003; Dunn, et al., 2006; Engel et al., 2003; Kristian & Luis, 2008).

**Measures**

Another limitation relates to the use of translated instruments. For example, the translation of the surveys from one language to another can reduce the content validity and generate conceptualized errors in meaning and in the measurement of the selected variables (Esposito, 2001). To address this limitation a widely used and recommended process of translation, based on Brislin’s (1986) model of translation, was performed. The strength of this model lies in the step-back translation through which translation errors can be effectively identified (Yu, et al., 2004). Furthermore, to enhance the generalisation of the findings, the data were collected from three different regional institutions. This outcome provided confidence in the findings being able to truly reflect the Jordanian CRC patients’ perspectives. Importantly, the preliminary analysis was undertaken to assess the reliability of the translated scales before the whole study was conducted.
As the current study aimed to measure the psychosocial aspects (hope, coping, depression, anxiety, and QOL) by using psychological scales, the answers to different questions vary for each particular respondent, based on their mood, psychosocial status, and the affect of the disease. Thus, a preliminary analysis for the pilot sample of.... was undertaken to measure the reliability and consistency using the Cronbach’s alpha before conducting the main study. The researcher acknowledged that the respondents’ psychosocial status (hope, coping, depression and anxiety) could be an impact or influence of a number of factors related to the respondents’ responses to the study survey, such as mood or physical symptoms. Therefore, the use of clear inclusion criteria (e.g. the exclusion of patients with mental/psychiatric problems) limited the impact of these factors. In addition, the researcher instructed the respondents to spend enough time thinking about the questions, and then to answer the items so that they reflected their conditions.

**Phase II**

**Data Collection Approach**

The collecting of data using a semi-structured interview approach has some limitations, including being time consuming, and requiring skill and training before starting the data collection (Holloway & Wheeler, 2006). However, using a semi-structured interview allows participants to express their feelings by providing them with the space and time to talk freely about their emotions; thus, a rich and in-depth resource of data will be collected (Holloway & Wheeler, 2006; Polit & Beck, 2009). To overcome the limitations of using semi-structured interviews, the researcher conducted two interviews to practice and improve his interviewing skills, before conducting the main study. In addition, the interview analysis and interpretation were
undertaken under the close, direct, and comprehensive supervision of two experts (namely, the supervisors).

Another limitation of this phase of the study was the relatively short duration of the interviews, which averaged about 30 minutes each. A longer interview may have elicited more information, however, consideration of the participants’ physical state and degree of tiredness dictated their duration.

RECOMMENDATIONS

The following section discusses the implications of the research in relation to recommendations for future nursing research, practice, education, and health policies.

Recommendations for Nursing Research

The results from the present study have identified a number of psychosocial predictors of QOL at the time of diagnosis and during the treatment period. However, due to time constraints, the study was unable to explain the impact of these factors on medical outcomes (such as physiological outcomes, length of stay at hospital, survival rate and response to treatment). Thus, it is recommended that further research focus on these factors, along with their role as predictors of QOL. Additionally, further research should involve different cancer patient groups to provide comparative data and to identify shared factors that contribute to patient QOL. Such findings will inform the development of standardized intervention protocols, such as psychotherapy intervention programs (Rosenbaum et al., 2004) that focus on enhancing patient QOL using effective coping skills, by sharing thoughts and expressing feelings and by fostering a greater level of hope among the patients.
The findings of the current study highlighted the importance of communication and the sharing of feelings with others. For this reason, group psychotherapy intervention may be more effective and powerful in improving the QOL than individual psychotherapy sessions for patients with CRC, and so require investigation. These recommendations support the notion of sharing by earlier researchers (Dunn, et al., 2003; Dunn, et al., 2006), who strongly recommended conducting further research to integrate the hypothesized factors (such as physical outcomes) on patients’ QOL. Additionally, they highlighted the importance of identifying these predictors in the development of interventional programs.

While the findings of the current study show the importance of nursing support in improving patient QOL (through fostering their ability to manage their condition, inspiring hope, and decreasing confusion by providing appropriate information related to their condition), further research is needed to identify: the types of caring behaviours provided by oncology nurses; and the patient perceptions and satisfaction associated with these behaviours. These findings would help to determine what type of caring skills or behaviours are most beneficial for patients with cancer. Furthermore, research to describe the impact of the nurse-patient communication/interaction on the patients’ outcome (such as length of stay, mortality, and QOL) is recommended. These recommendations support those of Cossette et al. (2005), who saw the importance of assessing the nurse-patient interactions, as well as the impact of effective interactions on the patient’s outcomes, to develop/extend this area of research (Cossette, Cara, Ricard, & Pepin, 2005). Furthermore, enhancing communications, encouraging sharing in the patient’s conversations and assessing the
patient’s satisfaction was identified by Fleischer et al. (2009) as an important area for future research in the health group, and in nursing in particular.

Another area for future study is spirituality. In the current study, spirituality was identified as playing a key role in patient QOL, and was described, in the qualitative phase, as an important element in enhancing patient coping and fostering abilities to manage and handle their cancer diagnosis. However, the spiritual dimensions of QOL were not empirically assessed. Hence, future research to assess the impact of spirituality on patients’ QOL, and the factors that may contribute to patients’ beliefs and attitudes at the time of diagnosis and during the illness period, would be appropriate. Other researchers have also recommended a similar area of study. Krupski et al. (2006) highlighted the need to investigate the relationships between spirituality and HR-QOL, among prostate cancer patients, using interventional research. Further research was also recommended to identify how the relationship between spirituality and HR-QOL could be clinically relevant to the cancer patients’ experience and life (Krupski et al., 2006; Mytko & Knight, 1999).

Importantly, the current study identified coping as a vital factor in helping patients at the time of their diagnosis and during their illness period. Indeed, different coping strategies enabled the patients to manage their situation in a positive manner, in addition to improving their QOL. Consequently, further research, using Structured Equation Modeling (SEM), is recommended to determine what factors mediate or contribute to the effective use of coping strategies. This knowledge will help the patients to use and perform such strategies to minimise the impediments that reduce the patients’ coping abilities. This recommendation is consistent with that of Chan and
colleagues (2004), who recommended further work to understand the coping strategies used by patients undergoing cancer surgery. Such knowledge would greatly assist in the development of more effective care programs for oncology patients (Chan, Hon, Chien, & Lopez, 2004). Furthermore, there is a strong recommendation for conducting subgroup analysis between patients with stoma and those without to determine if there is any difference in their QOL.

The final recommendation is that research be undertaken to clearly identify the relationship between psychological distress and QOL among CRC patients. The knowledge and understanding gained would inform the development of an effective intervention program to improve the patient’s QOL through decreasing their psychological distress and reducing other aggravating factors. These recommendations are consistent with those of Mystakidou and colleagues (2005). They concluded that increased understanding of the most common psychological distress will enable researchers to establish and apply interventional protocols which will lead to improvements in clinical care (Mystakidou, et al., 2005).

**Recommendations for Nursing Practice**

An important area needing further research is in relation to nursing practice. Generally, nurses are more involved in the direct care of cancer patients than are other professionals. They are responsible for providing helpful, meaningful interventions that maintain and improve patients’ level of hope and encourage them to use a range of coping strategies to improve their QOL.

The assessment of psychosocial elements (such as hope, coping, depression and anxiety) should be a part of daily nurse caring behaviours and practices. Indeed, it is
essential that nurses assess and evaluate the patient’s coping strategies, while identifying what factors contribute to the effectiveness of these coping styles (all a part of their nursing practice). Additionally, nurses should conduct intervention workshops, incorporating programs to teach and enhance the patients’ abilities through the use of effective coping strategies, as well as strategies to maintain and increase hope. Furthermore, the current study and those of others (Cotrim & Pereira, 2008; Honda, et al., 2005; Nugent, Daniels, Stewart, Patankar, & Johnson, 1999) highlight the need to assess the patient’s emotional status and their reactions to having cancer. For this to occur, to the patient’s benefit, collaboration between health team professionals (such as psychologists, nurses and social workers) is required to provide and maintain the full and optimal care needed by the cancer patients.

The importance of future research into the psycho-education area, and daily assessment of the psychological predictors, such as hope, and coping, was also recommended by Matsushita and colleagues (2005). They rationalized that, by explaining this approach, the patients with cancer would be able to utilize more appropriate, as well as different, styles of coping strategies. Furthermore, the daily assessment would help in following up the patient’s psychological conditions (Matsushita, et al., 2005).

Recently, the care system for cancer patients has shifted from the in-patient clinic to the at-home setting (Shattell, 2004). Accordingly, family involvement in patient care has also undergone a change, with the family performing an essential role in the treatment plan (Given, et al., 2001). Shifting care to the at-home setting, and involving the family in the care plan, has identified the need for health care
professionals to prepare and teach the families how to provide appropriate care. Thus, the family is now instrumental in offering guidance, advice and an appropriate treatment plan (Given, et al., 2001; Shattell, 2004). This need has also been further supported by the current study, especially in relation to the vital role of communication between the patients and their families. Hence, it is recommended that more research be undertaken that will assist nurses to develop and use an effective range of communication strategies to facilitate the two-way flow of information, such as face-to-face, group teaching, and demonstration. These findings, along with those from the current study, will facilitate the incorporation of these approaches into a nurse’s daily clinical practice, and encourage discussion of the main issues of concern to the patient and their family (the treatment plan, possible complications and their treatment or prevention). These recommendations support the previous work of Davis et al. (2003); namely, that different strategies (such as conferences and meetings) be implemented to enhance the communication between nurse and patients/families.

**Recommendations for Nursing Education**

The current study also makes recommendations in relation to nurse education. Of particular importance is the impact of the psychological status on the patients’ QOL and health status. Therefore, improving nursing education around psychosocial assessment and training nurses in how to provide psychosocial support for patients diagnosed with life-threatening diseases, such as cancer, is an important issue in nursing education and preparation. Accordingly, there is the need to develop an educational support program for the oncology nurses, starting from strategies on how to assess the cancer patient’s psychosocial status and QOL, to how to relate to cancer patients at all stages of their illness (i.e. diagnosis, during the treatment period, and
crisis management). For this reason, extensions to the undergraduate and postgraduate oncology nursing programs are strongly recommended to enhance the nurses’ abilities to help their patients manage problems associated with cancer, particularly CRC. Additionally, there is the need to educate nursing students about the psychosocial effects of cancer, from its early management, to providing a comprehensive care plan. Other researchers have made similar recommendations to enhance the curriculum for undergraduate and postgraduate nursing students (Gaffan, Dacre, & Jones, 2006).

Furthermore, there is a recommendation for education relating to cross-cultural communication and negotiation to assist nursing students, registered nurses and physicians to obtain and understand culture-specific information during assessment and implementation of nursing and medical care plans for patients with CRC. The practice paradigm of caring for any patient demands that health professionals be well trained to handle diverse cultural expectations, practices and perspectives on health care. To achieve this goal, both educators and trainees must acknowledge and address the need to modify the current educational systems to cover cross-cultural perspectives.

**Recommendations for Health Care Policy**

Within any health care policy, professional intervention is important in improving care for cancer patients (Reiss & Gibson, 2002), thus, there is the need to provide patient consultations that maintain and inspire hope, and coping. The current study highlighted the importance of effective/positive nurse-patient communication, and the essential contributions made by professional support teams during the illness period. Therefore, it is the responsibility of the health system to build a positive environment
in which care can be given to cancer patients. To this end, the current study recommends the implementation of three strategies. The first involves providing leadership and advocacy. Other researchers have also recommended strategies to increase awareness, establish open and regular channels of communication between health organizations to establish standard interventional programs, and the sharing of knowledge and experiences (Epping-Jordan, Pruitt, Bengoa, & Wagner, 2004).

The second strategy involves establishing management plans for all patients rather than having a management plan for one patient at a time. This “care pathway”, originally developed by Pearson and colleagues (1995), would be developed by setting plans for patients with CRC that aimed to maximize the quality of care by improving patient medical outcomes, patient safety, and increasing patient satisfaction about the care. To be most effective, the plan would need to encompass prevention, promotion, and control strategies, along with explicit links to other governmental programmes and community-based organizations (Pearson, Goulart-Fisher, & Lee, 1995).

The third strategy involves maintaining consistent financial support in order to translate recommended strategies (education, research, workshops) into reality (Pearson, et al., 1995). This continued financial support will enable the health institutions to implement the following strategies to improve the quality of care, namely: ambulatory oncology clinics to implement practices such as online-consultations (e.g. a cancer help line); as well as online consultation programs that would enable the patients to consult a range of health professionals and maintain any
follow-up support that is required, including psycho-educational support (Haggerty et al., 2003).

**CONCLUSIONS**

The diagnosis of a critical disease, such as cancer, is considered a disaster for the patient and their family, relatives and friends. Indeed, this devastating reality has the patient and their loved-ones seeking help from a range of interventions (new developments in medicine, medical technology, different treatment modalities), and a range of health professionals, as well as being surrounded by family and friends. While the role of the health professional and level of medical care is important, coping strategies that enhance QOL are also important. This is especially so as the diagnosis changes a person’s perception of his/her life, breaks-down their life’s rhythms, and disrupts their plans and goals for the future. In addition, cancer diagnosis generates a range of emotional, psychological, and social distress due to new and debilitating health conditions, physical symptoms, and complications of treatment modalities. Clearly, these and other changes are often followed by fears of being a burden or socially isolated, and changes to their meaning of life, which can lead to a decline in their QOL.

The current study has been important in extending our understanding of the QOL for Jordanian CRC patients. The data and framework allowed for an investigation into the psychosocial predictors of QOL, at the time of diagnosis and during the active treatment period. In addition, the results identified the impact of CRC on the patients’ QOL, as well as their lives. While supporting prior research findings, the current findings underline the importance of these psychosocial factors on the patient’s QOL. Further, the study: provided a comprehensive description of the patients’ experiences
following their diagnosis of CRC; highlighted the common intrusive thoughts that patients must learn to handle, and how the patients’ perceptions needed to change to enable them to bring meaning back into their life. The results also provide a greater understanding of the essence of QOL, by identifying their associations and their implications for future therapy.

Furthermore, in terms of the conceptualization of the QOL term, the current study’s phases (both quantitative and qualitative) provide a holistic approach and a clearer picture of QOL as an important concept in CRC patients. In fact, Phase I of the current study has focused on assessing HR-QOL, while Phase II extended this, as well as extending our understanding about QOL through explaining, in-depth, the impact of disease (CRC), treatment, and complications on the patients’ QOL. Thus, it is important to identify the factors that influence and impact upon the patients’ QOL, such as staff support, spirituality, and attitudes towards life and prognosis. Such information captures both the subjective and objective views of QOL, and addresses the QOL from different perspectives.

Importantly, the present study identified the importance of undertaking psychosocial assessment and intervention within daily nursing practice. The study also showed the essential role played by educating and preparing medical professionals and nurses with enough skills and knowledge to enable them to assess and diagnose the psychosocial problems that exist among cancer patients. There appears to be a need to develop and utilize a psycho-educational program to improve the patients’ QOL, and to prevent or minimize the impact of CRC diagnosis and treatment.
Significantly, the current study concluded that providing patients and their families with sufficient, useful, and powerful resources to minimize feelings of fear, stress, anxiety, denial, worry about the future, and fear of the unknown.

Importantly, the original instruments used in the current study were developed and conceptualized in different cultures and languages. These instruments were tested and used in different countries around the world, and showed high reliability. Nevertheless, the increasing diversity in populations worldwide, and the need for cross-cultural studies have highlighted the need for well-developed, valid, reliable and useful instruments that can be used with different languages-speakers. Thus, using a standard translation process enhances the validity and applicability of these instruments.

In the current study, the scales were used by non-native speakers (Arabic speakers). Thus, a well-standard translation process was performed; as discussed earlier, the results showed high reliability of the translated surveys. This finding has clinical implications for physicians, nurses and other health professionals who provide care for diverse populations. Clearly, quality care depends on the accurate assessment and deeper understanding of an individual’s cultural, linguistic and ethnic background. Therefore, the researcher has provided the authors of the original instruments (specifically JCS, HHI) with copies (Arabic) to be used in the future.

Finally, this mixed-method study allowed oncology care-giving research to be optimised, especially in relation to the nursing care for cancer patients. This outcome was achieved by identifying the elements that contributed to, and predicted, the patients’ QOL. To continue to improve the care given to cancer patients, further studies need to focus on a wider range of elements and outcomes, as well as test the
effectiveness of interventional studies/programs that will enable a more effective implementation of strategies/plans for patients with a cancer diagnosis.
REFERENCES


APPENDIX

Information Sheet

Title: Psychosocial Predictors of Quality of Life (QOL) among Jordanian Colorectal Cancer Patients

Researchers

- **Loai M. Abu Sharour RN, MN (Hon), PhD candidate.** Nursing & Midwifery School. Griffith University. Gold Coast. Queensland. Australia

- **Professor Elizabeth Patterson RN, BSc, GradDipNursSt, MHSc (N), PhD.** Head of Nursing & Midwifery School. Griffith University. Gold Coast. Queensland. Australia.

- **Dr Brigid Gillespie RN, RM, BHlth Sc (Hons), PhD.** Nursing & Midwifery School. Griffith University. Gold Coast. Queensland. Australia.

This study is aimed to (1) explore the relationships between coping, hope and psychological distress and QOL, (2) identify predictors of QOL, and (3) describe experiences and perceptions about QOL during illness period among Jordanian CRC patients through using both quantitative followed by qualitative approach in two phases.

The incidence and prevalence of CRC is increasing worldwide, and in Jordan particularly. In spite of increasing in survival rate, CRC patients are experiencing physical, psychological, and emotional effects. QOL is considered one of the main factors that increasing survival rate and offer patients power for cancer fighting. Numerous studies were examined the factors associated with QOL among CRC patients, the majority were focused on demographical factors, treatment and disease-related factors, patients-related factors, and meaning of illness from physical domain mainly.

Enhancing knowledge of QOL predictors will further understanding and enable nursing care to be more focused toward the specific needs and demands of the individual patient particularly in relation to problems and restrictions in daily living. The findings that arise from this study will inform the care that Jordanian nurses provide for this particular group of patients. The findings may also inform the ways in which QOL strategies may be integrated in nursing education, practice, research and policy making.

Please note that you have full right to decide voluntarily whether to participate in a study, right to full-disclosure, and refuse participation. If you have any queries/concerns related to this study, please do not hesitate to contact the student researcher (the hospital has contact details). Additionally, you can inform the ethical committee at the hospital about your concerns.

Thank you: Loai Mohammad Abu Sharour
CONSENT FORM FOR PARTICIPATION IN RESEARCH

I ………………………………………………………………………………………………………………………………..
being over the age of 18 years hereby consent to participate as requested in the Survey and follow-up interview for the research project on Psychosocial Predictors of QOL among Jordanian Colorectal cancer Patients.

1. I have read the information provided. The research explained the purposes and methods of the research to my satisfaction.

2. Details of procedures and any risks have been explained to my satisfaction.

3. I agree to audio recording of my information and participation.

4. I understand that:
   • I may not directly benefit from taking part in this research.
   • I am free to withdraw from the project at any time and am free to decline to answer particular questions.
   • While the information gained in this study will be published as explained, I will not be identified, and individual information will remain confidential.
   • Whether I participate or not, or withdraw after participating, will have no effect on any treatment or service that is being provided to me.
   • I may ask to participate in the phase II of this study through semi-structured interview. During this I understand that the audio recording be stopped at any time, and that I may withdraw at any time from the session or the research without disadvantage.

5. I have had the opportunity to discuss taking part in this research with a family member or friend.

Participant’s signature……………………………………Date……………………..
I certify that I have explained the study to the participants and consider that she/he understands what is involved and freely consents to participation.

**Researcher’s name**……………………………………………………………………………….

**Researcher’s signature**…………………………………*Date*…………………………

6. I, the participant whose signature appears below, have read a transcript of my participation and agree to its use by the researcher as explained.

**Participant’s signature**……………………………………*Date*…………………………

7. I, the participant whose signature appears below, have read the researcher’s report and agree to the publication of my information as reported.

**Participant’s signature**……………………………………*Date*…………………………
Appendix B
Individuals Items: Demographic and Disease-Related Items

This section has general demographic, patient-related factors, and treatment-related factors.
Please write and tick for the following questions

☐ Hospital Name: KAUH ☐ JUH ☐ AL-Bashir ☐

☐ Patient Name:
☐ File Number:
☐ Age:
☐ Gender: Male ☐ Female ☐

☐ Educational Level:
☐ Illiterate ☐ Primary ☐ Secondary
☐ Diploma ☐ Undergraduate (Bachelor) Degree
☐ Postgraduate Degree

☐ Marital Status
☐ Single ☐ Married
☐ Widow ☐ Divorce

☐ Annual Income: plib--------------------JD

☐ Family Member Number: .................

☐ Religion:
☐ Muslim ☐ Christian ☐ Other (please Specify: ............

☐ Tumor Site:
☐ Primary Tumor Stage :
☐ Regional Metastasis :
☐ Time Since diagnosis: ................. Month

☐ Treatment Modalities
☐ Chronic disease
☐ Complications
### Appendix C

**Jalowiec Coping Scale**

<table>
<thead>
<tr>
<th>Coping method</th>
<th>Part A: How often have you used each coping method?</th>
<th>Part B: If you have used that coping method, how helpful was it?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Never Used</td>
<td>seldom Used</td>
</tr>
<tr>
<td>1. Worried about the problem</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>2. Hoped that things would get better</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>3. Ate or smoked more than usual</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>4. Thought out different ways to handle the situation</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>5. Told yourself that things could be much worse</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>6. Exercised or did some physical activity</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>7. Tried to get away from the problem for a while</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>8. Got made and let off steam</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>9. Expected the worst that could happen</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>10. Tried to put the problem out of your mind and think of something else</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Description</td>
<td>0</td>
</tr>
<tr>
<td>---</td>
<td>----------------------------------------------------------------------------</td>
<td>---</td>
</tr>
<tr>
<td>11.</td>
<td>Talked the problem over with family or friends</td>
<td></td>
</tr>
<tr>
<td>12.</td>
<td>Accepted the situation because very little could be done</td>
<td></td>
</tr>
<tr>
<td>13.</td>
<td>Tried to look at the problem objectively and see all sides</td>
<td></td>
</tr>
<tr>
<td>14.</td>
<td>Daydreamed about a better life</td>
<td></td>
</tr>
<tr>
<td>15.</td>
<td>Talked the problem over with a professional person (such as a doctor, nurse, minister, teacher)</td>
<td></td>
</tr>
<tr>
<td>16.</td>
<td>Tried to keep the situation under control</td>
<td></td>
</tr>
<tr>
<td>17.</td>
<td>Prayed or put your trust in god</td>
<td></td>
</tr>
<tr>
<td>18.</td>
<td>Tried to get out of the situation</td>
<td></td>
</tr>
<tr>
<td>19.</td>
<td>Kept your feelings to yourself</td>
<td></td>
</tr>
<tr>
<td>20.</td>
<td>Told yourself that the problem was someone else's fault</td>
<td></td>
</tr>
<tr>
<td>21.</td>
<td>Waited to see what would happen</td>
<td></td>
</tr>
<tr>
<td>22.</td>
<td>Wanted to be alone to think things out</td>
<td></td>
</tr>
<tr>
<td>23.</td>
<td>Resigned yourself to the situation because things looked hopeless</td>
<td></td>
</tr>
<tr>
<td>24.</td>
<td>Took out your tensions on someone else</td>
<td></td>
</tr>
<tr>
<td>25.</td>
<td>Tried to change the situation</td>
<td></td>
</tr>
<tr>
<td>26.</td>
<td>Used relaxation techniques</td>
<td></td>
</tr>
</tbody>
</table>
27. Tried to find out more about the problem  | 0 | 1 | 2 | 3 | 0 | 1 | 2 | 3
28. Slept more than usual                  | 0 | 1 | 2 | 3 | 0 | 1 | 2 | 3
29. Tried to handle things one step at a time | 0 | 1 | 2 | 3 | 0 | 1 | 2 | 3
30. Tried to keep your life as normal as possible and not let the problem interfere | 0 | 1 | 2 | 3 | 0 | 1 | 2 | 3
31. Thought about how you had handled other problems in the past | 0 | 1 | 2 | 3 | 0 | 1 | 2 | 3
32. Told yourself not to worry because everything would work out fine | 0 | 1 | 2 | 3 | 0 | 1 | 2 | 3
33. Tried to work out a compromise        | 0 | 1 | 2 | 3 | 0 | 1 | 2 | 3
34. Took a drink to make yourself feel better | 0 | 1 | 2 | 3 | 0 | 1 | 2 | 3
35. Let time take care of the problem     | 0 | 1 | 2 | 3 | 0 | 1 | 2 | 3
36. Tried to distract yourself by doing something that you enjoy | 0 | 1 | 2 | 3 | 0 | 1 | 2 | 3
37. Told yourself that you could handle anything no matter how hard | 0 | 1 | 2 | 3 | 0 | 1 | 2 | 3
38. Set up a plane of action              | 0 | 1 | 2 | 3 | 0 | 1 | 2 | 3
39. Tried to keep a sense of humor        | 0 | 1 | 2 | 3 | 0 | 1 | 2 | 3
40. Put off facing up to the problem      | 0 | 1 | 2 | 3 | 0 | 1 | 2 | 3
41. Tried to keep your feeling under control | 0 | 1 | 2 | 3 | 0 | 1 | 2 | 3
42. Talked the problem over with someone who had been in a similar situation | 0 | 1 | 2 | 3 | 0 | 1 | 2 | 3
<p>| | | | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>43. Practiced in your mind what had to be done</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>44. Tried to keep busy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>45. Learned some thing new in order to deal with the problem better</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>46. Did some thing impulsive or risky that you would not usually do</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>47. Thought about the good thing in your life</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>48. Tried to ignore or avoid the problem</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>49. Compared your self with other people who were in the same situation</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>50 tried to think positively</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>51. Blamed yourself for getting such a situation</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>52. Preferred to thing work thing out yourself</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>53. Took medications to reduce tension</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>54. Tried to see the good side of the situation</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>55. Told yourself that this problem was really not that important</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>56. Avoided being with people</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>57. Tried to improve yourself in some way so you could handle the situation better</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>58. Wished that the problem would go away</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>
If there are any other things you did to handle the stress mentioned at the beginning. That are not on the list, please write those coping methods in the spaces below. Then circle how often you have used each coping method, and how helpful each coping method has been.

<table>
<thead>
<tr>
<th></th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td>59. Depended on others to help you out</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td>60. Told yourself that you were just having some bad luck</td>
<td></td>
<td></td>
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<td>63.</td>
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<td>64.</td>
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<tr>
<td>65.</td>
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</tbody>
</table>
### APPENDIX D

**FUNCTIONAL ASSESSMENT OF CANCER THERAPY-COLORECTAL (FACT-C)**

Below is a list of statements that other people with your illness have said are important. By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.

<table>
<thead>
<tr>
<th>PHYSICAL WELL-BEING</th>
<th>Not at all</th>
<th>A little bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>GP1</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>GP2</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>GP3</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>GP4</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>GP5</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>GP6</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>GP7</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SOCIAL/FAMILY WELL-BEING</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Not at all</th>
<th>A little bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>GS1</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>GS2</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>GS3</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>GS4</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>GS5</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Question</td>
<td>Description</td>
<td>Options</td>
<td></td>
<td></td>
</tr>
<tr>
<td>----------</td>
<td>-------------</td>
<td>---------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>GS6</td>
<td>I feel close to my partner (or the person who is my main support)</td>
<td>0 1 2 3 4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q1</td>
<td>Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please check this box and go to the next section</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>GS7</td>
<td>I am satisfied with my sex life</td>
<td>0 1 2 3 4</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.*

**EMOTIONAL WELL-BEING**

<table>
<thead>
<tr>
<th>Question</th>
<th>Description</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>GE1</td>
<td>I feel sad</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>GE2</td>
<td>I am satisfied with how I am coping with my illness</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>GE3</td>
<td>I am losing hope in the fight against my illness</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>GE4</td>
<td>I feel nervous</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>GE5</td>
<td>I worry about dying</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>GE6</td>
<td>I worry that my condition will get worse</td>
<td>0 1 2 3 4</td>
</tr>
</tbody>
</table>

**FUNCTIONAL WELL-BEING**

<table>
<thead>
<tr>
<th>Question</th>
<th>Description</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>GF1</td>
<td>I am able to work (include work at home)</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>GF2</td>
<td>My work (include work at home) is fulfilling</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>GF3</td>
<td>I am able to enjoy life</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td></td>
<td>I have accepted my illness</td>
<td>0</td>
</tr>
<tr>
<td>---</td>
<td>----------------------------</td>
<td>---</td>
</tr>
<tr>
<td>GF4</td>
<td>I am sleeping well</td>
<td>0</td>
</tr>
<tr>
<td>GF5</td>
<td>I am enjoying the things I usually do for fun</td>
<td>0</td>
</tr>
<tr>
<td>GF6</td>
<td>I am content with the quality of my life right now</td>
<td>0</td>
</tr>
<tr>
<td>GF7</td>
<td>By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.</td>
<td></td>
</tr>
<tr>
<td>ADDITIONAL CONCERNS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>C1</td>
<td>I have swelling or cramps in my stomach area</td>
<td>0</td>
</tr>
<tr>
<td>C2</td>
<td>I am losing weight</td>
<td>0</td>
</tr>
<tr>
<td>C3</td>
<td>I have control of my bowels</td>
<td>0</td>
</tr>
<tr>
<td>C4</td>
<td>I can digest my food well</td>
<td>0</td>
</tr>
<tr>
<td>C5</td>
<td>I have diarrhea</td>
<td>0</td>
</tr>
<tr>
<td>C6</td>
<td>I have a good appetite</td>
<td>0</td>
</tr>
<tr>
<td>C7</td>
<td>I like the appearance of my body</td>
<td>0</td>
</tr>
<tr>
<td>Q2</td>
<td>Do you have an ostomy appliance? (Check one box)</td>
<td>No □ or Yes □</td>
</tr>
<tr>
<td></td>
<td>If yes, please answer the next two items:</td>
<td></td>
</tr>
<tr>
<td>C8</td>
<td>I am embarrassed by my ostomy appliance</td>
<td>0</td>
</tr>
<tr>
<td>C9</td>
<td>Caring for my ostomy appliance is difficult</td>
<td>0</td>
</tr>
</tbody>
</table>
**FACT-C Scoring Guidelines** (Version 4)

Instructions:*  
1. Record answers in "item response" column. If missing, mark with an X.  
2. Perform reversals as indicated, and sum individual items to obtain a score.  
3. Multiply the sum of the item scores by the number of items in the subscale, then divide by the number of items answered. This produces the subscale score.  
4. Add subscale scores to derive total FACT-G score. *The higher the score, the better the QOL.*

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Item Code</th>
<th>Reverse item?</th>
<th>Item response</th>
</tr>
</thead>
<tbody>
<tr>
<td>PHYSICAL</td>
<td>GP1</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>=</td>
<td></td>
</tr>
<tr>
<td>WELL-BEING (PWB)</td>
<td>GP2</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>=</td>
<td></td>
</tr>
<tr>
<td></td>
<td>GP3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>=</td>
<td></td>
</tr>
<tr>
<td></td>
<td>GP4</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>=</td>
<td></td>
</tr>
<tr>
<td></td>
<td>GP5</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>=</td>
<td></td>
</tr>
<tr>
<td></td>
<td>GP6</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>=</td>
<td></td>
</tr>
<tr>
<td></td>
<td>GP7</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>=</td>
<td></td>
</tr>
</tbody>
</table>

Score range: 0-28

**Sum individual item scores:**

________

*Multiply by 7:*

Multiplying by 7:  

________  

= PWB subscale score

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Item Code</th>
<th>Reverse item?</th>
<th>Item response</th>
</tr>
</thead>
<tbody>
<tr>
<td>SOCIAL/FAMILY</td>
<td>GS1</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>=</td>
<td></td>
</tr>
<tr>
<td>WELL-BEING (SWB)</td>
<td>GS2</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>=</td>
<td></td>
</tr>
<tr>
<td></td>
<td>GS3</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>=</td>
<td></td>
</tr>
<tr>
<td></td>
<td>GS4</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>=</td>
<td></td>
</tr>
<tr>
<td></td>
<td>GS5</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>=</td>
<td></td>
</tr>
<tr>
<td></td>
<td>GS6</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>=</td>
<td></td>
</tr>
<tr>
<td></td>
<td>GS7</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>=</td>
<td></td>
</tr>
</tbody>
</table>

Score range: 0-28

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Item Code</th>
<th>Reverse item?</th>
<th>Item response</th>
</tr>
</thead>
</table>

**Divide by number of items answered:**

________
Sum individual item scores:

\[ \text{Multiply by 7: } \quad \]
\[ \text{Divide by number of items answered:} \quad \]

\[ \square = \text{SWB subscale score} \]

<table>
<thead>
<tr>
<th>EMOTIONAL WELL-BEING (EWB)</th>
<th>GE1</th>
<th>GE2</th>
<th>GE3</th>
<th>GE4</th>
<th>GE5</th>
<th>GE6</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>4</td>
<td>0</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>4</td>
</tr>
</tbody>
</table>

Score range: 0-24

\[ \square = \text{EWB subscale score} \]

<table>
<thead>
<tr>
<th>FUNCTIONAL WELL-BEING (FWB)</th>
<th>GF1</th>
<th>GF2</th>
<th>GF3</th>
<th>GF4</th>
<th>GF5</th>
<th>GF6</th>
<th>GF7</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

Score range: 0-28

\[ \square = \text{FWB subscale score} \]

TOTAL SCORE:

\[ \square + \square + \square + \square = \square = \text{FACT-C Total score} \]

(PWB score) (SWB score) (EWB score) (FWB score) + (additional concern)
# APPENDIX E

**HERTH HOPE INDEX**

Listed below are a number of statements. Read each statement and place an (X) in the box that describes how much you agree with that statement right now.

<table>
<thead>
<tr>
<th></th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>I have a positive outlook toward life.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td>I have short and/or long range goals</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td>I feel all alone</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td>I can see possibilities in the midst of difficulties</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td>I have a faith that gives me comfort</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6.</td>
<td>I feel scared about my future</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7.</td>
<td>I can recall happy/joyful times</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8.</td>
<td>I have deep inner strength</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9.</td>
<td>I am able to give and receive caring/love</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10.</td>
<td>I have a sense of direction</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11.</td>
<td>I believe that each day has potential</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12.</td>
<td>I feel my life has value and worth.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix F: Hospital Anxiety and Depression Scale (HADS)

Hospital Anxiety and Depression Scale (HADS)

<table>
<thead>
<tr>
<th>Name:</th>
<th>Date: ___________________________</th>
</tr>
</thead>
</table>

Clinicians are aware that emotions play an important part in most illnesses. If your
clinician knows about these feelings he or she will be able to help you more.

This questionnaire is designed to help your clinician to know how you feel. Read each
item below and underline the reply which comes closest to how you have been feeling
in the past week. Ignore the numbers printed at the edge of the questionnaire.

Don't take too long over your replies, your immediate reaction to each item will
probably be more accurate than a long, thought-out response.

<table>
<thead>
<tr>
<th>A</th>
<th>D</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel tense or 'nervous'</td>
<td>I feel as if I may have a panic attack</td>
</tr>
<tr>
<td>Most of the time</td>
<td>Nearly all the time</td>
</tr>
<tr>
<td>A bit of the time</td>
<td>Very often</td>
</tr>
<tr>
<td>Occasionally</td>
<td>Sometimes</td>
</tr>
<tr>
<td>Not at all</td>
<td>Not at all</td>
</tr>
<tr>
<td>I still enjoy the things I used to enjoy</td>
<td>I get a sort of frightened feeling</td>
</tr>
<tr>
<td>Definitely as much</td>
<td>'butterflies' in the stomach</td>
</tr>
<tr>
<td>Not quite as much</td>
<td>Not at all</td>
</tr>
<tr>
<td>Only a little</td>
<td>Occasionally</td>
</tr>
<tr>
<td>Hardly at all</td>
<td>Quite often</td>
</tr>
<tr>
<td>I get a sort of frightened feeling as if something awful is about to happen</td>
<td>I have lost interest in my appearance</td>
</tr>
<tr>
<td>Very definitely and quite badly</td>
<td>Definitely</td>
</tr>
<tr>
<td>Yes, but not too badly</td>
<td>I don't take as much care as I should</td>
</tr>
<tr>
<td>A little, but it doesn't worry me</td>
<td>I may not take quite as much care as I</td>
</tr>
<tr>
<td>Not at all</td>
<td>I take just as much care as ever</td>
</tr>
<tr>
<td>I can laugh and see the funny side of things</td>
<td>I feel restless as I have to be on the move</td>
</tr>
<tr>
<td>As much as I always could</td>
<td>Very much</td>
</tr>
<tr>
<td>Not quite so much now</td>
<td>Quite a lot</td>
</tr>
<tr>
<td>Definitely not so much now</td>
<td>Not very much</td>
</tr>
<tr>
<td>Not at all</td>
<td>Not at all</td>
</tr>
<tr>
<td>Worrying thoughts go through my mind</td>
<td>I look forward with enjoyment to things</td>
</tr>
<tr>
<td>A great deal of the time</td>
<td>Rather less than I used to</td>
</tr>
<tr>
<td>A lot of the time</td>
<td>Definitely less than I used to</td>
</tr>
<tr>
<td>Not too often</td>
<td>Hardly at all</td>
</tr>
<tr>
<td>Very little</td>
<td>I get sudden feelings of panic</td>
</tr>
<tr>
<td>I feel cheerful</td>
<td>Very often</td>
</tr>
<tr>
<td>Never</td>
<td>Quite often</td>
</tr>
<tr>
<td>Not often</td>
<td>Not very often</td>
</tr>
<tr>
<td>Sometimes</td>
<td>Not at all</td>
</tr>
<tr>
<td>Most of the time</td>
<td>I can enjoy a good book or radio or</td>
</tr>
<tr>
<td>I can sit at ease and feel relaxed</td>
<td>television programme</td>
</tr>
<tr>
<td>Definitely</td>
<td>Often</td>
</tr>
<tr>
<td>Usually</td>
<td>Sometimes</td>
</tr>
<tr>
<td>Not often</td>
<td>Not often</td>
</tr>
<tr>
<td>Not at all</td>
<td>Very seldom</td>
</tr>
</tbody>
</table>

Now check that you have answered all the questions.
Appendix G
Ethical Permissions for Conducting the Study

16-Mar-2009

Dear Mr Abu Sharour

I write further to the additional information provided in relation to the provisional approval granted to your application for ethical clearance for your project "Psychosocial Predictors of Quality of Life (QOL) among Jordanian Colorectal Cancer Patients: A Mixed-Method Study" (GU Ref No: NRS/29/08/HREC).

The additional information was considered by Office for Research.

This is to confirm that this response has addressed the comments and concerns of the HREC.

Consequently, you are authorised to immediately commence this research on this basis.

The standard conditions of approval attached to our previous correspondence about this protocol continue to apply.

Regards

Dr Gary Allen
Manager, Research Ethics
Office for Research
Bray Centre, Nathan Campus
Griffith University
ph: 3735 5585
fax: 3735 7994
email: g.allen@griffith.edu.au
web:

Cc:

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Dr. Elizabeth Patterson  
Associate Professor  
School of Nursing and Midwifery  
Griffith University  
Australia

Dear Dr. Elizabeth,

Referring to your letter of 1st May 2008 in which you confirm that Mr. Losi Mohammad Junnah Abu Shour is currently studying for a PhD in the School of Nursing at Griffith University, and researching to explore Psychosocial predictors of QOL among Jordanian colorectal cancer patients.

We are pleased to allow Mr. Losi Abu Shour to conduct his research in our hospital for the purpose mentioned above.

Hoping that you will provide us with the final results of the research.

Sincerely,

Prof. Mahmoud Al-Sheyyab  
Acting CEO, KAUH  
Vice President, JUIN

[signature]

Tel. 1921  Fax: 1923  E-mail: jass@jass.com  Bk: 630011  Ibl: 123110  Jordan  6 grade: online post education
Associate Professor Elizabeth Paterson  
Dean and Head of Nursing and Midwifery School  
Griffith University  
Australia  
E-mail: s.bray@griffith.edu.au  

Dear Prof. Paterson,

With regard to your letter, dated on 1st May 2008, concerning seeking permission for Mr. Loai Abu Sharour to conduct a research project including having access to the medical records of patients with colorectal cancer as well as involving them into a written questionnaire and interviews.

We would like to inform you with our approval to give Mr. Abu Sharour permission to conduct his research project at the hospital.

With Regards,

General Director / Jordan University Hospital
Prof. Dr. Abdelkareem Al-Qudah

Copy:
- Vice Director for Medical Affairs.
- Head of Interior Medicine Department.

/ R.D
16th February 2009

Manager, Research Ethics
Bray Centre
Nathan Campus
Office for Research, Griffith University

Dear Dr Allen

This is to certify that Ghazi Alhamed is working to be a counsellor for the project conducted under the title of "Psychosocial predictors of QOL among Jordanian Colorectal cancer patients (GUn Ref No: NRS/29/08/HREC)" by Loan Mohammad Abu Sharo.

His role as following:

- Supervision research conducting by the researcher, and promptly notified if a complaints received by any of the Jordanian participants.
- Provide support/assistance if the participants become distressed during interview.
- Results and feedbacks communication.

This also to certify that the oncology nurse at the oncology department approaches patients who interesting to participate and then the student research approach the patients.

Kind regards

Ghazi Alhamed, PhD Hospital Administration
Administrative assistant/Radiotherapy Department, Hospital
0011-9627956686

Ref. 16th February 2009

Manager, Research Ethics
Bay Centre
Nathan Campus
Office for Research, Griffith University

Dear Dr. Allen,

This is to certify that MR KHALAF AHMAD AL-HARAHSHEH is working as a counsellor for the project conducted under title of "psychological predictors of QOL among Jordanian Colorectal cancer patients (GU Ref No: NRS/29/068/11R/IC)"

Lout Mohammad Abu Sharour. His role is as following:

- Supervision research conducting by the researcher, and promptly notified if a complaints received by any of the Jordanian participants.
- Provide support/assistance if the participants become distressed during interview.
- Results and feedbacks communication.

This also to certify that the oncology nurse in the oncology department approach patients who interesting to participate and then the student research approach if patients.

Kind regards
MR KHALAF AHMAD AL-HARAHSHEH, BSN,CNS
Head of oncology-hematology department
KAUH
Tel: 00962-2-7700600, ext: 40306

Appendix H
A Sample of Interview Guide

**Example of**

**Semi-structure Interview Questions**
How has your life changed since your diagnosis with Colorectal Cancer including:

- Physical Well-being (Weight changes, Bowel control, Sleeping pattern, pain)
- Social / family life
- Emotional well-being
- Functional well-being (daily activity, employment)
- Sexual life
- Spiritual and religious life

What does quality of life (QOL) mean to you?
How has your QOL changed since your diagnosis of colorectal cancer?
What factors influence how you cope with your condition?
What does hope mean to you?
What factors foster hope in you?
Where does your inner strength (hope) come from? And how do you maintain this level of hope?
What situations/events make you feel anxious and/or depressed?
What kinds of things have you found yourself thinking about since your diagnosis?
How has your colorectal cancer diagnosis affected your QOL? And if you have a colostomy, how has this affected your QOL?
What are you doing to overcome or manage your feeling of depression and anxiety?
Appendix I

Frequency and Percentage of JCS Items
<table>
<thead>
<tr>
<th>Coping method</th>
<th>Part A</th>
<th>Part B</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>How often have you used each coping method?</td>
<td>If you have used that coping method, how helpful was it?</td>
</tr>
<tr>
<td></td>
<td>Never Used</td>
<td>seldom Used</td>
</tr>
<tr>
<td></td>
<td>N (%)</td>
<td>N (%)</td>
</tr>
<tr>
<td>Worried about the problem</td>
<td>18 (6.9)</td>
<td>106 (40.8)</td>
</tr>
<tr>
<td>Hoped that things would get better</td>
<td>1 (0.4)</td>
<td>16 (6.2)</td>
</tr>
<tr>
<td>Ate or smoked more than usual</td>
<td>56 (21.5)</td>
<td>75 (28.8)</td>
</tr>
<tr>
<td>Thought out different ways to handle the situation</td>
<td>8 (3.1)</td>
<td>75 (28.8)</td>
</tr>
<tr>
<td>Told yourself that things could be much worse</td>
<td>17 (6.5)</td>
<td>188 (72.3)</td>
</tr>
<tr>
<td>Exercised or did some physical activity</td>
<td>13 (5.0)</td>
<td>35 (13.5)</td>
</tr>
<tr>
<td>Tried to get away from the problem for a while</td>
<td>6 (2.3)</td>
<td>36 (13.8)</td>
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<tr>
<td>Got made and let off steam</td>
<td>98 (37.7)</td>
<td>80 (30.8)</td>
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<tr>
<td>Expected the worst that could</td>
<td>41 (15.3)</td>
<td>51 (19.1)</td>
</tr>
<tr>
<td>Description</td>
<td>Frequency 1</td>
<td>Frequency 2</td>
</tr>
<tr>
<td>----------------------------------------------------------------------------</td>
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<td>-------------</td>
</tr>
<tr>
<td>happen</td>
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<td>(58.8)</td>
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<tr>
<td>Tried to put the problem out of your mind and think of something else</td>
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<tr>
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<td>(10.0)</td>
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<tr>
<td>Talked the problem over with family or friends</td>
<td>4</td>
<td>12</td>
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<tr>
<td></td>
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<td>(4.6)</td>
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<tr>
<td>Accepted the situation because very little could be done</td>
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<td>75</td>
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<tr>
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<td>(28.8)</td>
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<tr>
<td>Tried to look at the problem objectively and see all sides</td>
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<td>(11.2)</td>
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<tr>
<td>Daydreamed about a better life</td>
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<td>85</td>
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<tr>
<td></td>
<td>(16.2)</td>
<td>(32.7)</td>
</tr>
<tr>
<td>Talked the problem over with a professional person (such as a doctor, nurse, minister, teacher)</td>
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<td>4</td>
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<tr>
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<td>(1.5)</td>
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<td>(11.2)</td>
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<tr>
<td>Prayed or put your trust in god</td>
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<td>0</td>
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<tr>
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<td>(0.0)</td>
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<td>Tried to get out of the situation</td>
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<td>(16.9)</td>
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<td>Kept your feelings to yourself</td>
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<td>88</td>
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<td>(33.8)</td>
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<td>Action</td>
<td>Frequency</td>
<td>Percent</td>
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<tr>
<td>----------------------------------------------------------------------</td>
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<tr>
<td>Told yourself that the problem was someone else's fault</td>
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<tr>
<td>Waiting to see what would happen</td>
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<td>18.8</td>
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<tr>
<td>Wanted to be alone to think things out</td>
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<tr>
<td>Resigned yourself to the situation because things looked hopeless</td>
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<td>68.1</td>
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<tr>
<td>Took out your tensions on someone else</td>
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<tr>
<td>Tried to change the situation</td>
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<td>Used relaxation techniques</td>
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<td>Slept more than usual</td>
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<td>Tried to handle things one step at a time</td>
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<td>Tried to keep your life as normal as possible and not let the problem interfere</td>
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<tr>
<td>Thought about how you had</td>
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Note: The numbers in the table represent the frequency of occurrence and the corresponding percent of the total responses.
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<th>15.4</th>
<th>0.4</th>
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<td>Told yourself not to worry because everything would work out fine</td>
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<td>24</td>
<td>154</td>
<td>76</td>
<td>5</td>
<td>35</td>
<td>169</td>
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<td>Let time take care of the problem</td>
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<td>Tried to distract yourself by doing something that you enjoy</td>
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<td>31</td>
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<td>(18.1)</td>
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<td>Told yourself that you could handle anything no matter how hard</td>
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<td>76</td>
<td>6</td>
<td>39</td>
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<td>101</td>
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<td>57</td>
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<td>141</td>
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<td>14</td>
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<td>(25.0)</td>
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<td><strong>Practiced in your mind what</strong></td>
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<td>36</td>
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<td>244</td>
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<td>1</td>
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</tr>
<tr>
<td>Told yourself that this problem was really not that important</td>
<td>16</td>
<td>55</td>
<td>146</td>
<td>41</td>
<td>19</td>
<td>72</td>
<td>135</td>
<td>32</td>
</tr>
<tr>
<td></td>
<td>(6.2)</td>
<td>(21.2)</td>
<td>(56.2)</td>
<td>(15.8)</td>
<td>(7.3)</td>
<td>(27.7)</td>
<td>(51.9)</td>
<td>(12.3)</td>
</tr>
<tr>
<td>Avoided being with people</td>
<td>152</td>
<td>72</td>
<td>32</td>
<td>4</td>
<td>153</td>
<td>80</td>
<td>25</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>(58.5)</td>
<td>(27.7)</td>
<td>(12.3)</td>
<td>(1.5)</td>
<td>(58.8)</td>
<td>(30.8)</td>
<td>(9.6)</td>
<td>(0.8)</td>
</tr>
<tr>
<td>Tried to improve yourself in some way so you could handle the situation better</td>
<td>10</td>
<td>78</td>
<td>142</td>
<td>24</td>
<td>11</td>
<td>98</td>
<td>130</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td>(3.8)</td>
<td>(30.0)</td>
<td>(54.6)</td>
<td>(9.2)</td>
<td>(4.2)</td>
<td>(37.7)</td>
<td>(50.0)</td>
<td>(5.8)</td>
</tr>
<tr>
<td>Wished that the problem would go away</td>
<td>1</td>
<td>18</td>
<td>136</td>
<td>105</td>
<td>1</td>
<td>26</td>
<td>164</td>
<td>69</td>
</tr>
<tr>
<td></td>
<td>(0.4)</td>
<td>(6.9)</td>
<td>(52.3)</td>
<td>(40.4)</td>
<td>(0.4)</td>
<td>(10.0)</td>
<td>(63.1)</td>
<td>(26.5)</td>
</tr>
<tr>
<td>Depended on others to help you out</td>
<td>90</td>
<td>102</td>
<td>63</td>
<td>2</td>
<td>92</td>
<td>122</td>
<td>42</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>(34.6)</td>
<td>(39.2)</td>
<td>(24.2)</td>
<td>(0.8)</td>
<td>(35.4)</td>
<td>(46.9)</td>
<td>(16.2)</td>
<td>(0.4)</td>
</tr>
<tr>
<td>Told yourself that you were just having some bad luck</td>
<td>169</td>
<td>77</td>
<td>12</td>
<td>2</td>
<td>168</td>
<td>82</td>
<td>8</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>(65.0)</td>
<td>(29.6)</td>
<td>(4.6)</td>
<td>(0.8)</td>
<td>(64.6)</td>
<td>(31.5)</td>
<td>(3.1)</td>
<td>(0.8)</td>
</tr>
</tbody>
</table>
### Appendix J

**Correlation Matrix**

<table>
<thead>
<tr>
<th></th>
<th>coping (JCS)</th>
<th>Hope (HHI)</th>
<th>Anxiety and Depression (HADS)</th>
<th>QOL (FACT-C)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Age</td>
<td>-.162**</td>
<td>.078</td>
<td>-.027</td>
<td>.033</td>
</tr>
<tr>
<td></td>
<td>.009</td>
<td>.208</td>
<td>.670</td>
<td>.598</td>
</tr>
<tr>
<td>Patient Gender</td>
<td>-.124*</td>
<td>-.074</td>
<td>.128*</td>
<td>-.135*</td>
</tr>
<tr>
<td></td>
<td>.046</td>
<td>.234</td>
<td>.039</td>
<td>.030</td>
</tr>
<tr>
<td>Patient's marital status</td>
<td>-.024</td>
<td>.036</td>
<td>.111</td>
<td>-.036</td>
</tr>
<tr>
<td></td>
<td>.703</td>
<td>.560</td>
<td>.074</td>
<td>.567</td>
</tr>
<tr>
<td>Patient's monthly income</td>
<td>-.055</td>
<td>-.029</td>
<td>-.090</td>
<td>.045</td>
</tr>
<tr>
<td></td>
<td>.383</td>
<td>.650</td>
<td>.156</td>
<td>.481</td>
</tr>
<tr>
<td>Time Since Diagnosis/Month</td>
<td>-.019</td>
<td>.110</td>
<td>-.120</td>
<td>.162**</td>
</tr>
<tr>
<td></td>
<td>0.766</td>
<td>.078</td>
<td>.053</td>
<td>.009</td>
</tr>
<tr>
<td>Coping</td>
<td>.428**</td>
<td>-.431**</td>
<td>.552**</td>
<td>.000</td>
</tr>
<tr>
<td></td>
<td>.000</td>
<td>.000</td>
<td>.000</td>
<td>.000</td>
</tr>
<tr>
<td>Hope</td>
<td>.428**</td>
<td>-.494**</td>
<td>.556**</td>
<td>-.757**</td>
</tr>
<tr>
<td></td>
<td>.000</td>
<td>.000</td>
<td>.000</td>
<td>.000</td>
</tr>
<tr>
<td>HADS</td>
<td>-.431**</td>
<td>-.494**</td>
<td>-.757**</td>
<td>.000</td>
</tr>
</tbody>
</table>
## Appendix K

### CRC studies : Critical Tables

<table>
<thead>
<tr>
<th>Study and objective</th>
<th>N</th>
<th>Design</th>
<th>Sampling</th>
<th>Instruments</th>
<th>Reliability &amp; Validity</th>
<th>Key Findings</th>
<th>Limitations</th>
</tr>
</thead>
</table>
| Jolanda, Hagedoorn  | 137| Longitudinal | Data collected from 10 hospitals, colorectal pts who underwent surgery were selected. Assessment were collected in 3 stages: Within 2 weeks, 3 months and 6 months after surgery. | Center for Epidemiologic Studies Depression Scale (CED-S) | .88-.91                | Both patients and their spouses had a high level of psychological distress prior and after the surgery. | - Response rate (77%)  
- Pts asked to answer the baseline measurement prior the surgery (unsuitable time)  
- Researcher need to explain factors that causes the psychological distress (intervention, body image, role, sexual, fear of recurrence…etc).  
- Inclusion criteria were restricted to patients with a fairly good prognosis, so generalization limitation.  
- Pts disease characterises (stage, location, Metastases, …etc not available).  
- Some pts were not informed about their diagnosis. |
| …etc, 2004          |    |              |                                                                          |                                                  |                        |                                                                              |                                 |
| To examine pattern of psychological distress in couples facing colorectal cancer within 6 months of surgery. In addition, correspondence in psychological distress was investigated between patients and their spouses taking into account gender. |    |              |                                                                          |                                                  |                        |                                                                              |                                 |
| Akira, Kentaro..etc | 128| Cross-sectional | The pts underwent surgical treatment between 1994-2001 were assessed. 140 pts still a live and mailed to participate in the study. | Center for Epidemiologic Studies Depression Scale (CED-S) | N/A                    | No significant differences regarding sex, tumor location and time since operation noted in QOL and HADS. | - Sample bias (only one institution)  
- Some pts were not informed about their diagnosis. |
| 2005, Japan         |    |              |                                                                          |                                                  |                        |                                                                              |                                 |
| To investigate the relationship between the HADS and the Emotional Functioning (EF) of |    |              |                                                                          |                                                  |                        |                                                                              |                                 |
QOL-C30. And to analyse the relationship between anxiety and depression as measured by the HADS and selected dimension of the QOL-C30 in colorectal cancer pts.

Sharstein, Nina, etc 2000.  
1. Impact of anxiety and depression on the QOL dimension of the EROTC QOL-C30.  
2. Compare cancer pts response to emotional functioning with those to HADS.

<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Sample Size</th>
<th>Measures</th>
<th>Correlation Coefficient</th>
<th>Findings</th>
<th>Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Cross sectional</td>
<td>568 pts</td>
<td>EROTC –C30 and HADS used in the study. Consent form was obtained before beginning of the study.</td>
<td>0.88</td>
<td>- Depression was more highly correlated with reduction of QOL dimension than anxiety.</td>
<td>Assess the factors contributed depression and anxiety.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>716 pts seen at the outpatient's clinic, after informed consent obtained. All pts were asked to complete the EROTC and HADS. 568 were selected who had completed all questions on QOL-C30 and HADS.</td>
<td>EROTC</td>
<td>0.87-0.89</td>
<td>- High correlation was found between HADS anxiety and EF in EROTC.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>HADS</td>
<td></td>
<td>- Males and older pts reported better emotional functioning than female and younger pts regarding depression (gender and age coloration to depression)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>- No relation for age and gender</td>
<td></td>
</tr>
</tbody>
</table>
was found between HADS – anxiety and emotional functioning.

- All dimension of QOL (PF, CF, SE, and Pain) were significantly associated with depression and anxiety (except fatigue).

- HADS has been shown to be a valid and reliable screening instrument in large cancer pts and even normal population

- None of the socio-demographical variables was strongly related to the 1 yr attribution.

| Kurtz, Stommel..etc | 2002 | Longitudinal study | 158 pts | 234 pts aged 65 or older diagnosed with CRC were recruited from 23 sites. Pts were interviewed in 4 waves. 1. between 4-6 weeks following their surgery or 2-4 weeks following radiation or chemotherapy Tx. 2. after 12-16 weeks 3. 26-30 weeks 4. after 1 yr | 1. Center for Epidemiological studies depression scale (CES-D) 2. Medical Outcomes study (MOS) (SF-36) to assess physical and social functioning 3. symptoms experience scale 4. co- morbidity (pts listed 11 co- morbid chronic conditions) | 0.85 0.889 for physical subscale 0.81 for social subscale N/A | 1. Restricted on pts age over 65 yrs only. 2. response rate ( drops in sample) |

Recommendations

1. Assess cancer –related symptoms on psychological distress
2. Treatment modalities and relation to depressive symptoms.
characteristics and the variables that change over time, such as marital status, employment status, symptom experience, PF, SF, and treatment predict changes in depressive symptoms at the 4 assessment following a diagnosis of CRC? Fu-ling, Wang…etc 2005.

To investigate the impact of co-morbid anxiety and depression (CAD) on QOL and cellular immunity changes in pts with digestive cancer.

<table>
<thead>
<tr>
<th>Study Type</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>- 49 pts with colorectal cancer</td>
</tr>
<tr>
<td></td>
<td>- 45 gastric</td>
</tr>
<tr>
<td></td>
<td>- 39 esophageus</td>
</tr>
<tr>
<td></td>
<td>- Liver, gallbladder, pancreas, duodenal.</td>
</tr>
<tr>
<td></td>
<td>- Medical records were reviewed.</td>
</tr>
<tr>
<td></td>
<td>- 3.5ml of peripheral blood sample was obtained from each pt to assess T cell and NK</td>
</tr>
<tr>
<td></td>
<td>- QOL-C30</td>
</tr>
<tr>
<td></td>
<td>- Hamilton depressive scale (HAMD)</td>
</tr>
<tr>
<td></td>
<td>- Hamilton anxiety scale (HAMA)</td>
</tr>
<tr>
<td></td>
<td>- Social support rating scale (SSRS)</td>
</tr>
<tr>
<td></td>
<td>- Simple coping style questionnaire (SCSQ)</td>
</tr>
<tr>
<td></td>
<td>- T-lymphocyte and natural killer.</td>
</tr>
</tbody>
</table>

- 156 pts completed wave 1
- 142 in wave 2
- 132 in wave 3
- 118 in wave 4

- 60% of CRC pts suffered from 2 or more co-morbid chronic condition.

- The incidence of CAD was 21.1% in pts with digestive tract cancers.

- The overall of global QOL was poor due to change in physical function, role function, sleeplessness and constipation.

- Depression was negatively correlated lymphocyte.

- CAD was negatively correlated with QOL and active coping and NK.

- Social support, active coping, fatigue, depression, monocyte, natural killer were the significant contributing to QOL.
<table>
<thead>
<tr>
<th>Study</th>
<th>Year</th>
<th>Design</th>
<th>Sample Size</th>
<th>Setting</th>
<th>Consent</th>
<th>Measures</th>
<th>Results</th>
<th>Reflection</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mary, Cristine…etc 2003, Canada</td>
<td>To describe pretest psychological functioning in a sample of colorectal cancer (CRC) undergoing genetic testing. And also to explore the relationship among demographic, medical family history and loss variables and current pretest distress and those related to anticipated posttest distress.</td>
<td>Prospective population case-control study</td>
<td>220 pts</td>
<td>Data collected in a cancer center in Ontario, consent form was obtained from the pts who met the criteria.</td>
<td>Impact of events scale (IES): measure distress related to specific event (test)</td>
<td>State anxiety (STAI) scale: 0.85-0.95</td>
<td>- 73% of the sample experienced loss - pts experienced psychological distress: A. 22% of the sample demonstrates high level of distress on the STAI state anxiety. B. 15% reached the clinical cut off the CES-Depression scale. - Female showed a significant higher level of intrusion and avoidance than male. - Pts under the age 50 had a higher level of anxiety and depression than diagnosed above the age 50. - Young people (under 25yrs) more anxious than old peoples related to CRC diagnosis in relatives. - Pts experienced a high level of anxiety and depression and lower levels of QOL.</td>
<td>- Study did not measure the social support and coping style. - Loss is qualitative aspect more than quantitative area.</td>
</tr>
<tr>
<td>Aass, Fossa…etc 1997,</td>
<td>To investigate the prevalence of anxiety and depression in cancer pts.</td>
<td>Cross sectional</td>
<td>716 pts</td>
<td>Data were collected in regional cancer hospital. After obtaining consent. The pts asked to fill the questionnaires and return them in</td>
<td>Hospital anxiety and Depression scale (HADS).</td>
<td>N/A</td>
<td>- 13% of pts had anxiety - 9% of pts had depression - Pts with haematological, gynaecological, and GI cancers reported more depression than others.</td>
<td>- Restricted only for pts need treatment modalities (chemoradiation). - The study did not assess pts knowledge of their disease, treatment, and prognosis.</td>
</tr>
</tbody>
</table>
the same day.
- Female reported a high level of anxiety.
- Increase impairment (physical, social, fatigue, pain) was associated with higher level of anxiety and depression.
- Hospitalized pts had a higher level of anxiety and depression than outpatients.
- Relapse associated with high level of depression

Keller….etc, 2004
To determine the prevalence of psychiatric morbidity and distress among cancer pts upon admission to surgical oncology wards.
And to investigate the recognition of distressed pts by medical staff.

189 Pts were recruited to the interview before undergoing surgery, and asked to answer the questionnaire.
A well trained psychologist conducted the interviews 1-3 days before the surgery.

Structured Clinical interview (SCID-1) N/A

HADS N/A

- 28% of pts diagnosed with psychiatric problems.
- Adjustment disorder was diagnosed in 17 pts (22%)
- Major depression 5%
- Anxiety 3%
- Psychosis one pt only according to HADS scores:
  - 19% of pts had anxiety
  - 13.9 had depression
  - 17 of 22 pts diagnosed with psychiatric problems were identified by their doctors as a highly distressed.
  - Nurses recognized 15 pts had mild distress.

- Response rate
- No explanation of how or what the criteria that used by medical staff to identify psychiatric problems.
- Stress and anxiety are common in all pts undergoing surgery so this study focus in cancer pts only (what is the difference).
- Pts knowledge about their surgery and complication, in addition to management after surgery that play a key role to decrease stress and anxiety (not mention in the study)
<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Sample Size</th>
<th>Participants</th>
<th>Measures</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nordin et al. 2001</td>
<td>Longitudinal</td>
<td>522 pts</td>
<td>- Out of 729 eligible pts, 527 pts (72%) agreed to participate thus 522 pts were actually participate in this study at the diagnosis and 415 pts completed the study at 6 months.</td>
<td>HADS, IES</td>
<td>- At diagnosis pts with breast cancer reported higher level of anxiety than colorectal or prostate cancer, where no significant difference seen after 6 months. - Mean level of anxiety and depression decreased over the time. - Pts with advanced disease reported higher level of depression than those with non-advance disease. - Pts with breast cancer reported higher level of intrusion and avoidance than colorectal group. - Early sign of anxiety and depression predict the same status in the future.</td>
</tr>
<tr>
<td>Kirle, Brown et al. 2003</td>
<td>Longitudinal</td>
<td>205 pts</td>
<td>Data were collected through 4 stages; a. 11 weeks of diagnosis b. 4 months c. 8 months d. and 12 months</td>
<td>Center for epidemiology studies for depression (CED-D), IES (impact of)</td>
<td>- 125 pts complete the study (80 pts died) - Depressive symptoms dropped significantly over the time. - CED-D scores in higher among pts receiving more toxic - Drop-out pts - 75% of the sample was women (they reported more depressive symptoms than men). - Clinical risk factors not included in the study (socioeconomic status, smoking,</td>
</tr>
</tbody>
</table>
To assess the relationship between psychological characteristics such as anxiety and depression, and QOL and coping style among pts with digestive cancer.

85 pts

Longitudinal

Data collected from Tokyo hospital, oncology surgical ward. After obtaining consent form, pts were assessed before the surgery, before discharge, and 6 months after discharge.

<table>
<thead>
<tr>
<th>Scale</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>HADS</td>
<td>N/A</td>
</tr>
<tr>
<td>EORTC-QOL</td>
<td>N/A</td>
</tr>
<tr>
<td>Coping inventory for stressful situations (CISS)</td>
<td>N/A</td>
</tr>
<tr>
<td>Zungs self rating depression scale</td>
<td>N/A</td>
</tr>
</tbody>
</table>

- Depression score before discharge higher than before surgery. And no difference in score before discharge and after 6 months.

- Anxiety levels relatively the same over the 3 periods.

- QOL score decreased from before the surgery to before discharge and returned to perioperative level at 6 months after discharge.

- Strong relation was found between depression and anxiety level of QOL scores (specially emotional and cognitive functioning).

- Factors affected QOL (Educational level, employment, medical equipments using).

- Factors contributing coping style: educational level, emotional support.

Recommendations:

1- More researches in order to assess the relationship between social support and coping style and affect on QOL and Psychological distress.

- Assess impact of medical insurance, self-help group, and counselling system in coping style.
1. To identify everyday stressful events (related and unrelated to cancer)
2. Types of coping strategies do pts employ to handle stressful events
3. Assessment of anxiety and depression among those pts.

Out of 151 eligible pts 95 respond to the study (62%).
- 62 pts cured and 33 pts non-cured.
- 81 pts with colorectal cancer, 4 gastric, 10 biliary.

Daily coping assessment (DCA)
HADS
Daily assessment of mood (worry and happiness/sadness)

- The most stressful events (somatic aspect, everyday concern, psychological, and social aspect).
- The most coping strategies were "acceptance, relaxation, distraction, direct action) the least used strategy was religion.
- There was no difference between cured and non cured pts regarding depression and anxiety.
- There was a correlation between events and depression and anxiety level among those pts.
- Higher level of psychological distress was accompanied by reported use of a higher number of coping strategies.
- There was a +ve correlation between worry/happiness and score level of HADS.
- Response rate (62%)
- The researchers used psychological items that need an operational definition to be constant to all pts (happiness/worry, relaxation).
- Qualitative description of coping strategies also missing e.g. how pts define acceptance, distraction.

- 156 researches were included in the analysis
- 67 researches addressed

Recommendations
1. Develop a set of reliable, valid instrument to assess satisfaction
literature on the outcomes research related to colorectal cancer screening and treatment and to make recommendations about study designs, population, and measures in the future research.

using MEDLINE for all researches conducted between 1990 and 2001.

- Pts risk factors
- QOL and surveillance
- Economic impact of surveillance
- QOL regarding Tx. Time
- Outcomes of surgery
- QOL and treatment modalities
- Psychological (anxiety and depression) and treatment
- The most common instruments that used to assess QOL were EORTC, Rotterdam checklist, FACT-C, SF-36, QOL-index
- HADS assess psychological distress.

screening.

- 18 researches examined surveillance of high risk groups.
- 22 researches examined the treatment of colorectal cancer
- End-of-life (1 research only): described pts dying function, symptoms, and care preference
- 19 articles were conducted in order to:
  A. 9 articles assessed either QOL of pts undergoing treatment, QOL of survivors
  B. 4 about pts perception of cancer
  C. 1 focused doctor-pts communication.
  D. 4 examined instruments for measuring HRQOL.

and attitude toward screening.

2. Examine racial, ethnic, multicultural differences in colorectal cancer and factors that improve pts compliance with screening.

3. Examine factors that associated with QOL with colorectal and predictors also.

- 18 researches examined surveillance of high risk groups.
- 22 researches examined the treatment of colorectal cancer
- End-of-life (1 research only): described pts dying function, symptoms, and care preference
- 19 articles were conducted in order to:
  A. 9 articles assessed either QOL of pts undergoing treatment, QOL of survivors
  B. 4 about pts perception of cancer
  C. 1 focused doctor-pts communication.
  D. 4 examined instruments for measuring HRQOL.
Study and objective

N

Design

Sampling

Instruments

Reliability & Validity

Key Findings

Limitations

Jeff Dunn, Brigid, …, 2002, Australia

To describe what is known of QOL for colorectal cancer patients. To review what has been done in the Australian setting and to identify emerging directions for future research.

41 articles

A literature search using MedLine, CINAHL, and Psycho info

By using key words’ QOL, colorectal, impact…etc. a review of articles that published between 1981 and 2001.

Literature review

- 15 articles was a cross-sectional.
- 6 prospective
- 3 were descriptive
- 17 editorial
- 5 instrument development
- No standardized instrument for measuring QOL and related constructs.
- 3 main areas were identified:
  1- Definition of QOL
  2- Predictors of QOL
  3- Relationship of QOL and survival.

Recommendations:
- Longitudinal study to assess QOL among colorectal cancer before, during, after, and survival also.
- Assessing additional factors

1- Large researches analysis in more than 3 resources.
2- Focus on Middle-range theory that conceptualizes QOL, And models that used to guide the researches.
3- Not mention limitation for applied such like these researches.

QOL definition contain main domains, physical, emotional, sexual, psychosocial.

Specific-disease QOL measurements have higher internal validity than Generic one.

QOL predictors:
1- Demographical ch.ch
2- Disease descriptors (morbidity and mortality)
3- Time since diagnosis
4- Support received
5- Life style mainly physical activity.

Depending on prognosis of disease, staging, grading.
Jeff Dunn, Brigid… 2006. Australia

1- Explore the findings of seven Qualitative studies on the QOL.
2- Add the body of qualitative knowledge about colorectal cancer and to provide descriptive data about QOL.

1- Qualitative studies on describing QOL were identified between 1979 and 2004 using CINHL, MedLine, Psycho-info,

2- 15 pts were recruited after they met the eligible criteria and respond to consent letter. 11 – in-depth interview, 3 focus group, and 1 in both.

1- Findings of Qualitative papers offer some insight into pts experience of colorectal cancer that not provided by Quantitative research.
2- Findings by researcher:
- 6 themes emerged from the stud :
  1- Body image
  2- Reviewing life
  3- Consequence of cancer
  4- Change outlook, self, others, and life
  5- Fear, living with cancer
  6- Symptoms; pain, fatigue

Papers sharing in many points regarding QOL.

Measures:
- Semi-structure interview
- Open-ended questions

1- satisfaction with Dx and Tx
2- Support
3- QOL
4- Benefits of diagnosis (Dx)
5- Making sense
6- Coping Strategies

- Sample limited to all pts were English – speaking only.
- varies time Since diagnosis
- Small focus group
- External threat for participants (pts Condition during interview, physical conditions, psychosocial conditions).
- Disease ch.ch. For pts (stage, grade, prognosis) that affect pts QOL.
<table>
<thead>
<tr>
<th>Study</th>
<th>Methodology</th>
<th>Sample Size</th>
<th>Design</th>
<th>Data Collection</th>
<th>Analysis</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sarah L, Blair…, 2003, USA</td>
<td>To describe unique QOL issues to formulate a specific tool for patients with colorectal metastasis and intrahepatic chemotherapy.</td>
<td>16 pts</td>
<td>Mixed Quantitative and Qualitative - Cross-sectional Descriptive/comparison - Semistructured</td>
<td>1- Pts complete the city of Hope Quality of Life Scale/ Cancer patients. 2- In-depth interviews to answer 6 QOL related Questions</td>
<td>Valid</td>
<td>- After a comparison of City of Hope results with norms, a significant lower subscale scores for Psychosocial, social, spiritual, but not physical. - Decrease in overall QOL score. - Several themes emerged from interviews: a- physical activity b- body image c- social well-being d- Physical well-being (sleep).</td>
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<td>Jane, Heidi….etc 2002.</td>
<td>To compare short-term QOL outcomes after laparoscopic-Assisted coloectomy (LAC) vs. Open coloectomy for colon cancer</td>
<td>449 pts</td>
<td>Randomized controlled study Comparison study.</td>
<td>Data were collected from 48 medical centers after examine eligible criteria of pts. - Pts were assessed periodically 2day. 2 weeks, and 2 months. - symptoms Distress Scale (SDS) - Quality of Life index. - Global rating scale.</td>
<td>Valid</td>
<td>- QOL results show better overall score among pts with LAC. - Missing data .e.g. (pts NPO after 2 days of surgery so no assessment for bowel functions and appetite. - Difference centers might affect environment of study (quality of care, communication ….).</td>
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<tr>
<td>Study</td>
<td>Methodology</td>
<td>Details</td>
<td>Findings</td>
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<td>Trentham, Remington… etc, 2003 USA</td>
<td>Longitudinal study</td>
<td>Cases reported between 1990 and 1991, pts completed questionnaire regarding QOL and variables.</td>
<td>- Follow-up average 9 yrs - Mean age 72 yrs - Main variables contributed QOL were medical condition, aging, body wt, - Physical and mental score were decreased.</td>
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<tr>
<td>Scott, Robyn…2000 USA</td>
<td>Longitudinal study</td>
<td>- Pts subjects were selected from the cancer registry if colon or rectal carcinoma was their recorded malignancy - Pts assessed in the first 3 yrs after diagnosis and after 3 yrs also - 74 pts in the first 3 yrs - 98 pts after 3 yrs.</td>
<td>- QOL lowered in the first 3 yrs after diagnosis. - Pain, Functional well-being, and social well-being were affected negatively across all stages and times from diagnosis. - Low income status was associated with worse outcomes for pain, ambulation, social, and emotional status.</td>
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<tr>
<td>Thomas, Charlene…, 2001</td>
<td>Case –control design, comparison study</td>
<td>Eligible participants were accrued over 3-yrs period (1997-1999) at a single institution. - 3 groups in the</td>
<td>- No difference between CRC/S and CRC-S/A regarding weight, appetite, bowel and bladder functioning. - Pts in both the CRC-S and</td>
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</table>
HRQOL compared with surgery for benign colorectal disease, (2) to ascertain differences in HRQOL for CRC patients based on adjuvant treatment.

Systematic literature search

159 Rand-clin trials (RTC)

- Search criteria
  a- types of participants (breast, colorectal, prostate, and NSCLC).
  b- Intervention (Radiation, surgery and chemotherapy).
  c- Outcomes (main domains of HRQOL such as physical, emotional…..)

- EORTC-QOL C30- valid (CRC-s/A groups scored higher in the category (physical, pain, role-function, general-health perception).

Volker, Henrik….etc 2004, Germany

To identify specific limitations of QOL in survivors of colorectal cancer in comparison with men and women from the general 1 yr after diagnosis when acute treatment effects are expected

Population- based study

Participants with colorectal cancer who were diagnosed between 1996 and 1998 were identified and reported.

- Colostomy reported by 20.1% among pts.
- 80% of all participants reported limitations such as feeling depressed, irritable, tense, or worried. ????explain
- Almost 80% reported problems with fatigue and insomnia. ??????? explain

- Study design did not give the pts space to explain their feeling and causes of such feeling that mentioned by the researchers (depression, irritable……).
- The results showed that majority of pts suffered from fatigue and insomnia with explanation of the causes (disease related or treatment….)
Both group reported almost identical mean scores of global health/QOL and physical functioning.
- Deficit in emotional, social among pts with colorectal cancer.
- Minor differences were observed for cognitive and role functioning.
- All symptoms (N&V, Dyspnea, constipation, diarrhea) were high among colorectal pts.
- Pts condition (surgery, type and phase of chemotherapy, another medical condition that might affect pts status.

<table>
<thead>
<tr>
<th>Year</th>
<th>Country</th>
<th>Study Design</th>
<th>Number of Pts</th>
<th>Inclusion Criteria</th>
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<tbody>
<tr>
<td>2002</td>
<td>USA</td>
<td>Cross-sectional</td>
<td>45 pts</td>
<td>Pts enrolled between 1999 and 2000 at surgery clinic at the Texas university, cross-sectional analysis for 45 posttreatment pts was performed after obtaining consent form and met eligible to the study criteria.</td>
</tr>
</tbody>
</table>

- Female pts reported sever pain and worsening in QOL after treatment.
- Female scored lower on the physical well-being.
- Pelvic and sciatic pain was a strong predictor of poor outcome.
- The presence of colostomy and urine conduit at the time of assessment had no apparent impact on pain or QOL.
- No association between radiation therapy and
Christian, Schmidt et al. 2005. Germany

To assess differences in perceived QOL over time among patients treated with Anterior Resection (AR) or Abdominoperineal resection (APR).

**Time-series study.**

Prospective

- 249 pts with rectal cancer who had undergone resection in the surgery department from 1997 to 2002. 46 pts treated with AR and 203 treated with APR.
- Assessment was done at discharge, 3, 6, and 12 months after operation.

EORTC-QOL Tumor-specific module.

- No significant differences were found between both group according to QOL that measured by EORTC.
- The symptoms of nausea and vomiting and diarrhea were worse among AR pts.
- APR pts reported worse in sexual function.
- Pts without colostomy were more confident about their future.

- No specific modules for colorectal cancer pts valid till now.
- Sample size of AR (46 pts) it will affect generalization.

Christine, Bradley….etc, 2007 California, USA

To summarize the conceptual basis for symptom cluster research, describe two conceptual approaches to symptom cluster research, and discusses the implications of symptom clusters for QOL research.

**Literature review**

Review of the researches last 6 yrs that had been published on symptom cluster in oncology pts.

- Symptom cluster definition: 'three or more concurrent symptoms that are related to each other but are not required sharing the same etiology, and occurring together.
- 6 studies were conducted between 2000 and 2006 to determine symptom clusters among oncology pts. The results showed that cancer pts suffered from different symptom clusters (GI, Resp, Sickness, emotional, pain, Debility (edema, confusion).

GI cluster; N&V, diarrhea, dry mouth, lack of appetite.

Resp cluster; Cough, dyspnea, and Orthopnea

Psycho cluster; Depression, anxiety, fear

Recommendations:

1. Future research to evaluate the impact of various symptom clusters on pt QOL.
2. Using generic or disease – specific instruments to measure QOL among oncology pts.
- Of the 6 studies, only one hypothesized that advance cancer has negative impact on functional and emotional status. But unfortunately a global assessment of QOL was not administered in this study.

- The study of Miaskowski et al (2006) is the first study designed to identify subgroups of patients with different symptoms cluster and impact of these cluster on pts QOL and functional status. The findings suggest that subgroups of oncology pts with different symptoms experiences report clinically meaningful differences in the various domain of QOL.