

# Changes in Quality of Life among Jordanian Colorectal Cancer Patients: A Qualitative Study

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#### **Abstract**

**Purpose:** This paper is a report of the study exploring the impact and of colorectal cancer diagnosis and treatment on the Jordanian patients' QOL.

**Methods:** A semi-structured interview were conducted with a purposeful sample of ten participants diagnosed with colorectal cancer and undergoing treatment period in Jordan, interviews were audio taped and notes were taken. Content analysis approach was performed.

**Findings:** from the textual analysis, four categories were emerged reflecting the change of the participants' QOL during CRC diagnosis and treatment that including perceptions of QOL (diminishing strength and physical fitness, and side effect of treatment), cancer as distress (experiencing range of emotions, changing perception of the future, and losing self confidence), changing roles (changing in role responsibilities, becoming dependent on others), and changing in social life (becoming socially isolated, disrupting family life).

**Conclusion:** the dominant experience of the study participants focused on four main aspects of their illness. Nurses and health professionals who work with colorectal cancer patients should offer support and teaching patients about active coping strategies to survive.

Keywords: Social support, professional support, oncology, spirituality, attitude towards prognosis.

#### 1. Introduction

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 (JMOH & JCR, 2008).

CRC is considered one of the most common cancers among the Jordanian population, as reported by the JMOH, and the JCR, (JMOH & JCR, 2008). Table 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. Numbers of New Cases by Primary Site and Gender (Jordan, 2008)

Primary site	Male		Female		Total	
	N	(%)	N	(%)	N	(%)
Colon	210	9.2%	145	7.7%	355	16.9%
Rectum	119	5.2%	74	4.2%	193	9.4%
Total	329	14.4%	219	11.9%	548	26.3%

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). Furthermore, patients may experienced range of complications related to the disease itself or related to different treatment modalities, 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, 2009). 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).

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, Matsushima, & Maruyama, 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). 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-focussed, 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 the changes in patients' QOL after being diagnosed with CRC. Thus, 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 CRC diagnosis and treatment on these patients' lives and health, and to provide optimal care.

### 2. The Study

#### Aim

The aim of this study was to describe Jordanian colorectal cancer patients' experiences and perceptions about QOL during their illness period.

#### Design

A qualitative research approach was utilized using semi-structured interview. A semi-structured interview approach was used as this approach encouraged patients to talk freely about various aspects in relation to QOL issues and to describe their experiences. In addition, participants had the freedom to respond in their own words, providing details as much as they desired (Polit & Beck 2004).

## **Participants**

In this study, a sample of ten participants was chosen purposefully using maximum variation. The selection of participants for individual interviews was guided by the need for a better understanding of what and how the diagnosis of and treatment for CRC affected their QOL.

### **Data collection**

#### Recruitment

In order to address the purpose of this study, the researcher provided all the participants with an information sheet that explained the study purpose, 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 study, 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.

#### **Ethics Considerations**

Appropriate ethics permissions were obtained to conduct the study, additionally, compromising package containing information sheet about study's purposes, procedures, risk and benefits was given to all participants. A consent forms were signed by the participants to participate in the study, access medical files and records.

# Data analysis

Content analysis approach was used to identify the main domain presented by the participants. The process of analysis involved open coding, categorizing, and identify the main domains. Directed approach of Content analysis was performed to identify the impact of CRC diagnosis and treatment on the participants' QOL; the same processes of analysis were performed with all transcripts.

#### Trustworthiness of the Study

The processes of truth value, fittingness, consistency, neutrality were undertaken in the current study. In the current trustworthiness of the qualitative data was achieved through prolonged engagement with participants (i.e., sufficient time for gaining rapport with the participants, listening to their stories and responding to their level of comfort/discomfort with the interview process) to have in-depth understanding of the phenomena, and to ensure useful, accurate and rich information was obtained. Moreover, the participants were presented with a summary of their interview, and the researcher's interpretation of their words and field notes to check for authenticity. In addition, the researcher carried out two pilot interviewers to develop interviewing skills. The researcher tried to use a standardized interview schedule to increase consistency of the data collected.

#### 3. Findings

# Sample characteristics

A total of ten participants participated. 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 2 presents the characteristics of the selected participants.

Table 2: Characteristics of the Selected Participants (n = 10)

Group	Participant	Gender	Age	Married	Time Since	Colostomy	Treatment	Regional
	Survey #.			Yes/No	diagnosis (Month)	Yes/No	modalities	metastasis Yes/No
A	109	M	40	Yes	7	No	Chemotherapy & Surgery	No
	83	M	66	No	13	Yes	Chemotherapy & Surgery	No
	84	M	45	Yes	11	No	Chemotherapy & Surgery	No
	240	M	43	Yes	24	No	Chemotherapy & Surgery	No
В	6	M	63	Yes	6	No	Chemotherapy & Surgery	No
	7	M	47	Yes	15	Yes	Chemotherapy & Surgery	No
	11	F	60	Yes	4	Yes	Chemotherapy & Surgery	No
С	146	M	58	No	12	Yes	Chemotherapy & Surgery	No
	28	M	45	Yes	11	No	Chemotherapy & Surgery	No
	157	M	45	Yes	10	Yes	Chemotherapy & Surgery	No

The participants were selected to illustrate maximum variation in scores measuring hope, coping, psychological distress (depression, anxiety), 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). Table 3 displays the participants' scores for the main variables under study.

Table 3: Participants' Scores of OOL, Hope, Coping, and Psychological Distress

Group	Participant QOL Coping Hope Psychological Distress				Psychological Distress
Group		QOL	Coping	Поре	
	Survey #.				Range (0-56)
		Range (0-	Range (0-180)	Range (12-48)	
		144)			
A	83	120	103	42	9
	84	120	102	42	7
	108	119	115	42	8
	240	117	100	46	8
В	7	98	88	42	9
	11	95	94	35	15
	6	95	122	37	21
С	146	73	66	31	19
	28	59	70	28	29
	157	47	85	35	25

When all of the contextual data from the semi-structured in-depth interviews were considered, two domains emerged from the data analysis: *Participants' experience of change during CRC diagnosis and treatment, and factors influencing QOL*. The first domains are described below, with categories and subcategories italicized, and are summarized in Table 4:



Table 4: Impact of CRC on Jordanian Patients' QOL

Categories	Subcategories		
Perception of QOL	Diminishing strength and physical fitness		
	Side effects of treatment		
Cancer as Distress	Experiencing range of emotions		
	Changing perception of the future		
	Losing in self confidence		
Changing Roles	Changing in roles responsibilities		
	Becoming dependent on others		
Changing in Social life	Becoming socially isolated		
	Disrupting family life		

# Participants' experience of change during CRC diagnosis and treatment

The qualitative findings indicated that there was universal agreement among 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.

### Perception of OOL

The participants shared that diagnosis and treatment of CRC affected the participants' physical well-being, in addition they agreed that physical (dis)ability affected their whole life and health. The following subcategories were identified from the data: Diminishing Strength and Physical Fitness and side effect of treatments. The following section presents these subcategories

# Diminishing Strength and Physical Fitness

The participants perceived a good QOL as the ability to do all of their daily activities such as shopping, driving children to school, sharing in home organising and related duties, and with the physical capacity to share and participate in social activities and be active in the community. They 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, 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. The following quotations represent that:

Male, # 146: 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, #84: 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

## Side effects of treatments

Many participants reported 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.

Male, # 6: 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 cause many problems particularly vomiting and diarrhoea......

Hospitalization period increased as a result of experienced physical complications, this disrupted the participants' lives in relation to work, physical fitness.

Male, #83: I must come to the hospital frequently for chemotherapy and suffering from its complications-diarrhoea, oral infection, I am feeling tired after the course and unable to handle my life as previous.

#### Cancer as Distress

It refers to the participants' psychological status, feelings, and reactions at the time of CRC diagnosis and during



the treatment. 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. Two psychological subcategories were identified including: experiencing range of emotions, changing perception of the future, and *losing in self confidence*. The following sections present the findings in these subcategories.

## Experiencing range of emotions

The Participants viewed the diagnosis of cancer as a sentence of painful and impending death which caused a great psychological impact. The participants experienced numbers of distressing feelings and thoughts including shock, denial, fear, worry, and anxiety as a result of being diagnosed with and treated for CRC.

Male, #7: 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, #83: 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? I spent two days refusing to talk to anyone, just thinking that I have a couple of months before dying.

#### Changing Perception 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 their families. The participants often experienced uncertainties and unpredictable feelings about their future, condition, survival, and about their families' future also.

Male, # 7: 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.

# Losing in self confidence

It 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 in the society. Diminished 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 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 because of fears of incontinence or flatus which limited their self confidence: the following quotations illustrate that:

Female, #11: 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.

Male, #7: It 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.

## **Changing Roles**

It reflects the participants' ability to undertake their usual family and employment roles. CRC diagnosis and treatment generated a wide range of impairments, disabilities, limitations, and malfunction for the participants caused by localized, obvious, and visible problems including stoma appliance and generalized problems including physical symptoms such as 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 subcategories emerged from the data - *changes in role responsibilities* and *dependence on others*. Seven participants reported a reduction in their functional ability and had difficulty in maintaining their family responsibilities and employment because of the effects of CRC treatment.

## Changing in Role Responsibilities

Following 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 were shifted to the other parent due to lack of physical ability to physically manage and provide family care. This feeling of inability to manage the role effectively and hand over the 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 changed through the stages of the illness and treatment:

Male, #83: 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 again all problems.

CRC diagnosis and treatment had an effect and impact on the participants in terms of role responsibility; it



negatively affected males and females participants. A female participant shared similar thoughts to the male participants when she said:

Female, #11: 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.

#### Becoming Dependent on Others

It reflects the dependency of participants on those around them to meet and perform their daily activities. 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 led to the participants feeling upset and useless which negatively affected their OOL.

Male, #240: 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.

# Changing in social life

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 subcategories were identified in this domain *social isolation* and *disrupted family life*. One male defined QOL as:

Male, # 109: 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.

## 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 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 participate in social activities.

Male, #83: 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.

# Disrupting Family Life

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. Additionally, patients' families faced and experienced numbers of feelings such as shock, fear, and feelings of difficulties in managing the new situation.

Male, #83: 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.

Moreover, the family perceived the diagnosis of cancer as the end of life and could not see a cure or treatment for this disease:

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

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

Male, #7: My family's attitude toward this disease at the first month after my diagnosis... my family refused this and this makes me feel stressed.

# 4. Discussion

In the present study, the participants' reported and explained the impact of CRC diagnosis and treatment on their QOL; several categories and sub-categories were emerged from the textual data.

The first category illustrated the impact and changes of the participants' perception of QOL including their diminishing strength and physical fitness and side effect of treatment modalities. Physical

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, Berglund, & Nordgren, 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 et al., 2003; Ma, Harvey, Stewart, Andrews, & Hill, 2007; Sailer, Fuchs, Fein, & Thiede, 2002; Simon, Thompson, Flashman, & Wardle, 2008).

# 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.

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.

#### Cancer as distress

The findings from the qualitative phase of the present study highlighted that a CRC diagnosis, and the results of the 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, Goodwin, & Neugut, 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.

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