

**Exploring knowledge and information needs among
cancer patients in the United Arab Emirates during
their cancer treatment journey**

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**TO EVERY CANCER PATIENT SUFFERING
IN SILENCE, TO EVERY CANCER PATIENT
WHO NEEDS MORE INFORMATION
I PRESENT THIS WORK**

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List of Abbreviations and Terms

AAMDHREC: Al Ain Medical District Human Research Ethics Committee

Arabian Gulf Region: Includes six gulf countries including United Arab Emirates, Saudi Arabia, Bahrain, Qatar, Kuwait and Oman located all around the Gulf Arabian Sea and follow the WHO-.EMRO

ACS: American Cancer Society

AED: Arab Emirates Dirham equivalent to 3.74 USD

CDC: Centre for Disease Control and Prevention

Emirati Nationals: UAE citizens

EMR: Eastern Mediterranean Region which include countries of Middle East and Arabian Gulf.

FISH: Fluorescence in situ hybridization (a diagnostic test for breast cancer)

FOCS: Friends of Cancer Society

GBD: Global Burden Report

IARC: International Agency for Research on Cancer-GLOBOCAN

IPFCC: Institute for Patient- and Family-Centred Care

JCAHO: Joint Commission on Accreditation of Healthcare Organizations

HAAD: Health Authority Abu Dhabi

HER2/neu: Receptors on cancer cell that stimulate breast cancer cells growth

Herceptin : A targeted therapy drug. It acts on the HER2/neu receptors and blocks their action that usually stimulates breast cancer cell regrowth. It blocks the ability of HER2/neu receptors to receive growth signals (Herceptin website)

HPH: Health Promoting Hospital

Muslims: Followers of Islamic religion

NCCN:National Comprehensive Cancer Network

NHMRC:The Australian National Health and Medical Research Council

NICE:The United Kingdom National Institute of Clinical Excellence

NCD: non- communicable diseases

ONC: Oncology Nursing Society

Oncotype DX: a genomic test that analyses the activity of a group of genes that can affect how a cancer is likely to behave and respond to chemotherapy treatment (Breast cancer .org)

Patient Centred Care: PCC

PFE: Patient and Family Education

Quran: Muslims Holy book

Ruqya: Reading verses from the Quran for the sick in the intention to be cured

Zamzam water: Water from Mecca in Saudi Arabia that is considered holy water for Muslims.

SBREC: Social and Behavioural Research Ethics Committee at Flinders University

SEHA: Health Services Abu Dhabi

Tawam Hospital: A tertiary hospital located in UAE-Al Ain city in Abu Dhabi Emirate

UAE: United Arab Emirates

WCRFI: World Cancer Fund Research International

WHO: World Health Organisation

WHO-EMRO: Eastern Mediterranean Regional Office of the World Health organisation

Summary

Cancer education is one of the foundations of oncology patient-centred care. Research has shown that to enable a successful management plan, patients need education about their condition, their treatment plan and about the management of long term and short term possible complications, as well as the prognosis for their disease. During the cancer journey, patients and their families need information related to their disease; and that might be specific to each stage of the cancer continuum.

However, cancer patients' knowledge and education needs might differ from one patient to another. Furthermore, their educational needs and the level of knowledge required might change and vary depending on their physical condition, psycho-social status, personality type, available psycho-social support and their cultural and religious background. Providing patients with education and support has been shown to help patients and their families deal and cope better with the stress and fear associated with their diagnosis and treatment. Patients who receive information and education during their cancer journey are usually more satisfied and have better survival and health outcomes.

Researchers around the world have identified different information needs for cancer patients with different types and stages of cancer, during the cancer journey. Cancer patients in the United Arab Emirates (UAE) do not differ from other cancer patients around the world except for some cultural and social influences that are particular to this country and to the surrounding region in general. Little is known about the experience of patients in the UAE health system. There are no studies about cancer patients' information needs within health services or in the community. This is the first qualitative study that has explored cancer patients' information needs in the UAE and in the Arab world throughout the stages of the cancer journey: diagnosis, treatment and recovery/follow up.

This study aimed to identify cancer patients' knowledge and information needs as they move throughout the cancer journey. The study has investigated ways to improve cancer literacy for cancer patients in the UAE by understanding their knowledge transition and their information needs.

This study employed a qualitative approach to explore patients' views, ideas and perceptions about their information needs and the potential for improving patients' education experiences. A longitudinal research method was used in order to record the knowledge and information transition of these patients during the cancer journey that includes the diagnosis, treatment and follow up or recovery stages. Twenty eight cancer patients attending Tawam hospital, in Al-Ain city in Abu Dhabi the capital city of UAE, were interviewed for three times over a period of eight months during their cancer journey. Every patient was interviewed once at each stage of the cancer journey (diagnosis, treatment and recovery follow up stage).

Patients reported high information needs at the baseline (diagnosis stage). Their information needs fluctuated during the treatment stage, increasing and remaining high during the follow up/ recovery stage. Patients reported having unorganised and patchy education that was challenged by lack of resources and mistrusted and limited sources of information.

The findings of this study suggest that cancer patients in the UAE are in need of continuous education and that patients have high information needs over the course of their cancer journey. A well planned interdisciplinary education program that uses qualified health literate professionals and/or survivors may help improve cancer patients' literacy in the UAE. These measures may improve patients' ability to cope with their disease by providing them with the evidence-based information they need at the appropriate time.

Declaration

I certify that this dissertation does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text.

Iffat Elbarazi

Signed:



Date: 26-10-2015

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At one stage of my life I was diagnosed with cancer. It was a milestone that turned my career and my life toward a totally different direction. Therefore, I offer my first and outmost thanks to God who changed my life path. I am so grateful to Him that He gave me the opportunity to survive my cancer and to direct my career to work with cancer patients. I believe this is one of the blessings that I have received in this life. I worked in cancer education ever since and I always felt that I am on the other side, the patients' side.

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Introduction

Patient education is widely recognised as crucial for effective chronic disease management (Baum & Sander, 1995; Caraher, 1989; Comeford, 2004; Cottrell et al., 2004; Elf & Wikblad, 2001; Golper, 2001; Green & Kreuter, 1991; Labonte, 1993; Laverack, 2009; Muma et al., 1996; Rankin, London & Stallings, 2004; Redman, 2006; Susser, 1985; WHO, 2004, 2005). Despite the central role hospitals have in the health care system, relatively few health promotion and education activities are conducted in public hospitals (Stanton et al., 2008) and there are gaps in the research related to health promoting approaches in hospitals and in clinical settings (Glazer et al., 1996; Himel, 2008; Tonnesen, 2008; Tonnesen, 2012).

Health literacy has been gaining so much attention as an important foundation for better health outcomes (Nutbeam, 2000). Health literacy is defined by WHO (1998) as: “the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health”. It is about empowerment and access to information rather than giving reading brochures and pamphlets. Johnson (2014b) argues that health literacy research is still limited despite the fact it is an important factor to improve health outcomes in communities and health care services

When it comes to cancer education in clinical settings and cancer literacy, it is still in need of more evidence-based research about the best education and health promotion approaches to improve practice (McInally et al., 2012; Wyatt, 2007). The need for more evidence based research to improve cancer health literacy is not different in the Arab world, particularly the UAE (Silbermann et al., 2012). Cancer literacy and cancer education is not researched effectively and there is a big gap in research related to cancer education in the community and in the clinical setting, despite the burden of cancer on these countries.

According to Mokdad et al. (2014) and the Global Burden of Disease report (IHME, 2013) cancer is increasing alarmingly around the world as well as in the Middle East. It is classified as a chronic disease because of the increase in survivorship and of the higher morbidity among survivors (WHO, 2013; the World Cancer Fund Research International Cancer WCFRI, 2015). Globally the cancer burden is expected to nearly double by 2030, growing to

21.4 million cases and 13.2 million deaths worldwide which will increase the economic and social burden on communities (Ferlay et al., 2010; WHO, 2013). In the Eastern Mediterranean Region (EMR) cancer is the fourth leading cause of death after cardiovascular diseases, infections and injuries (Mokdad et al., 2014; WHO, 2013).

According to the WHO (2005) 70% of cancer cases around the world occur in developing, and low and middle income countries. The above alarming statistics has pushed the WHO to call for action to control the increase of cancer cases in those regions. The WHO Cancer Control Strategy was initiated to strengthen and accelerate the translation of cancer control knowledge into public health action (WHO, 2007). This strategy focuses on ensuring actions to reduce cancer cases and to improve the quality of life of patients and their families.

Cancer survival rates are increasing with the advancement in treatment options and with more availability of centres and staff that provide the care and support for them (IMO, 2008). Early detection and treatment of multiple types of cancer has significantly extended survivorship of patients in developed countries (IARC, 2015). Survival rates are improving and more than ever before, patients are more able to resume their normal lives and enjoy a better quality of life (Speigel & Giese- Davis, 2012). The goal of treatment has become more focused on cure and prolonging survival and on ensuring that patients enjoy the best quality of life during the cancer journey.

However, although the biomedical care for cancer has improved cancer survival rate, the psychological and social effects of cancer are still poorly considered during the patients' care (IMO, 2008). Calls to improve education and availability of information have become important measures of cancer patient care and are a major component of patient- centred care (WHO, 2007). Speigel and Giese- Davis (2012) confirm the importance of understanding the medical and psychosocial needs of survivors and the importance of available resources that can assist patients, caregivers, and health care providers to help them during the various phases of cancer survivorship. Many researchers have reinforced the importance of cancer education as one of the foundations of oncology patient-centred care practice (Barry & Egdman- Levitan, 2012; IMO, 2008; Lawn, 2010; Lawn & Shoo, 2010; NCI, 2015; Picker Institute, 2015).

Not only researchers have identified the importance of education, but also cancer patients and families are increasingly demanding more education. As reported by Matthews et al. (2004) cancer organisations such as the American Society of Clinical Oncology (ACSO) and the Oncology Nursing Society (ONS), rate requests by patients and families for information and education about the disease and its treatment as the most important. Also, according to WHO (2003) patients want to be involved in decision making related to their own treatment regimen and need more support. In spite of more patients receiving support, the number of cancer patients who are suffering from the social stigma of cancer is considered to be high globally, including Arab countries (IMO, 2008; Silbermann et al., 2012).

Studies suggest that patients and family members are still dissatisfied with the information and education they receive and the communication process during the cancer journey (Chapman & Rush, 2003; Epstein & Street, 2007). IMO (2008); Chapman and Rush (2003) and Fallowfield et al. (1990) reported that to decrease cancer patients' anxiety and emotional distress during the treatment, patients should receive information tailored to their needs. Rutten et al. (2005); Epstein and Street (2007) and IMO (2008) all reported that patients need a wide range of information that includes information specific to the type and stage of their cancer, treatment, prognosis, rehabilitation, coping strategies and related social concerns. Evidence also suggests that providing information for patients during their cancer journey about their disease, treatment and management can help patients manage their illnesses and the treatment side effects (Boberg et al., 2003; Eakin & Strycker, 2001; Mallinger, Griggs & Shields, 2005; Skalla et al., 2004).

Despite the fact that awareness of cancer prevention, early detection, treatment, and survival are on the rise; too many people still report that they feel uninformed when it comes to cancer. In specific relation to the UAE, there is very limited research and evidence on what health education patients need in UAE, indicating the need for more research investigating this important area of health care. Especially, given that it was reported by Margolis et al. (2003) after surveying patients' satisfaction, that UAE patients were dissatisfied with health education in health care services.

There are many benefits in providing patients and their families with needed information during their cancer journey. These include improving patients' satisfaction, improving patients' ability to cope, engendering trust in health providers; learning about treatment regimen and possible complications and gaining skills to help reduce them (Gray et al., 1997).

Fallowfield et al. (1990) reported that limited knowledge, misconceptions and certain beliefs about cancer and treatment affect the patient's ability to accept different treatment plans, including their ability to cope and accept certain unpleasant treatments. Fallowfield et al. (1990) reported that patients' knowledge helps build trust and confidence, and decrease anxiety and the stigma of cancer effects, hence their social isolation. Although, most of the research in the 1980s and 1990s suggest that the cancer stigma has decreased (Knapp, Marziliano & Moye, 2014); cancer continues to carry a significant amount of stigma, myths, and taboos (Daher, 2012). Education and knowledge may reduce patients' social isolation related to the cancer stigma as identified also by Peters- Golden (1982). Other benefits include increased knowledge of the disease, increased perception of control by patients over their lives and reduced anxiety and fear (Elm & Leonard, 1996).

Cohen and Lazarus (1979) suggest that information seeking is one of the most fundamental and early modes of coping with events about which the individual has limited information. Information and support (formal or informal), therefore play key roles in facilitating recovery (Kaps, 1994; Mor, Allen & Mallin, 1994; Roberts et al., 1994). Moreover, Boyes et al. (2008) stressed the importance of identifying the needs from patients themselves by measuring their own perceptions of their needs.

The importance of giving information to patients as well as the information needs of cancer patients in different stages of their cancer journey were researched and explored by many researchers over the last two decades (Adams, 1991; Ankem, 2006; Leydon et al., 2000; Matsuyama et al., 2012; Mills & Sullivan, 1999; Rutten et al., 2005; van Mossel et al., 2012, 2014; Vogel, Bengel & Helmes, 2008). Moreover, some of these researchers have identified the cancer journey stages and classified them into different stages that ranged from three to six stages. Rutten et al. (2005) have identified through their systematic review five major

stages. These are the diagnosis stage, the treatment stage, the recovery stage, the relapse or recurrence stage, and the death stage. However, not all patients necessarily pass through the last two stages as recovery and remission chances are improving. With so many treatment modalities and early screening measures now available, especially for certain types of cancer like breast cancer. Colorectal cancer and cervical, prognoses have improved also (IMO, 2008; WHO, 2013).

Mackenzie (2010) described the cancer journey as dynamic; starting with the diagnosis process, continuing through treatment, recovery and beyond, with the potential for developing metastases or recurrence, or living cancer-free. With the advancement in treatment and with the use of different lines of chemotherapy, hormonal, targeted and immunotherapies, metastatisation is sometimes contained with the result that patients are living longer. However, for some patients whose cancer metastasises, their journey may continue with further treatment and may possibly end with death (Rutten et al., 2005). Cancer may progress or respond to treatment, hence, patients might follow a different path in their cancer depending on their disease progression and their cancer types.

On the other hand, with improvement in screening measures and more available resources and cancer centres, patient numbers are increasing worldwide as well as in the Arabic countries (Tfayli et al., 2010). In the Arabian Gulf region including UAE, cancer rates and number of cases are on the rise (Silbermann et al., 2012; Tfayli et al., 2010). However, while in first world countries survival rates are increasing and early diagnoses are higher, in the UAE patients are still being diagnosed comparatively later and screening activities are still developing (Kaniklidis, 2012; Silbermann et al., 2013; Tadmouri & AlSharhan, 2012). Moreover, patient education and general health education are also underdeveloped in the region (Silbermann et al., 2012). More research and reforms are needed to improve the practice of this important public health issue that have been proven to affect cancer patients' survivals and outcomes (IMO, 2008; National Academy of Science Press, 2008).

Why this study?

This study is aimed at finding out cancer patient education needs from the patients', rather than the health professionals' perspective. Health professionals usually plan education based on education needs that are listed in textbooks, however, there are very limited research that

investigated the actual patients' needs. This study will try to explore these needs and to identify what patients would like to know about their condition, and how they would like to receive the information, and to understand these needs especially with the expected emotional instability they might endure. Exploring the patients' perspective about the best education method and the knowledge they need throughout their cancer journey is therefore the main objective behind this current study.

In the UAE there are very limited patient education programs in most hospitals and where it exists, cancer patients' education is mostly unorganised, fragmented and unsystematic (Aw et al. 2011, El Obaid 2013). Patient education programs in the region are not following evidence based practice and are mostly not multidisciplinary. However, patient centred care is gaining more attention at the primary care level. Education is provided by the treating doctor and the nurse during the process of medical care provision in most of the times. However, education provided lack continuity and reinforcement that is usually recommended, in evidence based education programs. To the researcher's knowledge, the availability of clinical health educators is very limited in the region and does not exist as a profession in most of the Arab countries and if it exists the status of health educators is not well recognised by registering bodies. In UAE, health educators are employed in the community not in the clinical setting yet (Sharif & Blair, 2011). However, in the primary care sector, health education has started to gain more attention as diabetes education and weight control are becoming important functions of the primary care setting (US-UAE Business Council, 2012).

On the other hand, the health care system in UAE has adopted the primary care approach which reinforces patient and family education programs as being essential in hospitals and in clinical settings to improve patients' quality of life (WHO, 2004). However, research in the area of clinical health promotion and cancer area is still limited and there is no evaluation done so far to measure the effectiveness of such family and education programs (Aw et al., 2011; Emirates Cancer Foundation, 2015; Silbermann et al., 2013; Tadmouri & Nair, 2012).

Moreover, research on health literacy and on how to improve patients and families health literacy in UAE is rare (Sharif & Blair, 2011; WHO, 2007). Sharif and Blair (2011) reported that there are some efforts to improve patient and family education (PFE) practices but they

are still in early stages of development. Loney et al. (2013) reinforced the importance of more research and interventions that are population based and that target major chronic diseases that are considered major public health challenges in UAE.

The Health Promoting Hospital (HPH) initiative by WHO (2004, 2005) confirms the needs for well-planned multidisciplinary patient and family education programs in hospitals. The HPH affirms that patient and family education programs do not only improves patients' adherence to treatment goals and improve patients' recovery and quality of life, but also, it is a cost effective practice that decreases patients' length of stay in hospitals and reduces readmissions due to complications. In UAE, HPH initiative is also not yet recognised. More efforts and research are essential to identify key areas to improve patient and family education practices in health care services.

Cancer as a chronic disease is also often associated with other diseases (Berry et al., 2014). Fifty per cent of cancer survivors in an Australian study were found to suffer from other chronic diseases (Berry et al., 2014). Also mental health problems, such as depression and anxiety disorders, are common in patients with cancer (Carlsen et al., 2005; National Academy of Sciences Press, 2008; Spiegel & Giese-Davis, 2003). The above reports indicates that there must be more research and programs to be focused on educating cancer about prevention of recurrence and about prevention and management of other chronic diseases.

Despite the fact that UAE has improved in meeting targets and indicators to reduce non communicable diseases burden (WHO, 2015), health education programs in UAE are still very limited especially when it comes to cancer. Health education in UAE is mainly focused on the prevention aspects of certain disease like diabetes, hypertension and obesity, rather than cancer (US-UAE Business policy, 2012). Further health education program and activities are still very limited in the secondary and tertiary care services. To meet the target for UAE as per (WHO, 2015) more efforts, programs and interventions are needed to improve health education practices. Especially, those chronic diseases cases are increasing rapidly and alarmingly around the world and in the UAE and neighbouring countries, leading to an increase in the cost of services and on the burden on the secondary and tertiary health

services (HAAD, 2013; IHME, 2013). Managing complications and helping patients to control their conditions is very important to help curb the socioeconomic effects of these chronic diseases on communities and health care systems (WHO, 2007). Arguably, as in other countries around the world there is a need for well-planned clinical health education multidisciplinary programs in UAE and in the region to improve the management as well as the prevention of chronic diseases.

In summary, understanding the needs of cancer patients is important to help in planning health education programs in health care services. To my knowledge no studies have explored the patients' perspectives about the appropriate education and information to be given throughout their cancer journey that will help them cope with their disease during this journey.

To address the gap in cancer education knowledge in UAE, this study explores the cancer patients' education needs in the UAE and how these needs might evolve and change throughout the patients' journey. In particular, it explores the information needs of patients over the expected three phases of a cancer journey: the diagnosis, treatment and recovery phases, and how patients' personal and social experiences may affect these information needs.

Patients are considered as individual cases in this study as patients' experiences and disease development and progression are different from one patient to another, even when patients share the same types of cancer. Therefore, a qualitative (rather than quantitative) approach was used to understand the patients' particular needs and experiences.

The UAE and the surrounding region have a dearth of research that uses qualitative methods which discuss patient experiences and needs (Aw et al., 2010; Khadr et al., 2011). Aw et al. (2011) recommend that successful execution of population research in the UAE requires an understanding of socio-cultural aspects of the study population and good communication between researchers and participants. This is the first study that has explored cancer patient information needs in the UAE and the transition of their knowledge and information needs along the cancer journey, which starts with diagnosis and continues through recovery,

possible recurrence, metastases or death. This study will help provide insight into cancer patients' experiences and feelings, their educational and information needs, and their preferred sources of education. This research aims to improve health professionals understanding of patients' information and education needs which have been neglected area of research in UAE. It will set the groundwork for more research in this area and will stimulate researchers to explore the area of patient education in cancer care in the UAE and surrounding regions. It may be also generalisable to other regional countries.

This dissertation consists of six main chapters: the literature review, the theoretical framework of the study, the methodology, findings of the research, the discussion, and lastly the recommendations to policy makers.

The first chapter, the literature review provides an overview of the study setting, including an overview of the United Arab Emirates generally and Tawam hospital in UAE where the study was conducted. It also provides a global description of the cancer burden, including the UAE and surrounding region. The chapter discusses health and cancer literacy, patient education and the effectiveness of both concepts in patient care, including patient centred care and health promoting hospitals. A summary of the existing research conducted on cancer patients' information needs during the cancer journey and throughout the cancer journey is also presented. The literature review ends with a summary of the gap in the knowledge in the UAE and worldwide and the needs for this research in UAE as a public health issue that can place a burden on the UAE social, economic and political structure.

The second chapter provides the theoretical framework, underpinning this study; it also discusses knowledge acquisition and learning. An argument on how cancer knowledge is constructed in UAE is provided also in this short chapter.

The third chapter presents the methodology used to conduct this study. As mentioned, the study uses a qualitative approach that aims at exploring views and experiences of cancer patients in the UAE. This chapter describes the rationale for using the qualitative method and then describes the research process, including ethical considerations raised by the research, and the process of obtaining ethics approval. A description of the interviews and the research

timeline is also described. Limitations and barriers that affected the process of this research including the researchers' reflexivity are also presented in this chapter.

The fourth chapter presents the study findings. The chapter is structured around the study objectives. The main study objectives include finding out what the patients already knew and what they have expressed they would like to know about the different cancer stages. The transition of that knowledge over the three stages (diagnosis, treatment and follow up/recovery stages) examined in this study is described also in this chapter as being an important objective. Also sources of information used by patients, and the factors that have affected their information seeking behaviours and decision making involvement are also presented. The last part of this chapter discusses the types of knowledge that patients have developed and that may have affected the patients' cancer knowledge and experience.

The fifth chapter discusses the findings of the study. As with the findings chapter, the discussion is structured around the study objectives and themes. The findings of the study objective and themes are summarised and discussed in relation to the available literature.

The sixth and final chapter concerns the translation of the findings into practice. As this study's overall goal is to improve the process and the practice of cancer patient education in UAE health services, this chapter will provide a practical view on how to make use of the results to achieve the study goal. Recommendations based on the findings and the discussions are presented, including a summary of the expected process that will disseminate the results and recommendations to improve the provision of information to, and education of UAE patients.

In summary, this study is expected to contribute to the area of patient education and cancer literacy in the UAE. Other neighbouring countries will also be able to make use of the study findings, as they have similar demographic, cultural and geographical components. This study addresses a very important area of research that is very limited in the Arab world and makes suggestions for future research that will improve the area of patient education and thereby improve quality of life for patients with cancer.

Chapter One

Literature Review

In this chapter, a review of the literature which informs the objectives and the aim of this study is presented. This study is investigating the information needs transition among cancer patients in the UAE, therefore, a discussion on the information needs of the patients and the factors that may improve patients learning experiences during the cancer journey is also provided. To present the literature review, a review on cancer, cancer education and research in general in the UAE in to the world is essential. As part of the discussion of the importance of cancer literacy for better and positive health outcomes, a highlight on the gaps in the research related to cancer patients' education needs along the continuum of the cancer journey that this study investigates is summarised. An overview of international and local research related to cancer education and patients' information needs is also provided.

This study explores the information needs of cancer patients in the United Arab Emirates (UAE) in an attempt to determine and understand what particular information needs they require and how their needs change over time as they progress through their cancer journey in the cancer continuum. As part of this focus on UAE cancer patients, this chapter provides an overview of the global literature, in UAE and in neighbouring countries that is available on cancer patients' education, knowledge and information needs as they change over time. The chapter begins with discussing the public health significance of this issue and the burden of cancer internationally and specifically in the UAE where the study was conducted. Also, as this research was conducted in the UAE at Tawam hospital (one of the tertiary care hospitals) an overview of the UAE and the hospital is provided. As part of the overview, a discussion on patient education and its effectiveness, cancer and its treatment, and the need for cancer patient education is also presented. Finally, it describes the cancer journey and discusses the information needs of cancer patients during their journey. A discussion of the factors that affect the patients' information needs as they transition during the journey is also described.

To start with an overview on the UAE and Tawam Hospital is provided in the next section being the setting of this research study.

1. An overview of the United Arab Emirates (UAE)

The UAE is one of the most rapidly advancing Arab Gulf countries and one of the most affluent in the region. Its economic and political climate is also relatively more stable than the rest of the region (Loney et al., 2013; Sharif & Blair, 2011). The UAE was united out of formerly disparate regions in 1971 by the late Sheikh Zayed Bin Al Nahyan. There are seven emirates (equivalent to states headed by princes called sheikhs in UAE context) of which Abu Dhabi is the capital, Dubai the major business hub and Sharjah the cultural heritage city. Ajman, Ras al-Khaima, Umm al-Quwain and Fujairah are the remaining emirates which are less populated. One in five residents is nationals (Emiratis) of whom two thirds are under thirty years of age and half under nineteen years (HAAD, 2013). Expatriates are mostly males and of South Asian origin, mostly from India, with the majority aged between twenty and forty years. A significant number are employed in construction and accommodated in labour camps. Mandatory health insurance in 2007 was introduced in Abu Dhabi, which provides all residents (mainly nationals) in Abu Dhabi access to high quality health care. Dubai and Sharjah followed Abu Dhabi's initiative and currently, nationals are enjoying comprehensive primary care in most of the UAE. The population has been growing rapidly over the last 20 years reaching over 10 million (HAAD, 2013).

2. Tawam Hospital

Tawam hospital is a major centre for cancer treatment in the UAE and in the Arabian Gulf region. Its services started in September 1979 and one year later, it launched a radiotherapy department, making radiotherapy treatment available for the first time in the UAE. In February 1983, oncologists in the UAE and the Ministry of Health (MOH) recommended Tawam Hospital as the cancer referral hospital for the entire country. Since 2006, Tawam Hospital has been accredited by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) and is one of the largest tertiary care hospitals in UAE. It is located in Al Ain, in the emirate of Abu Dhabi, Tawam Hospital is part of the Abu Dhabi Health Services (SEHA) network of public hospitals, owned by the Health Authority of Abu Dhabi (HAAD).

Tawam has 461 beds and is an important regional referral centre for specialised medical care. It is also a national referral centre for oncology services. The hospital is also one of the few

trauma centres in the country and is best known for not only its oncology services, but its neonatal care, fertility services, intensive care, and cardiac care. It has also one of the major diabetes centres in UAE which is working in collaboration with John Hopkins hospital. The national cancer registry is also located at Tawam Hospital and is linked to other cancer treatment centres in UAE and to the Health Authority of Abu Dhabi (HAAD). In its 2012 report there were 1,500 cancer cases in the registry, of which 83% of the patients received their initial treatment at Tawam Hospital and the remaining 17% were referred to Tawam Hospital (UAE Central Cancer Registry, 2012).

Tadmouri and AlSharhan (2012) reported that the tumour registry at Tawam Hospital was developed in 1998 and soon became the official UAE Central Cancer Registry after a ministerial decree making notification of cancer cases mandatory. Until recently, Tawam Hospital was the only hospital that treated cancer patients in the UAE. Lately, however, many hospitals have started providing cancer care and treatment; nevertheless patients who need radiation therapy and palliative care are still referred to Tawam, as it is the only hospital providing these particular services.

In addition, the only breast cancer centre in the country is located at Tawam. The centre provides comprehensive services, using advanced technology, surgical consultations and referral to the Oncology unit. Tawam receives patients from all nationalities in the inpatient and outpatient department (Tawam Newsletter, 2015). UAE nationals receive free treatment at Tawam, while other nationalities need referrals from governmental hospitals or private health insurance, or must pay full fees to receive treatment. The hospital employees also come from different nationalities and patients receive interpretation services when needed.

3. Cancer burden and policies

In this section, I provide an overview of the international burden of cancer, including the UAE, along with the importance of cancer information for patients and families in general.

a. Cancer worldwide

According to world reports, cancer cases and cancer mortality rates are increasing. According to the World Health Organization (WHO, 2013) non-communicable diseases (NCDs) are

comprised mainly of cardiovascular diseases, cancers, chronic respiratory diseases and diabetes. These are the world's biggest killers: More than 36 million people die annually from NCDs (63% of global deaths), including more than 14 million people who die too young, between the ages of 30 and 70 (WHO, 2013).

The World Cancer Research Fund International, WCRFI (2015) ascertains that behaviour change is a key to the prevention and control of non-communicable diseases; about the third of the most common cancers can be prevented through diet, maintaining a healthy weight and taking regular physical activity.

Low and middle-income countries comprise 86% of the burden of these premature deaths. Over the next fifteen years, cumulative economic losses of \$7 trillion USD are anticipated, with the result that millions of people will be trapped in poverty. Cancer is a leading cause of these deaths worldwide, accounting for 7.6 million deaths (13% of all deaths) in 2008. It is projected that cancer will cause 13.1 million deaths in 2030 (ASC, 2011; WCRFI, 2015; WHO, 2013). In keeping with world-wide deaths from non-communicable diseases about 70% of all cancer deaths in 2008 occurred in low and middle-income countries. The WCRFI (2015) report estimated 12.7 million cancer cases around the worldwide during 2008. Amongst them, 6.6 million cases were men and 6 million women. New statistics predict that cancer is going to affect 21 million people by the year 2030 (GLOBOCAN, 2012; Mokdad et al., 2014).

Specifically, lung, stomach, liver, colon and breast cancer cause the most cancer deaths each year. Breast cancer is the second most common cancer worldwide after lung cancer with nearly 1.4 million new breast cancer cases in 2008. It is the most common cancer among women both in developed and developing countries, with an estimated 1.38 million new cancer cases diagnosed worldwide in 2008, making it 23% of all diagnosed cancers (Ferlay et al., 2010). And the incidence of breast cancer, in developing countries in particular, has been steadily increasing (Parkin et al., 1997). Colorectal cancer is the third most common cancer, with over 1.24 million new cases in 2008. (Ferlay et al., 2010; GLOBOCAN, 2012). Around 1.2 million cases of bowel cancer were recorded in 2008, accounting for around 10% of all new cancer cases. It is predicted that the number of cases will rise to 2.2 million by 2030.

b. Current policies for cancer control and for better education

To overcome the burden of cancer, countries and policy makers are putting in place policies and programs that are aimed for cancer control and national and local strategies to improve education and prevention. Nowadays, public health programs are directed toward early detection, prevention and control of cancer. There is also a further need for public health programs that address cancer survivorship (CDC, 2015; Fallowfield & Jenkins, 2015).

Cancer control science is defined as: “the conduct of basic and applied research in the behavioral, social, and population sciences to create or enhance interventions that, independently or in combination with biomedical approaches, reduce cancer risk, incidence, morbidity and mortality, and improve quality of life” (NCI, Cancer Control Program Review Group, 1998). It includes effort to decrease incidence of cancer such as screening programs, initiating cancer registries, ensuring availability of services and trained professionals to provide treatment and follow ups for patients in all stages and at all levels of care.

In developed countries, cancer survivorship is increasing due to an increase in medical innovations and more investments in cancer care and screening (CDC, 2004). The Centre for Disease Control (CDC) (2004, p: 3) defines cancer survivors as “those people who have been diagnosed with cancer and the people in their lives who are affected by their diagnosis, including family members, friends and caregivers.” According to the same report, 62% of cancer survivors in the United States are expected to live at least five years post diagnosis. In poor and underdeveloped countries, cancer patients die early and usually cases are discovered in its late stages. Early deaths and late diagnosis are due to poor screening programs and poor health literacy within these countries. The CDC (2004) confirms that cancer survivors would benefit from a coordinated public health initiative, supporting their physical, psychological, social, spiritual and financial needs throughout their cancer journey and for the rest of their lives. Such initiatives must address the prevention of secondary diseases or recurrence of cancer and improve quality of life for each survivor.

In comparison to what is in the US, cancer survivorship was addressed through a national action plan by the CDC and other partners as an important public health goal (CDC, 2015). The plan proposed that this goal can be attained through ongoing scientific research on the

physical, psychological, social, spiritual and economic issues facing cancer survivors, and by identifying the appropriate mechanisms and resources for ongoing surveillance of people, not only living with cancer but after treatment is complete. The plan further recommended that training should also be provided to health care professionals to improve delivery of services and increase awareness of issues faced by cancer survivors.

In order to decrease the burden of cancer, prevention and education programs that are directed toward the community and toward patients and families are essential. Screening programs and early detection programs for many cancers (breast, cervical, prostate, colorectal and skin) became mandatory in most developed countries like (Australia, United States of America, Canada and almost all European countries). They are also increasingly spreading and being implemented in many developing countries around the globe including the Arab countries. The UAE has been one of the leading countries in the Arabian Gulf to initiate such programs. Around the world, breasts, cervical and colorectal cancer screening programs, are proven to be very successful in reducing mortality especially in the developed world (WHO, 2013).

In the United Kingdom, the National Institute of Clinical Excellence (NICE, 2004) cancer care guidelines recommend that patients should receive the best possible treatment. They also stress on the patients' right to be treated with dignity and respect for their culture, lifestyles and beliefs. The guidelines affirm that every patient should receive good quality information by a well-trained senior health professional. Fallowfield (2012) argues that if NICE cancer care guidelines are properly applied and implemented, the patients will have a better chance of getting the services crucial at all of their cancer stages from diagnosis to death and bereavement. She argues also that it is best practice to view information, communication and symptom control, together with psychological, spiritual and social support, as integral and central parts of quality cancer care.

The importance of providing patients with timely and appropriate support and information has been endorsed by a number of other authorities. For example, the national cancer prevention guidelines in the US, Australia, Canada and the United Kingdom all state that cancer patients and their families should be well cared for, well informed and well supported.

The Australian National Health and Medical Research Council (NHMRC, 2000) stated in their clinical practice guidelines that, based on scientific evidence, all cancer patients and their families are entitled to make their own decisions about treatments or procedures and should be given adequate information on which to base those decisions. The guidelines suggest that information should be provided in a manner that helps patients understand both the problem and treatment options available, and in terms that are appropriate to the patients' circumstances, personality, expectations, fears, beliefs, values and cultural background. The guidelines also reinforce that doctors should give advice, but should not coerce but rather encourage patients to make their own decisions. In regard to patients, the guidelines suggest they should be frank and honest in giving information about their health and doctors should encourage them to do so through appropriate communication channels and trust.

Elsayed et al. (2009) call for more research and more efforts to control the effect of cancer on Arab societies due to the increasing incidence of cancer in the Arab world causing more deaths and morbidities. The authors although they claim that there are many Arab scientists who are contributing to epidemiological research into the causes of cancer and how to develop effective control programs.

c. Cancer in the UAE

Before the epidemiological transition that happened with the improvement of screening and diagnosis and the change of lifestyle of UAE residents, the UAE had lower incidence of cancer in comparison to other Western countries (Loney et al., 2013). However, the prosperity and the dramatic change that took place in the UAE social, economic and demographic over the past forty years have led to an increase in non-communicable disease including cancer (Loney et al., 2013). Cancer became the third leading cause of death in the UAE, following cardiovascular diseases and accidents (HAAD, 2013). Data from HAAD (2013) indicated that cancer accounted for approximately 500 deaths per year from January 1998 to December 2002. It accounted for 7.7% of total deaths (443) in 2002 and 8.3% (486) in 2001 (Badrinath et al., 2004). Deaths from cancer have increased to reach in the year 2013 to reach 10% and 16 % of total deaths of the emirate of Abu Dhabi (HAAD, 2013). Stomach cancer was the leading malignancy among Emirati males, in 2013, closely followed by lung, colorectal, non-Hodgkin's lymphoma (NHL) and prostate cancer. While, breast cancer was

the leading malignancy in Emirati females, followed by leukaemia, thyroid, cervix, uterus and colorectal cancer (UAE Central Cancer Registry, 2012).

According to the Global Burden of Disease report (IHME, 2013) lung cancer and colorectal cancer have moved up in the rank of diseases that cause premature death and in general, cancer has moved up in the rank among diseases causing disability in the UAE. According to the same report, dietary risks, high fasting plasma glucose and high body mass index are the three major risk factors behind causes of mortality in the UAE. Another important factor identified as causing death and disabilities in the UAE are physical inactivity and smoking. All three are identified as risk factors for many chronic diseases, amongst them cancer. Another important factor identified as causing death and disabilities in the UAE are physical inactivity and smoking.

Breast cancer is ranked as the most prevalent cancer among women in the Arab world and women younger than forty years make up a large percentage of total breast cancer cases in the Gulf countries (Jassim & Whitford, 2013). According to HAAD (2013) breast cancer is the most common cancer type in the UAE accounting for 11.7% of all cases generally and 27% of all cases among women.

Data from UAE Central Cancer Registry also showed in 2014 report that in a single year there were 1,212 new cancer cases, including both nationals (Emiratis) and non-nationals (Non-Emiratis). Of the 389 UAE nationals that were diagnosed with cancer, 208 were males and 181 were females. In the year 2012, a total of 823 new cancer cases were diagnosed in non-nationals, amongst them were 422 and 401 females. After the age of 60, males had a tendency of higher cancer incidences than female nationals, while the age group from 45 to 49 of non-national females showed higher incidence compared to 50 to 54 in males. Mortality from cancer is increasing in the country; however it is higher among non-nationals.

According to HAAD (2012) breast cancer is the most common cancer in the UAE, accounting for 11.7% of all cancers. It is also the highest prevalence of all cancers that affect women in the UAE, accounting for 27% of all cases. Colorectal cancer is the next most diagnosed cancer, in females in the UAE, accounting for 11.5% of all cases. In men, it is

third, after lung cancer, accounting for 11.4% of all cases. In 2012, colorectal cancer was the most prevalent cancer in male patients registered at Tawam Hospital and the second most frequent cancer overall (9.5%). Breast cancer was the most common cancer among female patients (25%), which is a consistent trend over the years. The cancer patient population was 23% nationals and 77% non-nationals.

Late detection of breast cancer leads to significant increases in mortality. Nevertheless, female UAE nationals (Emiratis) aged 40 to 69 are invited to attend screening for breast and cervical cancer as part of their “Thiqa Insurance” renewal in Abu Dhabi. And education and awareness campaigns have increased screening rates for all nationalities; however, for non-nationals, cancer screening is not covered by the national insurance scheme and it depends on the individual’s socioeconomic status and their insurance coverage.

Breast and colorectal cancer screening programs have been successful in reducing mortality in the developed world (WHO, 2013). However, In the developing world, and no less in the UAE, breast and colorectal cancer are diagnosed at later stages than developed countries due to less prevalence of successful screening programs, less awareness among communities and unavailability of highly advanced diagnostic tools and highly trained professionals. In the UAE, screening programs are still fragmented and not applied on a national scale. There are breast cancer and cervical cancer screening program in Abu Dhabi, Dubai and Sharjah only which does not cover the other four emirates (FOCP, 2015; HAAD, 2014). A Colorectal screening program was launched in 2014 in Abu Dhabi (HAAD, 2014). Although there are well trained professionals in advanced diagnostic tools and treatment centres cancer patients are still admitted at later stages (Kaniklidis, 2012; Tadmouri & AlSharhan, 2012). Early detection and prevention programs available in the UAE are still considered to be in the development stage and have not proven effective yet.

Studies that measure early detection and prevention programs are needed in the UAE (Tadmouri & AlSharhan, 2012; Tadmouri & Nair, 2012). Tadmouri and AlSharhan (2012) confirms Wynder et al.’s (1960) observations that Arab nationals, including those from the UAE, tend to develop breast cancer at least a decade earlier than women in western countries. In addition to possible genetic differences, social customs may contribute to delay in

diagnosis, resulting in late presentations, which impacts on epidemiological data and clinico-pathological studies. Studies that measure early detection and prevention programs are needed in the UAE (Tadmouri & AlSharhan, 2012; Tadmouri & Nair, 2012). Patients with late diagnoses require more health professionals' time and care. They need longer hospitalisation periods and advanced patient centred care. They are also in need of more education and support. Unfortunately, the cost burden of late and advanced stages of cancer on health care systems, and societies, is one of the major problems associated with late diagnosis (Tadmouri & Nair, 2012).

Cancer patients are a reflection of the diversity in the UAE, as seen by the registry report (UAE Central Cancer registry, 2012, 2014). Patients come from different backgrounds, holding with them beliefs and practices that might influence their treatment, disease progression and possible remission. The economic situation in the UAE and the increase in awareness and education are contributing to the prolongation of cancer patients' survival time; however, caring for chronically ill people places a huge economic burden on the health care system, families, caregivers, labour market and social system (Lindsay & Vrijhoef, 2009). In diverse societies like the UAE, there is a growing need to increase awareness of chronic disease prevention, management and treatment on all care levels, and in the community, to decrease the economic burden on such a multicultural, fast growing society. Silbermann et al. (2013) describes the UAE medical practice and culture to be paternalistic that hinders nursing and medical care. The authors argue that as the UAE is multiethnic and patients come from different backgrounds and cultures; language is one of the main barriers of comprehensive care. They describe the patients as "lost in the sea of translation."

Moreover, as cancer patients in the UAE come from a variety of backgrounds, it is expected that patients will have different approaches, views and understandings toward cancer as a disease and the treatment options. Awareness among cancer patients is very important to prevent misuse of traditional herbal medicines and to help patients adhere to treatment plans and advice, and to improve patients chances for a better quality of life. In the UAE, family life and family support is still an important cultural practice, incorporated within the UAE value system.

A cancer experience has a great impact on patients and their families in the UAE. In some Arabic countries, families hide their diagnosis from others, especially when the patient has breast cancer, as this might decrease the chance for her daughters to marry (Al-Amri, 2009). Being a chronic disease that can recur and that can be familial, cancer education efforts should be equally distributed on all care levels for patients. Cultural differences, therefore, might negatively influence the cancer patient's experience. Well developed and tailored educational plans for cancer patients in this region and in the UAE will enhance their chances for recovery and better coping with their illness (Elbarazi & Grivna, 2015).

Recently, Abu Dhabi adopted the National Comprehensive Cancer Network (NCCN) Clinical Practice Guidelines in Oncology. These guidelines are very much clinical and do not include the psychosocial and support practice guidelines that are needed to improve patient involvement in the care and decision making process (HAAD, 2012). As the guidelines lack psychosocial and support practices, there was call from some of the cancer care professionals to revise these guidelines, to overcome the genetic, cultural and environmental differences that are particular to the UAE.

As stated above, cancer rates have increased in UAE due to the socioeconomic changes that occurred in the country especially with the fuel discovery. Cancer is often thought to be the problem of rich countries. The UAE is an affluent country that is developing very rapidly, which is affecting the public health system immensely. Currently, millions of Dirhams (AED) is being spent to treat advanced cancer cases in the UAE (Tadmouri & AlSharhan, 2012). Although the UAE is one of the early Arab countries that has adopted the Global Action Plan, proposed by the WHO to fight non- communicable diseases (NCD's) and is putting forward policies and actions to achieve the designated indicators, comprehensive programs and policies are needed to reduce this huge cost on the UAE public health system.

To summarise so far, a few studies in the UAE have investigated the general population's knowledge and attitude about screening, as well as behaviours related to lifestyle and prevention of cancer (Bener et al., 2002; El Obaid et al., 2014). Only one study has investigated the importance of clinical care and support for people who have cancer in the middle-east, however education and knowledge needs were not addressed in that study

(Silbermann et al., 2013). Although the oncology system of care is well developed in the UAE (Silbermann et al., 2013) there is a high need for general research in ways of providing better care for patients in health literacy, clinical health education and promotion in health services in the UAE.

4. Health education and patient education

a. Health education

This section will discuss health education and patient education being important components of public health and the main focus of this study. This study is aiming at exploring patients views about the importance of having developed health education and patient education programs to meet patients knowledge and information needs. Clinical health education or therapeutic patient education is an important emerging health promotion dimension that needs to be considered when designing public health strategies and in the discourse of public policy developments (Green et al., 2015; Redman, 2007). Empowerment, communication and participation in decision making are all essential concepts that make the basic foundation of successful clinical health education programs (Redman, 2007).

Encompassing the characteristics mentioned above, Green and Tones (2004, p. 28) suggest a new term for health education to differentiate it from old traditional concepts of health education which is a widely adopted definition of health education that states “Health education is any planned activity designed to produce health or illness related learning.” Green and Tones (2004) argue that health education is an essential component of health promotion that should lead to developing cognitive capabilities, developing skills in problem solving and decision making; and adopting new attitudes among educators.

Green and Tones (2004) consider the new understanding of health education to interconnect with health promotion as described by WHO (1998) being “Consciously constructed opportunities for learning involving some form of communication designed to improve health literacy, including improving knowledge, and developing life skills, which are conducive to individual and community health.”

Green and Tones (2004) argue that health education should be empowering to individuals and should help in developing the needed knowledge. These values and skills will assist individuals in the decision making process (that will be discussed later) and to make voluntary actions conducive to their health. Another important role of health education also is that it encompasses many of the health promotion functions, such as raising awareness among individuals in different settings including the clinical and other community settings. Further supporting the need for health education, Green and Tones (2004) call for the need for policy changes to support health choices, increasing community awareness about risky behaviours and motivating people to take action, engaging professionals to become advocates for the health and wellbeing of individuals and groups, including patients in the primary, secondary and tertiary settings.

Green and Kreuter's definition of health education (1999, p: 27) also affirms the importance of empowerment and encouraging people to take their own healthy related decisions. They define health education as:

“any combination of learning experiences, designed to facilitate voluntary actions conducive to health voluntary means, without coercion and with full understanding and acceptance of the purposes of actions” .

Further emphasising Green and Kreuter's view, the People's Charter for Health (2000) emphasises that “the people's voices as an important tool that will guide decisions that shape lives –hence community participation in decision making” (Baum 2008, p.476).

Green and Tones (2006) argue that health promotion involves a certain level of coercion, as well as limits to freedom of choice. Coercion implies making people adopt certain healthy practices by following policies such as banning smoking in public places. They argue that although that banning certain unhealthy practices might be coercive but is needed to protect the public interest. The difference between coercion and freedom of choice is what makes health education different from health promotion, in concept and in function, but these two concepts cannot be separated. Health education tends to convince people rather than forcing them to follow certain recommended health related practices. Importantly, however, health promotion and health education must build on the concept of commitment to major values and cultural sensitivity. Both need to follow models and theories however, health education

build on the empowerment model and uses individual health behaviour and encompasses a strong base of psychological models and behavioural changing models such as the health belief model, trans-theoretical model; social learning theories and socioecological theories (Keleher in Keleher, MacDougall & Murphy, 2008)

No matter what differences or similarities exist between health promotion and health education, both were proven and strongly recommended to be followed as they lead to better health outcomes as research indicates. A positive relationship between increased education, implementation of public health policies and improved health outcome was found (Blackmore & Kamp in Keleher & MacDougall, 2009).

b. Patient education

Patient education is considered an important component of health education in terms of encouraging and empowering people to make decisions important for their health, albeit in a specific context. Redman (2007) argues that the patient education movement is new approach to public health that has evolved out of conflicts by public health specialists with the concept of paternalism in health care. Paternalistic health care approaches, consider the health care provider to be the expert in making the best choice for the patient (McLeod & Sherwin, 2000).

Different concepts and approaches since then has evolved and appeared in the literature. In 2004, Redman, argued that patient education was still seen by policy makers as an action that depends on the health care providers with no involvement from patients.

In response, Redman called for patient education to become a separate function of patients' care, rather than being supportive for medical treatment. In this same text, Redman (2004) specified the goal of patient education as being "to support the patient's autonomous decision-making, not (as it has been conceptualized) to get patients to follow doctor's orders." She argued that this requires patients to understand that health professionals are offering advice and not telling the patient what to do, and that the final decision is up to the patient. Later in 2007, concepts of adherence then followed by concordance were introduced and in Redman had argued for a patient-centred education that should be critically aware of

physician limitations in medical knowledge and clinical judgements. All three concepts, adherence, concordance and patient centred care will be discussed later in this chapter.

In relation to the context of the proper use of health education technique, health education can be persuasive and can also be empowering. Communication in health education and patient education is important and linked to learning. Selection of methods and the development of the health message being promoted are essential too (Green & Tones, 2004). Different models and approaches of health promotion can be followed to achieve successful health and patient education. For example, according to the empowerment model of health promotion, individuals may facilitate the possibility to control their own health (self-empowerment) if they work together with health care providers to achieve a supportive environment (community empowerment). In this health promotion model, health care providers try to persuade individuals to change their behaviours by providing them with the right information and by involving them in the decision making process (Green & Tones, 2004).

Patient education is an important function of the empowerment model of health promotion, as it promotes the health of patients (Green & Tones, 2004; Rankin, London & Stallings, 2004; Redman, 2007). By definition, patient education is the process of enabling individuals to make informed decisions about their personal health-related behaviour. It aims to improve health by promoting healthy lifestyle choices, by empowering patients to make the right decisions about their health (Green & Tones, 2004; Rankin, London & Stallings, 2004; Redman, 2007). The term “adherence” replaced “compliance” in the literature to convey the patient's active participation in following a treatment regimen, rather than the patient's submission to a provider's directive (Roter et al., 1998). Nowadays, the term “concordance” has become more popular in patient education literature and is considered a main function of patient centred care (Bell et al., 2007). The term concordance refers the notion of negotiable consultations between clinicians and patients: a therapeutic alliance between the clinician and patient (Royal Pharmaceutical Society of Great Britain and Merck Sharpe & Dohme, 1996).

According to the notion of concordance, clinicians are expected to respect the rights of patients to decide whether or not to follow treatment recommendations or prescribed medicines (WHO, 2003). As part of patients' right to decide, concordance aims at creating an

autonomous attitude in a person (Bell et al., 2007). An autonomous person, as described by Redman (2007, p: 8) is “someone who makes decisions with a sense of control: one who creates and evaluates the best options through their own values, attitudes and beliefs to reach a final decision”. Redman (2007) argues that if patients do not reach this autonomous level they remain incapable of making decisions on their own. Their options will then be decreased and will have to resort to allowing their clinician make the final decision.

The consequences if a therapeutic partnership is not established are great: non-concordance may occur which will cause the interaction to fail, as well as non-adherence, which may prevent patients from gaining access to the best treatment. In this case of chronic diseases, being prevented from gaining access to the best treatment may be particularly problematic for patients with chronic medical conditions (Haynes et al., 2002).

To avoid the failure of the therapeutic relationship on the basis of patient not being able to make an autonomous decision Redman list five areas of competencies that patients and families are expected to develop through the patient education process. These competencies include the ability to self-manage chronic disease and events, requiring the patient to develop significant clinical judgement and confidence; to follow the screening and monitoring function and guidelines; to provide care to others and to understand the basis for ethical decisions. All these steps, she argues empower patients to develop the skills to independently make the right decisions related to their conditions. .

Alternatively, the Flinders Model of chronic conditions self-management provides an evidence based framework in helping patients managing their chronic conditions. The model is based on long-term research that is patient centred and holistic, as it includes the psychological aspect in its care plan (Lawn & Shoo, 2009). It incorporates six core principles to help patients manage their own condition independent and to empower them to make informed decisions and be their own carers. The six principles include patients gaining knowledge about their own condition, following a care plan, sharing actively in the decision making process, monitoring and managing signs and symptoms, coping physically, socially and emotionally and finally patients following and adopting a healthy lifestyle. In this model health care professionals are consultants: the care plan is agreed between the health care

team and patient or client where the problem is identified and goals are set together, achieved and reviewed together (Lawn, 2010).

Redman (2007) further suggests that patient education should be tailored to meet the needs of certain populations. Such populations include people with limited health literacy, people with complicated health problems; people with various cultural beliefs; people who suffer from memory loss or thought disorders and need extra help; and individuals who do not trust their ability to make decisions. Redman's (2007) suggestion is supported by studies such as the one conducted by Post et al. (2001) that found that racial and ethnic differences play a large part in the communication process between patients and health care providers. In addition, other researchers argued that some patients do not wish to learn as much as the health care provider want to teach them, and some do not have the educational background education to absorb complex teaching (Freda, 2004). What is more, from the health providers' perspective, Cooper et al. (2003) reported that not all providers want to work as "partners" with their clients.

Both arguments about the potential limits of patients' participation can lead to a conclusion similar of the one above by Redman. Her argument about the importance of meeting the needs of the patients through a proper assessment to what the clients already know, what they would like to know and how best to achieve the goal of helping the clients learn enough to make informed decisions about their own health will require careful education planning. While some of these areas of patient education and patient needs have been recognised internationally in many countries around the world they are still poorly addressed, especially in the gulf region and in particular in the UAE, hence, the importance and necessity of this research.

In conclusion, patients' education needs are essential key elements for the patient care in the clinical setting. Contemporary patient education needs to include patients and their families in the decision making process, it should be carefully planned to meet the patients and families' needs as stated by many researchers like Redman and Johnson as reported above.

Patient education incorporates many concepts that are essential for the success of the patient education process. Learning methods, behavioural changes, theories and models, the

communication process and health literacy are essential concepts in patient education. An important emerging area, where patient education has a large role, is the health promoting hospitals and the health promoting hospital initiative. Patient education can happen in different settings; however, when it takes place in the clinical setting, different terminologies can be used to describe it. Clinical health education, therapeutic health education, and therapeutic patient education are terms used interchangeably with patient education in the clinical setting. Interdisciplinary patient education is one of the very important concepts that is also acquiring more importance among researchers and educators.

These concepts were lately supported by the health promoting hospitals initiative and recommended by the primary care core functions. In the following sections, the Health Promoting Hospital (HPH) initiative and the role of Patient Centred Care (PCC), education and communication are discussed to highlight the public health significance of patient the importance of patient education and information needs.

i. Health promoting hospitals

Patient and family education (PFE) services are essential in hospital and clinic settings to improve patient concordance with treatment and thereby improve their quality of life (JCOH, 2015). The (HPH) Initiative by the WHO confirms the need for well-planned multidisciplinary patient and family education programs in hospitals (WHO, 2004, 2006). The HPH affirms that patient and family education programs not only improve patient adherence to treatment but improves patient recovery and quality of life.

The Health promoting hospital initiative is based on the health promotion philosophy outlined in the WHO Ottawa Charter for Health Promotion (WHO, 1986). The Ottawa Charter lists health care services as an important area for health promotion. The charter confirms that health promotion in health services is a shared responsibility among individuals, community groups, health professionals, health service institutions and governments for a better health care system. The HPH standards and strategies are based on the principles of the settings approach, empowerment and enablement, participation, a holistic concept of health, inter-sectoral cooperation, equity, sustainability, and multi-strategy (Rootman et al., 2001).

The HPH initiative set eight standards and sub-standards that focus on patients, staff and the hospital organisational management (WHO, 2004). Standards that are directed toward patients' education include having a written policy for health promotion in the hospital, set activities that include assessment of patients' needs for health promotion, disease prevention and rehabilitation, and providing the patient with information on significant factors concerning their disease or health condition. It also recommends that health promotion interventions should be established in all patients' journeys. The eight sub-standards relate to patient information and education commands recommending that all patients should be given clear, understandable and appropriate information about their actual condition, treatment, care and factors influencing their health. They also, recommend the organization must ensure that health promotion is systematically offered to all patients based on assessed needs. In addition to ensuring that information given to the patient and health promoting activities are required to be documented and evaluated, including whether expected and planned results have been achieved. Finally, the organisation must make general information on factors influencing health accessible to all patients, staff and visitors (WHO, 2004).

Taking the HPH initiative seriously, Johnson (2014a) has called for actions to improve health care services and organisations to become health literate and to improve health literacy among health care providers. She argues that health literacy is linked to poorer health outcomes and less safe and low quality services. In her study, Johnson (2014b) reported that low literacy in health care organisations lead to poorer communication and lower outcomes.

The HPH affirms that patient and family education programs not only improve patient adherence to treatment but improves patient recovery and quality of life. HPH is a cost effective practice that decreases the patient's length of stay in hospitals and reduces readmissions due to complications. According to Stanton (1996) health education is cost effective, as it improves community understanding of health care needs and patient education can improve patient satisfaction and enhance staff-patient relationships. HPH, therefore is an important initiative to ensure patient education is planned and implemented in hospitals i.e. thereby reducing cost and improving patients' outcomes. Cancer patients will benefit tremendously throughout their cancer journey from having well planned and continuous health education and health promotion activities, for themselves and for their families. This

concept in cancer patient care needs more exploration and more research to understand the HPH model effectiveness in the Middle East and in the UAE in particular, especially as there is only one HPH in the gulf region located in the capital city in Saudi Arabia. The initiative is yet to be well recognised by clinical services and policy makers in the region (WHO, 2005).

ii. **Patient- Centred Care (PCC)**

Patient-centred care is defined by the Institute for Family Centred Care as: “ an innovative approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families” (IPFCC, 2015, p:1). Patient- and family-centred care applies to patients of all ages, and it may be practiced in any health care setting (IPFCC, 2015). The patient centred care approach was initiated based on Picker Institute Research in 1993 which identified eight dimensions in which the patient perspective is core value and essential. These dimensions include the respect for patients’ preferences and values, ensuring that patients receive emotional support and physical comfort, providing information, communication and education to all patients, continuity, transition and coordination of care, the involvement of family and friends and finally ensuring full access to care (IAPO, 2007).

WHO uses the term ‘responsiveness’ in preference to ‘patient centred care’ and considers it an intrinsic goal of health systems to serve people. It describes responsiveness as meeting people’s expectations and respecting their wishes and effective communication between health workers and patients (WHO, 2007). There were many reviews on the concept of patient-centred care that have identified the core elements of this framework to be: education and shared knowledge, involvement of family and friends, collaboration and team management, sensitivity to nonmedical and spiritual dimensions of care, respect for patient needs and preferences and the free flow and accessibility of information (Goodrich & Cornwell, 2008).

As discussed above, communication is essential in health education, in fact it is usually interchangeably used for education and teaching (Fletcher, 1973, p.2) and is also used to describe the whole education process (Green & Tones, 2004). Communication is the transmission and reception of messages, and is essential for the learning process (Redman,

2007). The nature and success of the communication process will be influenced by the sender and the receiver. It is a two-way process which can be maximised when the sender checks the feedback of the receiver. Communication can be verbal and written, amongst others. Written communication is an important means by which health educators send their messages (Green & Tones, 2004). Communication is usually seen as empowering if directed to the target population and if it involves two ways communication.

Taking in consideration the role of communication in empowerment, communication is therefore, very important especially that the Health Promotion Empowerment Model Act attempts to improve health literacy by providing the correct information and by helping the audience to obtain the information needed; they can then challenge this information and use it to make the appropriate decisions (Green & Tones, 2004).

The health promotion empowerment model refers to the process of enabling communities and individuals to increase control over their lives. Empowerment in this context refers to “the process by which people gain control over the factors and decisions that shape their lives” (WHO, 2008). While Enabling implies that can only empower themselves by acquiring more of power's different forms rather than being empowered by others (Laverack, 2009). Therefore, good communication between patients and health care professionals is vital; if handled in a wrong way it can lead to patient mistrust leaving them confused and unclear about their management plan (Fallowfield & Jenkins, 1999).

Patient centred communication and patient centred care have been demonstrated to improve patients' care in all clinical settings including cancer care by McCormack et al. (2011). They argue that patient centred communication is the primary means through which patient-centred care is accomplished. For McCormack et al. (2011) the patient centred communication conceptual framework includes exchanging information, fostering healing relationships, recognizing and responding to emotions, managing uncertainty, making decisions and enabling patient self-management (McCormack et al., 2011).

For Richards et al. (2015) understanding the patient as a human being, entering the patient's world to see the illness through their eyes, understanding their experience, disease and illness,

and finding common ground for management by incorporating prevention and health promotion are all parts of patient centred care.

Based on the literature review by Mead and Bower (2002) patient centred care includes different dimensions that are vital for successful patient care. These dimensions include the psychosocial and biomedical factors that influence the illness perspective; that is the meaning of illness for each person, the decision making process and the involvement of the patients and their families in the decision making process and in the treatment planning process.

As stated above, in patient centred approaches empowering patients is the main target and goal, and involving the patient in the decision making process is one of the strategic goals and targets of patient centred care (Richards et al., 2015). It may appear that with all the information available to patients online and with the increase in the number of television and radio channels, patients are faced with more information than ever; some of this information might not be evidence-based leading to anxiety and potentially poor health outcomes. Actually, accessing incorrect information may lead to poor health outcomes and patients may lose their trust in the medical system. It is therefore important to empower health care professionals with the means and abilities to provide appropriate information in a timely manner for their patients. This will help their patients solve the issue of mistrust and will assist in providing patients the appropriate and needed information.

Social support is also important in supporting the well-being of patients and their ability to cope with diagnosis and treatment of cancer (Bevan & Peccioni, 2008). Family members and others within the cancer patient's support network can be involved in two essential aspects of health information management: They can firstly assist in providing information and secondly help in the decision-making process. They may also be the liaising member who will seek information from healthcare providers to best aid in the patient care (Bevan & Peccioni, 2008). Studies suggest that patients usually fail to recall information they heard in hospitals (Fallowfield & Jenkins, 1999; Ley, 1988). Therefore, the presence of a family member or support person may help recall to the patient what was said in the clinic. As most cancer patients share their diagnosis with their close family and/or friends (Bevan &

Peccioni, 2008) involving family and friends in the communication process is very helpful in improving the patient care process and the education plan.

b. Effectiveness of patient education

Various studies on the benefit of general education programs have shown that patients who receive education have fewer emergency visits, develop fewer complications and have shorter stays in hospitals than those who do not. Education also affects self-behaviour and has an influence on health professionals themselves, in terms of time management and caring for patients see (Bertakis & Azari, 2011; Fawzi, 2011; Jaarsma et al., 1999; Johnson & Sandford, 2005; Golper, 2001; Larson et al., 1996; Pannu et al., 2010; Shea et al., 2007; Tung & Chang, 2009). Studies have shown that patient and family education (PFE) lead to informed patients and families, allowing better social policies and prevents the exclusion of patients and families from services and systems (Viracelli & Bronzini, 2009). A meta-analysis by Kok et al. (1997) on health education interventions showed a positive effect on patient outcomes; however, the review revealed that potential effectiveness of health education could be much higher if interventions are planned systematically applying relevant principles of change.

Increasing evidence indicates that when a selected population of patients with similar medical backgrounds and problems are provided with planned educational experiences and take an active participatory role in their care, they will be able to cope with, and follow, prescribed medical regimens more adequately than those who are not offered comparable experiences (Susser, 1985).

Research is also an important step needed to improve patient and family education practice. Further exploration on how to improve patients' health literacy is essential. Exploratory studies of patient information needs and information changes can be very helpful in providing public health professionals with insight about the best approaches that might improve patient knowledge, and can positively impact the patient care process. As Rankin and Stallings (2007) point out, a well-informed patient is the cornerstone of patient care.

Johnson, Sandford and Tyndall (2003) explain in their systematic review of types of educational methods that patients prefer, patients are in need for more educational materials

in all forms as these will improve patients participation in their own care and will help empower them to make the best health choices for themselves and family members. They concluded from their reviews that the combination of different forms of verbal and written educational materials may improve patients' knowledge and satisfaction with health care management. In addition, they recommended more research to find out about the best suited forms of educational methods and materials that are accepted by patients and that are more culturally appropriate for patients' education.

c. Health literacy

Research has shown that health education programs can improve patient and family health literacy. Health literacy is considered a goal of patient education by assisting clients in learning about their healthcare to improve their own health (Susser, 1985). Health literacy is essential in the patient centred care that is argued to be the best suited approach for health care management that improves health outcomes and provide safer health care (Johnson, 2014b).

Health Literacy is defined as “the ability to read, understand and act on health information, including such tasks as comprehending prescription labels, interpreting appointment slips, completing forms and following instructions for diagnostic tests” (Redman 2004, p. 30). Health literacy takes on particular importance when it comes to a serious illness like cancer. Low health literacy can make cancer patients vulnerable to health disparities (Bevan & Peccioni, 2008). Health and patient education can improve health literacy and empowers patients and families to make informed decisions that will impact their health positively (Rankin & Stallings, 2004; Johnson, 2014a, 2014b). Cancer care is very complex, such as management of symptoms of chemotherapy. Individuals with less health literacy are at a greater risk of misunderstanding diagnoses, directions and instructions (Andrus & Roth, 2002). Health literacy may be an important predictor of increased risk and poor participation in cancer control programs.

Adams et al. (2009) states that health literacy depends on whether patients are able to embrace or disregard actions relating to health and make sound health decisions in the context of everyday life. Peerson and Saunders (2009) reinforce the point that health literacy

can help achieve changes in the social, economic and environmental determinants of health. Similarly, Roter et al. (2001) argue that inadequate literacy is a threat to patient autonomy and health, there should be partnering between patient-centred communication and patient activation and empowerment. Health literacy is also considered a goal for public health functions and a tool for public health practice (see Kickbusch, 2001; Nutbeam, 2000; Pleasant & Kuruvilla, 2008; Ratzan, 2001; Rudd, 2003; St Leger, 2001; Zarcadoolas et al., 2005).

To make use of the benefits of health literacy and to enjoy the results of effective patient education programs, proper training for health care professionals is necessary. Hoving et al. (2010) argue that both patients and health professionals need to be provided with the skills to optimize patient education. It is argued that major reasons why health professional often fail to provide recommended preventive services is due to inadequate reimbursement, fragmented delivery of health care, insufficient time with patients, and a reluctance to encourage preventive services due to a scepticism or lack of training and knowledge about their effectiveness (Barnes et al., 2002).

i. Health literacy in the UAE

As reported before health literacy is argued to be an important outcome and goal in the fight against chronic diseases and for better health outcomes in clinical settings (Johnson, 2014a, 2014b). However, while there have been health literacy programmes implemented in other parts of the world, research on health literacy and on how to improve patients' and families' health literacy in UAE is rare (Sharif & Blair, 2011; WHO, 2007). There are some efforts to improve patient and family education practices but still in early stages of development (Sharif & Blair, 2011). Health education in the UAE is mainly directed toward prevention and community programs, such as breast cancer and cervical cancer prevention education, smoking cessation and diabetes prevention (HAAD, 2012). There are few attempts directed at educating patients with an existing disease such as cancer, cardiovascular diseases etc., and among these few attempts patient centred care is rare. Therefore, there is a need to shift health services in the UAE toward patient centred approaches (Kronfol, 2012). As part of this need, there has been already some efforts as since the last decade, hospitals in the UAE have started seeking international accreditation to improve their hospital and care standards

(Kronfol, 2012). The first edition of Hospital Standards, in collaboration with Joint commission was published by (HAAD) in 2008. Patient and family education are important goals in these standards that is why accredited hospitals in the UAE have established some sort of patient and family education and are working on achieving some of the related standards.

Kronfol (2012) suggest that there is a need for immediate action to improve health literacy. Also there is a need for research in health literacy. Evidence in the literature already thoroughly discussed the need for clinical health education and health promotion in health services around the world (Whitehead, 2004). There is also a need to conduct this research in the UAE and direct some of it towards cancer education in community and clinical settings.

As Matsuyama et al. (2011) reported, individuals with limited health literacy have worse outcomes, including lower treatment adherence, more frequent hospitalizations and higher mortality than those with adequate health literacy. Johnson (2014) affirms that health literacy as an important predictor to health status and that poor health literacy is associated with poor health outcomes. Health literacy can be improved by creating a process that provides patients with the right and ability to acquire accurate information and develop health related knowledge needed for a healthy lifestyle and better quality of life. Johnson (2014b) suggests that improving health care professionals' knowledge about health literacy will help improve health outcomes and provision of safe health care. A health literate organisation is a new term that refers to organisations that recognise the importance of communication between the consumer and the provider by providing easy access to health information and services (Johnson 2014a, 2014b; Rudd & Anderson, 2006).

In the UAE, research in clinical health promotion and in cancer education area is also limited (Aw et al., 2011; Emirates Cancer Foundation, 2015; Tadmouri & Nair, 2012). PCC is yet to be achieved in the UAE especially with cancer patients (Silbermann et al., 2012, 2013). The process of empowerment can be hindered by the culture of paternalism that arguably exists in the UAE and by the UAE's multiethnic population. Often, patients and physicians are not fluent in the same language. Different cultural and language related barriers; including ethnicity, religion and countries backgrounds are considered important barriers for achieving

the ideal health promoting empowering system (Sharif & Blair, 2011). The complexity of the health care system in UAE which is still fragmented (as power and policy making is not unified between different emirates) makes the implementation of policies and guidelines more dependent on the resources and development of the emirate itself (US-UAE Business council, 2014). The US-UAE Business council argues that the unavailability of a unified health care scheme is a major hindrance for the advancement of the health care services (US-UAE Business council, 2014).

At present, there is a dearth of research exploring this area of patient care, making it difficult to give a clear picture of the situation in the UAE. Hospitals that are accredited in the UAE are supposed to implement the practice of patient education and communication, and interaction between patients and clinicians (JCHO, 2015). However, despite that the literature has been translated into recommendations to accredited hospitals until today, there is no accredited health promoting hospitals in the UAE, the concept of HPH is still not yet well recognised, within the hospital system.

ii. Informing cancer patients/cancer literacy

While there is a plenty of literature about the prevention of cancer, patient education in cancer care still needs more research as discussed by different researchers and in textbooks. Rankin, London and Stallings (2004) stress on the importance of cancer patient education especially that most medical and clinical curricula books discuss the importance of patient education during the treatment process; from diagnosis to recovery or end-of-life as well they describe patient education steps and tips needed in cancer care.

Bevan and Peccioni (2008) argue that individuals with lower health literacy are more influenced by their support networks (family and friends) and might not make the right decision about their health such as seeking treatment and screening. Cancer literacy also was demonstrated to be effective in improving patients' health outcomes. Compared with less informed cancer patients, informed cancer patients may feel a sense of control, can cope with uncertainty about their health, follow their plans of care more closely and recover faster (Bevan & Peccioni, 2008; Boyes et al., 2009; Butow et al., 1994; Cassileth, 1980; Coulter, 1998; Fallowfield et al., 1990; Fallowfield et al., 1995; Ford, Fallowfield & Lewis, 1995;

Girgis et al., 2000; Houts et al., 1991; Leydon et al., 2000; Meredith et al., 1996; National Cancer Alliance, 1996; Newel et al., 1998; Sanson-Fisher et al., 2000).

Newell et al. (1998) argued that it is important to educate patients and to meet their information needs to improve patients' compliance and to improve outcomes. They further identified in their studies that medical oncologists' perceptions about patients' needs were different from the needs reported by patients themselves. They called to address patients' needs for better compliance and better outcomes.

Studies have found that effective communication with patients when given information about their illness and treatment are all important for better coping of cancer patients (Cassileth, 1980; Cawley et al., 1990; Coulter, 1998; Fallowfield et al., 1995; Ford, Fallowfield & Lewis, 1995; Leydon et al., 2000; Meredith et al., 1996; National Cancer Alliance, 1996; Rutten et al., 2005; Sanson-Fisher et al., 2000). Uncertainty, fear and anxiety are reported to be alleviated by receiving information about the disease and treatment (Butow et al., 1994; Fallowfield et al., 1990; Girgis et al., 2000; Houts et al., 1991; Leydon et al., 2000; Rutten et al., 2005). Research has also shown that the vast majority of cancer patients want to be informed about their cancer journey (Leydon, 2000; Meredith et al., 1996; Rutten et al., 2005). However, information varies and may change during their illness (Leydon, 2000). Therefore, tailoring education according to the patients' needs is necessary and is highly recommended.

In general, research has reported that providing information and psycho-social support across all phases of cancer care will positively impact the quality of life by enabling individuals to initiate effective coping strategies, as well as to regain some personal control (Goodwin, Hunt & Samet, 1991; Northouse, 1988; Wortman, 1984). According to Fallowfield (1990) cancer has a detrimental effect on patients' quality of life, which is further worsened for patients who have poor comprehension of cancer and treatment options.

Elm and Leonerad (1966) found that in general anxiety is reduced amongst patients when they are given the necessary and appropriate information about their situation. Gray et al. (1988, 1997) reported that cancer patients who received information about their disease and

treatment showed better coping abilities at the diagnosis stage, as well as during and after treatment. Other benefits reported by Gray et al. (1997) are the increase of participation in decision making, better preparation for medical procedures, more satisfaction with treatment choices and with health professionals' interactions, decreased levels of anxiety, mood disturbance and affective distress, and better communication of illness related information to their families. Therefore, information and support provided to patients with cancer throughout the cancer journey stages may help improve patients' quality of life and improve their coping strategies.

Researchers have demonstrated that patients with more knowledge about their disease and treatment have better outcomes (Coulter et al., 2008). In spite the importance of information giving for better coping, cancer patients' coping strategies differ depending on their personal experiences, their personality characteristics including age, gender and education level, and the support they receive throughout their journey (Coulter et al., 2008). Therefore, when providing information to cancer patients, health care providers must consider these factors tailoring messages according to each individual patient needs. Coulter et al. (2008) argue that some patients show denial and eventually experience great fear of death and disabilities, while others experience different levels of anxiety that might transform into depression at some point during their journey. On the other hand, some others appear to accept their disease and show positive attitudes, making use of their faith and belief system to cope and may even become the source of support for other family members and friends.

Patients with cancer and their families are more likely than others to pass through various stages of shock, self-denial and depression, leading to poor coping (Eapen & Revesz, 2003; Shetty et al., 1997). Patients have to feel that the environment is comfortable and trustworthy to decrease their fear and tension. Most importantly, they should receive information throughout their cancer journey to alleviate their fears and to help them cope. Family members might modify their coping strategies in response to different clinical events, such as diagnosis, side effects, or death. Modifying responses is known as adaptation. Adaptation is as dynamic and consists of five components: confronting treatment, maintaining family integrity, establishing support, maintaining emotional wellbeing and searching for spiritual meaning. Revesz et al. (1990) people in the Middle East as there have a far more

philosophical approach to life and death than many westerners suggesting that possibly they adapt easily than other populations.

So as Ratzan (2009) and Johnson (2014a) suggest that planning a patient education process should start with needs assessment and shared goal setting to improve health literacy and to help patients cope in a better way. In addition, motivation, behavioural changing models and the three domains of learning should be part of the planning process (Coulter et al., 2008). Further a multidisciplinary and comprehensive education program is very important in the process of patient empowerment (Fallowfield & Jenkins, 1999). Moreover, Bellamy (2004) argues that patient education is a duty for all health practitioners and it should be a core component of medical school curricula.

Fallowfield and Jenkins' (1999) literature review revealed that the structure and content of the consultation influences the patient's ability to remember what was told to them. They concluded that it is important to make use of the opportunities to provide teaching and communicating with the patients and families. Also they reinforced that it is important that health care professionals be trained in communication, learning, motivation theories and empowerment skills. Girgis et al. (2000) have called for more studies that can identify patients' unmet needs for better outcomes and to meet their other psychosocial, physical and better quality of living needs.

In summary, a newly diagnosed cancer patient can pass through an exhausting journey. A well informed patient who is well aware of his/ her condition, treatment plan, side-effects, management, as well as long term effects of the disease and treatment and expected outcomes will be able to make well informed decisions related to his/her health with the support of their health care team and family. A patient who is not aware of own condition or who was not been informed about the projected journey may face difficulties in making each step, and this may negatively influence on his/her well-being, on his/ her family and on health care team satisfaction (Eapen & Revesz, 2003; Fallowfield, Trapala & Jenkins, 2012; IMO, 2008).

Some cancer patients will manage and cope with their treatment within the context of their social support network, while others will be intimately involved across the continuum of care.

Further, family members are important health information sources for both patients and healthcare providers. Specifically, informal caregivers who accompany patients to medical appointments serve as information sources for a physician, which tends to be a positive experience for all involved.

The literature reported so far, provides an insight on how to empower cancer patients through education. Empowering cancer patients through providing information can be achieved when combined with an effective communication process, when it is planned and continuous to ensure that memory, transfer of learning, and good quality and quantity of information and instructions are provided. Therefore, to empower cancer patients, the process of distributing information should be continuous throughout their cancer journey. Cancer care professionals should be trained in the communication process and should ensure an appropriate, trustworthy, environment for learning. Patient information and education needs to continually be assessed for a successful learning and empowerment process. The provision of information has been reported to lessen the patient and family fears and increase their sense of control and authority, providing empowerment (Wilkes et al., 2000).

iii. Shared decision making in the cancer care process

As stated before the decision making process in cancer care is an important criterion for concordance and for an effective patient centred care. Also communication is detrimental to the decision making and to the success of the message a clinician wants to convey to patients and families. However, till today, the paternalistic approach of a one way doctor – patient relationship still exists compromising the success of patient centred care. Different models of doctor patient relationship started around 60 years ago with Szasz and Hollender (1956) who set out three basic models in the doctor – patient relationships:

Activity-Passivity: The patient is an entirely passive recipient of the doctor's actions.

Guidance-cooperation: An imbalance of power in which the patient is expected to cooperate in whatever action the doctor deems appropriate.

Mutual participation: A partnership in which the doctor helps the patient to help themselves.

Friedson (1970) later added to that model the dominant role of the patient. While, Emanuel and Emanuel (1992) identified a four component model: the paternalistic, the informative, the interpretive and the deliberative patient. However, the latter model by Emanuel and Emanuel was argued to be the best and was widely adopted because the patient have the opportunity to reflects on their values and preferences before making any decision (Coulter 2011).

In 2010, both the UK and the US governments have introduced shared decision making into mainstream clinical practices (Coulter 2011). Shared decision making, according to Coulter (2011, p. 58) is defined as “a process in which patients are involved as active partners with professionals in clarifying acceptable treatment, management or support options, discussing goals and priorities, and together, planning and implementing a preferred course of action.” Coulter identifies three key components for shared decision making: providing information about treatment options and outcomes, offering professional counselling and recording patients’ preferences.

Shared decision making was also conceptualised into three models by other researchers such as Charles et al. (1997): the paternalistic, in which the physician decides what is best for the patient; the consumerist informative model, in which patients make a decision without direct physician involvement on the basis that they receive the correct and accurate information; and the shared decision making model, in which decisions are made through an interactive, deliberative process between patient and physician, and the decision is reached mutually. Despite conceptualising the shared decision making process, Charles et al.’s model is fairly similar to those reported by Coulter (2011).

All of the above models confirm the importance of patient’s involvement in the decision making by the physician and the health care team. On this basis, the paternalistic approach is no longer supported. And encouraging patient’s autonomy has become an important key to the patient’s involvement in his/her own care. Accordingly, informing patients, and taking the steps to improve patients health literacy through different health promotion models, theories and communication process are important key components to patients involvement in the decision making process.

Finally, there are three main reasons that demonstrate shared decision making is the best way to select treatment. It supports the ethical principle of autonomy, it improves the current informed consent procedure and ensures that patients will receive the procedures they need (Green & Tones, 2004). So far, shared decision making is still not well adopted in clinical practice, in the world and in the UAE in particular (IPFCC, 2015).

In summary, the above shared decision making process and models may influence cancer patients' education process, hence influencing on treatment goal and on the whole cancer journey. Well-developed planned and effective education programs that support patients autonomy and that involve the patient in the decision making process away from the authoritarian and paternalistic approach are strongly recommended and will ensure better health outcomes.

5. Cancer patients' information needs

In this section, literature on cancer patients' information needs, the decision making process and their preferred sources of information are presented. It discusses factors that affect cancer patients' information seeking behaviour and their effort to meet their educational needs. Charles-Barks (2000) had identified a list of critical issues or areas related to cancer patient information needs which were used in this literature review as a guide.

a. The cancer journey

Being a chronic disease and with the advancement in treatment that took place in the last four decades, the cancer journey might vary from one patient to another. It usually starts with diagnosis and may end up differently from one patient to another depending on the severity of the condition, the type of the cancer and the stage of the cancer. Different researchers have categorised the cancer patients' journey into stages, which range between three to six (Adams, 1991; Ankem, 2006; Leydon, 1999, Matsuyama et al., 2012; Mills & Sullivan, 1999; Rutten et al., 2005; van Mossel et al., 2012, 2014; Vogel, Bengel & Helmes, 2008).

Rutten et al. (2005) in their systematic review have identified five major phases that included diagnosis, treatment, recovery, possible recurrence, and possibly death. In each phase of the

cancer journey, patients may experience disappointment, mishaps and psychosocial difficulties. Every patient will experience this journey in their own way. Some might deal with each phase and continue with the treatment process, as expected; some might develop complications and relapse within the continuum or at the end of the journey. Others may become trapped in the coping cycle and develop depressive symptoms, denial and refusal, to the extent that they withdraw from the journey and surrender to the cancer threat.

Fig.1. is an illustration of the cancer care continuum as per (Rutten's et al., 2005) starting with the baseline the diagnosis stage and ending differently for patients. Rutten et al. (2005) have identified all the stages per the literature including recurrence and end of life for some patients.

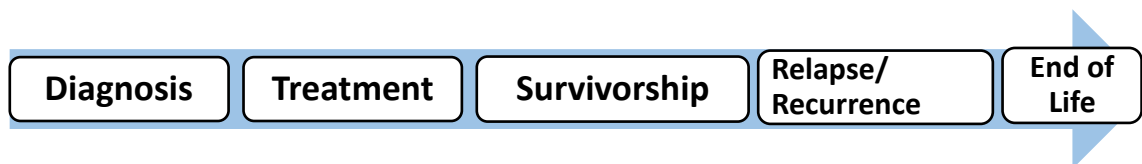


Figure 1. The Cancer Journey

b. Education needs of cancer patients in the world:

This section presents cancer patients' education and information needs from the patients' perspective. It will also include the literature review of knowledge needs over time and throughout the cancer journey.

Research has indicated that the vast majority of patients want to be extensively informed about their cancer, regardless of whether it is positive or negative (Boyes et al., 2008; Girgis et al., 2000; Newell et al., 1998; Vogel, Bengel & Helmes, 2008). Despite the common need for information, there is a substantial variability among patients as to what information is considered important (Boyes et al., 2000, Feldman et al., 2004; Feldman et al., 2007; Girgis et al., 2000; Meredith et al., 1996; Vogel, Bengel & Helmes, 2008). Research has indicated that the vast majority of cancer patients want to be informed about their illness; however, it is also recognised that patients vary in the amount of information they want and that this may change during their illness (Leydon et al., 2000). For example, younger patients, women with higher education and those receiving radical treatment in particular, want to know more about treatment options than others (Adams et al., 2009). Generally speaking, Meredith et al.

(1996) reported that all patients wanted to know about chance of cure and 91% wanted to know about side effects of treatment. Sanson-Fisher et al. (2000) were able to show that cancer patients in New South Wales in Australia had a long list of unmet needs on different levels including the psychosocial, care and the education level. Adams et al. (2009) claims that unmet needs were mainly related to the prognosis and its potential impact on the family. Unmet information needs have been always a worry for researchers. This was also backed up by Girgis et al. (2000) study. Furthermore, Meredith et al. (1996) reported that all patients wanted to know about chance of cure and 91% wanted to know about side effects of treatment.

Beliefs and existing knowledge about cancer might affect patients' acceptance and coping with their condition. Until today many people still believe that cancer is a death sentence (Pinnock et al., 1998) leading them to give up and to submit to their fate. Education and support across all the phases of cancer care and impact positively on an individual's quality of life and enable them to cope and to regain control of their lives (Goodwin, Hunt & Samet, 1991; Northouse, 1988; Wortman, 1984).

Researchers have identified the information needs of patients and some have classified them by areas of importance and urgency. Mills and Sullivan (1999) reported that information on treatment and side effects, the extent of the disease, prognosis and self-care are the most relevant for cancer patients. In a more recent review, Rutten et al. (2005) identified the type of information needs, the sources of information and specific needs across the continuum. They identified the following ten categories of information need: cancer specific, treatment-related, prognosis, rehabilitation, surveillance and health, coping, interpersonal, financial/legal, medical system and body image/sexuality.

Rutten et al. (2005) reported that 96% of the articles reviewed mentioned patients' need for treatment-related information and 65% mentioned a need for cancer-specific information. The most cited category of needed information according to the review was treatment-related information, and among the treatment-related information category the most frequent subcategories were the available treatments and treatment options: 17.2% wanted to know about the treatment, 20.5% wanted to know about the side effects of treatment/risks and

benefits of treatment (20.5%), (12.8%) wanted cancer specific information, while (12.2%) wanted rehabilitation information. The most common sub-subcategory mentioned in Rutten et al.'s research about cancer-specific information was the type of cancer/nature of the patients' disease (27.5%). The most common sub-subcategory in the rehabilitation information subcategory was self-care issues/home care during recovery (30.9%). Other researchers reported similar results (Ankem, 2006; Cox et al., 2006; Galarce et al., 2011; Lee et al., 2004; Matsuyama et al., 2011; Morrison et al., 2012; Rood et al., 2015). Moreover, Morrison et al. (2012) found that the most needed information reported by cancer patients included, its treatment and side effects.

c. Education needs of cancer patients in the UAE

To date, there are no published studies that have been conducted in the UAE about cancer patients' education and information needs, although, many studies have investigated community knowledge, practices and attitudes about cancer screening in the UAE (Bener, 2002; El-Obaid et al., 2014; Ortashi et al., 2012).

More broadly, in the Arab world, there is very limited number of studies around the topic of cancer information needs. Al-Amri (2009) conducted a study in Saudi Arabia that found that 99% of Saudi patients' wanted to know about their disease and 100% rejected the idea of health practitioner withholding information from patients. Almost all wanted to know about the benefits and adverse effects of therapy (98% and 99% respectively) and all wanted to know about prognosis. In Jordan, Obeidat and Khrais (2015) investigated breast cancer patients' information needs. They reported that there is high information needs among breast cancer patients, specifically concerning information about breast cancer diagnosis, chances of cure, and treatment side effects. Only AlQadire (2014) in Jordan too, investigated cancer patients' information needs across all stages. The author reported that Jordanian cancer patients are in high need for cancer related information. He also reported that most patients wanted most information about their diagnosis and the medical tests. The reported findings from these three researches conducted in the Arab world differ to that of Rutten et al. (2005) in terms of treatment related information but did not differ in terms of the change of information needs across stages. Rutten et al. (2005) findings suggest that the stage of the journey determines the needs of the patients which may affect the result of any study of this

kind. AlQadire's (2014) research also reported that the type of information needed by Jordanian cancer patients' changes as patients move from one phase to another. The findings is supported also by Matsuyama et al. (2012). Therefore, research studies should be aimed at identifying the information needs of cancer patients at each stage separately to identify their changes in their information needs as well as identifying their unmet needs.

In summary, studies of patient information needs have been conducted in a distinct selection of patients at limited periods of time during their care. Furthermore, many of the existing reviews of this literature have been limited to specific cancers (Rutten et al., 2005). van Mossel et al. (2012, 2014) were unable to identify one specific approach that works for every patient and not every patients' needs the same information. They concluded that information should be personalised so the content and method of delivery are appropriate to each person's characteristic. What, when and how of providing information should be considered. In the UAE no research has been conducted yet apart of this intended study. More research in this area is needed especially with the increase in number of cancer patients and with the increase in more health care facilities and clinical services.

d. Cancer patients education needs along the cancer continuum

Patient information needs along the continuum of care has been researched in different parts of the world (Mills & Sullivan, 1999; Rees & Bath, 2000; Rutten et al., 2005; van Mossel et al., 2014; Vogel, Bengel & Helmes, 2008). However, research till date has not provided a conclusion or a summary on specific cancer patients' information needs. Studies on the needs of patients with specific cancer types and in different settings are still limited. Rutten et al. (2005) and van Mossel et al. (2012) in their recent systematic review, found that studies have failed to pay sufficient attention to the needs at each individual stage of the cancer journey, and that most information is non-stage specific.

Also despite that research has discussed some factors that may affect patients' information needs along the cancer journey, this area of research needs more exploration and need specific related studies. Ankem (2006) argues that cancer patients' gender, education, the time elapsed since diagnosis of cancer and the stage of their illness may not be related to their information needs; however, the author stress on the need for, and the receptiveness to,

cancer-related information. Ankem (2006) argues that information needs is greatly influenced by patients' demographics especially age and by the various situations they find themselves in during their journey and their psychological state (Ankem, 2006). Different researchers have attempted to link information needs, time and the stage on the cancer continuum or what is referred to in this study as the cancer care journey (Rutten et al., 2005).

Similarly, Rees and Bath (2000) reported that information needs vary over time. According to their study at the diagnosis phase, most patients want information on the likelihood of cure, treatment options and the stage of the disease. At the beginning of the treatment stage, on the other hand, information on the treatment is very important, to patients, in addition to information on the disease, medical tests and the likelihood of recurrence. At the post-treatment stage, according to Rees and Bath (2000) patients wanted information regarding recovery and risk of other family members getting cancer. They also found that patients had a need for information in regards to self-care and rehabilitation.

In a study directed to identify information needs of breast cancer patients (Vogel, Bengel & Helmes, 2008) researched information needs of breast cancer patients over time (at diagnosis, after three months and after six months). Their research found that breast cancer patients have high information needs in the first six months after diagnosis, while there is no significant change in their information needs after this period. However, they found that there was a significant decrease in the importance to patients about information on diagnosis, prognosis, treatment, support services, the impact of illness and treatment after three months and six months after diagnosis. According to their study, breast cancer patients had the highest information needs at beginning of treatment, while these needs decreased during the course of treatment. There was also a significant decrease in the importance of information on medication and side effects from baseline (diagnosis stage) through time until post treatment or survivorship stage. Information on after care was most important at six months, followed by the post-treatment phase. Moreover, there was only one information need that was equally important at all assessment points: i.e according to (Vogel, Bengel & Helmes, 2008) assessment points which measured information on examination and medical tests.

Information on support services and information on impact of the illness and treatment were significantly less important, compared to all other information topics at the assessment points. In addition, information regarding diagnosis was significantly less at the other the points of assessment.

Rutten et al. (2005) investigated needs and resources across the cancer care continuum. They reported that most literature has investigated information needs only in the treatment and diagnosis period; their report was thus limited to these two stages. They reported that cancer specific information and treatment-related information were the most frequently reported needs during the diagnosis and treatment phase. Their systematic review found that the most frequently cited subcategories of needs were treatment options and side effects of treatment. The subcategories that were most frequently mentioned in the studies included, within the cancer-specific information category, were the stage of disease and specific diagnosis information. Also, the most frequently cited post-treatment information needs were treatment and rehabilitation information categories. Patients needed information about treatment options, followed by side effects of treatment and they frequently asked about them in the post-treatment phase. Regarding rehabilitation information, self-care issues/home care, follow-up care and treatment, and long-term side effects were also needed by patients.

As for the most prominent information resources used during the diagnosis and treatment phase, as Rutten et al. (2005) reported, were printed materials followed by health care team members and were considered to be an important source of information. On the other hand, brochures and libraries/unspecified readings were the most frequently used printed materials. Among the health professionals category, physicians were the main sources of information and other health professionals and interpersonal contacts were identified as key information sources. Finally, during the post-treatment phase, physicians, nurses and other health care professionals were cited as sources of information equally.

The researchers could not find significant differences in the information resources, by phase, of the cancer care continuum. Significantly higher needs were reported in the cancer-specific information category during the diagnosis and treatment phase than during the post-treatment phase. The authors recommended further investigation for cancer patient needs across the

continuum and specifically post treatment, due to the number of studies performed and due to limitations of the methodologies of some studies already conducted.

e. Cancer patients' involvement in decision making

According to Grol et al. (2000) not only do patients want more information but many would like to participate more in the decision making process of how to treat their health problems, this is also supported by (Butow et al., 1997; Vogel, Bengel & Helmes, 2008). Also Johnson et al. (2003) support somehow the same suggestion as they reported that there are increasing demands from the consumers' side in health services to know more and to be involved in the decision making. Researchers like (AlQadire, 2014; Matsuyama et al., 2011; van Mossel et al., 2012, 2014; Vogel, Bengel & Helmes, 2008) are calling until lately for more research on what the patients would like to know, how to learn and when to learn and how to be involved in their treatment process.

Moreover, Vogel, Bengel and Helmes (2008) argue that cancer patient participation in decision making enhances their control over their health care and results in more patient oriented decisions, and may lead to better health outcomes. Vogel, Bengel and Helmes' (2008) work underscores earlier work by Schofield and Butow (2004). However, the preferences for involvement of cancer patients vary substantially as reported by different studies (Degner et al., 1997; Janz et al., 2004; Vogel, Bengel & Helmes, 2008). Not all cancer patients want to participate in decision making, and some patients have difficulties in making decisions. In addition, there is evidence that reported difficulties in decision making lowers patient satisfaction (Keating, 2002; Vogel, Bengel & Helmes, 2008).

The need for patients to be involved in the decision making is not new. In 1997, Degner et al. reported that the most patients preferred the doctor to make the decision. While Hack, Degner and Dyck (1994) found that most patients wanted to play an active, rather than passive role, although patients changed their preference of involvement in the treatment phase compared to their actual role at baseline in the diagnosis stage. According to Vogel, Bengel and Helmes (2008) patients' preferences may change during the course of treatment and their opinions and decisions may vary according to the severity of the condition. As per Coulter (2011)

people with severe conditions may not prefer to be involved in the decision making process, in contrast to those with less severe conditions.

The literature is full of studies that report patients' needs to be involved in the decision making. For example, a British study (Beaver, Bogg & Luker, 1999) found that only 48% of breast cancer patients and 22% of colorectal cancer patients wanted to be involved in their treatment. In Australia, Davey et al. (2002) found that 90% wanted to have an active role in deciding which treatment and tests to choose. Research in England has shown that a large number of patients are disappointed as they are not given the opportunity in clinical decision making (Care Quality Commission, 2010).

On the other hand, some studies found that patients might prefer to refrain from making decisions at certain times during the cancer journey. For example, Vogel, Bengel and Helmes (2008) reported that breast cancer patient information needs and decision making preferences can change during treatment. They reported that 38% of patients preferred the physician to make the decision about treatment and 27% wished to share the decision, while 35% wanted to make the decision on their own. Overall, half of all patients had a stable preference and the other half changed their preferences at least at one assessment point. De Morgan et al. (2011) and Radina et al. (2011) reported stronger views as the majority of women with breast cancer involved in their studies in the US reported that they prefer a relatively passive role in decision making. To explain this difference between views, more studies are needed especially to identify whether certain groups, ethnicities might have different approaches when it comes to decision making. Coulter and Magee (2003) found in a comparison between eight European countries that cultural differences of patients can affect the decision making role. They also found that those with better education are more likely to want an active role. However, in other studies age was not found to be a variable that might affect people's preferences in decision making (Coulter, 2011, p. 65). It can be concluded that low literacy can limit patient's understanding of the complex information in regards to treatment, the quality of life and outcomes which can be a barrier to patient participation in decision making (Kim et al., 2001).

The literature has no consensus so far on the differences and how decision making is influenced among cancer patients. Studies are needed to identify different influences of cultural values and beliefs as well as gender, age, education, country and other demographics on the involvement of cancer patients in the decision making process as well as their specific information needs.

Finally, in the last decade, emphasis on empowerment and decision making has been greatly apparent in research and in arguments for better patient care. However, clinicians are still focused on the disease, rather than on the individual and they do not explore patient values and preferences (Corke et al., 2005). Patients are still not encouraged to share their beliefs, experiences and expectations (Coulter, 2011). Stevenson et al. (2004) reported in their review of 134 observational studies that patients were not encouraged by their health professionals to discuss their concerns. Taking in consideration the conservative culture and the preference of so many families to keep patients uninformed about their conditions, patients in UAE are similarly not encouraged to become active participants in the decision making process (Al-Amri, 2009).

In summary research reports that in general patients would like to be involved in the decision making as well as research has shown that being involved in the decision making has positive outcome on patients health and disease. Till today there is no strong consensus on what cancer patients want in terms of their involvement in the decision making related to their disease and treatment, more research is needed and more exploration of factors that may play a role in the decision making process is needed.

f. Factors affecting patients' information needs

In the next section, literature related to factors affecting information needs and information seeking behaviours are presented. Factors that affect information seeking and decision making are interrelated and cannot be separated. According to Coulter (2011) when patients get involved in the decision making process, they will most likely seek information and will look further for more sources of information.

Factors that were identified to affect the patients' information need included psycho-social and the physical status of the patient (Ankem, 2006; Leydon et al., 2000; Mills & Sullivan, 1999; Rutten et al., 2004, 2005; van Mossel et al., 2012). Moreover, communication skills, the communication process with the physician and other health care providers, patients' literacy, previous knowledge, patients' experience, previous exposure to cancer information, education, age, socioeconomic status and the type of cancer are also factors identified to affect patient information needs (Ankem, 2006; Boyes et al., 2009; Girgis et al., 2000; Mills & Sullivan, 1999; Rutten et al., 2004, 2005; van Mossel et al., 2012). Leydon et al. (2000) also identified three important factors that affect information needs; these are faith, trust in the medical care team and system, the belief that there are those who are worse off, and hope to get better. Leydon et al. (2000) argue that it is challenging for many patients to find a way to obtain credible information. Family and network support were identified to be factors that might encourage information seeking behaviour and might be a source of information itself (Jassim & Whitford, 2013).

Researchers have identified differences between cancer patients' information needs that are based on demographics, psychological state, type of treatment, severity of disease and role they prefer to play in decision making. Age and gender were identified in some studies to play an important role in information needs. Ankem (2006) reported some factors that influence information needs like age (gender, education and time elapsed since diagnosis). The elderly had lower needs (it may be their feelings of inhibition as Ankem suggests) while younger patients wanted more information and preferred active roles in decision making. Cassileth (1995) and Leydon et al. (2000) argue that older men still adopt a non-participatory role in the management of their illness and men in general are less likely to access additional information services.

Wallber et al. (2000) also found that the younger patients and those with a higher education background sought more information and preferred an active role. Papadakos et al. (2014) also reported that younger age and better education background played a positive role in seeking information and in decision making. Finally, an important factor that influenced information seeking behaviour is the socio-economic status of the patients and the family.

Meredith et al. (1996) reported that high affluent area patients wanted more information in comparison to patients from deprived areas.

Gender and religion were found to affect the need for information. Also Ali et al. (1993) and AlAmri (2009) found that culture affects decision making involvement, information specific to topics, and their condition: those whose conditions worsened wanted less decision making involvement. Tadmouri and AlSharhan (2012) argued that people with poor education in the UAE might not face much difficulty in understanding the concept of cancer, the need to carry out complicated tests to reach a diagnosis and the outline of the treatment. This might be due to the strong family support that exists in the UAE, as family attitudes and perceptions are integral parts of proper psychological development and self-esteem of the patient; however, cultural and religious beliefs might be important factors for not seeking information, for not knowing what type of information is needed and where to retrieve it from.

g. Sources of information

Researchers have identified different preferences among patients in regard to what best sources of information they would like to use. Rutten et al. (2005) reported, in their systematic review, that patients used mostly printed materials as sources of information while Bilodeau and Degner (1996) and Raupach and Hiller (2001) reported that most patients preferred health care professionals as sources of information. Other researchers have found that TV, newspaper and radio are major sources for medical and health information for cancer patients (Talsosig- Garcia & Davis, 2005). Seeking information through hotlines was more specific to cancer treatment, referral and screening. Raupach and Hiller (2001) reported that women with breast cancer wanted to know about recurrence and chances of cure. Women with breast cancer in Raupach and Hiller study most commonly used resources were family, then friends and surgeons while few sought internet information. They had a stronger preference for a diagnosis to be given by a doctor and mostly wanted to know the diagnosis, prognosis, treatment options and side effects. Squiers et al. (2005) have reported that minorities were more likely to seek phone services possibly due to language and cultural barriers.

In their review, Rutten et al. (2005) collected information on the most used information sources for cancer patients. They categorised these information sources into health care professionals, scientific resources, various media, and family and friends. Their research found that health care professionals were the most frequent resource to be consulted. According to their study, the most frequent printed material used was books, while television and radio were the most frequently use media. The support of family and friends was almost the highest for support services, while supports from hotlines were also important.

So in general patients prefer to know from different resources, health care professionals and specifically physicians stay the most trusted and preferred sources of information. Printed materials and readings are also preferred by patients. Other sources like online resources are becoming more popular and the presence of a support person to provide information is also a newly identified source of information.

6. Summary, Gaps in the Literature and Research Objective

In summary, cancer patient information needs is not a new area of research. Some studies were conducted more than four decades ago; however, the area of information needs along the cancer continuum and the transition of patient knowledge and information needs is a new area of investigation and has not reached a consensus on what type, amount and quality of information cancer patients feel is necessary. Worldwide studies have looked at specific cancers, mainly breast cancer, colorectal and prostate cancer. There were a few studies that looked at other types of cancer among the adult population. Most studies reported used quantitative cross sectional methods that employed validated survey tools that measure information needs (Rutten et al., 2005).

a. Gaps in the literature

In the Middle East, and specifically Arabic countries, there are only three cross sectional studies so far that have discussed information needs of cancer patients: AlAmri (2009); AlQadire (2014) and Obeidat and Khrais (2015). Only one of them considered the cancer continuum (AlQadire, 2014). Some other studies have investigated the needs of breast cancer patients, but overlooked the transition of information needs and knowledge. In the UAE specifically there are no studies in the area of cancer patient information needs let alone their

information and knowledge needs as they transition during the cancer journey. Despite cancer being on the increase in the UAE (like other chronic diseases), public health programs in the UAE directed toward cancer have concentrated more on preventive and pharmaceutical responses, neglecting the psychosocial clinical area that include comprehensive cancer patient centred care and patient-clinician communication (Silbermann et al., 2012, 2013). More specifically, studies that use qualitative approach in cancer research are very scarce (Aw et al., 2010; Aw et al., 2011; Emirates Cancer Foundation, 2015; Tadmouri & Nair, 2012).

Very few studies have looked at patient knowledge and information needs, and about health literacy levels about their disease mainly diabetes but not about cancer. In general, there is a dearth of research in patient education, in cancer patients' education needs and health education and promotion in health care services in UAE and the region. Around the world, with all existing research, it is not conclusively known what would be the best way to provide information to cancer patients during all three cancer stages taking into consideration different socio-cultural factors that may have an effect on patients learning, information needs and involvement in decision making. Available research so far employs more a quantitative approach that lacks the exploratory side of patients' needs that can be achieved through qualitative approach. Mixed method research is needed to explore the cancer patients information needs in the world and in UAE specifically and surrounding region.

As has been mentioned, patient and family education is an essential part for patient care and it is considered by many to be its cornerstone (Rankin & Stallings, 2007; Redman, 2007). For successful patient treatment, patients need to be well informed and involved in the decision making process related to their disease (Coulter, Parsons & Aksham, 2008). The way patients receive information and the type of information they receive are important as they will influence treatment' success and management. Cancer patients need to be aware of their condition and to be involved in the decision making process.

Effective cancer communication is needed to become a clinical and public health priority in the UAE. Empowering patients and encouraging them to be participants in the decision making process is important to improve health literacy (Kronfol, 2012). This can be done on

an individual basis through health education or on a community or society basis by providing public health education and developing health promotion programs aiming to improve health and cancer literacy.

Receiving the appropriate information is extremely important for cancer patients as they move through the illness trajectory. Cancer patients in the UAE suffer not only from the disease, but they also suffer from the social stigma, misconceptions, suffering and pain and fear of treatment failure. Patients might fail to cope and having the right information will help them cope better as proven by the literature.

This review suggests that patients with cancer need extensive education on cancer knowledge, treatment modalities, side effects and management. All patients need to know about their conditions and treatment options, in addition to the impact of the disease on their survival, quality of life and on their future. In addition, patients and families need to be educated on the importance of lifestyle changes to improve their quality of life and their chances for remission. Furthermore, patients with cancer need continuous support, education and counselling during their hospitalisation and after their discharge.

Nevertheless, according to previous research, not all patients are alike in the amount of information they need. There is a lot of specified information that are provided to patient as suggested by medical professionals rather than considering the patients perspective. Information needs among different cancer patients should consider the differences in the cancer types. Also, the stages and the condition of the cancer have not been extensively explored or considered yet.

Despite research indicating the importance of information giving at different stages of the cancer journey, to my knowledge, there are no published studies that investigated information needs, knowledge, or literacy levels of cancer patients in UAE. Available studies have only researched knowledge and attitudes on screening practices and early detection among patients and health professionals (Bener et al., 2002; El-Obaid et al., 2014; Ortashi et al., 2012, 2013).

Given that research into cancer patients needs is nearly non-existent in the UAE, this study will set foundation for patients' information needs and important cancer related knowledge

needed from the patients' perspectives in UAE. It aims at investigating cancer patients' education needs during the cancer journey. It will assess patients' knowledge and information needs about their disease, treatment and prevention during their cancer treatment journey. The current study aims to identify patients information need and will be an effort to confirm the importance of the implementation of evidence based patient and family education programs for cancer patients in United Arab Emirates to meet their information need and to improve their health knowledge during their treatment journey.

b. Research objectives of this study

Listed below are this study objectives.

- To assess patients' knowledge and information needs upon diagnosis of cancer
- To explore changes on cancer patients' knowledge and information needs during the process of their treatment
- To determine the sources of information that cancer patients seek during their treatment
- To identify the facilitations and barriers that can influence cancer patient literacy during their treatment journey
- To identify patients' different educational needs to optimize best treatment during their cancer journey

This study will help address some of the knowledge gaps in relation to cancer patients' education needs during their cancer journey. It will also highlight the important factors that might play a role in improving cancer patients' literacy in UAE. The next chapter is the theoretical framework of knowledge and learning. It will highlight the types of knowledge that might construct cancer literacy in UAE.

Chapter Two

Theoretical Framework

This chapter provides an overview of the theories of teaching, learning and knowledge acquisition concepts. Also it discusses types of knowledge and how cancer knowledge is constructed. These concepts are important for the discussion of this study that explores how cancer patients' knowledge develops throughout the three stages of cancer journey (diagnosis, treatment and follow up/recovery stages).

Learning and knowledge acquisition are important functions of patients' education. Learning theories are considered to be the conceptual framework for behavioural change (Glanz et al., 2002). A theory has been defined by Glanz et al. (1997, p. 21) as "a set of interrelated concepts, definitions, and propositions that presents a systematic view of events or situations by specifying relations among variables in order to explain and predict events or situations." These learning theories aimed at behavioural change are considered to be the main theoretical framework that this study is based on. Thereby, discussion of these concepts is essential to introduce this study being an epistemological framework of knowledge and information needs of patients. Knowledge is constructed via various means and methods and tends to be the result of teaching and educational models used with patients, learning environment, social constructs and knowledge acquisition skills.

Providing information to patients, teaching and learning are basic functions of health education and health promotion. Theories of health promotion and health education draw from the learning, teaching theories and use behavioural changing models to achieve their goals (DiClemente et al., 2002; Glanz et al., 1997, 2000). These theories are also important for this study's discussion being most commonly used in clinical education settings. There are different individual behavioural changing models that exist in the literature and that are argued to be effective in behaviour change (Noah & Zimmerman, 2005) These include the Health Belief Model (Becker, 1974); Theory of Reasoned Action (Ajzen & Fishbein, 1980); Theory of Planned Behaviour (Ajzen & Madden, 1986); Social Cognitive Theory (Bandura, 1986) and the Transtheoretical Model (Prochaska & DiClemente, 1983). Also Fishbein

(2000) has proposed an integrated theory that combines concepts from several existing theories.

In the section below, learning and teaching processes and knowledge acquisition are discussed in the context of patient education and patient learning. This section is important as the dissertation is discussing patients' knowledge needs and how they would like to acquire this knowledge. The dissertation aims at findings the barriers that might hinder learning and patients' knowledge and learning acquisition. A discussion on cancer knowledge construction with the social and political context and dimensions will be presented later in the last section.

1- Teaching, learning and knowledge concepts

In the following paragraphs, concepts related to learning, teaching and knowledge are discussed as well as the basic theoretical paradigm that determines patients' knowledge and information needs along the cancer continuum. Teaching is defined as "a special form of communication that encompasses and expresses knowledge about particular subjects" (Redman 2007, p.29). Some educators believe that teaching is limited to changing the learner's behaviour (Redman, 2004). While others argue that, as behaviour change cannot be appreciated immediately among learners, the intention of teaching should aim at initiating learning and should consider all interactions between the patient and the health practitioner as being an important contributor to the learning process (Redman, 2004). This intention of learning meet with the concepts of concordance and patient centred care, discussed in the previous chapter , in which patients are learning and being educated and informed with the intention of helping them take the right choices and decisions.

Taking into consideration these concepts, the process of teaching to change behaviour might be problematic if patient education to be considered as a scientific process that include theories and steps to achieve the best outcomes among patients and families. Therefore, Barlett's definition of patient education can be best adopted for a best patient education practice. Barlett (1985, p.325) defines patient education as "a planned learning experience using a combination of methods such as teaching, counselling and behavioural modification techniques that influence the patient's knowledge and behaviour." However, adopting this definition does not cancel also adopting the idea that continuous learning occurs through the

patient-clinician interaction that takes place during the treatment journey. This indicates the importance of the readiness of clinicians with the knowledge about the patients' condition, disease, treatment, with communication skills and having always the caring empathetic attitude that is recommended for a successful patient education process.

Teaching methods may include a variety of ways that range from one to one, to group work, to other methods such as role plays, problem solving, case studies, audio visuals, interactive games and others. Active learning is one of the adult preferred learning modes. Usually called experiential learning, participatory learning, and student centred or in other context, patient centred learning and confluent education (Green & Tones, 2004).

A teacher or an educator needs to be empowering and to use proper communication skills such as listening, drawing out, reflecting back, clarifying, questioning summarising, suggesting advising and prescribing. An educator needs to be competent in the knowledge about the issue being taught as well as the knowledge of behavioural changing models and learning styles and learning models.

In the cancer context, a teacher or an educator has to be highly competent with the knowledge that is based on the patients' needs as well being competent in teaching skills listed above. An educator needs to be conscious that cancer patients might be different from other patients. Their psychosocial status and their education needs are continuously missed and unmet as demonstrated in the literature. There is always a lack of understanding of the high sensitivity of cancer patients, fear and anxiety that they pass through during their journey and their loss of interest and hope to continue their lives. Patients with cancer differ in their approaches toward their ailment and therefore, an educator need to pull out all the skills listed and tailor it to adjust their education to fit the patients' education and support needs.

As teaching is supposed to create knowledge among learners for a behaviour change to happen and the learning process needs certain criteria also to take place. Learning is defined as: "a permanent change in capability or disposition" (Green & Tones, 2004, p.306). It involves knowledge and understanding, ways of thinking, beliefs, values and attitude and skills acquisition (Green & Tones, 2004; Redman, 2001). Learning also requires motivation

which is an important determinant of learning. This indicates that patients who are not willing to learn will not be receptive (Redman, 2007). It also indicates that health care providers need training in motivation and counselling skills and to find out the reasons behind of the lack of motivation. Sometimes the lack of motivation could be because the patient is not able to adapt to the illness or due to certain cultural or behavioural issues that prevent the patient from accepting to participate in the learning process. Motivation theories, as identified by Redman (2001) such as reinforcers, needs satisfaction, attribution to the cause of illness, cognitive dissonance, personality and expectancy can be used to enhance the learning process. Therefore, providing health care providers with the right information and skills is essential for patients' learning process.

Goals of learning are classified into three domains as per Bloom's Taxonomy. These three domains are the cognitive (knowledge and beliefs), the affective (values and feelings) and conative (the psycho-motor, the social interaction and the problem solving skills) (Green & Tones, 2004; Redman, 2004). The patient education process should set goals with patients that target the three domains. Patients should understand their condition accept the idea of the illness and the responsibility of self-care and learn the skills that will help in self-management. Redman (2004) argues that adult learning is focused on these three domains that include the technical work, the interactive or communicative domain and the emancipatory self-knowledge domains. The health care provider needs to consider all three domains for successful learning to empower patients with the knowledge, attitude and skills to make the right decision and to assume responsibility for their own care.

In the cancer context, patients are expected to learn in different ways taking into consideration their abilities and their psychological and physical statuses at diagnosis and during their journey. The three domains that Knowles has identified for a successful learning should be incorporated within the cancer care to help patients develop the needed knowledge to cope with the disease and the expected treatment, the attitude toward survival and treatment and the skills to live a better quality of life.

Theoretical frameworks are being used increasingly by clinicians and educators as means of developing and evaluating interventions directed to influence behaviour (Glanz et al., 2002).

These theories of behaviour include constructs and methods that help in understanding behaviour and that present explicit accounts of pathways that influence behaviour (Painter et al., 2008). These behavioural changes constructs and models such as the health belief model and the trans-theoretical model can be useful tools to stimulate patients to become involved in the learning process (Glanz et al., 2002). The health belief model provides a good model that discusses the importance of learning and gaining knowledge as essential blocks to change behaviour (Burns, 1995). Several educational models were developed and based on some of these behavioural theories have been developed to explain individuals' health-related behaviour. The health belief model is the most commonly used one in clinical settings (Green et al., 2015). The four principal components of the health belief model are the individual's perception of his or her personal susceptibility to disease, perception of the severity of the disease and perception of the benefits from and barriers to modifying behaviour. The health belief model can be used to design educational interventions that are most likely to be effective. Other behavioural changing models such as the trans-theoretical model or the stages of change model, however, has proven successful in certain lifestyle preventive actions such as smoking, drugs and dieting and can be highly useful to assist cancer patients through their cancer journey and particularly post treatment to prevent recurrence and to improve patients' quality of life. However, behavioural change in the clinical setting is a complex process and requires more than the simple acquisition of knowledge or learning (Mills & Sullivan, 1999; Redman, 2004). It needs trained clinicians who can apply these models within the patient care and education.

To motivate patients to learn, (Green & Tones, 2015; Redman, 2007) provides certain basic principles that can be used and that have proven to be successful in motivating patients. These principles include preparing the setting and the environment to make it suitable and encouraging for the learning process, the use of incentives and rewards, the use of the right time like when patients ask and wants to know about something and to set the education goals and objectives with the patients.

The choice of learning methods is usually governed by the type of learning required, the characteristic of the learner, the characteristics if the teacher and other factors like resources, place, time and feasibility. Therefore, we should always aim at improving these factors for a

better learning activity. Carl Rogers' approach to education adopts the concept of learning facilitation rather than teaching (Green & Tones, 2004). There are poor learners who have a passive attitude toward learning and have poor choice of learning techniques and sources. Rogers' approach would therefore be much better with such learners (Green & Tones, 2004).

All of the above adult learning and teaching principles were first outlined by Knowles (1980). These principles are nowadays considered to be essential in the planning process of effective health education programs. Knowles' principles include that adults learn best when there is a perceived need and that if an adult does not understand why he/she needs to be taught about a subject, little learning will occur. His principles also state that teaching of adults should progress from the known to the unknown: that is the teacher should always assess what the clients know about a topic before beginning a teaching session. Moreover, teaching of adults should progress from simpler concepts to more complex topics. According to Knowles (1980), adults learn best using active participation rather than classroom-type didactic lecturing. Knowles' principles also include the need for adults to have opportunities to practice new skills and to reinforce those new skills to change their behaviour. In general, teaching about health topics needs reinforcement continually and immediate feedback and correction of misconceptions increases learning.

Knowles ideas are reaffirmed by others behavioural psychologists who have also suggested that learning and gaining knowledge are important in changing behaviour and attitudes (Burns, 1995). Knowledge is argued by Downes (1996, p.31) to be as "a recognition of a pattern in a set of neural events or behavioural events". Additionally, knowledge is said to be "the experience of a mental state that is at best seen as an *approximation* of what it is that is being said in words or experienced in nature, an approximation that is framed and, indeed, comprehensible only from which the rich set of world views, previous experiences and frames in which it is embedded (Downes, 1996 p. 41). So Knowledge can be learned experienced or accumulate off past experiences, interactions, values and beliefs.

All three concepts of teaching, learning and knowledge are interrelated when it comes to the development of patients' knowledge and might clearly define their information needs during

their cancer journey. In the next section, an argument on how learning might happen and how knowledge may get constructed is presented.

2. How does knowledge get constructed?

Knowledge construction is an epistemological question that has been problematic for researchers (Hamlyn, 1970). Epistemology is about knowledge and about the search of certainties; it is the study of knowledge and justified belief (Stanford Encyclopedia of Philosophy, 2005). It questions the nature of knowledge as well as the general conditions that must be satisfied. In other words, epistemology is concerned with what knowledge is and how it can be constructed and acquired (Hamlyn, 1970). Knowledge and justified beliefs in epistemology when positioned within a particular social and historical context become conceived as social epistemology (Stanford Encyclopedia of Philosophy, 2005). Research related to adult education showed that the levels of confidence and learner autonomy, in addition to discipline, are crucial to the learners in a personalised learning environment (Lave & Wenger, 2002).

There is a variety of ways that knowledge has been argued to be acquired, for example in an active way or in a passive way (Lave & Wenger, 2002). Lave and Wenger (2002) researched how people learn suggesting that knowledge is developed through active engagement in their social lives. Constructivists and the constructivism theory reject the idea that knowledge is passively received (Hacker, 2013). In socio-psychological literature, constructivism is a theory that has continued to be developed and used to the present. Piaget and other socio-psychologists are known to discuss the radical or cognitive constructivism; social constructivism; the sociocultural approach; symbolic interactionism; and social constructionism epistemologies (Tynjala, 1999). According to constructivism, learning is not a passive reception of information but a learner's active continuous process of constructing and reconstructing his or her conceptions of phenomena will lead to knowledge acquisition.

There are diverse schools of thought about how individuals and societies construct knowledge. These schools of thought differ from each other mainly in the role they give to the individual and the social aspects in learning (Tynjala, 1999). Some of these schools of thoughts place great emphasis on language and discourse, whereas others attempt to include

both the individual and the social aspects. Others still place equal emphasis on both aspects (Gergen, 1995; Phillips, 1995; Shotter, 1995 in Tynjala, 1999).

The cognitive domain of learning stresses that understanding and making sense of the information provided is necessary for the transfer of learning (Hacker, 2013). Problem solving skills and decision making also improve learning and lead to the transfer of learning. In addition, reinforcement and repetitions will help improve these skills as well as memory and brain functions turning information into knowledge and literacy. Hacker (2013) suggests that the concept of knowledge is linked to the concepts of information and skill. The author describes knowledge as something sought, acquired, possessed, retained, kept to oneself, shared, and given with others that is how we present it to others. The author explains that information is a source of power and that if one is well informed; one can speak with authority on the subject and supply information to others.

In order to construct this knowledge to stay informed and to be kept well informed it is needed to acquire information from others and via various modes. In the following section, a discussion on the types of knowledge that usually forms through these various modes is presented in a quest to identify how knowledge among cancer patients in UAE gets constructed and develop. This also helps in mapping patients' information needs during their cancer journey.

a. Types of knowledge

De Jong and Ferguson-Hessler (1996) reviewed the literature and at the time found different types and quality of knowledge, classified differently according to what they refer to as ontological typologies based on tasks and functions. They distinguished four types of knowledge domains: the situational knowledge which is related to circumstances, the conceptual type of knowledge which is about concepts and facts, the procedural knowledge and the strategic knowledge which builds on problem solving and organising ideas.

Another classification of knowledge types of knowledge is reported in the literature. Three types of knowledge are identified in the literature by education and behavioural specialists. The first one is factual knowledge or conceptual knowledge that people build over the years.

Hacker (2013) describes factual knowledge as taking the form of recognitional ability; that is the ability to identify the relevant object of knowledge on encountering it. People build on earlier experiences and knowledge (Lave & Wegner, 2002).

The second type of knowledge that appears in the literature is embodied or experiential knowledge, as described by Fosket (2000, p.7-10) and Mackenzie (2010) that is ‘the knowledge built through experiences’. Experiential learning is defined as ‘education that occurs as a direct participation in the events of life’ (Houle, 1980, p.221). Supporting the idea of learning through direct participation, Jarvis (1995, p.75) states that experiential learning ‘is actually about learning from primary experience that is learning through sense experiences’. He continues, ‘unfortunately it has tended to exclude the idea of secondary experience entirely.’

Kolb and Fry (1975) created a learning model out of four elements: the concrete experience, the observation and reflection, the formation of abstract concepts and testing in new situations. They presented these four elements in what they refer to as the experiential learning circle, comprised of concrete experience, observation and experience, the formation of abstract concepts, and testing in new situations. Kolb and Fry (1975) argue that the learning cycle can begin at any one of the four points; that the circle should really be approached as a continuous spiral. They suggest that the learning process often begins with a person carrying out a particular action and then seeing the effect of the action in this situation. Following this, the second step is to understand these effects in the particular instance so that if the same action was taken in the same circumstances it would be possible to anticipate what would follow from the action. According to this pattern the third step would be for the person to understand the general principle under which the particular instance falls. This is illustrated in Fig.1. as presented by Kolb and Fry (1975).

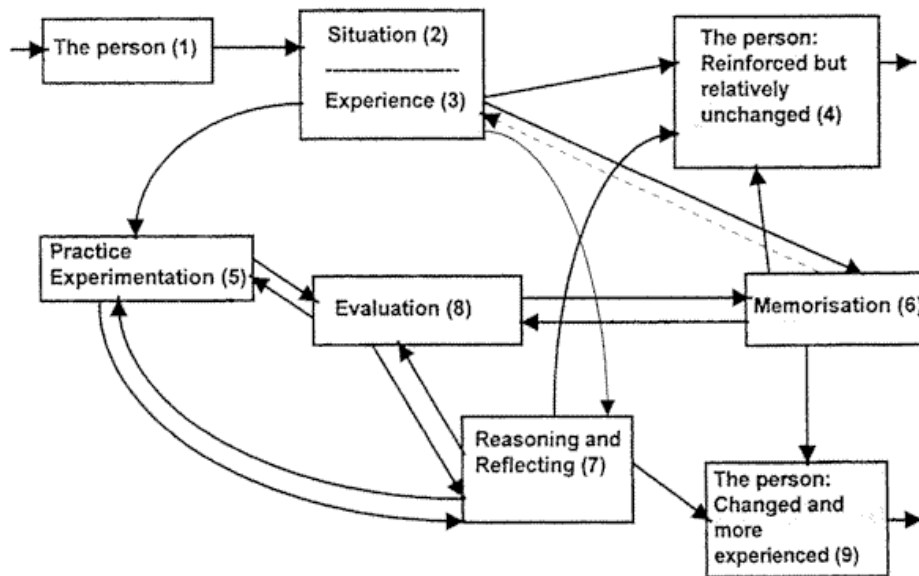


Figure 2. Four-element learning model (reproduced from Jarvis 1994).

The third type of knowledge identified in the literature is the acquired knowledge or the directly acquired knowledge about certain needed topics (Hacker, 2013). This form of knowledge according to Hacker (2013) includes the knowledge that may be acquired through by perception, observation, motivated scrutiny and investigation or engaging in an activity or practice. It may also be acquired by inference from information already available. This is the kind of knowledge that may be transmitted to a person by others through teaching or informing, or it may be received by noticing, recognizing, becoming aware, becoming conscious or realising that things are so. Hacker also describes the modes of knowledge-acquisition as active (direct learning modes) or passive through unconscious modes.

Figure. 3 is taken from Hacker (2013, ch.4) describes both of the information types that can be possessed or acquired and how a person can make use of these information and summarise the modes and sources of knowledge acquisition as well as the transfer of information and learning into knowledge.

The current study will investigate the types of knowledge that patients have and will be compared with the three above described types of knowledge (the embodied knowledge, the experiential knowledge and the acquired knowledge). These types of knowledge will be the basis for the patients' exploration of information needs and current knowledge.

a. *Is providing information enough?*

Information is defined as “stimuli from a person’s environment that contribute to his or her knowledge or beliefs” (Green & Tones, 2004: p.259). If information is given it does not mean that the learning process will occur; a transfer of learning is required. Knowledge is usually built when learning is transferred. For the transfer of learning to occur a person must observe that any new situation is similar to other situations. Studies have also proven that transfer of learning occurs when overall training and application coincide. For training and application to coincide, there must be important factors such as: the learner’s ability, motivation, quality and quantity of instructions that depends on factors related to the learner, such as memory and problem solving skills and the teacher’s skills, such as competency and empathy (Hacker, 2013).

The transfer of learning concept is essential to knowledge development among patients as individuals will remember general ideas, attitudes, and ways of thinking and skills that are meaningful to them and that they have applied and learned thoroughly (Redman, 2006). Knowledge is usually built when learning is transferred, which depends on factors related to the learner. Such factors include memory and problem solving skills as well as the teacher’s skills, such as competency and empathy (Hacker, 2013). See Figure.3 where Hacker illustrate the process of learning and knowledge development.

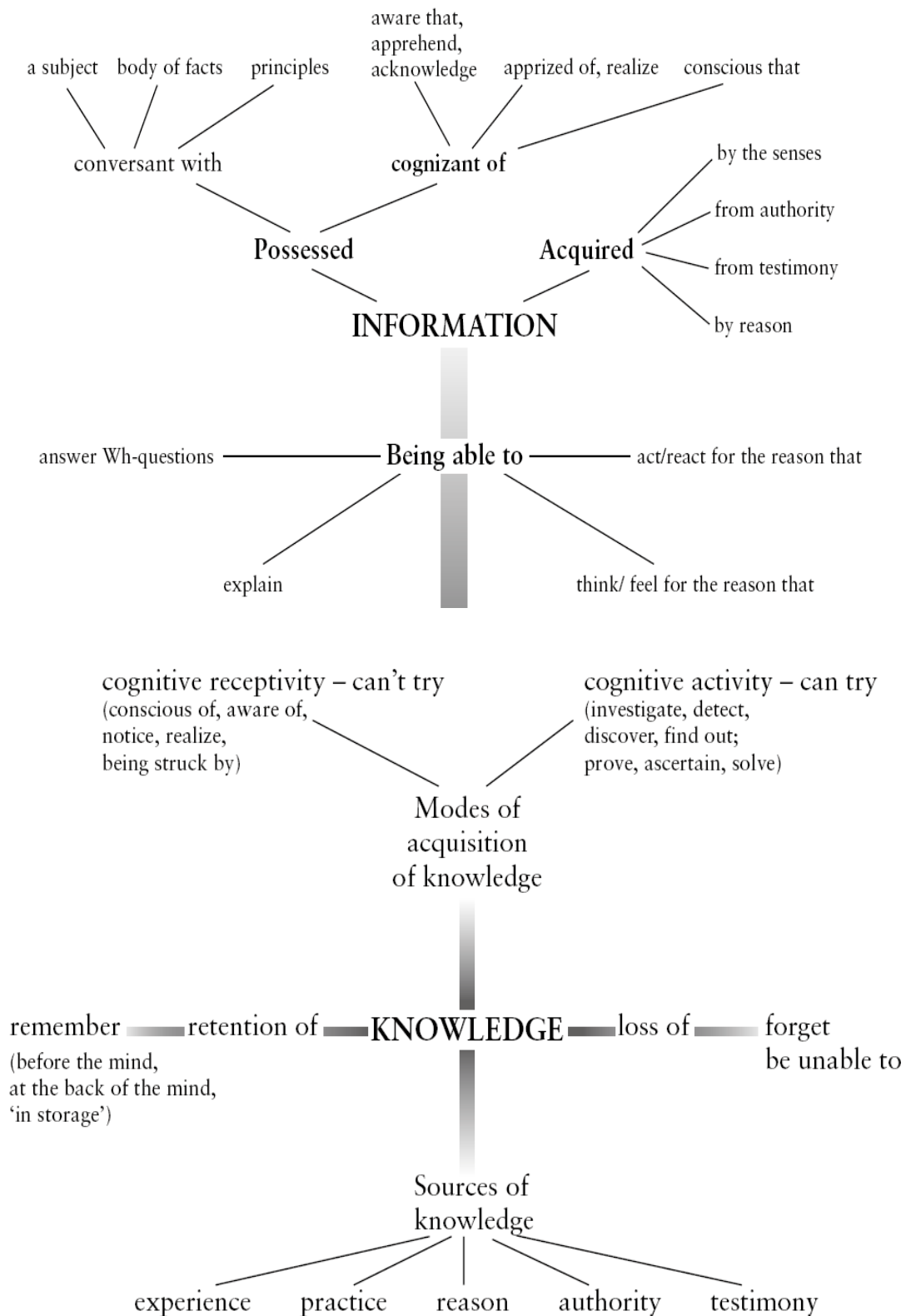


Figure 3. Representation of the cognitive conceptual network (adopted from Hacker (2013)).

In the UAE, these concepts of learning, knowledge and information acquisition, teaching and the types of knowledge patients with cancer possess are all new concepts that have not been discussed from before and were never been explored. How patients develop their knowledge and how this knowledge is constructed is still vague as there has not been any effort to dissect it and to describe it. Moreover, patient education has been always built on the western countries identification of what cancer patients should receive in knowledge and learn. There was no single study that has explored these needs and identified how these patients would prefer to learn and to be taught. Behavioural changing models and empowerment models are not being used at all with cancer patients during their journey. Some of these models are used as basis for cancer prevention programs but has never been incorporated with the teaching of cancer patients in the clinical area.

2. How is knowledge about cancer constructed?

Fosket (2000) and Ferguson and Casper (2000) discuss the emergence of knowledge about breast cancer from a social and biomedical approach. They argued that the biomedical scientific-clinical approach to breast cancer, the efforts of pharmaceutical companies and charity organisations have led to the development of particular kinds of cancer knowledge. Fear of death and the concept of cancer being an incurable disease have been built within individuals, social groups and communities throughout the year. Fosket (2000, p.10) labels the type of knowledge that people acquire from past experiences and from their social interactions as “embodied knowledge.” She describes embodied knowledge as the lens that cancer patients use to see their experience, their illness and their whole cancer journey.

Fosket (2000) also describes the experiential knowledge through which women with breast cancer acquire their knowledge. This creates a conflict between the two means of knowledge: the biomedical knowledge that is powerful and dominant and the knowledge acquired through experiences.

Smith’s (1990) feminist theory of knowledge back up the above argument which links biomedical knowledge to power and dominance as an interpretation of the dominance of the biomedical approach effect on cancer knowledge about breast cancer among women and communities. The biomedical approach and the science and scientific research groups have

directed their efforts, resources and money toward finding out about the genetic predisposition of cancer, vaccines to eliminate cancer and treatment that can prolong life and possibly leads to remission.

A cancer diagnosis is always confronted with social norms; perceptions of cancer are highly influenced by cultural beliefs, values, and attitudes, which is no less the case in the Arab world. For many in the Middle East, cancer is still considered as a social stigma (Bou Khalil, 2013; Donnelly et al., 2013). Also most patients in the Middle East fear cancer and consider it a disease that might lead to death (Mellon et al., 2013). An example again of what Fosket terms embodied knowledge, constructed over years of dealing with cancer. Loss of hair, disability that can be a result of cancer treatment as well as the effects of chemotherapy from nausea to low immunity are among the major fears of cancer patients (Donnelly, 2013). Body image and poor control over own lives are also part of the embodied beliefs and understandings that cancer patients and their families carry with them throughout their journey with the disease (Mellon et al., 2013; Silbermann et al., 2013). Health care systems and availability of treatment and resources, in addition, to the access to these resources can be also an important factor toward the embodied knowledge construction of cancer in the world and again this might not be different to the Arab world. Patients living in countries that provide high quality cancer care and treatment might show less fear and better trust and understanding of the system (WHO, 2005).

To understand how cancer knowledge is constructed in the UAE it is essential to understand the present cancer care practice and situation in the country. As mentioned above the advanced cancer care and availability of treatment might result in patients showing less fear as oncology systems and care are all highly advanced in the UAE (Silbermann et al., 2013). Availability of resources, technologies and services is not an issue for most patients; however, non UAE national patients have less access to oncology services and resources than nationals. The knowledge about cancer is fairly new in the Emirati society. Oncology services started in the eighties, however, it can be argued that in the last two decades cancer and oncology services have increased tremendously with a very rapid speed in the use of the most advanced technologies and therapeutic resources. Awareness campaigns about cervical cancer and breast cancer appeared in with the new millennium with the increase in the cancer

incidence. This change can be argued to have changed the embodied experience of cancer patients. On the other hand, cultural barriers and educational issues may contribute to poor health literacy and awareness about cancer (GLOBOBCAN, 2012). However, it is obvious that things have been changing lately with more professionals and community organisations and individuals calling for awareness and directing the attention toward efforts, policies and programs that can reduce the burden of cancer on the society.

Earlier, cancer was a taboo word that people in the gulf and in the Middle East feared to use verbally and use instead different metaphor. The use of terms like “that disease” or “the disease that cannot be named” or “that malignant cursed disease” were common metaphoric synonyms for cancer (Tadmouri & Nair, 2012).

While cancer is still a disease that creates stereotype in the gulf communities, the embodied knowledge created all over the last fifteen years through awareness and the resulting openness about the disease has created better understanding and acceptance for cancer generally and specifically for patients with the disease. Fear, anxiety and the view about cancer as a killing disease, continue to be apparent in the UAE community, in particular, however, this does not stop people in the UAE from seeking treatment for cancer (Bener et al., 2002; El-Obaid et al., 2014).

Beliefs, faith and spirituality are also important factors that can shape views, knowledge and beliefs about cancer in the UAE. Being a Muslim society, the belief in fate, destiny and God’s will are important factors that shape how a Muslim patient regards this disease (Rasool, 2000). Muslims believe that diseases and calamities are sent to a people to shed their sins and a test for their patience and faith (Khayat, 1997). This view of disease in general and about cancer in particular, being a disease that can lead to heaven, makes it more acceptable and inclines people to accept what they perceive as their fate. However, Muslims also believe that they should seek treatment which is also an important belief that shapes people reaction to such a disease (Rasool, 2000). Although, there are some misunderstandings among some Muslims about fatalism which lead to passivity in seeking treatment, the majority of Muslims seek treatment and accept medical interventions (Elbarazi, 2005). The availability of traditional and spiritual healers and the belief in traditional and prophetic

medicine play a role in how patients seek treatment. Due to the side effects of medical treatment such as chemotherapy and radiation therapy, cancer patients might seek alternative medical therapies and use of some traditional healers.

Cancer knowledge and beliefs in the UAE are shaped by many factors and views circulating in the society and between communities. Some of these factors are common with the rest of the world such as: the biomedical views toward cancer; the feminist views especially regarding female cancers; community and social groups views (charity and possibly faith based organisations), the political approaches and public health specialist views; and by the different types media. In UAE there are specific factors that might have shaped and still shape the knowledge and the view about cancer, include the cultural, social and spiritual beliefs. Also the unique distribution of population in UAE, the health care system and the availability of resources all have shaped and still impacting on cancer beliefs, treatment and acceptance among the community.

As described the study aims is to understand the transition of cancer patients' knowledge and information needs along the cancer journey in the UAE. To better understand the transition of cancer patients' knowledge and information needs, this study will help identify some of the factors that might shape cancer literacy and will help identify the conflict between the biomedical and professional approaches to cancer patients' educational needs and the patients' own information and knowledge needs. It will also identify the sources of patients' information and their suggestions for education in a quest to describe better ways for learning as per the patients' preferences. The understanding of patients changing knowledge and info needs will both contribute to building a structure for the specific knowledge about cancer needed by patients and how to construct better cancer literacy both of which are important building blocks in the patient centred care practice.

Next chapter describes the methodology used to conduct this study, the interview process and the data analysis process.

Chapter Three

Methodology

This chapter provides a detailed explanation of the rationale behind choosing a qualitative research method and particularly, the in-depth interviewing of participants using a longitudinal approach. The chapter describes how the study was conducted, the ethical guidelines followed, and the recruitment and sampling process. In addition, the coding and data analysis process are described. Finally, the chapter lists all the limitations and barriers faced during the data collection.

1. Research assumptions

a. Theoretical paradigm

A paradigm is defined as the “basic belief system or world view that guides the investigation” (Guba & Lincoln, 1994, p. 105). Guba & Lincoln (1994, pp: 105-106) have classified research four paradigms of research: positivism, post-positivism, critical theory and related positions, and constructivism, also known as the naturalist (Lincoln & Guba, 1985); hermeneutic (Guba & Lincoln, 1989) or interpretive paradigm (Roberts & Taylor, 1998). Out of all four paradigms, the constructivist method is most suited to this study of cancer patients because it aims to understand the complex world of so called “lived experience” from the point of view of those who live it (Schwandt, 1994). Directed at understanding lived experience from the point of view of those who live it, it is well suited to understanding and interpreting the experiences of participants (Guba & Lincoln, 1994).

A constructivist methodology is hermeneutical and dialectical (Guba & Lincoln, 1994). Hermeneutics is a way of interpreting human behaviour (Holloway, 1997). It is defined by Ferraris (1996, p.1) as "the art of interpretation as transformation" and as a "contemplation of eternal essences unalterable by their observer." Guba and Lincoln (1998) emphasized the importance of a dialectic approach and Schwandt (1994) explains that the hermeneutic dialectic approach is the best means of achieving researcher and client construction of reality because of its interpretive nature. It also fosters comparing and contrasting divergent constructions to achieve a consensus on issues that define the nature of the enquiry. The same

author also points out that a hermeneutic thought serves as a major source of ideas for qualitative enquiry.

The constructivist paradigm fits best the viewpoint of my research, as it was aimed at understanding and interpreting the experiences of my participants (Guba & Lincoln, 1994). The interaction between the researcher and the participant was essential to facilitate the patients' expressions of their experiences and needs.

Within a constructivist methodology, it is appropriate to use interviews that allow the participants to offer their own interpretations of their experience and, at the same time, acknowledge the interaction between the research and the participant. Thematic analysis was used as the main theoretical framework of this qualitative study. The study objectives were used to define the main themes of the findings.

b. Major assumptions

Ezzy (2002) in debating rigour and ethical considerations in qualitative research, it is more helpful for a researcher to be subjective, to acknowledge that the research conducted might be influenced by his/her own preconceptions and biases. The same author argues that new theoretical paradigms, such as feminism, post-modernism, and hermeneutics, all adopt the importance of having multifaceted interpretations that may embed the position of researchers. This is important for this research described here as participants being cancer patients have different emotional, physical and social needs and factors that might affect their views and discussions. Also being a cancer educator the researcher in this might have carried her own beliefs and biases about the patients' education and information needs throughout the stages. Therefore, the researcher tries to use a longitudinal methodological approach to avoid some of these biases as well as trying to be as reflexive as possible in reporting and accounting patients experiences as told by patients themselves.

As the study is carried in one of the Arabic countries and as there is a dearth in research related to patient education in the United Arab Emirates (UAE) assumptions about patient education in the whole region are presented below. The United Arab Emirates (UAE) share many social and cultural beliefs and customs with other Arab countries. Arabian Gulf

countries are multicultural and have also common spiritual and religious practices and beliefs. So patients and families education needs may be considered very similar in all of these countries. However, this area of research is very limited and it could be beneficial to draw some comparisons between patients and families education needs in these neighbouring. In general, patient education in this region is still underdeveloped. Not all hospitals and primary care centers provide planned education or employ educators. Moreover, most of the national health policies and programs in most of these countries did not address patient education needs yet. Patients' information needs have to be explored more closely to inform policy makers about the ways to address those needs.

Moreover, the availability of clinical health educators is very limited in the region and does not exist as a profession in UAE health care services. Health education programs in the UAE are mainly focused on the prevention aspects of certain diseases, such as diabetes, hypertension and obesity, and are available in a limited number of secondary and tertiary services (US-UAE Business council, 2014). Chronic disease cases are increasing rapidly and alarmingly, around the world, in the UAE and its neighbouring countries, leading to an increase in cost of services and on the burden of secondary and tertiary health services (IHME, 2013). The US-UAE business council (2014) showed that there was significant loss in the healthcare workforce in 2012. This report stated that there is inadequate healthcare education and training which is severely limiting the UAE population's ability to gain the knowledge and skills necessary to become qualified health care professionals. The council argued that an important step to improve health care in the UAE is by developing and ensuring significant and sustained growth of health workforce over the next decade. Therefore, the presented gap in the literature about health education in UAE, cancer education and cancer literacy in addition to the poor infrastructure of health education in health care services were important concerns and premises for conducting this research.

c. Qualitative Method

The most appropriate way to meet the objectives of the study, which is to explore patients' education needs along the cancer journey, is to use a qualitative approach to allow participants to recall their experiences and to encourage them to discuss their knowledge and education needs.

There are various theorists that promote a qualitative method. For example, Morse (2006) emphasises that qualitative research allows the researcher to extract meaning, from participants recalled experience and knowledge and education needs, rather than frequency of repeated information and numbers. Crouch and Mackenzie (2006) also stress that qualitative research is concerned with meaning and not with making generalised hypothesis type statements and that even one occurrence of data can be helpful to understand the process investigated.

In comparison, Holloway (1997, p. 2) emphasises that qualitative research is “a form of social inquiry that focuses on the way people interpret and make sense of their experiences and the world in which they live.” Holloway (1997, p. 2) stresses the importance of qualitative research and argues that although qualitative research can have different approaches, they have similar aims:

“to understand the social reality of individuals, groups and cultures. Researchers use qualitative approaches to explore the behaviour, perspectives and experiences of the people they study. The basis of qualitative research lies in the interpretive approach to social reality.”

Also Richardson (1990, p. 24) argue that:

“A good qualitative research article has the capacity to open up a world to the reader through rich, detailed and concrete description of the people and places. It can take the reader into the context and experience of person or a community’s life. Writing up qualitative research converts private problems into public issues, thereby making collective identity and collective solutions possible.”

Denzin and Lincoln (1994) describe qualitative research as a multi-method approach that involves an interpretive, naturalistic, approach to its subject matter. They state that “qualitative researchers study things in their natural settings, attempting to make sense of, or interpret phenomena, in terms of the meanings people bring to them.”

Despite the different opinions, Ezzy (2002) points out that a qualitative approach is the best choice for a research similar to the current study it is good for examining meanings and

interpretations although it could be problematic technique to construct theories, as meanings are constantly changing and might be difficult to grasp.

In this research study, I am trying to understand the information needs of patients through their experiences and voices manifested by conversations between the researcher and the participants. I am trying to understand the changes of the needs with the changes that patients might pass through during a cancer journey. This cannot be achieved in this study except by following a qualitative approach as I am trying to draw on concepts that have not been explored before from patients' perspectives and definitely based on their experiences

d. In depth Interviews

I chose to use one-on-one in-depth interviews, as this method helps to explore the information and knowledge from the participants without the researchers' preconceived biases. Qualitative research and in-depth interviewing allow for the emerging of themes and information that might not be expected or sought. In-depth interview allow participants to tell their own stories by retelling their experience (Liamputtong, 2013) and it is the patients' experience which is what I am seeking from this research. Therefore, the aims from the interviews were to have the patients discuss their current knowledge, information needs and knowledge seeking behaviour they follow to meet their needs.

As exploring the knowledge change and illustrate the transition of this change throughout the cancer journey stages was the aim of this study, a single interview was not going to be enough to achieve my aims and objectives Therefore, on-going interviews were conducted by researchers with each patient to find out how their knowledge changes following a timeline and through different stages of cancer treatment, starting with diagnosis, passing through the treatment stage, until end of treatment and the start of the recovery and follow-up stage.

e. The cancer continuum

As I mentioned in the literature review, Rutten et al. (2005) have identified a cancer continuum comprising a diagnosis stage, treatment stage, post-treatment/survivorship, relapse/recurrence, and end of life. I chose to take the first three stages of the cancer continuum to identify the education and the information needs of the patients during these

stages. I called the last stage the ‘follow-up stage’ or ‘recovery stage’. I decided not to use the other stages that Rutten et al. (2005) identified for the following reasons:

1. The time frame limitation of the study, as this was a one year project.
2. The study explores the change of knowledge during the cancer journey among first time cancer patients (newly diagnosed patients). If the patient finishes the first three stages and then proceed to the relapse and recurrence stage, he/she are not considered new patients. These patients would already have knowledge from their previous experience and this might cause some overlap between the information and knowledge that patients acquired or need.

A longitudinal approach was essential to draw an illustration on how the patient’s knowledge changed throughout the three stages, and to identify the information and education needs the patient might require at each stage. As the aim was to explore the changes throughout the cancer journey, the study plan is designed to conduct one interview during each stage (diagnosis, treatment and follow-up) with every patient. Following this plan, each patient will therefore be interviewed three times to identify both their knowledge at each stage of their cancer journey and to determine the information needs as stated by the patients themselves.

2. Research process

a. Location of the research

This research study was conducted in a tertiary hospital (Tawam Hospital) in Al Ain, in the Emirate of Abu Dhabi. Abu Dhabi city is the capital of United Arab Emirates (UAE). Tawam Hospital has an affiliation with The Johns Hopkins Hospital in the USA and has 461 beds capacity with more than 1,000 employees as per SEHA website. Until recently, Tawam Hospital was the only hospital that treated cancer patients in the UAE. Lately, many hospitals have been providing cancer care and treatment; however, patients who need radiation therapy and palliative care are still referred to Tawam, as it is the only hospital providing these services. Moreover, the only breast cancer centre in the country is located at Tawam. The centre provides comprehensive services using the most advanced technology, surgical consultations and referral to the Oncology unit. All breast conditions are seen in the centre first, before referral to other services. Doctors, radiologists and nurses provide education to all breast cancer patients throughout the diagnosis process until referral to medical oncology

and radiation oncology. Surgeons provide education at the centre and patients, post- surgery, are seen by the surgeons in the centre or in the oncology clinic for further evaluation. Other cancer patients are seen usually in specialised medical or surgical clinics and then referred to the oncology clinics.

b. Ethics approval

Two ethics approvals were obtained to conduct this study. The first one was sent to the Social and Behavioural Research Ethics Committee at Flinders University (SBREC). The second was sent to Al Ain Medical District Human Research Ethics Committee (AAMDHREC), for research approval as a required by Tawam Hospital. This second application was filed after I received the approval from SBREC.

c. Ethical Considerations

A rigorous research criterion includes ethical and moral conduct within the new theoretical paradigms of qualitative research (Ezzy, 2002). Ezzy states that rigour and ethics in research are interrelated and should not be limited to following ethics committee guidelines, but also to include other ethical considerations related to dealing with human beings. Ethical guidelines should ensure that no physical or psychological harm is caused during, or after, the research process. As the sample population in this study are considered vulnerable subjects being affected with cancer, I had to ensure that patients had the complete choice to withdraw from the study at any time.

Therefore, an information sheet with all the information about the study and the requirements from each participant was given to each patient before the interview, along with an introduction letter that provided the name and the contact of the researchers. Each patient was given enough time to read, comprehend the information, ask questions and discuss their concerns. Once patients had been given time to digest the information and discuss their concerns, informed consent ensured patient willingness to participate, formalised through patients , and a witness (either from the family or from the health care team) signing a consent form. All patients were reassured that the study is optional and will not affect their treatment at any stage of the process during their care at Tawam Hospital.

d. Confidentiality and anonymity

All participants were given a copy of the information sheet and a copy of the consent form. The information sheet stated clearly that patient personal information are kept confidential and that their names will never be disclosed to anyone. At the time of each interview, the participant was reassured of the confidentiality and the anonymity of the study and was reminded that they could withdraw from the study at any time.

e. Study timeline

Proposal writing	September 2012 to December 2012
Proposal approval	December 2012 to January 2013
Ethics approval	March 2013 to June 2013
Oncology centre head approval	August 2013 to September 2013
Data collection	September 2013 to April 2014
Data transcription and analysis	April 2014 to September 2014

Table 2. Study timeline

f. Interview timeline

Each patient was interviewed three times between September 2014 and April 2014. Each patient was interviewed upon diagnosis, during treatment and toward the end of hospital treatment, a decision based on the patient's treatment plan as provided by the doctor. It is important to note that due to the time constraint of the study, some patients were interviewed at the end of their treatment for their third interview, before starting the actual recovery process. I sought patient consent to be able to contact them by telephone after the interviews; however, as it is always important to respect the patient's rights to refuse contact, a message was sent before calling them to ensure availability and willingness to be contacted.

All of the interviews took place in a private room in the oncology clinic except for the first sixteen interviews conducted with breast cancer patients. These interviews were conducted in a private room in the breast cancer centre which is a comprehensive centre for screening and diagnosis located in Tawam hospital.

3. Recruitment process

The recruitment process started in September 2013 after finalising the communication needed with the staff in the oncology centre and in the oncology clinic. After obtaining the approval of the ethics committee at Tawam Hospital, approval from the oncology centre head was sought after providing him with all the information needed. The researcher had to assure him, in person, that complete confidentiality and respect to the patients' care will be taken into consideration.

A contact person for the research committee at the oncology centre was assigned to communicate with the researcher and to arrange for the recruitment process. The same person contacted the staff in the oncology clinic and in the treatment area and informed them about my study and asked them for cooperation. The head nurse and the charge nurse in the treatment area were my contacts in the oncology clinic.

After receiving the initial approval from the oncology centre and from the resource person to start data collection, the researcher met with the head nurse and the charge nurse and briefed them about my study. The researcher requested to call her when there is a new patient with any type of cancer. A meeting with the clinical nurse coordinator in the breast cancer centre was conducted also to inform her about my study, and she asked the charge nurse in the centre to call me when there is a new patient. All the nurses were given a copy of my ethics approval forms and a copy of the information sheet. A short note on the study, with my contact number, was also handed to the three nurses to display in their offices and in the clinic to remind the staff to contact me when a new patient arrived.

a. Inclusion criteria

All patients newly diagnosed with cancer, over the age of eighteen, of any gender and with any type of cancer in stages I, II or III were included in the study. These patients were chosen as they were receiving treatment with curative intent and were expected to pass through the three stages of the cancer journey.

b. Exclusion criteria

As stage IV patients might be receiving palliative care treatment, their education needs are expected to be different. Therefore, I excluded them from this study as I expected that their physical condition might be a barrier to participate in the three interviews. Patients who

relapsed or were previously diagnosed with cancer and received treatment for cancer earlier were also excluded as the study explores the change in information needs throughout the cancer journey from first diagnosis, rather than after a relapse. Having a previous experience with cancer, such patients are expected to draw their embodied experience and knowledge they acquired earlier which does not serve the objectives of this study.

4. Sample and sampling strategy

a. Sampling strategy

The study followed a purposive sampling strategy. Liamputtong and Ezzy (2005) and Liamputtong (2013) argue that qualitative research is not concerned in representing certain populations or in generalisability, therefore, purposive sampling can meet the purpose of the study. Therefore, this was the best sampling strategy for this study, as I needed to include as many patients with any cancer types.

b. Saturation

Successful qualitative research data collection is continued until saturation occurs, which means no new significant findings are generated (Morse, 1995). However, as this study was conducted in a relatively limited period of time, saturation and redundancy was not fully obtained. In qualitative research, the criteria of sample size is also qualitative; that is, the researcher will decide on how much detail and breadth is required in the research.. It is always hard to predict the best sample size as stated in (Liamputtong & Ezzy, 2005). Qualitative research is more concerned with examining the phenomenon or the experience and therefore does not involve reporting distributions (Liamputtong & Ezzy, 2005). For this research, as I was intending to interview each patient three times, I decided to avoid using large samples as it would complicate my data analysis on one hand, on the other, I was not looking for generalising my findings, given my research is qualitative. In addition, I had to limit my sample due to time constraints. The sampling continued until early January to ensure that patients would receive three spaced interviews over that period of time.

In this research twenty eight patients were interviewed in total. Amongst them, seventeen patients had breast cancer and the rest had other types of cancer. It was expected that breast cancer patients would constitute the majority of the sample, as breast cancer is the most diagnosed cancer in the UAE (GLOBOCAN, 2012 & UAE Cancer Central Registry, 2012, 2014).

5. Data collection

a. Interview process

Patients recruited came from different educational backgrounds and nationalities. Therefore, it was not possible to always use the English language during every interview, as some of the patients were not fluent in English. Some of the participants spoke Arabic, and, as I am a native Arabic speaker, I was able to interview them in Arabic. For some of the patients who had both limited Arabic and English skills, communication was a bit more limited and the interviews took longer to complete than usual. Each interview lasted between thirty to forty five minutes. With those who had limited English or Arabic language, the interviews took closer to one hour.

All patients received information about the study from the nurses and an invitation to participate. Those who expressed interest in participation received detailed information from me about the aim of the study, both verbally and in writing. As mentioned, they also received an informed consent sheet on which they signed their approval to participate in the study and to be interviewed three times during their course of treatment. They also signed an approval to receive phone calls to arrange interview appointments.

b. Interview tool

Pickard (2012) explains that qualitative research should involve collaboration and a dynamic and mutual relationship between the research participant and the researcher. Further, it should involve the use of appropriate data collection techniques to produce meaning from data collected.

To collect the data in a way that allowed me to get the meaning and to interpret the patient experiences, as I mentioned, I used an in-depth interviewing method that uses semi-structured interview questions. Liamputtong (2010) describes this data collection method as providing a means to explore themes and issues that might arise during the interview and at the same time, ensuring all participants are asked similar questions.

I constructed an interview schedule with the help of my research supervisors. The schedule included questions that were based on my research objectives which include exploring the patients' knowledge and education needs at each stage of the cancer continuum. The

questions were revised many times by me and my supervisors until we had a final agreement on the main questions and the probing questions. Interview questions were mainly open ended questions and I included some demographic questions at the beginning of the first interview to develop a profile for each patient. I piloted the interview guide with two patients, who were in different stages of the cancer continuum. Piloting the interview guide with the patients helped me identify the missing questioning areas that are needed to meet my objectives. Also, I piloted the interview guide with one of my colleagues (a researcher who gave me some ideas to improve the questions and the probes). The data collected with these two patients were not reported in this study as I did not conduct three interviews with each at the different stages of the continuum. As I was conducting three interviews with each patient, I divided my interview guide into three sections. Below I give a brief summary of each interview questions.

c. Interviews

Below I provide a more detailed explanation of the interview process at each stage.

i. First Interview

The first interview aimed to identify patients' current knowledge about their diagnosis, disease type, stage and grade, as well as the diagnostic procedures to identify the treatment plan. The patients were asked about their treatment plan, possible or expected prognosis and their sources of information. The patients were asked about what they would like to know more about at this stage and whether they felt that the information they have been given, and that they have acquired on their own, are enough. Each patient was asked about his/her knowledge seeking practices and preferences, sources of, and how they found the information they needed.

ii. Second interview

At this stage, patients had started their treatment. No matter what the treatment was, the patient was asked about their knowledge of their specific treatment. Patient knowledge about treatment rationale, types, time and length of treatment, dose, side effects, complications and management was examined. The sources of information were also explored. Then the patients were asked about the information they would like to know or would have liked to receive. As

with the first interview, each patient was asked about his/her knowledge seeking process and sources, as well as how they would find the information needed.

iii. Third interview

At this stage, the patient had finished his/her treatment and was asked about their recovery and follow-up process. Each patient was asked about his/her knowledge about the follow-up plan and their disease prognosis. Each patient was also asked about lifestyle changes and prevention measures, as well as knowledge on preventing a recurrence. In addition, each patient was asked about their fears and expectations for the future. Then the patients were asked to identify the information they needed at this stage. The sources of their information were again defined and their preferred sources were explored. Finally, each patient was asked about his/her satisfaction with the education they received and how they would suggest a better education process.

d. Recording the Interviews

Each patient was asked to sign a consent form that allowed for the interviews to be recorded. Interview records were kept only with the researcher on a flash drive, in a safe drawer.

Each patient interview was recorded using a tape recorder and for back up, a mobile phone was used as a recording device at the same time. All recorded interviews were coded with patient pseudonyms and were stored and transferred directly onto the researcher's personal computer.

e. Data storing

After transcribing all of the interviews, the original recordings were all saved on a flash drive and were removed from the researcher's personal computer. The flash drive is now kept in a locked drawer in the researcher's office.

6. Data Analysis

a. Transcription of interviews

The data analysis started at the beginning of the data collection. Grbich (2007) describes the preliminary data analysis stage as an ongoing process undertaken every time data is collected

and involves a process of checking data and evaluating areas that need to be followed up. As I collected the data, I checked and tracking it, identifying areas that required follow up. At times I contacted the participants to fill in some of the gaps that were missed during the interviews.

As patients' individual interactions during the interviews, at all stages, it was very important to relate the patients' emotional status at the time of the interview at each stage, and report their answers as understood by the interviewer, within each interview context.

b. Translation of interviews

It is important to note that, to avoid bias, I tried to quote the participants as much as possible during the transcription process, but there were points when I had to interpret what the patient said. Most of the patients interviewed were from an Arabic speaking background. There were sixteen from different Arabic countries, four from the Philippines, one from Iran, three from Pakistan, two from India, one from Australia and one from Ireland. The interviews were conducted in both Arabic and English. Pakistani and Iranian patients were able to communicate either in Arabic or English, while Filipinos spoke in Arabic and English for most of their communication. As some of the interviews were conducted in Arabic, they were transcribed and were translated by the researcher into English. To avoid bias, where possible, I translated the interviews word-for-word. It is important to note that while I tried to quote the participants as much as possible, there were points when I had to interpret what the patient said where there was poor sentence structure. For example, some participants were using an unfamiliar language, therefore, some of the translations needed to be rephrased to make complete sentences.

c. Coding

Morse (2012) explains that qualitative research analysis follows an inductive process. The inductive process consists of reading through textual data, identifying themes in the data, coding those themes, and then interpreting the structure and content of the themes (Guest, MacQueen & Namey, 2012). Grbich (2007) argues that there is diversity on how to process the preliminary data analysis and that it is an individual process based on the research and the researcher. Generally Grbich (2007) describes the process of preliminary data analysis as

beginning with data collection by reviewing and tracking interviews, and then collating summaries and major points gained from the interviews, following the end of data collection.

In this study, to understand the patients' voices about information needs, I read all transcriptions thoroughly and many times, so I became familiar with each patient's experience. Also, with the verbatim transcription and audio recording, I became more familiarised with the interview data and was able to re-live and recall each interview and record all the observations made with that patients. A complete profile for each patient was created based on his/her three interviews, which the researcher kept recalling during the analysis process. Creating a complete profile, which I kept recalling during my analysis helped to provide an overall impression and feeling of every patient's needs throughout the three stages.

I followed Koch's (1993) approach to data analysis which identifies themes common to the participant interviews. My data analysis process was derived from this approach. Below are the steps I followed in coding and transcribing my data:

- All patients were given a pseudonym to identify them.
- During the interviews, I was taking notes and coding information by themes. However, this process was revised and recoding was done after transcribing all interviews.
- After transcribing all interviews, main findings were extracted (based on study objectives) such as the knowledge of the patients and the information needs of patients. Quotes related to each area were classified, then themes that emerged from these findings and from the analysis of these quotes were collated to be presented as emerging themes. All themes and quotes were first placed in a separate document. Later, the themes derived from each interview, at each particular stage (including similarities and differences) were collated using NVIVO (data analysis software).
- NVIVO software was used as an organizing and storage tool for my research findings. After entering the data, I classified the themes based on similarities and differences that were derived from the interviews as nodes and sub nodes as termed in NVIVO.
- I classified all the relevant quotes for each identified theme and put them in one separate file to use in my analysis.

- I repeated the same process with each of the three interview stages, and identified the emerging themes.
- I gathered all significant statements and information under clusters, as I will explain in the next section.

d. **Significant statements and information clusters**

Gribch (2007) describes the post data collection process as the data reduction which follows a thematic analysis process. The process includes reducing the data into meaningful groupings which are thereby easier to be carried by a block and file, or conceptual mapping approach to analysis. To form clusters. I used the block file approach. The block and file approach involves clustering the information into groups of different headings and subheadings related to the topics discussed such as (Current knowledge, information needs treatment as major headings and side effects, management, prevention methods etc as subheadings). This is where I coded data under separate entities or headings. Then I grouped them in a table with headings that clarified the contents, or what can be called an information cluster.

As mentioned before I did eighty four interviews. A large number of statements were derived from these 84 interviews. I clustered the statements and classified them according to my study objectives. To form the clusters, I rearranged all the themes I first identified using NVIVO into clusters of information.

At the end of the process, all transcripts were compared separately for significant statements that represented similar findings. Across each participants interviews differences were collated to draw more conclusions based on them. Examples of the information cluster include knowledge transition through the stages. At each stage themes and subthemes were extracted. For example, at the diagnosis stage sub-themes included knowledge about the disease, stages and condition. Under that sub-theme came another sub-theme that included the patients' current knowledge and what the patients wanted to know. Another example of an information cluster is patients' knowledge seeking behaviour, the sources from which they gain their information and their satisfaction with the education process. All of these clusters and themes will be discussed in detail in the findings chapter.

e. Thematic Network analysis

A thematic map or a web was developed based on the themes interconnectedness and after following a thorough interpretation for the findings. Attride-Stirling (2001) discussed the thematic network analysis as being based on extracting basic themes, organising themes and global themes and then presenting them in a map or a web-like map in a way to illustrate the relationship between them or their interconnectedness. Bazely (2013) reinforced the use of thematic maps in qualitative research for better data representation. I found that this is a good way to summarise and to represent my themes especially that I collected a large amount of information and many themes were identified. The thematic map will be presented in the findings chapter see Figure.6.

7. Study reliability and researcher reflexivity

Rigour in qualitative research often requires the use of triangulation of sources of data (Liamputtong, 2010; Southern & Luby, 2011). Triangulation which is the use of different research methods and approaches is needed for better research results. However, due to time limits of this study, only semi-structured interviews were used as a tool for data collection. Nevertheless, a longitudinal approach that used the three interviews to follow up the knowledge change and information needs is considered to be strength for this study. Rigour also demands keeping an audit trail, or a record of what was done (i.e. notes, tools, decisions made to keep track of ideas, responses, or 'biases', and to acknowledge them to ensure reflexivity and rigour (Southern & Luby, 2011). To ensure rigour, I kept a diary where I made a profile for each patient and recorded all my notes from the interviews, the interview process, and participants' possible weaknesses and strengths. The diary helped me to make use of the information I collected in the past interview and to build my next interview around patients' answers and specific needs. I found that the diary helped to facilitate the second and third interviews and helped me communicate better with the participants. Using a diary, I was able to tie the interviews together and build rapport with participants because you could raise topics they talked about in previous interviews.

The diary notes I took were also important to identify missing or vague information, and with recollection and confirmation of information collected with the patients. This process was

repeated and followed with all participants during their second and third interviews. Ideally, to avoid interviewer's bias and to ensure reflexivity it is recommended to acknowledge patients' responses by allowing them to review the transcribed interviews and to confirm their responses with the interviewer (Southern & Ruby, 2011). As I conducted three interviews with each patient and due to the difficulty to ask patients to come to Al Ain, where the study was conducted (as many of the patients were from outside Al Ain). I reviewed the recorded interviews and I took notes before I meet with the patients in the second and in the third interview. I was trying to clarify each time I meet with the patients their unclear answers and vague information provided in the first and second interview, but I could not do that in the third interview. Nevertheless, I was able to ask two of the participants to review their three transcribed interviews after the data collection finished. The two patients provided their comments via email and confirmed the data collected and transcribed with me. Some patients declined to review the transcripts and said "we trust you", while the rest of the patients were either unable to come to Al Ain and/or did not provide me with e-mail addresses to send the transcribed interviews to them. This process was an effort to help me be as reflexive as possible and to help in reducing the researcher's bias as much as possible.

8. Limitations and Barriers

A number of factors impeded this research. For example, the study ethics approval took longer time than usual by both Flinders university ethics committee and Tawam hospital. Also the limited time of the research was as a barrier achieving the saturation concept, defined by Morse (2006) as I discussed earlier.

Other limitations included the inability to represent all cancer types in my sample due to the limited time, as well as the refusal of some patients to participate and because some patients preferred to get treated outside the country. In addition, Tawam is not considered close to patients from Dubai, Sharjah and other emirates due to the distance involved. Therefore, some patients prefer to go to other centres like Dubai hospital for treatment. Moreover, patients who do not have health insurance cannot be treated in Tawam for free; therefore, they usually seek treatment in public hospitals. Although, they can be accepted in the hospital as full fee paying, many patients and families are unable to afford the treatment and prefer to go to other accessible public hospital. As for UAE nationals (Emiratis), these patients can get

treated outside the country (like in USA, Europe or other countries) on government expense. Due to all of these reasons, it was difficult to get many UAE national patients in my sample.

9. Summary

This chapter has provided an overview of the methodology used and the methods followed to extract the data that will be discussed in the next two chapters. To answer my research questions, I used a qualitative approach as it is the best way to understand patients' experiences and to determine some of the information and education needs that might help improve the quality of cancer care processes in hospitals and in the community. In-depth interviewing is thought to be the best approach to help exploring patients' experiences and stories. In the next chapter, I present my findings.

Chapter Four

Findings

This chapter presents the results of the total of eighty four interviews conducted on twenty eight cancer patients of different types of cancers during their cancer journey. It describes themes identified from the interviews and from the interviews as per the study aims and objectives. The study objectives include finding out about patients information needs and the transition of this information needs throughout the three major stages of the cancer journey (diagnosis, treatment and follow up/recovery stage). As emerging themes is a common occurrence in qualitative studies (Bendassolli, 2013) this chapter also describes themes that emerged from the interviews and they were not part of the research objectives.

As explained in the methodology chapter, each patient was interviewed three times over the three stages of the cancer journey to track the transition of their knowledge and education needs, throughout their cancer journey. Each patient was interviewed once during the diagnosis, the treatment and the follow up/recovery phases, identified by Rutten et al. (2005) as comprising part of the cancer continuum. Because only newly diagnosed cancer patients with stage I, II, and III were included in the study, the last two of the five stages that Rutten et al. (2005) identified, the relapse/recurrence and end of life phases, were not included as patients with recurrence and palliative care patients were excluded. I chose the three major stages of cancer that most patients will pass through with successful treatment of cancer

This chapter is divided into five major sections that are based on the study objectives. The first section provides an overview of the patients' demographics and characteristics. The second describes the findings of the patients' current knowledge and information needs as described by the patients. A description is provided of the current knowledge about the stage and the information needs at each stage of the cancer continuum (the diagnosis, the treatment and the follow up stages). I classified the information needs or the needs to know about the topics as the major themes extracted by the study. In this section, information seeking behaviour as emerging themes are also presented under each category. The third section will present the knowledge transition how the information needs and knowledge have changed

and progressed throughout the journey. The fourth section discusses types of knowledge identified among the patients. This section describes important findings related to the fourth objective of this study that describe facilitators and barriers and determinants of patients' health literacy. The fifth section describes patients' satisfaction about the information they have received and their suggestions to improve patients' experiences with receiving information and education at all stages. Finally a summary of all themes is presented in a map format to represent the correlation between all themes.

Later in the discussion chapter the patients' education needs and their knowledge will be contrasted to what the literature and scientific evidence defines the patients' education needs and how these education needs can influence the patients' journey with the disease.

1. Patients demographics and characteristics

Patients recruited were mostly females. Out of the twenty eight patients, only three were males. As cancer is an aging disease, most of the patients, except for some of those with breast and cervical cancer, were above fifty five years of age.

At the time of the recruitment, active awareness campaigns on breast cancer, early detection and prevention were taking place around the UAE. October is breast cancer awareness month, and usually there is an increase in breast cancer diagnosis after October, which decreases after a few months. This raising of awareness is considered to be related to breast cancer month and has the effect of prompting active screening (HAAD, 2013). The raise in awareness might provide an explanation to why half of my sample had breast cancer. More detailed information about the sample recruited will be provided in the findings section.

In Table. 2 , interviewed patients' characteristics are given. Pseudonyms are used throughout this dissertation to protect patient privacy and anonymity. However, I preferred to use other Arabic names as pseudonym rather than letters and numbers to make it easy for the reader to relate to each patient's own experience. Overall, thirty five patients were invited to participate over a period of five months (September 2013 to January 2013). Three patients refused to participate. Another three left the hospital after the first interview and one patient decided to stop participating so they were excluded from the study. Overall, twenty eight

patients participated in the whole study and were consequently included in the study sample.

Also, steps followed in this study are presented in the study flow diagram given in Figure. 4.

Patients	Nationality	Age	Work	Education	Marital status	City	Type of cancer	Stage
1	Australian	44	Housewife	University	Married with one child	Al Ain	Breast cancer-	III
2	Scottish	52	Housewife	School	Married to an Emirati with 4 children	Dubai	Breast cancer-	II
3	Emirati	47	Housewife	School	Married with 3 children	Dubai	Breast cancer	I
4	Sudanese	57	Business	University	Married with 4 children	Abu Dhabi	Breast cancer-	II
5	Tunisian	45	Academic	University	Married with 2 children	AlAin	Breast cancer-	II
6	Sudanese	53	Housewife	High school	Married with 2 children	Abu Dhabi	Breast cancer-	III
7	Emirati	37	Housewife	High school	Married with 3 children	AlAin	Breast cancer-	II
8	Lebanese	54	Health /Academic	Postgraduate	Married with 3 children	Sharjah	Breast cancer-	I
9	Lebanese	45	Health	Bachelor	Married with 5 children	Sharjah	Breast cancer-	II
10	Egyptian	51	Business	School	Married with 4 children	Al Ain	Breast cancer-	III
11	Indian	58	Health	Bachelor	Married with 3 children	Abu Dhabi	Breast cancer-	II
12	Philippino	40	Domestic	Primary	Married with 2 children	Abu Dhabi	Breast cancer-	III
13	Lebanese	43	Business	Bachelor	Married with one child	Abu Dhabi	Breast cancer	II
14	Palestinian	54	Housewife	Secondary	Married with 5 children	Abu Dhabi	Breast cancer	III
15	Egyptian	55	Housewife	Secondary	Married with 3 children	Abu Dhabi	Breast cancer	II
16	Syrian	54	Housewife	Secondary	Married with 3 children	Sharjah	Breast cancer	III
17	Emirati	63	Housewife	Primary	Married with 5 children	Dubai	Breast cancer	III
18	Omani	67	Worker in a petrol company	Limited education	Married with 5 child	Hatta-Oman	Lung cancer	III

19	Lebanese	30	Shop owner	High School	Single	Dubai	Testicular cancer	III
20	Iranian-	67	Retired Public servant	Limited education	Married with 7 children	AlAin	Colon cancer	III
21	Philippino	38	Child care assistant	Secondary	Married with 4 children	AlAin	Cervical cancer	II
22	Philippino	43	Hairdresser	Primary	Married with 2 children	AlAin	Cervical cancer	II
23	Syrian	40	Housewife	High school	Married with 2 children	Dubai	Cervical cancer	II
24	Iraqi	67	Housewife	High school	Widow with 5 children	AlAin	Ovarian cancer	III
25	Indian	57	Housewife	Primary	Widow with 3 children	Abu Dhabi	Colon cancer	III
26	Pakistani	64	Housewife	Illiterate	Married with 4 children	Dubai	Colon cancer	III
27	Philippino	51	Marketing	College	Married with no children	Dubai	Ovarian cancer	III
28	Pakistani	63	Housewife	Primary	Married with 6 children	Dubai	Rectal cancer	III

Table 2. Patients' demographics and characteristics.

As can be noticed, there were more breast cancer patients than patients with other types of diagnoses. This is most likely to be because of a higher breast cancer incidence than other cancer types in the UAE (GLOBOCAN, 2012; HAAD, 2013). The mean age of all participants was 50.82 years.

To present the findings in a systematic way, the study objectives and aims were used as the main headings in this chapter as well as in the discussion chapter. The main aim of the study was to identify the knowledge of the patients in all three stages and how this knowledge have changed throughout the stages. The main objectives included:

- To assess patients' knowledge and information needs upon diagnosis of cancer.
- To explore changes of cancer patients' knowledge and information needs during the process of their treatment through to the follow up stage.
- To determine sources of information cancer patients seek during their cancer journey.
- To identify the facilitations and barriers that can influence cancer patient literacy during their cancer journey.

- To identify patients' different educational needs to optimize best treatment during their cancer journey.

Below is a flow diagram of the method and the findings structure

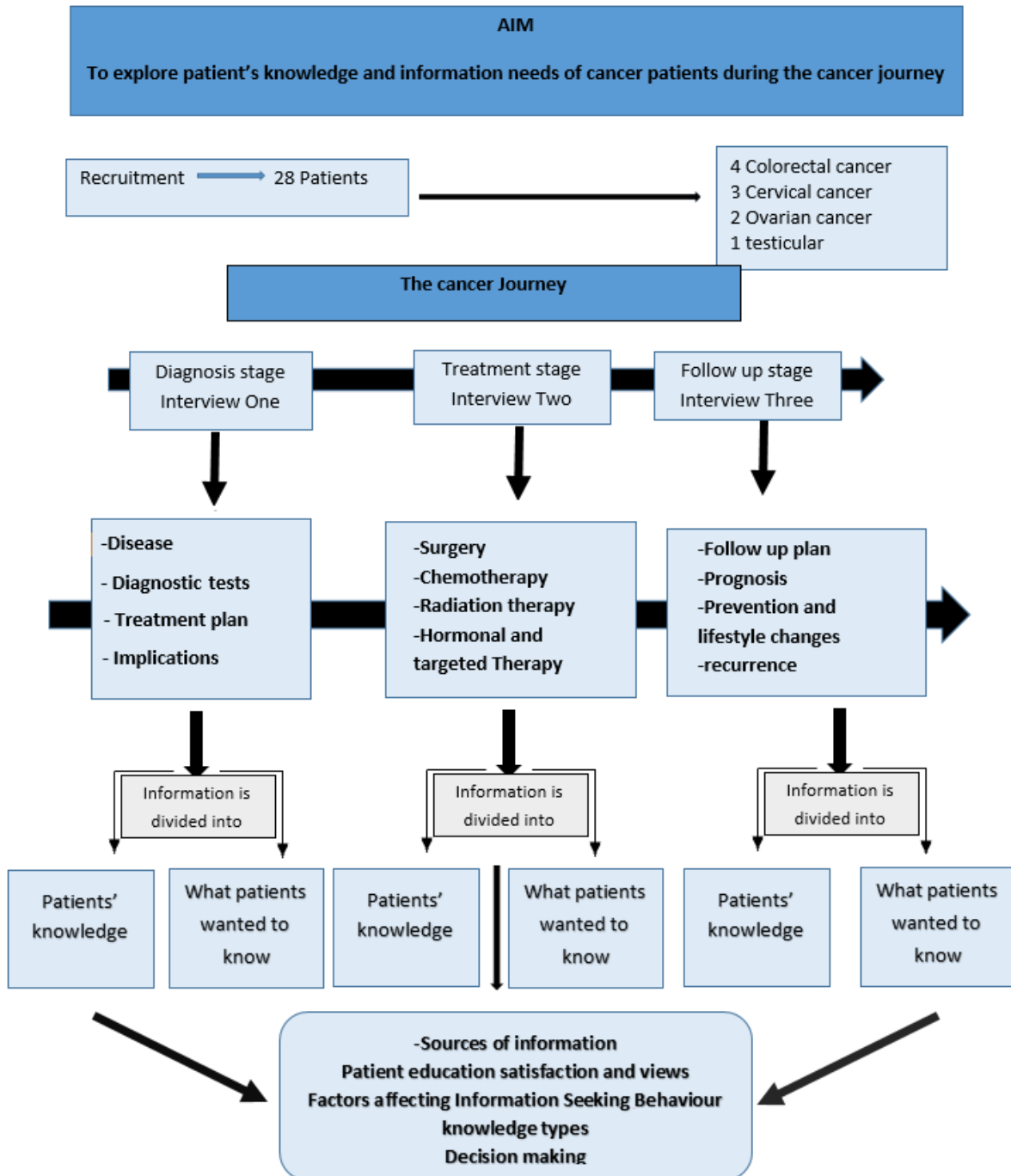


Figure 4. Study Flow Diagram

In the following section, findings related to the patients' knowledge and their knowledge needs in each stage of the cancer journey are presented.

2. Patients' knowledge and information needs at the three identified stages:

As mentioned, the first objective of this study was to identify the current knowledge of the patients and the information needs of the patients at each stage. This section presents the knowledge and the information needs at the three stages of the cancer patients' journey (diagnosis, treatment and follow up stage/recovery) as identified above. In this section, I describe patients' knowledge at each stage and their information needs or what they wanted to know at each stage. Patients' current knowledge about related topics stage has been used as a sub-heading or subthemes and finally the information seeking behaviour and decision making process are presented as emerging themes (refer to Figure. 4 and Figure. 6).

It should be noted that the study objectives were not directed toward finding patients' information seeking behaviours and their involvement in the treatment decision making involvement. However, both topics were important emerging themes that I identified from the interviews. As exhibited earlier in the literature review chapter, information seeking behaviour and decision making process are major components of information needs and knowledge transition; therefore, I included under each major stage a subsection that present the data related to these two emerging themes. Finally, sources of information (a major theme and important objective of this study) are presented within the text and within the emerging themes section as they are strongly related to the information seeking behaviour and the decision making process.

The topics of each stage were drawn from the literature that looked at patients' information needs and that pointed to what patients need to be informed about and what patients would like to know about (Ankem, 2006; Leydon et al., 2000; Mills & Sullivan, 1999; Rutten et al., 2005, 2006; Squiers et al., 2007; van Mossel et al., 2012; Vogel, Bengel & Helmes, 2008). In summary, the layout of the next section includes the major themes of what patients knew and what patients wanted to know about each category and subcategories. Also it includes the sources of information as important finding and the emerging themes about information

seeking behaviour and the involvement in the decision making process identified in each stage. The main findings in each of the three stages of the patients' cancer journey are presented below beginning with the diagnosis stage.

a. **Diagnosis stage:**

The topics presented in the following section are the topics that arose in the interviews at the diagnosis stage. These topics include the knowledge about the disease, the knowledge and implications about the diagnostic procedures and the knowledge about the treatment plan and expected prognosis. Below I describe what the patients knew, what they said they did not know and what they stated they would like to know about each particular category of knowledge. The headings are used accordingly. Simply, this section describes the gaps in knowledge as identified by the patients about their disease and related topics relevant for diagnosis and the implication on treatment plan and prognosis.

i. **Knowledge about disease**

This section presents patients' knowledge about their disease and their diagnosis in details, location, grade and stage of the disease and the expected prognosis.

- Patients' current knowledge

All except one of the patients knew about their disease diagnosis. Most of them had some understanding of the severity of the disease and their diagnosis. They tended to have some expectations about possible consequences of their disease. This understanding was associated with fear of death and fear of recurrence. A common knowledge shared by most of the patients with different diagnosis and stages was that cancer is a chronic disease that might recur.

Only one patient, Akram (Colon cancer, 69 years old from Iran) was not sure of his diagnosis although his daughter knew it. He said on two different occasions:

"I don't think I have cancer."

And then he asked:

"Do I have cancer?"

Most patients could not identify their stage and grade and indicated that it must be in their medical report given to them by their doctors. However, when asked whether they knew what the report said, they could not recall it.

Typical of many patients, Iman (Breast Cancer, 52 years old from Scotland) said:

“I remember that it was mentioned to me by my doctor but I cannot recall it now. It's written in my medical report. I will check it next time.”

Similarly, Amal said:

“I don't know what my stage is ... maybe stage two, it's in my medical report. I should check it”

Maher (lung cancer, 67 years from Oman) did not know about the stage and the extent of his lung cancer, stating:

“I know I have lung cancer and that I should get chemotherapy and then possibly radiation therapy. I have no idea what the type or stage or grade of my disease is but my doctor told me that I should be fine.”

The trust in the doctor words and decisions was shared by most of the patients and I consider it a very important finding of this study. As part of trusting their doctors, most patients exhibited limited information and low enthusiasm to learn. Most of them accepted the diagnosis and showed that they trusted in the doctors' information. Their lack of knowledge about the stage and grade of their disease might have been one of the reasons that they did not feel the need to know further information about the disease. This trust and the acceptance of the situation might explain their limited knowledge and the low enthusiasm to know more.

In general, most of the patients knew about the diagnosis and the disease itself, but mostly did not know or reported limited knowledge of their expected prognosis at this stage and about the implication of the stage and the grade of the disease on their future and on their prognosis. This suggests patients did not feel it was not necessary to know about the stage and the grade; however, it was highly important for many patients to know about the progression of the disease and the prognosis.

Most of the patients feared the treatment and expressed fear that it will affect the quality of their lives. It appeared through the interviews that there were some embodied beliefs about

cancer as being a fatal disease or a disease that might be incurable and that it is going to cause suffering and pain. This appeared to be an important determinant to their fear and doubts about their case and their prognosis especially with patients Arwa and Somaya.

Arwa's (breast cancer, 55 years old from Egypt) account illustrates the role of embodied belief about cancer being a fatal disease:

"I know about cancer and the treatment of cancer because my mother died of uterine cancer. I lived with her the experience. I know that I might have to have my breast removed and then I will receive chemotherapy and radiation therapy. I am ready for that. This is my destiny and I accept it."

Arwa's past experience with the disease has affected her belief as she implied in another statement:

"If I die from the disease it will be my destiny, and I accept everything from God."

Like Arwa, Barira (breast cancer, 47 years old from UAE) and Somaya (breast cancer, 37 years old from UAE) had a past family history of breast cancer. Barira recently watched two of her sisters treated for breast cancer, and Somaya's mother had breast cancer before. Somaya's had lots of questions and misunderstandings, including the choice of her, treatment; In particular she was concerned about why her cancer will be treated with chemotherapy while her mother's cancer was treated with hormonal therapy.

Somaya stated:

"I cannot understand why the doctor is going to give me chemotherapy; I am so scared that my case is much worse than my mother's."

Barira said:

"You know my other two sisters had breast cancer lately. It's a familial thing. We are all afraid of this disease as it can recur. I am thinking about going to a faith healer who is in Kuwait. I heard that she can help cure this disease."

Both Barira and Somaya's accounts suggest that they had hidden fear of the complexity of the disease and the prognosis. Their statements suggest a fatalistic view toward cancer. However, Lina (cervical cancer, 37 years old from Philippines) and Nadine (Breast cancer, 43 years old Lebanese) expressed through their accounts contradicting beliefs to most patients

about cancer. Both patients believed that cancer may not kill and that it can be a curable disease.

Lina said:

“I knew before that cancer can kill, but my doctor told me that my case is highly curable and that not all cancer cases result in death.”

While Nadine said:

“Nowadays everyone knows that breast cancer can be treated and that not everyone dies of it....”

These quotes show that there were different beliefs about that cancer. Some believed that cancer might be fatal and others had a belief that cancer is not necessarily fatal and patients can go into complete remission. Also these quotes show that the formal education given by the health care team can change the patients’ beliefs and knowledge especially when the patients trust them. Some of the patients have changed their belief about the fatality of cancer after they learnt that many cancer cases were cured and people went onto live normally.

For example, Nafisa (breast cancer 51 years from Egypt) said:

“To be honest I was so scared of the disease and of my diagnosis, I did not sleep for days when the doctor told me that I had cancer, but after I spoke with the doctor and the surgeon I learned that many patients were cured. He also reassured me that my case can be cured.”

Afaf (breast cancer 45 years old from Tunisia) said:

“To be honest I was devastated when I knew that I have cancer, but after I spoke with the doctor and after I read extensively about the disease, I learned that it has become curable and survival rates are very high nowadays. Also I know a friend who had breast cancer, and she is now cured and has resumed her normal life.”

-What patients wanted to know about:

Most patients stated at this stage that they wanted to know about the disease and the meaning of their diagnosis, as well as the causes of, and possible prognosis of their disease. Specifically, most of the patients were interested to know more about the cause of the disease

and the implication of their diagnosis on their lives, their prognosis and their expected future in general. Some accounts illustrated different views of the patients and different needs related to these topics. Some of the patients displayed general misconceptions about cancer as a disease that happens to those who lead unhealthy lifestyle. For example, Mustafa (testicular cancer, 30 years old from Lebanon) said:

“I would like to know how I got cancer; I am an active person; I eat healthily; I cannot understand: How did I get this disease?”

He continued by saying:

“I cannot understand where this disease came from; I never expected that. I used to smoke but I never heard that it can cause testicular cancer.”

On the other hand, other findings most of the patients have posed some questions and acknowledged their needs to know about the cause of the disease in their discussion. For example, Maher (lung cancer from Oman) said:

“Do you think my lung cancer is a result of me working in the petroleum industry for years?”

As Maher statement indicates, some participants used different approaches to account for how they got cancer, such as blaming their work and avoided blaming themselves. For example, while Maher tried to blame his past work for his cancer, Mustafa was surprised that he had cancer especially that he thought that he was leading a healthy lifestyle.

Both Arwa and Shahrazad tried to figure out a cause of their disease, through a possible link between their work and exposure to petrol, r or exposure to air pollution and unhealthy lifestyle.

Arwa posed a question that was also posed by her husband who was with her during the interview. She said:

“Is breast cancer nowadays a result of pollution and unhealthy foods, pesticides and chemicals?”

Shahrazad (breast cancer, 57 years old from Sudan) wondered about the cause of her cancer, saying:

“I am an accountant and I worked in the company from more than twenty five years. Before we used to depend on papers a lot and the employees who worked in the field used to bring in their bills and papers, smelling of petrol. Do you think this has any relation with my breast cancer?”

While most cancer patients referred to the potential cause of their cancer as unhealthy food and practices, chemicals pollution and the new technology dependent life, some had more spiritually related rationale and were afraid that their cancer was some kind of a punishment or a test from God.

Haleema (colon cancer, 57 years old from India) said:

“I think God is cleansing my sins by this disease. However, I would like to know the reasons: Why did I get this disease? I have been a good person all my life.”

Other patients displayed some feelings of guilt and the tendency to blame their own actions or others' for the disease. A good example that illustrates this point is Mayada (cervical cancer, 40 years old from Syria). When enquiring about the cause of her disease, she said:

“Do you think I got my cervical cancer because my husband is married to another woman? Maybe she is the reason?”

Mayada did not know about cervical cancer causes and its aetiology, and stated that she did not know what to ask the doctor for. She was trying to find explanations for herself. However, she did not express her concerns either because of the cultural stigma of having a husband married to another woman or because she was not sure whether she has to ask. She exhibited the need to know what the cause of her disease is and her stage and grade.

When asked whether she tested positive to Human Papilloma Virus, she said:

“I don't know why this virus causes cervical cancer? Ah.... I don't know, but the doctor told me I have stage II disease I think....”

From the statement above I gathered that most patients had some interpretation for the possible reason of how they got this disease. Most showed more interest to know causes and explanations rather than knowing details about their current treatment. For some there were some unanswered questions. Some said that they had expressed their concerns about the unanswered questions while for the rest, they said that they kept them to themselves and expressed them only in the interviews. For example, Sharazad said:

“I asked the doctor how I got this disease, was it my lifestyle? I want really to know if this is going to be cured or will it recur?”

On the other hand, some patients took the approach of not knowing and of avoiding asking. For example, Nadine repeated in many occasions:

“I don’t want to know about anything, I don’t want to read or ask ...”

For others not asking was either because they might not have been given the chance to ask or that they might not have even allowed themselves to ask for social or cultural reasons. For example, Barira said

“You know I want to see a faith healer in Kuwait. I heard that many patients were cured by this faith healer after they went to her. I do not want to mention that to my doctor but I might go there soon. I contacted her; she sent me some booklets and told me that I can go to her if I want.”

It should be noted that after a short discussion with the patient, she accepted my advice that it is better to finish her treatment before going to that faith healer. I told her that breaking up her treatment plan might influence her health negatively and that it is highly advisable to discuss the matter with her doctor.

In general, patients did not express their need to know about the stage and grade of their cancer, until prompted by my questions. Even after my prompting, however, they seemed more interested to know what it meant to have a stage II or III for example rather than knowing what the stage of the cancer they were actually at. For example, Amal said that information about her stage was in her report. However, she said:

“I will look it up on my medical report and try to find out. But what is the difference between stage II and III? Is there a big difference in terms of treatment? Does it mean that stage III might not be cured?”

Some patients did not know what they should know or, ask for possibly because of their limited knowledge about the disease and or about their diagnosis. For example, Akram indicated that he did not have much information, as he said at the diagnosis stage:

“I don’t know what my stage is. I don’t know about my condition except that I had a tumour and they removed it and they made an opening in my abdomen. They explained to my daughter. Mmmm ... I don’t think I have cancer now. They told me that I am getting this treatment.... This chemotherapy, but I don’t know ... They gave me that thing at home intravenously then I am back to get this medicine today, but I don’t know for how long ... I think I am going back to the other hospital and the doctor where I had my surgery.”

It was not clear whether Akram knew that he had cancer or he meant that as he had the surgery he no longer has cancer.

In summary, patients’ education needs at the diagnosis stage was more concentrated on knowing about the cause of the disease and whether it was an unhealthy practice that caused it, or whether it was transmitted to them so they can blame others, or whether it is a punishment or a test from God. At this stage patients' information needs included knowing about the implications of the diseases and specifically whether the cancer will kill them as well as the meaning of the stage and the phase of their cancers.

Most patients knew about their disease; however their concerns were more about its cause of and the development of their disease rather than its stage. The findings were similar between all patients of different types of cancer. However, most of breast cancer patients believed and indicated that lifestyle was one of the main causes behind their disease.

ii. **Diagnostic tests and procedures' knowledge and implications:**

During the diagnosis stage, patients have to undergo certain procedures to confirm the diagnosis and the stage which usually influences their treatment journey. Some of the diagnostic procedures are very particular to certain types of cancer. For example, for breast cancer patients there are certain pathological tests that can define the stage and the grade of the disease and will help in making the best decision in terms of the treatment plan. As for testicular and prostate cancer, there are specific blood tests (tumour markers that also help in the planning for the treatment and similarly with other cancers). Not all patients interviewed shared the same diagnostic procedures as for some it depended also on their specific condition. The interview questions were mostly general at this stage, unless I asked specific questions about certain diagnostic procedures.

-Patients' current knowledge

Most patients stated that they were not aware of most of the different diagnostic procedures until they were told about them. Breast cancer patients were more aware of different diagnostic procedures like mammography, ultrasound and biopsy than patients with other types of cancer. The FISH test (fluorescence in situ hybridization) was new to most breast cancer patients, while the genetic oncotyping DX was a new procedure for everyone; no-one had prior knowledge about it, even the patients who have higher education and those from medical background. Most of the patients stated that they learned about genetic oncotyping from their doctors. However, not everyone understood what it meant, except that the test is done to help doctors make decisions about chemotherapy and radiation treatment. Mariana said:

“The oncotype test is a new procedure that I have not learnt about, and I found about it from my doctor and from the books I read lately about breast cancer”

Ghina (breast cancer, 45 years old from Lebanon) who has also a medical background said:

“I don't know about oncotyping, my friend who is getting treated also for breast cancer told me about it and I have to ask my doctor if I need to do it.”

Afaf also was not sure about her diagnostic procedure and what it means. In regard to her treatment she said:

“Until now I don't know what my plan will be, and no one has told me about all the tests that I have to do. Every time I come to the clinic, there is a new test that I learn and I am told about. I was told that I have to go for a surgery and then they will decide on the rest of my treatment plan. I don't know what will happen and what other tests will be done. They told me about some test for hormones and another one eh....something spelled with two, but I do not know why and what will happen after that.”

Most of the non-breast cancer patients, except for cervical cancer patients, did not know in detail what was happening. All suggested that they knew that they had to come for more tests but did not know what these tests were specifically. However, most of them knew about radiological procedures like X- rays and MRI. Although, patients did not express their discomfort about tests done or to be done, they mostly lacked information about their diagnostic procedures, the reasons they were needed, as well as some of the diagnostic procedures types and the routine procedures and plans. For example, Mustafa knew that the doctor depends on a certain tests to decide on the course of treatment, but he could not state the name of the test or identify it as a tumour marker test. He said:

“You know they always run tests for me but I don't know what they are for and the doctor keeps saying one of the tests is high so we have to give you chemotherapy. I don't know what the blood test is and what the test is. I asked my cousin and she told me it is something like markers for cancer.”

In general, cervical cancer patients had more information in regards to their diagnostic procedures and their stages and, in comparison to other cancer patients, expected the treatment plan and prognosis. Omayya (Cervical cancer, 43 years old from Philippines) said:

“They have done all the tests needed for me, and they told me I have second stage cervical cancer. The doctor told me that I will not need more than five weeks of chemotherapy and radiation therapy, and then I will be ok and later there will be no treatment.”

Also cervical cancer patients appeared more comfortable with their health care team. For example, Lina said:

“You know, I was told everything and the doctors explained everything to me in detail. “

Apart from the cervical cancer patients, for most of the other non- breast cancer patients, there showed some uncertainty about their treatment plans and they had to wait for the doctors to explain about their conditions and the proposed treatment plan. For example, Haleema said:

“You know no one told me what is happening, I know I have colon cancer but I don’t know anything except I had surgery last week. They told me that I had a big tumour and they had to clean around it. And I am so tired.”

In summary there was a limited knowledge among most of the patients about some of the tests and procedures done for them. Many have stated that they received very limited knowledge and they were not involved much in the decision making process. Regarding the treatment, there were lots of discrepancies at this treatment stage between patients with different cancer types that influenced the involvement of patients in the decision making, understanding and implications of certain diagnostic tests.

Although diagnosis plan and routines were not clear for most patients, almost all patients knew that there was diagnostic procedure they had to undergo like a biopsy. However, when asked about types of biopsy, most patients did not know the differences. Patients with medical backgrounds, however, did know about different types of biopsy. In addition, other patients did not show an interest in knowing about the procedure itself or the type of the biopsy. Some displayed indifference to knowing, such as Somaya. She was more concerned about the result. In relation to her express interest in the result she said:

“You know I am more concerned about the result and how this is going to affect my treatment especially that it's in the family.”

- What patients wanted to know about:

The findings indicated that there was more need to know about the implication of the diagnostic procedure rather than knowing about the procedure itself. The study showed that there were hidden fears among some patients about the long term effects of diagnostic procedures causing cancer. It also showed, there was a need to know about routine and plans rather than knowing about the way the procedures are done.

Though patients appeared to need to know more about the implications, some of the patients expressed their needs to know about certain procedure. On the other hand, some did not show any interest to know. For example, Haleema could not identify the diagnostic procedures she underwent. Her concerns were more about the surgery for her colon cancer and what will happen after the surgery.

She wanted to know about the implications on her health:

“They ran some tests for me and they did not explain anything to me. But for me, it is ok I want to know what will happen. They told me that I need a surgery and that they will remove the tumour and then will make connections in my colon. I would like to know if this is going to affect me later and how I will live and what will happen after that.”

For the other types of cancer the diagnostic procedures and tests are not as complicated as those of breast cancer. For example, the tumour marker tests were mostly unclear for patients like Mustafa and Bahiya, who did not know anything about them. Bahiya (ovarian Cancer 67 years old from Iraq) said:

“I know that I have to do some blood test but I don’t know anything about the results.”

Overall, in contrast to highly educated patients, those who did not have high formal educational background did not ask much about the diagnostic procedures. Their concerns were more directed toward the treatment plan and how these procedures might influence their future life.

Breast cancer patients were more knowledgeable about the types of diagnostic procedures needed to plan their treatment, than those with other cancer types, but lacked information about routine and how the procedures are done. Some of the breast cancer patients did not understand why some of the tests were repeated in Tawam hospital while they had the same tests in other centres. For example, Faten (breast cancer 54 years old from Palestine) said:

“We already wasted a lot of time. I was diagnosed last month in Abu Dhabi and then I was referred to Tawam. Since then they have repeated the mammogram and the ultrasound. They repeated the biopsy and they have done other blood tests to find out about my cancer status.They told me, I am hormonal positive. Oh ...My daughter who is a dentist explained to me all about these tests. But I am really confused why they had to repeat all the tests..... They are wasting time and I am really concerned...”

Faten here is expressing her need to know about tests done, their implications and whether she needs to repeat them and waste time. And she was not the only one. The routine at the clinic was one of the main concerns for other patients.

For example, Amal said:

“You know I would prefer if the team at the hospital provided better information about the expected routine and what will happen from the first visit. You know what happened with meif you haven't called me to set an appointment me with me on the day of my MRI, I would not have known that I had an MRI, you know ... because no one had communicated with me and told me about the MRI appointment. It was by luck that I found out from you....Or sometimes they call you a night before and they ask you to come the next morning; they do not give you enough time to prepare yourself ... there should be better explanation of the routine.”

Amal said that she would like to know about the routine and procedures. Underscoring her concern about knowing about the routine and procedures, in relation to neo-adjuvant chemotherapy, for which she scheduled, she said:

“I do not know why I am having the operation post the eighth chemotherapy cycle. I would like to know more. I need explanations about the basis on which my treatment plan was chosen.”

Most of the breast cancer patients wanted to know about the implications of the diagnostic procedures on their treatment plan and how these procedures may affect their future, rather than details of the procedures done. Somaya on the other hand wanted to know whether the biopsy can lead to spread of cancer. Two more patients, Fatma and Mariana had similar

concerns. For these patients, the side effect of the procedure was a concern rather than the procedure itself. Somaya said:

“You know, my mother also had breast cancer, after she had her biopsy. She had surgery and then hormonal therapy, then the cancer spreads after that, and I read that biopsy can help spread of cancer. I am concerned because after I had the biopsy I felt that my breast became more painful and I felt that there were some sharp pain in my breast, like tingling and then the biopsy spot was very painful. I asked the doctor who said not to be concerned, but I still feel that the biopsy is going to make the cancer spread quickly....”

As mentioned above, Nafisa (Breast cancer, 51 years old from Egypt) was upset that she had to go for three operations because she believed that at the diagnosis stage the doctors misguided her and did not inform her about the best option based on her current condition.

She stated:

“I wish that the doctor told me about possible complications..... If I knew from the beginning I would have preferred to go for mastectomy....”

The patient expressed her wish that she had received a better explanation and was given the choice. Nafisa's case is a good example of patients' need to know, in detail the positives and negatives of certain procedures as well as alternative plans to avoid complications.

Ovarian and cervical cancer patients were more comfortable with their diagnostic procedures than patients with other types of cancers, as most of them were given information by an interdisciplinary team. They did not specify any knowledge needs as they received enough information from their health care team. For example, Lina said:

“I think my main concerns now are to know about my future prognosis; everything was explained to me by my doctors.”

Similarly, Aya (ovarian cancer, 51 years old from Philippines) was very clear about her condition and about her procedures, and was concerned more about the success of the treatment and her ability to regain the quality of her life. She said:

“I had a very good doctor in Dubai and the whole team explained everything to me, regarding my ovarian cancer and at each step they explained every procedure to me. I am more concerned now about my future and the water in my abdomen. See how I'm barely able to breathe. ...Last time they aspirated the water in Dubai and they told me that with the chemotherapy I will be better ”

Mariana was concerned with the spread of the cancer as result of the biopsy she said:

“I read that a biopsy might help the spread of cancer and may lead to the invasion of the disease to other tissues. This was a concern for me that is why I asked the doctor to remove my lump as soon as possible.”

In addition to Mariana, Afaf expressed her concerns about the biopsy and said:

“I heard that a biopsy might activate the cancer cells and lead to the quick spread of the disease.”

After probing her if she has discussed her concern with her doctor, she said:

“No, I did not have the opportunity to ask ... ”

Moreover, Mariana and Afaf were informed about oncotype test. Both patients were aware of the role of oncotype result in the treatment plan. Mariana made an informed decision not to take chemotherapy based on her tests results, while Afaf said:

“My oncotype result was negative... My doctor told me that I don't need to have chemotherapy as it will not be beneficial. I will only be given hormonal treatment. You will not believe how relieved I am Thank God.”

In summary, most patients wanted to know about how the diagnosis may affect their treatment, rather than knowing about the diagnostic tests and how they are performed. Some wanted to know about the routine ahead of time and the expected tests, while others wanted to know about some of the complications of certain diagnostic tests like biopsy. Most of the breast cancer patients had some unanswered questions in relation to their diagnostic procedures while the non- breast cancer patients mostly did not worry much about their diagnostic procedure. Breasts cancer patients were more concerned about the implications of,

and possible complications of the diagnostic procedure. Specifically, misconceptions around biopsy possibly spreading the cancer were one of the concerns about diagnostic procedures. Patients' involvement in the decision making as a result of the diagnostic procedure such as oncotype was also one of the main findings of this study for breast cancer patients.

iii. **Knowledge about treatment plan and prognosis**

This section presents patients' knowledge prior to the diagnostic stage and then what they learned at the diagnosis stage regarding the expected or proposed treatment plan.

-Patients' current knowledge

Most patients knew the type of the treatment they were having except for Akram who was not sure that he was having chemotherapy. Additionally, he was not sure about his future treatment and the next step. Akram wanted to go back to his surgeon and to the hospital where he had his surgery as he trusted that doctor and believed that he was the main treating physician. He was clear about his surgery and explained:

“I underwent a large operation that included taking out a part of the colon and making an opening in the abdomen for the stool.”

When asked whether he understood how to take care of his stoma he replied:

“My daughter is the one who is handling that and she is taking care of me; I don't know if the doctor is going to close or it will remain like this forever.”

For other patients and specifically for certain cancer types the treatment plan was clear. The cervical cancer patients Lina, Omayya and Mayada, mentioned above described their treatment plan and were able to state the expected dates to finish their treatment. Lina's only uncertainty was whether she will need brachytherapy. She said:

“I met a patient in the treatment area and we usually commute together. She had chemotherapy and radiation like me and then her doctor put some seeds inside her cervix. I might have the same treatment after I finish.”

This patient's uncertainty about her treatment plan appeared after she met another patient. However, she stated that her doctor explained to her the expected treatment plan. By contrast, Mayada and Omayya were sure that they were going to have chemotherapy and radiation therapy concurrently for 5 weeks. The breast cancer patients' knowledge about their treatment plans varied with the various diagnostic procedures and with different stages and grades of the disease. Most of them were expecting surgery and chemotherapy. Some also expected radiation therapy and hormonal treatment, but none were sure of the detailed treatment plan at the diagnosis stage except that they will have surgery and some sort of treatment. Some of these patients, only knew that they will have a lumpectomy, while some knew that they will have total mastectomy and possibly reconstructive surgery later on.

Amal knew that she will have a surgery after the end of her chemotherapy treatment:

“...I am going to get eight cycles of chemotherapy and then we will go for a mastectomy. The chemotherapy is given to shrink the tumour size and to allow for better success. The surgeon showed me pictures and told me that they will do a reconstruction straight away and that they will put silicon in my breast. I haven't decided yet whether I will go for a reconstructive surgery...”

She continued:

“...I'm not sure whether I will go for a bilateral mastectomy or not. The doctor told me that this is an option to prevent recurrence as in my condition recurrence is highly possible. I read about it and I asked my friends, my husband and my doctors, and I am still thinking whether I will do it or not...”

Amal, later went for bilateral mastectomy and had silicone inserted.

Overall, most breast cancer patients were uncertain of their treatment plan at the diagnostic stage. However, after the results of diagnostic procedures, patients became more knowledgeable about their general treatment plan. Most of them knew they will have surgery and chemotherapy. For some it was not clear whether they would have radiation therapy and some did not know whether they will have hormonal therapy. While some of them were going to receive targeted therapy (Herceptin) but did not know about it. Others identified the Herceptin as the smart injection as their doctors and nurses told them but did not know the real name of the drug, type or why it is used. Patients who had a medical

background thought they will receive targeted therapy but later on found that that they would not have it. .

Shahrazad learned about Herceptin from her sister who is an Anaesthesiologist. She said:

“The doctor told me that I will receive a smart injection as part of my treatment, I did not ask him about it because my sister explained to me about it.”

Nafisa and Insaf (breast cancer 54 years old from Syria) knew that they were receiving Herceptin as part of their treatment but could not identify the rationale behind it and they thought it part of the chemotherapy treatment.

Amal and Afrah (breast cancer, 53 years old from Sudan) on the other hand, had a more clear idea about their treatment plan; both of them were going to receive neo-adjuvant treatment and knew that they will receive eight cycles of chemotherapy over six months and that they will undergo surgery followed by radiation therapy for one month, and then hormonal treatment for five years.

For some non breast cancer patients, their treatment plans could not be certain as their treatment depended on their response to the treatment. The testicular, the colon and the lung cancer patients, however, did not know that there was a possibility to change the treatment plan depending on their cancer stage. They only knew that they will have certain chemotherapy doses and then have a test to determine whether the treatment is effective or not. Mustafa (testicular cancer) knew that he was having a surgery and then chemotherapy high dose. He said:

“The doctor informed me that I will have surgery to remove the tumour and then I will get five cycles of chemotherapy. He wrote their names on a piece of paper for me. Then he said that I might get radiation therapy, but I don’t know when.”

Maher (lung cancer) said:

“They told I am getting chemotherapy, but I don’t know how long, or how many times or what is next.”

Later Maher's chemotherapy was changed as there was no response after two cycles of chemotherapy and he received a different type. However, at both stages he could not identify the types of the chemotherapy. At that time he was sure of his treatment plan.

At the diagnostic stage, there were differences between patients' knowledge about their treatment plan. Breast cancer patients and cervical cancer patients had better knowledge at this stage about their treatment plan based on their diagnostic procedures. Other non-breast cancer patients, especially the colon cancer patients, were not clear about the treatment plan. The colon cancer patients in particular were not clear about their treatment plans, could be either because patients interviewed were mostly with lower education level, or because they depended mostly on their relatives. Of course, it may simply have been because possibly they did not receive enough information. In fact, patients such as Balqees and Shaharazad who had person in the family or as a friend as a medical doctor or with past cancer experience were much more aware of their treatment plan.

Those who had earlier experience with cancer with one of their friends or families also showed better knowledge and some showed more ability to cope. For example, Amal, Iman, Badriya, Somaya and Arwa all had previous experience with cancer through one of their relatives or friends, than others without such as experience. Those who had medical background like Mariana and Ghina also displayed better knowledge. However, not all of them were able to cope similarly. Somaya and Arwa felt threatened by the treatment and feared that they will end up like their mothers. Arwa showed fear but used her faith to cope with that fear. She said:

“My mother died of uterine cancer; I know I might die of cancer similarly, but I have strong faith: I believe that no matter what happens this will be my destiny. I am a believer, thank God.”

Somaya was scared and displayed fears and concerns. She said trembling:

“I am really scared, my mother had breast cancer and she is now receiving hormonal treatment after the spread of her disease. I am really afraid of my disease. I have little kids.”

In sum, almost all patients of all cancer types showed different degrees of uncertainties about their expected treatment plan except for the cervical cancer patients who were very clear about their treatment plan, duration and even intensity.

-What patients wanted to know about:

The findings of what patients wanted to know about suggest that patients have a greater need to know earlier about the treatment plan and the expected routine. At the diagnosis stage, most patients wanted to know about their treatment plan in detail, the number of cycles and timeline of their chemotherapy and other treatments.

In general, most of the breast cancer patients were more uncertain about their treatment plans and appeared not to know much about their expected treatment timeline, felt insecure and lost. As a result, they wanted to know more in detail about the treatment plan. Iman said:

“I would have just preferred that the doctor tell me the expected finish time of my treatment and what my whole treatment will be. I feel the picture is not very clear.”

While Balqees said:

“I am not sure what to do because I have a wedding coming up soon, and I am not sure if I will be finished by that then, and whether my hair will regrow. My husband who is a doctor discussed the treatment plan with me, but I feel things are unclear and vague so far.”

At this stage the fear of not being cured from the disease and the possibility of recurrence was one of the major concerns of most patients. What they mostly needed as a result was reassurance and support. Bahiya said:

“I know that ovarian cancer is related to a hormonal problem but I wonder if this is going to be cured.”

Many other patients had similar questions and fears. Amal, Somaya, Arwa and Barira were all in doubt about full recovery and were scared about recurrence; all were expecting that their cancers might strike again.

Both Barira and Farah expressed their plans to pursue alternative medicine and faith healing measures to avoid recurrence. Farah said

“I am planning to go to Jordan to get treatment by a faith healer who has many past successes in treating patients with cancer. I'm not sure about proceeding with the chemotherapy treatment as planned”

Barira also said:

“I contacted a faith healer in Kuwait; I read her books, and I am planning to go to her.”

The findings at this stage suggest that knowing in advance can help relieve fear and anxiety among some patients such as Balqees, Nafisa and Mariana. The findings also imply that there is always fear of recurrence, especially among familial cancer patients, as shown by Arwa and Somaya, and that some patients such as Baira and Farah have lack of trust in contemporary medicine therapies and approaches. .

Most of the patients were told step by step about their treatment plans. For some patients, such as Amal, to inform them slowly and at the right time, was a good strategy. Amal stated:

“I believe that it is better to give the information at the right time not from the beginning. For example, I would rather know about radiation therapy in details when I start the treatment. But I think also that the patient should have brief information at the beginning about the plan and the treatment they will receive, but not in detail.”

In contrast to Amal, most did not mind if they were given information gradually and at the right time. However, for many of the patients there was a preference to know about the *general* plan from the beginning, as small details can be given later. For example Aya said:

“No I prefer to know about everything from the beginning. I would like to feel comfortable and know my whole treatment plan from the beginning.”

Iman and Omayya made similar comments confirming their preferences to know ahead of time.

iv. Sources of information, information seeking behaviour and decision making process at the diagnosis stage

In this section, I present, patients' information seeking behaviours and their involvement in the decision making process, in addition to the sources of information patients have used during the diagnosis stage. As pointed in the literature review, being informed will lead to an informed shared decision making process.

At this diagnostic stage patients were seeking information through their support persons, their health care team, especially their doctors, and through reading from different sources such as books, internet sites and brochures when available. Balqees said:

“My husband who is a medical doctor gave me all the information I need; he sent me articles and websites. He also sent me some scientific papers that are related to my disease”

Patients' information seeking behaviour varied. As her husband was a doctor, Balqees implied that she was in safe hands:

“I don't need to ask anything to anyone, whenever I have a question I ask my husband.”

Balqees did not need to seek information about everything from the beginning as she had her husband as a backup source that she can access whenever she needed. Having a backup was also the case for Shahrazad, Mustafa and other patients who had a relative playing the role of medical source and support person.

On the other hand, Mariana looked for information everywhere. She sent her reports to almost three centres outside UAE, spoke with oncologists in three different countries including the UAE, searched the net, bought books written by oncologist in both Arabic and English and asked all health care team members she encountered. She also read scientific articles and research in regards to many topics, including the oncotype DX test. Her sourcing of a vast and varied amount of information has influenced her treatment plan, and she was involved in the decision making process in all three stages. She said:

“I made the decision about having a lumpectomy after consulting with many doctors, reading articles, papers, books and websites, and after I spoke with the surgeon and the oncologist. They told me it is my decision.”

Mariana was assertive in seeking her information she said:

“I need to know all the details and to get different opinions.”

She continued:

“I consulted different doctors in different parts of the world. I was really scared to remove my whole breast especially that there are different opinions related to my case. Given that I am a medical professional and I know that it depends on the doctors sometimes. I decided to have a lumpectomy after researching everywhere; I read books, and scientific articles, went to conferences and spoke with surgeons.”

In general, patients at this stage depended mostly on surgeons' information, especially patients with no prior knowledge about cancer or prior family history. For example patient Maher, Mustafa, Akram and Bahira all specifically stated that they were depending on their doctors and the health care team to know about their disease, diagnostic procedures and treatment plan.

Patients who had a support person, however, like Balqees, Shahrazad and Faten all ascertained that their support persons will give them the information when needed, in addition to their doctors. While patients with a medical background, such as Mariana, depended mainly on their readings, on asking everyone, and on searching for information themselves. .

Patients Ghina and Nadine decided that they did not want to ask or to find out anything and that they will follow their doctors' advice. Patients, such as Maher, Esra and Aya, whose caregiver was in contact with their health care team depended on their care givers. Other patients like Insaf and Nafisa, Farah and Mayadah felt that the doctors' information was enough and were happy with the treatment plan. As already mentioned above, Nafisa displayed unhappiness about her three surgeries, as mentioned above, and implied that knowledge prior to her surgeries could have helped her make a decision rather than following the doctors' recommendations.

She said:

“I wish I knew from the beginning, this would have saved me the three surgeries and saved me time.”

Finally, patients who had prior family history or who had a family member or a friend who was a cancer survivor depended on their previous knowledge and on the survivors to get the information they needed to make certain decisions. For example, Amal said:

“My best friend had breast cancer last year and I stayed with her throughout her ordeal. Now I tend to talk to her and to recall her experience. She helps me a lot with my decisions. I have changed my diet and my lifestyle as she did.”

Some patients read about their disease, but most felt that there was no need as the doctors provided them with information, especially those who did not speak Arabic and had poor English. English speaking patients said they looked for information from different sources and they asked their doctors for more information about their procedures and treatment. Iman said:

“I read on the net about breast cancer treatment; I asked my surgeon about the type of surgery I was receiving. He explained it to me. I am comfortable with the information given, but I wish there were some booklets here in the hospital that explains about the chemotherapy and hormonal therapy.”

In conclusion to the findings related to the diagnosis stage, almost all patients knew about their diagnosis except for Akram who was not sure if he had cancer. In addition, the radiological procedures, including the instructions they needed to follow, were clear to almost all patients. New diagnostic techniques (specific to breast cancer patients) like the FISH and the oncoprotein tests were not known and were difficult to understand for all breast cancer patients. Moreover, educated patients, younger age patients and female patients knew more about their condition and diagnosis, about stage related information and about diagnostic procedures; they also tried to seek more information from different sources.

While some patients had a certain amount of knowledge, overall, however, there was a lack in the knowledge of most patients, about their disease, prognosis, treatment plan and different

diagnostic procedures. Most of the patients had prior knowledge about cancer as a disease and possible treatment plan, however, their embodied knowledge improved through education given by doctors and the health care team. Some patients on the other hand searched other sources for information as well as depended on reading and asking others like friends, relatives, and ex patients to improve their knowledge.

All patients expressed their need to know more at the diagnosis stage about their condition and their prognosis as well as the diagnostic procedure and treatment plan they needed. . When asked about their conditions most of them could not state their stage and grade, expected treatment plan and possible consequences. Most patients knew about major cancer treatment available but could not specify their designated treatment plan. Patients' fear and uncertainties of their future was apparent among almost all patients at this stage.

b. Treatment Stage

As already mentioned, the treatment stage is the second stage of the cancer patient's journey. At this stage, patients receive different types of treatment and protocols, depending on their cancer type, stage and prognosis. Because patients necessarily receive different types of treatment and protocols, they have different knowledge needs and education needs about their treatment.

Findings on general knowledge and education needs about treatment plan side effects and management are provided below. The topics discussed in the interviews during this stage are: current knowledge and information needs about the different types of treatment, their side effects and management. These treatments discussed, include surgery, chemotherapy, radiation, hormonal and targeted therapy. This section presents the findings about patients' knowledge and the information needs for their treatment, in the order indicated.

i. Knowledge about surgery

Patients who underwent surgeries or were expected to undergo surgery were interviewed about their current knowledge about their specific surgery and about their related unmet information needs. Usually, most cancer patients will undergo surgery within less than two weeks after diagnosis, unless they are scheduled for neo-adjuvant chemotherapy treatment or

radiation therapy. Neo-adjuvant chemotherapy means that the patient will receive chemotherapy first to decrease the tumour size, as radiation therapy, to make it easier for the surgeon to remove the tumour.

Most of the non- breast cancer patients had a surgical removal of the tumour as a first line treatment, except for the lung cancer patient and one of the ovarian cancer patients. Only Afrah and Amal of the breast cancer patients had chemotherapy before the surgery, while the rest had either mastectomy or lumpectomy prior to the chemotherapy or other treatments.

When asked about their surgeries most non-breast cancer patients knew about their surgery plans, except for the patients who were receiving neo-adjuvant chemotherapy because their surgery was not yet scheduled. However, all patients of all cancer types who were receiving neoadjuvant treatment still met their surgeons and were given as much information as possible about the procedure. Moreover, breast cancer patients received information about the possibility for a plastic surgery

- Patients' current knowledge

Patients had some information about their surgeries, types, options and rationale. However, there were big variations between different cancer types. Non-breast cancer patients knew that they had surgeries with certain details, such as size of their excised tumours and whether they had any anastomosis or external openings, such as a colostomy for colon cancer patients. In regards to complications such as infections and the management of these complications, some of patients knew about them and received information about hygiene and wound care, while the rest depended on their spouses and children in this matter.

As stated above by Akram when he stated that he did not know much about his condition as his daughter was taking care of him, he said implying that he depends on his daughter for colostomy care:

“My daughter is the one who is handling my colostomy and she is taking care of me; I don't know if it will be closed or it will remain like this forever.”

Aya also said:

“My doctors in Dubai explained everything to me, in detail. They will give me two cycles of chemotherapy and then I will have surgical removal of my ovaries and uterus. The surgeon explained everything to me here in Tawam the doctor and his team are excellent, they told me not to worry about the operation, you will be fine.”

On the other hand, breast cancer patients had more knowledge about their surgeries; they were more aware of the procedures done and whether they had a lumpectomy or a total mastectomy, lymph nodes removed and the number of lymph nodes that were positive. For example, Nadine said:

“They removed my whole breast and all the nodes because I had more than four positive nodes.”

While Shahrazad said:

“... They removed my whole breast and only two nodes. My nodes were negative; they did not need to remove them. The surgeon was very good; he did a reconstruction at the same time.”

Mariana said:

“... I refused to have a total mastectomy; I asked the doctor to perform a lumpectomy, but I signed an agreement that if he found the margins positive, to undergo a total mastectomy. Thank God, everything went well and he removed only the lump.”

Nafisa was not sure about her surgery and as explained above she was taken to surgery three times and ended up with a total mastectomy and all lymph nodes removal. As noted earlier that she would have preferred to be involved in the decision making in relation to her surgery,, she said:

“I wish I knew from the beginning, this would have saved me the three surgeries and saved me time.”

Most of the patients knew about their surgeries through their doctors, however, breast cancer patients knew more also from readings and from their friends. Amal as well as Barira were

aware that evidence suggests that in their cases a bilateral mastectomy would be better. However, they were not sure whether the double mastectomy would be for prophylaxis. Amal asked all of her friends, read books, asked her surgeons and oncologists about the best choice. However, Barira did not ask anyone, she kept thinking about it herself and said:

“There is time; after I finish my chemotherapy I will think about it.”

In regard to the complications of their surgeries and the implications on their treatment, most patients knew about the possible infection of the wound and the importance of follow up. Everyone was clear about that except for Akram who, as quoted above, was not aware about the closure of his colostomy and whether he has to see his surgeon again.

- What patients wanted to know about:

The most recurrent information patients needed related to surgery were knowing about the results and the success of the surgery. Most of the patients did not express the needs to know much about the details of the operations or possible complications; they just wanted to know the likelihood of success of the surgery and the results afterwards. Also patients were more concerned to avoid the complications and the failure of the surgery as Nafisa implied that she would have preferred to avoid multiple surgeries from the beginning if she knew that a lumpectomy would not be enough. Apart from knowing the results or success of surgery, what did concern some of the patients, who were scheduled for surgery post the chemotherapy treatment, was whether they were making the right decision. Amal and Barira were concerned whether they should go for a prophylactic bilateral mastectomy as an option given to them by the surgeon. Barira had two sisters with breast cancer who underwent mastectomy and treatment. She was scheduled for a lumpectomy but was not sure whether she should go for a bilateral mastectomy prophylactically to protect herself from recurrence. Similarly Amal was worried and wanted to know whether she should go for a bilateral mastectomy as she had grade III carcinoma. Her doctor explained that there is a significant chance of recurrence with similar grades and stages of breast cancer. Both patients asked me to advise them. It was obvious that they were not sure what to do. I had to refer them back to their surgeons and oncologists and encouraged them to read about the risks and benefits of bilateral mastectomy.

Amal's account suggested that she felt confused regarding her decision about surgery because she had conflicting advice:

"I saw the surgeon initially before and had a chat very early when we did not know if I was going to be operated on before chemo. So she already told me a bit about surgery. This time I wanted to know whether I should go for a double mastectomy. I wanted her opinion. She didn't make up my mind for me. I wanted her opinion to know if I have higher risks of recurrence, and what to do. Her opinion is that there is a higher risk for recurrence in the other breast and it will look different to have one breast operated on, and not the other, there will be two different sizes; she showed me photos of her work, of single breast removed and the difference between the two breasts if the other breast is not operated on and how it might affect the shoulders. I asked the oncologist's opinion: he said that it is too radical, while she is more inclined to have both breasts operated on, although but she did not say it, but that is what she meant."

The surgeon provided Amal with the information, giving her the ability to choose the best option for her case. That the surgeon provided Amal with the information led her to seek more information and to ask the opinion of the health care professionals, her family, her friends and other cancer survivors. As mentioned before, her friend who is a survivor had a bilateral mastectomy and advised her to also do it.

Some patients were also concerned about breast reconstruction post mastectomy and whether it was necessary. Generally, breast cancer patients who underwent mastectomy preferred not to go for reconstructive surgery. When asked why, many showed concerns about the complications and the importance of the procedure as they thought it was not necessary for the treatment. That patients thought reconstruction was necessary for the treatment, suggests, they were more concerned about their health and well-being. Cosmetics and looks were possibly the least of their concern for them at the treatment stage. Arwa, Nafisa, Shahrazad, Afrah and Insaf preferred not to go for a breast reconstruction. Insaf and Sharazad believed that there was no need as they are older in age while Nafisa did not want to go for any surgery after her three surgeries. Afrah said that:

"I am scared and I don't want to take the risk."

Amal, Iman and Ghina were not concerned about the reconstruction either. Amal was a bit concerned about the silicon that is usually used, in breast reconstruction. Showing her concern, she said:

“I heard that it can be cancerous.”

When I asked if she spoke about it with her surgeon she replied:

“Yes of course and she told me it is better as it is long lasting, and the risk is very low that it will leak or cause any cancer.” So when I asked her if she decided to have it she replied positively

In general, most of the patients were concerned with the next step post-surgery and the effect on their lives. Only patients who were scheduled for surgery later wanted more information about it such as Aya (Ovarian), and Maher (lung cancer) patient. Aya said:

“The doctors explained everything to me ... but I still would like to know more about my surgery when the time comes.”

Maher was not sure if he would have surgery. He said:

“They told me I will need surgery later on after the chemotherapy, but I am not sure what they will do. I am not sure if they will remove the whole lung.”

Akram was concerned with the colostomy bag and whether the colostomy will be closed later on. He said

“I don’t know if it will be closed or it will remain like this forever. I want to ask my surgeon. I will go back to him after this treatment and I think he will close it for me.”

In regard to the rest of the patients concerns were mainly about the rest of the treatment rather than the surgery itself. The risks and benefits of prophylactic and elective surgeries, such as breast reconstruction were also a concern.

ii. **Knowledge about chemotherapy and targeted therapy**

As the targeted therapy is usually given in combination with the chemotherapy treatment at the start, I decided to join both the chemotherapy and targeted therapy under the same section.

Patients who were going to receive or were already receiving chemotherapy and targeted therapy were interviewed about their knowledge and unmet information needs about chemotherapy. Chemotherapy was given to all study participants in the intravenous form in the hospital. Only two of the colon cancer patients received 5-Fluorouracil (a type of chemotherapy) through a pump at home over five days. 5-Fluorouracil is the initial chemotherapy type usually given in the advanced stages of colon cancer. The targeted therapy treatment was given to only some of the breast cancer patients, who were received Trastuzumab, traded as Herceptin. Trastuzumab is approved for use early stages and with metastatic breast cancer as well as gastric cancer patients (ASC, 2015).

The cycle number, the doses and the types of chemotherapeutic agents given to non-breast cancer patients differed from those given to the breast cancer patients. Breast cancer patients with stages II, III, IV are usually given a common protocol that includes four cycles of Doxorubicin and cyclophosphamide known as A/C, followed by four cycles of Docetaxel known as Taxotere. Those who have positive HER2/neu receptors receive Herceptin with the Docetaxel. Herceptin is given every three weeks with a maximum dose of seventeen cycles. It acts on the HER2/neu receptors and blocks their ability to receive growth signals, which stimulate the breast cancer cell regrowth.

- **Patients' current knowledge**

Most of the patients generally knew about their type of treatment and that it involves chemotherapy, but could not identify names or doses and differences between chemotherapy types and side effects. They reported that they only received brief information about side effects and their management plans, and that it was left to the patient to find out information about the types of chemotherapy and their specific side effects. Overall, patients who had a support person in the family with a medical background were able to identify the types of chemotherapy and had more information about their treatment's side effects, complications

and management. While patients who had a family member with cancer had more knowledge about chemotherapy and how to manage complications, they did not necessarily know about the types, or names of the chemotherapy they were receiving.

Nadine was the only one amongst the interviewed patients who decided that she did not want to know about anything related to the chemotherapy treatment. She said:

“I decided not to find out any information about my chemotherapy and treatment; in general I am happy like this.”

When asked why she did not want to know. She implied that this was better for her and said:

“I was told everything by my doctors in France; I don't want to know more than that.”

When interviewed again at the end of the treatment, she said:

“Everything went ok and I am fine; I didn't have many problems with my chemotherapy.”

For those patients who had knowledge about side effects and their management, it was very general. For example, these patients knew they might develop nausea and that they can use anti-emetic drugs and need to have light meals to control it. Almost everyone except Balqees, also knew that they will have some hair loss and some gastrointestinal effects, such as diarrhea and constipation. However, most patients did not know details, such what to do in case of diarrhea and constipation, while some were given some pills to help if they developed constipation.

Barira said:

“The doctor told me that I may develop constipation and he gave me some pills that I can use.”

Most patients knew that they might have nausea and vomiting as a result of their chemotherapy treatment and knew that the drugs were given to them to treat emesis. However, only Barira and Farah said that they received enough information about the use of

these anti emetics drugs, while the rest claimed that they learnt about it through experience. Barira and Farah both said that they received information from a clinical pharmacist who came to their treatment room and provided them with detailed information about the drugs they were going to use during their treatment. They claimed that she educated them on how to use these medications and when to use them. Both of them said that they also received information about anti-emetic drugs and the mouth wash solution used to prevent mouth ulcers. Barira was given Diazepam to reduce nausea and said that the pharmacist explained its use to her.

When asked about this type of education and whether they felt better, both patients claimed that the clinical pharmacist's education helped them to manage their nausea and vomiting, and that they did not experience any mouth ulcers as they used the medicines as recommended.

The rest of the patients said that they were not visited by the pharmacist and were not given information about the medicine. As a result most of them claimed that they suffered somehow and they would have preferred if they received information on the importance and the use of the medications.

Most of the patients knew that they may develop mouth ulcers but they said that they were not told that they should have used as a prophylactic procedure. Amal said:

“I thought I will use the mouth wash only if I develop mouth ulcers. But my friend told me later to use it even if I don't get mouth ulcers. It helped me in the second cycle

Other patients said that they were given the names of their drugs only. They read about them on their own and were able to state some of the expected side effects.

For example, Balqees said:

“My husband gave me some instructions and told me that I need to keep my immune system strong. He gave me a sheet with the drugs' name and its expected side effects and management. I was shocked to learn that I will lose my hair.”

Most of the patients on the other hand did not know about the management of the side effects, of their treatment in any detail. Amal, for example, did not know that it was better to take the anti-emetic before the nausea starts and that it was better to use the mouth wash to prevent mouth ulcers. The patient claimed that she was told to take them when needed while the recommendation is always to use them as a prophylaxis for the first three days. She said that she learned that she needed to take the anti-emetic before the nausea starts after she suffered at first cycle of her chemotherapy. She stated:

“Last time I had severe nausea and vomiting; after I used the drugs I felt better. Then someone told me that I should use them before I start getting the symptoms. I’ll make sure to use them this time before I start having symptoms -even my husband told me to do that.”

Somaya and Shahrazad also said that they were told that they can take the pills when needed. As Somaya said that she was told to use the pills when needed, she also claimed that she suffered. During the interview, I informed her that she can use them prophylactically. At her third interview, she said that using her anti-emetic drugs from the first day and that the medication has helped her a lot. However, Shahrazad said that she asked her sister who is a doctor and she was told her to use them prophylactically from the first day. Finally, others knew that they have to increase fluid intake during chemotherapy. Farah and Barira said no one told them that they were supposed to increase their fluid intake and they were dehydrated.

In general, most patients of all cancer types did not know the importance of the mouth wash, the high fluid intake and the anti-emetic drugs. Patients with a medical background knew the types of chemotherapy they were receiving, read about them and their possible complications and management. Similarly, those who had a friend or a family member with medical background knew more about their chemotherapy, its side effects and management than other patients.

At this stage most of the breast cancer patients were able to state the number of their chemotherapy cycles and some of the possible complications and their management. Knowledge among the non-breast cancer patients however differed from one patient to another.

Cervical cancer patients knew almost in details about their chemotherapy treatment and about expected complications and management. Ovarian cancer patients also were clear about their chemotherapy plans, except for Aya who was receiving neo-adjuvant chemotherapy. She was not sure about her plan because it depended on her response to chemotherapy. She said:

“I am not sure how many cycles of chemotherapy I am going to have because it depends on my response ... He is giving me two drugs; I don't know their types exactly, but he told me I might receive six cycles.”

After the discussion with the patient she asked her nurse about the drugs she is taking. She wrote their names and said:

“I am going to read about these two drugs next time ...”

On the second interview, the patient was asked whether she read about the drugs. She stated that she had and asked about some of the possible side effects she had read about. After a discussion on the side effects of chemotherapy and their management the patient said:

“It's better if patients receive more information about their medications. I prefer to know and to get more education...”

Akram did not know what to ask about his condition and or treatment. He did not know that his new treatment will cause severe side effects. When asked, he said:

“Yes the doctor said that I might get nausea and vomiting like I got with the thing they gave me last month at home. They told me I should drink warm water and have my medicine...”

When asked whether he was told about other side effects like diarrhea and mouth ulcers. He similarly said:

“... I had mouth ulcers and diarrhea last time. The doctor did not say that it will happen this time. Maybe he told my daughter.”

As he depended on his daughter, Akram did not know what to ask for He did not show any fear or anxiety; on the contrary, he was a relaxed and content patient who showed acceptance of his illness and strong faith that he will be well.

The three cervical cancer patients (Mayada, Lina and Omayya) knew almost all major side effects of their treatment, such as diarrhea, nausea and fever and were well informed about how to manage them. Only Mayada was confused about diarrhea being a side effect of her treatment, as she thought that it was because she ate something contaminated. .

Mayada said:

“I have diarrhea. I am using Flagyl.”

When asked why she was using Flagyl and whether it was as per her doctor’s advice she said:

“No, I ate from a restaurant and I believe it caused my diarrhea, so I bought Flagyl and I used it, and I am feeling better.”

Mayada knew that concurrent chemotherapy and radiation therapy can cause diarrhea, however, she did not go back to her doctor and health care team for advice. When asked why she did not talk to her doctor and consult with the health care team she said:

“I don’t know, I thought because I ate food from a restaurant. I did not think it was related to my treatment.”

When prompted why she did not relate the diarrhea to her treatment, although she knew that this was a complication of her treatment, she said:

“No, I didn't think there was a need.”

When asked whether she knew that radiation therapy can cause diarrhea she said:

“Yes.”

Mustafa (testicular cancer) knew about possible side effects from his doctor, his cousin and from reading. He said:

“I was told to use mouthwash to prevent mouth ulcers; I used it and it worked very well. Also I used the anti-nausea medication and I didn't experience lots of nausea and vomiting. It's going well ... Also I knew that if I get fever I should call my doctor; it happened many times to me and I had to go to the hospital..... It was because my immunity was low.”

Maher (lung cancer) said

“I know that I might get fever and I might get nausea. I'm ok, I have a report with me; if I go back to Oman I can go to the hospital if anything happens.”

He did not feel that he needed to know anything more than he might be fever and nausea He said:

“The doctor told me everything, I have a report...”

All patients were told that if they develop fever they should go to the nearest hospital, but when asked about the rationale most of them did not know why or when fever might develop. Some knew that it was related to the effects of chemotherapy on their immunity but could not specify the meaning of immunity or what might happen.

Barira who has sickle cell anemia, said at her second interview that she had to receive a blood transfusion but she did not relate that to her chemotherapy. She thought that she needed blood because of her sickle cell anemia. When asked whether she developed fever or low immunity she said:

“I don't think so, I have sickle cell anemia and I usually have blood transfusions.”

When asked whether she has received any information about the effects of her treatment on her existing condition. She said:

“No”

It was noted also that patients who suffered from other chronic diseases, such as diabetes and hypertension, stated that they did not receive any information about the possible complications and effects of chemotherapy on their existing condition. Patients who were receiving corticosteroid pills and who had diabetes or hypertension could not state that they received any education about the management of their condition or about the importance to follow up with their treating doctor.

Both Bahiya and Maher had diabetes. Also Sara (colon cancer 64 years from Pakistan) and Isra (rectal cancer, 63 years old from Pakistan) had hypertension.

When asked, whether anyone gave her instruction or whether she knew that chemotherapy can affect blood sugar level, Bahiya replied:

“No, I was not given any information about diabetes here in the hospital, but I have been diabetic for long, I know how to manage it.”

I then advised her to discuss the matter with her diabetes managing doctor.

All of the colon cancer patients were supposed to receive their first chemotherapy cycle of Fluorouracil via a pump at home for 5 days and then they were scheduled to receive the rest of the six cycles (Oxaliplatin) in the hospital. Most of these patients knew they were receiving chemotherapy at home but did not know about the plan in detail and did not know the difference between the two types of chemotherapy. Also they did not know why the first chemotherapy was given to them through different routes and at home rather than in the hospital. For them, all cycles were chemotherapy, without any difference. Haleema said:

“I have to have the drug at home, I'll come on Tuesday, and they'll explain to me about the pump. Then I will come back to the hospital to continue with the treatment. I don't know the difference...”

Akram said:

“I was given medicine at home, they gave me a pump, and they told me to come to the hospital to continue my treatment. I don't know what this is and what they gave me before.”

From his comment, it appeared that Akram did not even identify the two types of treatments as chemotherapy.

These findings suggest that most patients had limited knowledge about their chemotherapy, side effects and management, especially at the beginning of their treatment. Most of them were not aware of what they should expect and what to do in case they develop any side effects. The findings also suggest that there are some misconceptions and misunderstandings, such as chemotherapy might cause finger and toe nails to fall off permanently, or for some patients they did not know that they might lose their hair while the rest knew very brief information about the general side effects such as nausea, vomiting, lethargy, hair loss, mouth ulcers, fever and possible constipation. As for their understanding of the management of the

side effects of the various forms of chemotherapy, they mostly knew that they have anti-emetics pills, in case they have severe vomiting, or fever, and that for any other side effects they can contact their doctor or go to the closest clinic. They also knew that any hair loss was temporary and that they do not need to worry.

Most patients when interviewed for the second or the third time showed enhanced knowledge about the side effects. Their knowledge about the side effects and how they can manage them was improved. Those patients that did not know about how to use for example the mouthwash to reduce side effects they said that they learned by the second or third cycle. Similarly, some patients said that after their bad experience with nausea and vomiting in the first cycle they learned that it is better to start taking their medicine prophylactically prior to having symptoms. Also other patients had learned that they have to use the mouthwash beforehand and did not develop any further ulcers. Out of all patients whose knowledge had improved some learnt through experience, while others were either advised by other patients or by their support person. The rest read about chemotherapy in general and about their drugs specifically and tried to follow instructions.

Of those patients that received the targeted therapy Herceptin, mentioned above, none of them knew the type of the targeted therapy given to them; all that they knew was that there is “a smart injection” as they all referred to it, they will receive in the second half of their chemotherapy treatment: They did not know why it is used, or its side effects. However, some knew that they are receiving it every three weeks for almost one year, while the rest did not know when they receive it and for how long.

- What patients wanted to know about:

Generally, there was a high need to know about chemotherapy and targeted therapy short term and long term complications, management and prevention. Not enough education was provided by doctors and health care providers about chemotherapy, its side effects and management. As mentioned above, patients with higher education had more knowledge about complications and management, while those who had a support person showed better knowledge about chemotherapy and less fear of its potential complications

Most patients said they were given very brief information, rather than details about their chemotherapy and its possible side effects. Nevertheless, some of them were relaxed and felt that they can get back to their doctors at any time if they have any side effects, and that they have the chance to ask what to do if they had any problem. On the other hand, some of them felt anxious because they did not know what to expect, and implied that they would prefer to receive more information about the possible complications.

At the second stage of the cancer journey most patients wanted to learn more about their treatment side effects and management. They wanted to know more about the short term side effects and how to alleviate any symptoms resulting from that treatment. For example patients receiving chemotherapy wanted to know more about how to relieve nausea and vomiting symptoms, how to improve their appetite, what to take in case they had headache, body or joint aches.

Somaya, when asked about her diet and her headache, said:

“I had severe headache last week and I didn't know what to take. Also I didn't use the mouth wash; I had some mouth ulcers. Because, I didn't know that I should use it to prevent mouth ulcers. I didn't know what to eat and what to drink. I used the medicine they gave me but I didn't know how to prevent my nausea.”

While Amal said:

“Also I would like to know what to eat and what to avoid. I read that milk products and meat and sugars can cause cancer; I stopped eating dairy products. I am using Soy milk and Almond milk. I am following a diet suggested by the China study. I'll send it to you by email. I'm only buying organic foods; I even changed my family diet. I believe this is better”

Even the cervical cancer patients who were more satisfied with the knowledge they had at the diagnosis stage they felt that they needed more information about treatment side effects, prevention and management. They especially wanted to know about diarrhea management and how to deal with fatigue. For example, Mayada said;

“... I had diarrhea last week and I think it was because I ate from a restaurant and I must have contracted some germ. I am using Flagyl (I bought it from the pharmacy

without prescription ... I'm sure it's not from my treatment I'm not sure about the cause of this diarrhea. I would like to know what's next."

In regard to patients' educational needs at the treatment stage, for some patients it included needing more information about their options to be involved in decision making for their treatment. Their educational needs included more detailed knowledge and information about the treatment stage, the expected plan, the name and types of the treatment. At this stage patients also needed to have a clear idea about the next step and what is the expected outcome. For example, Lina said:

"I have received education about my treatment from the doctors but I'm still not sure whether I will receive more treatment or what I should do in case I have side effects like diarrhea. ... I'm having diarrhea but I'm eating everything ... No one told me to stop eating any foods"

Another cervical cancer patient, Omayya, was more concerned about her social problems and her conflict with her employer, who is asking her to show up to work daily even that she knows she is getting treatment daily. Omayya (cervical Cancer from Philippines) said:

"I don't know what to do I am tired I cannot go to work and my employer is threatening me that she can terminate my job if I don't come to work everyday...I gave her a sick leave report but she still wants me to come... I'm concerned about my condition if I go to work. I am tired..."

Arwa (ovarian Cancer from Philippines):

"I'm fine and I know everything and the doctors have given me all the information I need about my condition and my treatment. My only concern is if I will get treated and whether I will be cured. But I have faith in God and my husband is very supportive. I feel in safe hands."

Turning again to the targeted therapy patients, when asked most, what these patients most wanted to know was what targeted therapy means, its side effects and the difference between this treatment and chemotherapy. Before asking them they did not show any concerns about knowing about targeted therapy and what it means. However, when asked during the

interview and prompted about what a smart injection does, most patients showed some interest to know about it and why it is given. Insaf said:

“... I know that I'm receiving chemotherapy and a smart injection.”

Upon asking her about what she knew about smart injection, she said:

” I am not sure what is it is and why it is given. I had some complications last time I received chemotherapy and I'm not sure if the smart injection has worsened it.”

After probing her about whether she knew why it is given, and what the doctor told her about it, she said:

“This is what the doctor told me: it is a smart injection and it will help fight the cancer and I need it. I'll take it every three weeks for nearly nine months. So tell me what is it and why it is given to me. Does it mean that my case is worse than other cancer patients?”

Similarly, Nafisa said:

“The doctor told me I'm going to receive a smart injection. Honestly I don't know why and what it's for. Can you explain to me? Does it cause any side effects like the chemotherapy I'm having?”

During the treatment stage, some patients were concerned about the long term effects of chemotherapy. They wanted to know more about whether the hair will regrow normally, whether their immune system will be damaged by the chemotherapy permanently, and whether the chemotherapy itself might cause secondary cancer. Balqees asked:

“Will my hair regrows like before? Is it going to be permanent?”

She also said:

” I'm using some honey from the pharmacy; they told me it will strengthen my immune system and it will fight the effects of the chemotherapy. Do you think I should I continue on that after the treatment?”

It is important to note that as I have background in cancer education I had to respect my nursing oath and when I was asked, I was required to reinforce to patients the importance of drinking fluids, to use mouth wash regularly and to avoid a high fat diet. I also had to

instruct patients to refer to their doctors in case of fever, fatigue, bleeding or other concerns. I encouraged all patients to ask their doctors and to find out for more information to avoid complications.

iii. **Knowledge about radiation therapy**

Not all breast cancer patients were having radiation therapy at the treatment stage time of the interviews except for four patients out of seventeen who finished their surgery and chemotherapy. Patients with cervical, ovarian and testicular cancer were receiving radiation therapy. One of the colon cancer patients received their radiation with chemotherapy before the surgery, while, the other was not scheduled for radiation treatment, and so was not interviewed. As with one of the colon cancer patients, the rectal cancer patient received radiation treatment with chemotherapy, while the ovarian cancer patient was scheduled for radiation post her chemotherapy.

-Patients' current knowledge

Those who were receiving radiation therapy or who were scheduled to receive radiation therapy showed strong knowledge about the treatment type, cycle and dose and the expected side effects and management.

The cervical cancer patients all were comfortable with the knowledge they had about radiation therapy. As they were receiving concurrent treatment with chemotherapy, they were seeing their radiation therapy doctors and the oncologist regularly. This management plan enables patients to discuss their concerns with their doctors regularly. Only Mayada as mentioned above had diarrhea and thought that it could be that she ate something unclean.

The patient knew that diarrhea is a complication of radiation therapy yet she decided not to seek treatment. This raises concerns about whether the patient was not sure about her knowledge and information given or whether it was a matter of non-compliance.

Some of the patients who were scheduled to receive radiation therapy later on, preferred not to know about it until the time of the treatment comes like Amal who said:

“I think it is too early to know about it now.”

Also Barira said:

“They told me they will give me radiation therapy after I finish my chemotherapy, I will ask about it when the time comes.”

Other patients preferred to know about it before hand like Somaya who was very anxious from the beginning of the interviews. She said;

“Is it going to burn me? Is it painful, is it like chemotherapy?”

The patient was concerned about the effects of the radiation therapy.

Mariana who was receiving radiation said:

“I was given instructions and I am doing fine. It burns slightly. You know, a staff is preparing a patient education booklet in the radiation therapy department. She gave it to me to read it and to give m her opinion. I am impressed.”

Cervical cancer patients were the most knowledgeable about radiation therapy rationale, protocol, side effects and management. Breast cancer patients knew that it might cause skin sensitivity and irritation. While the rest of the patients showed less knowledge and learnt by experience. So patients’ knowledge varied between being aware of plan and side effects and management. Patients overall did not worry much about radiation therapy possible because of prior knowledge or because it was not their concern at the time of the interview.

- What patients wanted to know about:

There was a high need to know about complications and management of radiation therapy

When asked what they wanted to know about radiation therapy, patients said that they would like to know whether it hurts or it might cause severe side effects. Bahiya wanted to know why she should take it as long she is getting eight cycles of chemotherapy and then surgery.

She said:

“Why is radiation needed? I heard that some patients do not get it.”

So there were more concerns about side effects and rationale but it was not a major concern for most patients. Nadine also did not want to know about it. While Mustafa was concerned

whether the radiation therapy was going to be effective with his cancer especially that his tumour markers were still elevated after he took five cycles of high dose chemotherapy.

So in general those who were receiving radiation therapy were concerned more about the short term side effects. For example, Mariana was concerned about the effect on the skin and the redness, however, she asked her doctor and she was given some cream that helped her. Instructions were given to her in details even she was asked to review an education booklet that the radiation therapy department was preparing for the patient education. She gave them her feedback and felt very happy that she reviewed it. Patients who were receiving radiation therapy were the only patients who stated that they received written educational handout from their team that included expected side effects and management tips.

iv. Knowledge about hormonal treatment

Only breast cancer patients were receiving hormonal therapy but not all of them were scheduled to receive hormone as some of them were estrogen and progesterone receptors negative. This meant that hormonal therapy was not going to be effective in their cases.

Three of the interviewed cancer patients were put on hormonal therapy directly after the surgery. One of them received radiation therapy and the other two received directly hormonal therapy. While ten out of the rest of the patients were supposed to receive hormonal treatment post their radiation treatment. Patients were not again concerned with hormonal therapy.

- Patients' current knowledge

When asked about it most of the patients who were not yet receiving the hormonal therapy did not know much about it except that they will receive it later. Those who were started on the hormonal therapy were able to state the name of the drug used and the period they will use it for. However, when asked about whether it has any complications, they could not state any except for Mariana who was experiencing headaches and dry mouth as a result of the Tamoxifen. Mariana said that she went back to her doctor twice asking him to change it for her. She said:

“He kept reassuring me that I will get used to it. He did not change it.”

The patient at the last interview stated that she got used to it and to the pain. Some of the patients believed that their doctors will tell them about it when the times come, so this was not a concern for them. The rest had very limited information about the expected hormonal therapy. Their knowledge was built either on previous encounter with patients receiving hormonal therapy or from previous readings. For example, almost everyone knew that they will take it for five years. However, a new drug like Femara which is given for three years was not known information. Some of the patients stated that osteoporosis is a side effect of hormonal therapy but could not identify which type of hormonal drugs that may cause osteoporosis.

- What patients wanted to know about:

There was a high need to know about hormonal therapy side effects and management

Mariana who is receiving Tamoxifen after she took radiation therapy said:

“I have been having migraine and dry mouth since I started the Tamoxifen; I went back to the doctor and asked him whether he can change it for me to another drug. He said that this is side effects of Tamoxifen and that it will ease after a while..... I don't know if I can continue with it for another five years.... I would like to know if there are any alternatives and if I stop it what will happen...”

Afaf said:

“The doctor told me that I need to take Tamoxifen as part of my treatment as there is no need for chemotherapy and radiation therapy. I am fine with that....I read about it, my concern that it will cause for me early menopause. It is ok... The doctor explained to me about it. But what will happen after I finish the five years.... Would there be any other treatment???”

Amal who was supposed to have hormonal therapy after the chemotherapy and surgery said:

“I am not concerned about hormonal therapy, when I will start taking it I am sure the doctor will explain to me. My friend is taking it and she is ok. I know that I am taking it because my cancer is hormone positive. I guess I will ask more when time comes.”

Similarly to Amal, Iman and Shahrazad did not show much interest to know about the hormone.

Iman said:

“My friend is taking hormone and she said there are no side effects, it is used for protection to prevent recurrence.”

While Shahrazad said:

“My sister told me that she will tell me everything about it after I finish my radiation treatment.”

Similarly, Balqees said that she will ask her husband about it as definitely he will explain to her when the time comes.

So patients who had a support person with medical background were more relaxed and felt that their support person will explain to them when it is needed.

The use of hormonal therapy was regarded by some patients as an insurance tag used to prevent recurrence. Similarly for the targeted therapy it was regarded by patients as being a drug that will help concur the disease and prevent recurrence. Therefore, there was not much concerns form most of the patients about both type of therapies. The most important concerns at this stage were chemotherapy and its side effects and how it affects lifestyle and quality of life. Most patients were concerned about how to cope and deal with this stage rather than long term effects.

v. Sources of information, information seeking behaviour and decision making process at the treatment stage

At this stage, many of the patients were also getting their information from their doctors, health care team, readings, support persons and survivors as well as other patients in the hospital. Information seeking behaviours differed from one patient to another, some felt they needed to know details about their treatment, side effects and management others felt satisfied and vocalised that not knowing make them more comfortable like patient Nadine and Isra.

Some patients were not happy with the information given to them which have encouraged them to seek information from other sources like Amal, Awatef and Mariana. Other patients

like Insaf who was busy with her social problems and with side effects that she was not concerned to look for any information. Patients whose language was not Arabic or English also were not asking more and not looking for much information possibly because of the language barrier. Some of them like Lina said that she ready some information in her language as well as Aya. Malak was very distressed crying most of the times, had language difficulties and had no relatives or support in UAE did not show concerns to know about her treatment and side effects. Her main concern was when to finish her treatment and what will happen after she finishes. She said:

“I am afraid that they will send me back to Philippines after I finish my treatment. I have children who depend on me there, I have to raise them.”

At this stage, involvement in decision making was not very strong among most patients. Most Patients accepted the treatment plans except for few.

Mariana, Barira and Amal were the patients who stated that their knowledge have allowed them to make a decision about their treatment. Nafisa regretted no knowing and showed her distress about her lack of knowledge as it has affected her treatment plan.

The rest of the patients did not show any involvement in any decision making related to their treatments. All of these patients have shown acceptance of the specified treatment plans as per their doctors’ decisions. These patients did not show any dissatisfaction and were mostly comfortable with their doctors’ decisions and with their treatment plans. There were some concerns by some patients that they did not receive enough information about possible side effects and management. Some like Amal, Iman and Somaya have stated that knowing about the management of side effects in more details might have been more helpful for them in the coping process.

Cultural and religious beliefs, language, social conditions, physical condition, family history, age and education were important factors that have impacted on the patients seeking behaviours at this stage. Also the presence of a support person or survivor being a source of information was an important factor that affected patients’ knowledge seeking behaviours. Some patients have shown total acceptance of the disease that have impacted on their seeking

knowledge for example Isra, Sara, Hajar and Akram all have displayed acceptance of their conditions and felt no need to know more. Arwa, Barira and Bahiya have made remarks that they believe in God's plans and destiny and they accept everything. They did not show much enthusiasm to know noting that whatever happens is God's will. Even Nafisa who was discontent with her surgery outcomes, she showed later full acceptance of the doctors decisions and God's will.

Finally, patients whose side effects were worse than others have displayed more need to know about side effects and displayed dissatisfaction with information they received. These patients looked for more sources of information when they started having side effects like Iman, Amal and Mariana.

In conclusion, the findings of this study have shown that there was more knowledge among most patients at this stage in comparison to the diagnosis stage. Patients were more aware about their treatment plan, types, cycles or length, implications about possible side effects and their management. However, most knowledge was very shallow and there was rarely profound knowledge of these patients at this stage. Again there were factors that affected this knowledge. Although they had better knowledge at this stage but most of the patients lacked detailed knowledge about the treatment, side effects, complications and management.

c. Follow up/ recovery stage

The recovery stage or the follow up stage is the third stage of the cancer journey that represents the end of the treatment and the start of the follow-up plan and the recovery path. The following section present the findings of the knowledge and the information needs of the patients interviewed at this stage. The topics included in this section are the follow up plans, recurrence and prognosis, prevention and survival.

i. Knowledge about follow up plans

Most of the patients interviewed were anxious about their follow up plan, the routine and the expected changes to their life. Almost all patients expressed their needs to know about their future plans and possible prognosis. There was lots of information needs and most patients expressed clearly that they did not know much about this stage.

- Patients' current knowledge

Most patients could not identify clearly what will happen after they finished their treatment. Some of them knew that after they will finish their treatment there will be regular follow up with their doctors as well as blood and radiological check-ups, however, it was more general knowledge rather than details. They could not specify what kind of check-ups or how many follow ups will be with the doctor. For breast cancer patients they were clearer about the timeframe of their treatment similarly to some of the non breast cancer patients like the cervical cancer patients and the ovarian. However, for the rest of the non breast cancer patients the treatment plan and time frame were unclear. This poor knowledge can be explained by the fact that their treatment plan depended on their response to the treatment or because the patients were not aware of it due to lack of education from the health care team side or lack of concentration from the patients' side.

Almost all patients stated that they did not know what will happen after they finish their treatment. In fact the concerns of most of the patients was at the stage of the treatment was their present rather than the future. When the patients arrived to the stage of the follow up and recovery there was sort of darkness and unknown future. Most patients did not know what to expect at this stage and what will happen. So when Iman was asked so what will happen next? She said:

"I don't know I guess I will wait for my appointments."

-What patients wanted to know about:

Some of the patients wanted to know about their future plans and what will they do if they leave the country and what sort of follow up they need. Those who had a support person felt more relaxed and did not feel that they need to know about the future plans. Also, Emirati patients did not show any concern about their follow up as much as they showed concern about their prognosis and the treatment success. Patients like Mariana who did not have a stable job and who was planning to leave the country was concerned about this issue. She said:

"I am not sure what to do I guess if I go to Canada I will follow up there but at this stage I am not sure about my future."

So her concern was more related to her social circumstances.

Nadine, who tried to shut down all sources of information and who tried to show no interest in learning or knowing about her treatment, showed unexpectedly an interest in knowing about the routine of follow up She said:

“I would like to know what the next step is.”

Also Amal was concerned that she might not be told about the follow up routine like at the beginning of her treatment.

She said:

“Ummmmm..... I will make sure to ask this time about my follow up schedule and checkups...laugh.”

So in general at this stage the routine and the follow up and what will happen with their treatment plan were the most important concerns.

ii. Knowledge about prognosis, recurrence and survival:

Also most of the patients have shown some uncertainty about their future prognosis and whether they were cured or not. Recurrence was always a concern for most of the patients even if the doctor has told them that they were going to be fine.

- Patients' current knowledge

Most of the patients whether they were breast cancer or non- breast cancer were uncertain about their prognosis. Most of them did not know about their future prognosis and were concerned about the effectiveness of their treatment. Even the cervical cancer patients, who seemed to have more knowledge and were more comfortable throughout their treatment with the education they received and the knowledge they had, when they were asked about their future and about the next step they all vocalised their fears and concerns about the effectiveness of the treatment they received as well as the future of their disease. All patients were concerned about future recurrence. Almost everyone knew that there is a chance of recurrence and that their treatment measures are taken to prevent recurrence, except for Maher who did not know much about his disease and was not concerned much about the future. This patient did not specify any information and did not show any knowledge about recurrence and future prognosis and at the same time did not show any interest.

Insaf who was admitted toward the end for possible metastasis knew that there were possibility of recurrence but could not have any knowledge about her prognosis. At that time she was concerned about her children's welfare if anything happen to her especially that she had lots of social and economic problems. The patient was not clear about the metastasis, she believed until the end that she was going to be fine. She did not know the extent of her condition.

She said when she was admitted for investigation:

“The doctor told me that there could be something in the lung they will take me to X-Ray today. He said if there is anything we will think then about it.....”

The patient was anxious and in fear but it was clear that she had hope. Unfortunately, this patient passed away couple of days later. Patients' knowledge about prognosis and possible recurrence lead them to make decisions that are not really common. Amal was concerned with her quality of life and about the best preventive measures; however, she stated her concerns on whether the disease can recur. She said:

“The doctor told me that I have a bigger chance for recurrence due to the type of my disease I decided to go for bilateral mastectomy as a prophylactic procedure...”

Patient Barira also said:

“I have higher chance to have recurrence as you know..... My cancer is genetic, so the doctor told me to consider bilateral mastectomy, I am considering it....”

While Mariana was given the chance to decide to take chemotherapy or not, she decided not to take after her doctor explained to her that her cancer is not aggressive and that her onco-type was not high. Though, knowing that there is a lower chance for recurrence she decided not to go for chemotherapy. However, at different times, Mariana expressed her fears of recurrence.

- **What patients wanted to know about**

So almost all patients were concerned about their future prognosis about their future life, whether they will live or whether they will die because of their disease. Most patients when asked about their future showed concerns about what will happen and they would like to know if they will survive.

For example, Aya said:

“My only concern is whether I will get rid of the cancer cells from my body.”

Also, Bahiya said:

“I want to know whether the treatment will prevent recurrence of the disease.”

While Haleema said:

“I would like to know if I will be cured.”

Balqees and other patients also showed their concerns. Mustafa was afraid of his elevated tumour markers and the tumour that was not extracted due to its location. Mustafa kept asking what will happen if my tumour markers got elevated again and what will happen if the tumour that was treated with chemotherapy and radiation therapy regrows. So the patient had unclear vision of the future of his condition and said:

“I can understand that I might not be cured at all and I am going to live my life like any normal person but I know that it will recur. I don't know then what will happen and whether they will give me chemotherapy again because my doctor said that he gave me the full dose.”

iii. **Knowledge about prevention**

Similar to the above two category of knowledge, patients were anxious and uncertain about the best way to be healthy and possibly to prevent recurrence.

- **Patients' current knowledge**

Some of the patients searched about preventive measures to prevent recurrence. These patients read about diet and exercise and the use of certain herbs to prevent recurrence. When some asked their doctors they were told to just try to maintain a healthy diet and exercise regularly only. However, few of the patients read more about prevention, some asked their friends who are survivors or asked their support persons who advised them about diet.

Balqees was told by her friends who are doctors to take certain honey that she is buying from a pharmacy, while Amal read about certain studies and about macrobiotics that uses diet to prevent cancer.

She said:

“I changed my family diet, we stopped drinking cow’s milk I am using Almond milk..... We are following a vegetarian diet, only organic....” “My husband and my daughter are fine with it they got used to it....”

Barira was advised by her relatives to go for a spiritual healer. She was told there is a good healer in Kuwait. She contacted her and she has shown a belief that the healer will cure her disease and will prevent recurrence. She said:

“The spiritual healer told me to have black seed and honey drink daily as this will prevent cancer, in addition to reading certain verses from the Quran, I am planning to go to her....”.

- What patients wanted to know about

Most breast cancer patients asked about preventive measures and what to do to prevent recurrence and if there is any need to change their lifestyle and their current practices. Most patients asked about during the interviews about preventive measures however, when asked if they discussed it with their physicians none of them mentioned they did except for Amal who said that she asked her doctor about milk products and animal fat and proteins and their relations with cancer. She said:

“He told me it is up to me and that there are no studies that back up these claims...”

While Balqees discussed it with her husband who is a doctor and she decided to use honey. Nadine refused to discuss it and she felt that she is happy with her life and that she will not look for any preventive measure.

Interestingly only breast cancer patients decided to change their diet and lifestyle while the rest of the non-breast cancer patients even they showed concerns about their future life and prognosis and lifestyle changes but none of them changes their lifestyle or read about dietary changes and cancer prevention. Even they did not show any interests in knowing about any preventive measures.

During this stage, most patients showed poor knowledge. This stage was very mysterious and uncertain for most of patients. At this stage patients either knew or needed to know about their follow up plan, expected prognosis, the expected quality of life and if they need to know about any lifestyle changes and preventive measures.

Most patients knew about their follow up plan in general, however, most of them as well needed to know about the possibility of remission and full recovery, their prognosis and the chances of recurrence. Also there was a need to know about the occurrence of other cancers and the best options for prevention. Patients wanted to know about whether there is a need to change their lifestyle.

iv. Sources of information, information seeking behaviour and decision making process at the recovery/follow up stage

At this stage patients were looking for information from other sources than the doctor and the health care team. Many were reading from the internet and books that give information about prevention. Some patients specified that they used some different dietary methods as a way of prevention. Amal was looking for studies related to diet and decided to follow the macrobiotics diet. Barira was looking for more information on prevention that were adopted by the Emirati culture. She was still convinced that she has to go for a faith healer to help her recover.

Somaya and Arwa mentioned that they were using Ruqya (verses from the Quran) and drinking holy Zamzam water (Holy water that comes from Mecca in Saudi Arabia) as measures of prevention. Other patients like Mustafa decided not to smoke again and to change his lifestyle. Others have indicated that they accepted their doctors who advised to go to their normal diet and lifestyle.

At this stage the fear of the future and the recurrence indicate that this was an important factor for seeking knowledge and to learn more. Patients' stage and condition was also an important factor. Patients who were suffering from fatigue and lethargy had less concerns and

less enthusiasm to know more. They were more concerned about dealing with current conditions like Isra, Sara, Somaya and Insaf.

3. Knowledge transition and information needs transitions throughout the three stages.

The second objective of this study was to describe the knowledge and the information needs transition of cancer patients throughout the cancer journey. This section summarises the information needs transition throughout the three stages based on the above described findings. The journey started with high information needs and limited current knowledge among most patients at the diagnosis stage. Patients needed to know more about almost everything: disease, cause, diagnostic plans, procedures and implications, prognosis, and treatment plan. These needs kept increasing with the moving of the patients throughout the diagnosis stage, as they kept having unanswered questions. Towards the end of the diagnosis stage, the information needs kept increasing in a constant way and continued to be high until the next stage (treatment) during which more information needs emerged. The information needs about different treatment modalities increased with the start of the treatment phase and continued to rise. The information needs fluctuated among patients who received more than one type of treatment or different types of the same treatment, and increased every time there was an introduction of a new treatment. There was a peak of information needs for treatment options, side effects and management that decreased toward the end of the treatment stage. The follow up stage and the future plans remained vague for all patients throughout the journey and until the last stage. During the follow-up stage, information needs remained high among all patients, especially, about survival and recurrence topics. Throughout all the three stages, there was high information needs about specific topics.

Figure.5 explains the fluctuation and the change in the information needs of the patients during their journey. The journey started with high information needs at the diagnosis stage that remained high with the start of the treatment stage. At the treatment stage the fluctuation started and depended on treatment types, plan, and routine changes. At the beginning of every type of treatment there was an increase in information needs. At this stage, there was high information need about long term side effects of treatment received and/or maintenance treatments, such as hormonal therapy. The information needs then decreased toward the end

of the treatment as the patient learned more with more experience. Then it was followed by an immediate increase in the information needs about the future plan, the follow-up process and the prognosis of the disease. The information needs at the follow up stage did not drop as there was always the fear of recurrence and the need to know about preventive measures.

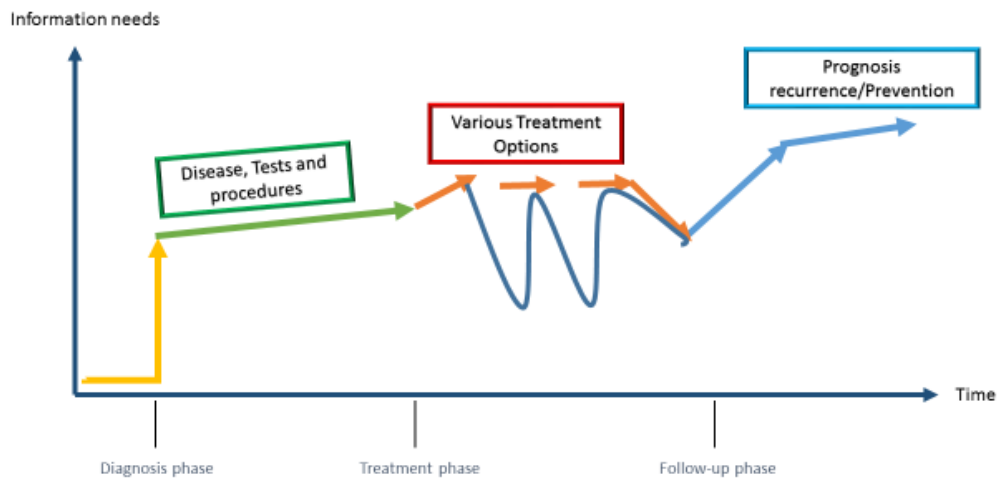


Figure 5. Illustration of knowledge transition and fluctuation between the three stages.

This study has identified different sources of information from which patients have searched information. These sources included, the direct one to one education from the health care team, survivors from social connections or through formal support groups, support figure who is a relative or a friend with medical background, internet, magazines and journals, scientific books and articles, educational booklets, posters and videos distributed or displayed in hospitals. As for sources of information used throughout the cancer journey, direct education and information given by health care professionals mainly doctors and nurses was the most commonly used followed by the information given by a support persons from family and friends (who comes either from medical background or is himself or herself a survivor).

The patients were asked whether they read about cancer when they were told that they have cancer or potentially they have cancer. Throughout the first two stages patients confirmed that they have done some readings and they have asked their family and friends who had a past cancer experience or have medical or other health professional qualifications.

Mariana's account (breast cancer, 54 years old from Lebanon) illustrates this:

"You know I have medical qualifications and I have worked in the health field for more than twenty five years so I directly went back to my resources, books and to my acquaintances. I read a book by one of the well -known surgeons in my country."

In addition, Balqees (Breast cancer 58 years old from India) said:

"My husband is a doctor, he explained to me a lot of things and then he gave me some articles and reading materials to know more."

Amal (breast cancer, 47 years from Australia) and Iman (breast cancer, 52 years from Scotland) also confirmed reading over the internet about cancer. However, some patients were not interested to read and they felt satisfied with the information they were given, like Bahiya (Ovarian cancer, 67 years old from Iraq) who said:

"I was given enough information about my disease I don't think I need to look for more information."

Others stated that they had could not read because of different reasons, like Omayya (cervical cancer, 43 years old from Philippines) who had no internet access to read as she said:

"I don't have time to read as I have to go to work daily and you know I don't have internet at home"

Almost all patients confirmed that they have received some sort of education from the health care team. Only three breast cancer patients have stated that they were given written educational materials from the hospital. Only cervical cancer patients stated that they were given printed educational materials and extensive education the by health care team and showed high satisfaction with the education they received. Mariana was given a booklet in the radiation therapy department to review it. The patient said:

"They are developing a comprehensive booklet on radiation therapy treatment and side effects and management. The physicist asked me to read it and to provide comment as a patient. I liked it is well written. I gave them my suggestions."

Patients who had a previous medical or health background received education during their studies and from their readings.

Mariana stated:

“I read books written by oncologists and breast surgeons; also I read scientific papers and journals.”

Balqees said:

“My husband who is a medical doctor gave provided me with readings that included websites and scientific papers about breast cancer, treatment and management”

Amal stated that she read about cancer on the Australian cancer council website. Mariana and Balqees were the only one who stated that they read on internationally recognized cancer websites. Other patients like Faten, Arwa, Isra, said that their children read over the net and then provided them with information.

Patients were not aware of any audio-visuals resources or web based information available for them through the hospital. However, some of the patients were aware of certain Arabic websites available in UAE and other resources available in the society such as the (FOCS) Friends of Cancer Society. Non Arabic speaking patients were able to identify cancer information websites that are known internationally or in their countries.

The findings suggest that education given to patients by health care professionals and from their support person are the most trusted by cancer patients in UAE no matter was their background and culture. Patients have expressed preferences to receive more formal education in the hospital by health care professionals and by a specialized person and possibly by a survivor. None of the patients showed doubts to any of the sources of information. However, the health care team (specifically the doctor) and the support person in this study appeared to be the most trusted.

Also the findings suggest that patients depended more on the health care team and their support person, except for one patients Mariana who searched and looked for sources of information almost everywhere. English speaking patients used the internet more than the other patients possibly because of the abundance of information in English.

Most of the patients showed that they were satisfied with their health care team education. They felt that their questions were always answered and that they were given some kind of education throughout their journey. However, most of them preferred if they were given more education especially about their future plans, prevention and about side effects and management of certain treatment. Most of the patients asked for more organized education. Amal said:

“I think an ex patient who can talk to patients and teach them would really be helpful.”

Most of the patients asked for a planned program where either a patient or an educator is available to provide patients with planned education sessions throughout their journey and to answer patients’ questions. As for educational materials, most of the patients showed their dissatisfaction and their discontent with the unavailability of the materials and that they were not provided with educational materials. Mariana said:

“I was really surprised that there were very few booklets about breast cancer. I was looking for some booklets on other topics I could not find. When asked in the radiation therapy, they gave me a booklet that was prepared for patients and wanted someone to read it. I liked the idea. But there should be a committee or someone responsible for providing patients with related educational materials.”

To reiterate, the third objective of this study was to determine the sources of Information for cancer patients in UAE. As sources of information cannot be separated from the process of learning and the process of knowledge acquisition, I presented the sources of information under each stage in the previous section and I am highlighting them in the next section too. I am presenting in the next section the findings related to the barriers and factors that affect cancer literacy among patients including the identified knowledge types of the patients, and I found that the sources of information should not be disregarded in this section too.

4. The different knowledge types

The fourth objective of this study was to identify the facilitators and barriers that might be considered as determinants to cancer patients’ literacy. The following section presents the types of knowledge identified by the interviews as important determinants to cancer literacy

among patients. Three types of knowledge were identified among the patients with no effect of the cancer type. These knowledge types identified included factual/embodied or existential knowledge, experiential knowledge and learnt or acquired knowledge.

a. ***Existential or embodied knowledge:***

The existential/ embodied knowledge is the knowledge that patients have from past experiences or through past reading or from their social interactions such as knowing that cancer patients might need chemotherapy which may cause hair loss. Or knowing that breast cancer patients most probably will lose their breast and this might be traumatic. This type of knowledge was common among most the breast cancer patients who had some idea about the process of breast cancer treatment such as the possibility to lose the breast and the hair. As for non-breast cancer patients their existential knowledge about cancer and its treatment was much more limited than the breast cancer patients' knowledge.

Breast cancer patients' existential knowledge was the best among all groups and this can be explained by the awareness campaigns about breast cancer and screening in the world and in the UAE. Amal statement confirms the existential knowledge when she said:

“I know about the importance of the mammogram and the breast self- exam from Australia and from the awareness campaigns. Also one of my close friends had breast cancer last year. I was supporting her throughout her journey, I kind of know what to expect.”

Arwa and Barira both had family history of cancer. They had clear idea on what to expect. However, for Arwa, cancer was associated with death as her mother died as result of her cancer. She had a fatalistic view of cancer having said:

“I have faith in God (Allah) I know that it is Him who can cure me. I submit to my destiny and fate.”

Barira also had previous knowledge about breast cancer from her sisters' breast cancer experience. She stated that:

“I know what to expect I have two of my sisters diagnosed with breast cancer. They were treated ...”

For most patients, cancer was associated with death and suffering. Most patients expressed fear of the future and the cancer prognosis. Aya said:

“I am really scared of this disease, I wish I will survive it for my love (meant her husband). He has been very supportive and will be devastated if anything happens to me.”

Mariana did not express her fears very openly but in many occasions, she mentioned her friends who had breast cancer which recurred. One of her friends was dying at the hospital while she was getting her treatment. She expressed her sadness at many occasions and said:

“I cannot go to see her in this condition. This is very traumatising.”

For most non breast cancer patients there was vague understanding and knowledge about cancer. Their embodied knowledge about cancer was mostly that this is a severe disease that might not be cured. Hajar said:

“Do you think I will be cured I heard many times that cancer is not curable.”

Similarly Bahiya said:

“My late husband was a doctor and I learnt about cancer from his accounts of cancer patients’ stories. I cannot say except thanks to God because I don’t know what will happen with me.”

Mustafa mentioned in many occasions that he was depressed and that he is really scared especially that he was in pain especially at the beginning of the treatment. He said:

“I am really scared I know of some people who died of cancer. My cousin keep saying to me that treatment options have changes and there is better survival but I am not really convinced. I am really in pain; the doctor told me that the tumour on my side is big and might not disappear even with my full treatment.”

The embodied knowledge for all patients of all types was confined to the knowledge about cancer as a disease associated with death and suffering and with the general treatment types such as chemotherapy, surgery and radiation. Targeted therapy and hormonal therapies were

only known to those who came from a medical background or had a support person with medical background.

Women knew about the importance of screening and some of them said they discovered the cancer after they went for a screening mammography. Insaf, Mariana, Arwa, Amal, Barira, Somaya, Iman and Gina said that they have discovered their breast cancer after they went for regular screening. They had embodied knowledge about the importance of screening, knowledge about treatment types, some knowledge about surgeries and plastic surgeries. All three cervical cancer patients knew about the Pap smear but discovered their cancer through regular screening. All three did not know about the relationship between Human Papilloma Virus and cervical cancer. All three had not idea about cervical cancer treatment options and prognosis. For them cancer was something that not expected to happen to them and associated with fear and death like other patients. Mayada said:

“I have never expected that I will have cancer, I always knew in our country that cancer can be killing. We never pronounce cancer as such, we say the other disease, you know it is malignant and do not get cured. The doctor has told me that there are different types and that mine is curable.”

As for other cancer patients there was previous embodied knowledge about cancer as a malignant disease but patients did not know about colorectal screening and other ways to screen for cancer. Some females with non- breast cancer have specified that they have done mammogram and Pap smear like Aya but did not know that there are other ways to screen for cancer.

Maher did not have any idea about cancer from before except that it is a very aggressive disease. His embodied knowledge was confirmed by his doctor who told him that his cancer might not be responsive and that it was a bit advanced.

In general, this type of knowledge suggests that there is poor cancer literacy among most of the patients. Their embodied knowledge holds many misconceptions and fear. Also, it suggests that there is better knowledge about screening rather than about treatment and survival of cancer. This might also suggests that patients’ attitude toward knowing about

certain issues related to cancer during the three stages possible was affected by the poor previous or existential knowledge about cancer.

b. *Experiential Knowledge*

This type of knowledge is usually acquired throughout the cancer journey. It is usually learnt by experience and not by direct education. Patients who pass through certain treatment and might experience certain side effects or complications and who try certain successful management will learn from this experience. Their learning will influence definitely on the rest of the treatment and will help them to prevent further complications.

As mentioned earlier most of the knowledge that the breast and non breast cancer patients built was mostly experiential and was developing throughout the journey with time. Most of the patients learnt about the diagnostic procedure, about the treatment types, side effects, management and routine by experience. All patients have acquired certain knowledge throughout their experience and that was clear toward the end of their treatment stage. However, there were differences in the learning level depending on the cancer type and cancer treatment method. For example those who received all types of treatments developed more knowledge and better understanding of the whole treatment process. Mariana said:

“I knew about the side effects of radiation therapy and hormonal therapy but it is different when you experience it yourself. I was so scared from radiation but after I received it, I felt that it is not so- hard. As for the hormonal, everyone was assuring me that it does not cause serious effects, unfortunately I am not able to tolerate it I went twice to the doctors asking him to change the drug for me.”

Amal also said:

I knew that chemotherapy might cause nausea and mouth ulcers and dryness, but no one has told me that I have to use the medicines given to me prophylactically even if I don't have side effects. I suffered from the nausea and the dry mouth the first time then I learned later from the nurses that it is better to use them even if I don't side effects. Since I started using them regularly I stopped having nausea and mouth dryness. They should give these instructions to all patients to guide them instead of telling them to use them when needed.”

Patient Aya was very happy and comfortable as she got very detailed explanation about her treatment plan, side effects and prognosis. She said:

“Thanks God I had very good doctors in Dubai and here in Tawam, they explained everything for me. I know what to expect now, I think this helps the patients cope better. However, I am not sure about my chemotherapy, I think I have to experience it to know what to expect.”

During the second and third interview this patient has stated that she has done very well with the chemotherapy especially that the fluids in her body decreased after she took two cycles. Other patients who stated that they did not receive much information in relation to their treatment side effects have implied later during the interviews that they learned how to cope with the side effects by experience. For example, Arwa said:

“My mother’s experience with chemotherapy was very much different than mine, I had a bit of nausea and I did not have any bowel or infection problem. She used to suffer. I used the medicines given to me and I am fine.”

While Somaya said:

“I did not get enough education about chemotherapy side effects, my mother did not take chemotherapy, I felt so bad the first cycle and the second cycle, and then I learned that I have to eat slowly drink soups and rest to make me feel better. My husband was reading over the net and teaching me what to do.”

In general, patients experiences with different treatment types were various between one patient to another. Most patients implied that their knowledge got better with experience. Most of the patients started with very poor knowledge of their treatment plan and side effects. They mostly finished their treatment with much better knowledge especially acquired by experienced rather than by direct education. Many of the patients also stated that they learned a lot as part of the treatment.

This type of knowledge that cancer patients build by experience during their journey may indicate that patients might need more solid and well informed education to make their experience easier. On the other hand, it may also indicate that patients' experiences are different, it is always better to tailor the education messages and the information as per the patients' needs.

c. Acquired or learnt Knowledge

This type of knowledge is usually learnt through direct one to one education or through reading or through different types of media. This is the knowledge that patients acquire from education including education they receive from other patients in support groups or from support people like relatives from medical background.

In this study most of the knowledge was acquired and experiential. The acquired or learned knowledge levels differed from one patient to another and by diagnosis and stage. Knowledge among patients who had more than one source of knowledge developed more quickly and deeply. Knowledge for those who depended on their health care team differed. Cervical cancer who received information from their multidisciplinary team had better knowledge and less information needs. Patients who depended on their own readings and their own search for the information such as Mariana and Amal had more deep and profound knowledge about the treatment options and preventive methods. Patients who had support persons with medical background or who were cancer survivors had better knowledge and less information needs. They were less anxious and more comfortable during their journey. Shahrazad statement confirms this finding,

She stated:

“I am relieved because my sister is an anaesthesiologist in England; she came to stay with me and to support me. I asked her about everything and she has informed about the possible complications and the possible treatment plan. She is in contact always with my doctor and I know that even if she goes back to England she will be there for me and she will answer all of my questions.”

All cervical cancer patients stated that their health care team explained everything to them in details. They implied that they had no previous ideas about the treatment plan side effects and expectations. They were so satisfied and happy with the knowledge they acquire from their doctors.

Most patients have identified that their learning at all stages happened through direct education from a member of a health care team, a support person or a survivor. Some have identified other sources like books, internet and media as being their main channel of direct learning. Mustafa who had very limited information about cancer before his diagnosis said:

“I had very limited information about cancer previously, I learned a lot from my doctor and from my cousin.”

For Isra and Sara their learnings happened through direct teaching as per their accounts.

Isra said:

“The doctors have informed my daughter about everything related to my treatment and my daughter has explained to me.”

Sara said similarly:

“I don’t know Arabic and English very well and I don’t know how to read, everything was explained to my children. They explained to me everything.”

The study findings suggest that formal direct patient education can change patients’ previous knowledge and beliefs.

Barira has changed her plans toward seeking the help of a faith healer during the treatment. She decided to postpone it until she finished her treatment. She said:

“You know after I spoke with you and after talking to my doctor as you advised me I decided to postpone visiting that lady in Kuwait until I finish my whole treatment.”

Arwa also said:

“I learned from my doctor that my case is different from my late mothers’ condition and that I can be cured. Thanks God.”

In summary, three types of knowledge and learning were identified in this study among the patients. Most patients have learnt by acquiring all three types of knowledge, however, some learnt by direct education only. The most common and abundant type of knowledge and learning was experiential followed by direct learning and education.

The findings have suggested that patients' involvement in decision making was limited to patients with higher education and to those who were strongly involved in information seeking. Most of the patients were not involved in the decision making process especially when the decision involved a resection of the tumour like a mastectomy or a lumpectomy. Breast cancer patients who underwent total mastectomy were told that it was their best option and then they had the mastectomy after their approval except for Mariana. Mariana decided to go for a lumpectomy against her doctor's opinion. This same patient was offered to have an oncotyping test. Based on her result, the doctor gave her the choice to go for chemotherapy or not as it was not clear whether chemotherapy was going to be helpful. She decided not to take chemo instead she received radiation therapy and hormonal therapy. Oncotype is usually offered patients with stage one and two with positive hormone receptors. Based on the oncotype result a decision will be made whether the patient will need chemotherapy or not. Mariana said:

“The doctor told me that my oncotype result was twenty two and that it means that chemotherapy might be helpful or might not be helpful so I decided not to take chemotherapy. He advised me that it might be better to take it but I decided I don't want to take it. “

On the other hand, Nafisa had three surgeries prior to starting her chemotherapy. She was told that she will have a lumpectomy and in case the margins are positive she might go for another operation. She agreed on that and had a lumpectomy, her margins turned out to be positive so she was called for another surgery to clean the margins. After few weeks her doctor told her that she must have a total mastectomy. So Nafisa expressed her discomfort and concerns that she was not involved in the decision making by saying:

“They should have offered me to go for a mastectomy from the beginning instead of having a surgery three times. The doctor did not inform me what the best choices ...are. Uh..... I was following his orders. Thanks God in all cases, Uh..... You know I was delayed three months to start with my treatment.”

Non breast cancer patients especially the colorectal cancer patients had much less involvement in the decision making especially that they had the most limited knowledge among the other patients. Cervical cancer patients also showed no involvement on the decision making although they had the best knowledge about their condition. Aya the ovarian cancer patient showed high involvement in the decision making but it cannot be clear whether being diagnosed in another hospital and taken care by a multidisciplinary team in that hospital could explain her decision making process. The patient was very happy with that team and stated:

“I was well taken care by the team in the hospital in Dubai, I was told everything in details and I was involved in every step while I was there.” She continued: *“the team here also is very good, I am so lucky and I have a very supportive husband who is taking care of me and involved in everything.”*

Finally, so many of the patients have shown more preference to be given the information to be given gradually and at the right time.

5. Satisfaction with education and suggestions

The last objective of this study was to identify patients’ different educational needs to optimize best treatment during their cancer journey. The following section presents the findings related to this objective.

Patients were asked about their satisfaction with education they received and they acquired in the hospital and from the distributed booklets in the hospital. Most of the patients were satisfied with their health care team education. Aya said:

“I feel that I am in safe hands. My doctors are excellent they explained everything to me. They are very supportive”

All cervical cancer patients were satisfied with their health care team and accounted their contentment to their treatment process. Omayya said:

“I don’t feel that I need to read or to find any more information. The doctors have explained to me everything.”

So many patients reported that their questions were always answered and that they were given some kind of education throughout their journey. For example, Maher said:

“The doctor explained to me and to my son my treatment plans including the possibility that it might not succeed.”

Mustafa also said:

“The doctor did not hide anything. He told me that the cancer might not be fully cured. To be honest I was afraid but it is good that he explained everything to me. He gave me the option to go for a stem transplant but I refused after he explained to me the success rate.”

Although, other patients have shown satisfaction about information they have received and about their experiences, some have expressed more need for formal and planned education as well as the need for educators or specialised professionals to provide patients with education. Some also have expressed their dissatisfaction with the shortage of educational materials and suggested that there should be more educational materials available for all patients with different languages. Amal said:

“I believe that I am lucky as I was given enough education, but I feel that this happened because I was asking questions and I was doing my own search. I think some patients are unlucky and are not receiving enough information because they simply do not ask. There should be more education given to all patients at all times.”

When asked about educational materials and resources, Amal said:

“I was not given any booklet here or any educational materials. In fact, I saw outside some booklets about mammography and breast self-exam but no one has given me written information related to my case. There should be some available resources for the patients. Being an Australian, I am reading and searching for information on the Australian cancer council website. I think those who don't have access to resources will miss out.”

Most of the patients asked for a planned program where either a patient or an educator is available to provide patients with planned education sessions throughout their journey and to

answer patients' questions. As for educational materials, most of the patients showed their dissatisfaction and their discontent with the unavailability of the materials and that they were not provided with educational materials.

Mariana said:

"I was really surprised that there were very few booklets about breast cancer. I was looking for some booklets on other topics I could not find. When asked in the radiation therapy, they gave me a booklet that was prepared for patients and wanted someone to read it. I liked the idea. But there should be a committee or someone responsible for providing patients with related educational materials."

Most of the patients preferred if they were given more education especially about their future plans, prevention and about side effects and management of certain treatment. Most of the patients asked for more organized education. Amal, Somaya, Arwa, Barira and Balqees all have pointed that having a survivor to provide support and education to the patients will be very helpful. Amal said:

"I think an ex patient who can talk to patients and teach them would really be helpful"

Mariana said:

"I think having a full time educator is very important. You know most of the patients forget their questions during the doctors' encounters and they need someone to refer to if they have any question. You know especially for those who take chemotherapy. In the radiation therapy you see the staff daily, you can ask them your questions. I do not think this is available for patients who receive different treatment. There should be a planned program. This is from my experience as a medical professional and as a patient".

6. Thematic Map

As discussed above a map for all important themes and their interconnectedness is presented to make it easier to appreciate the findings of this study. Below is the thematic map presentation.

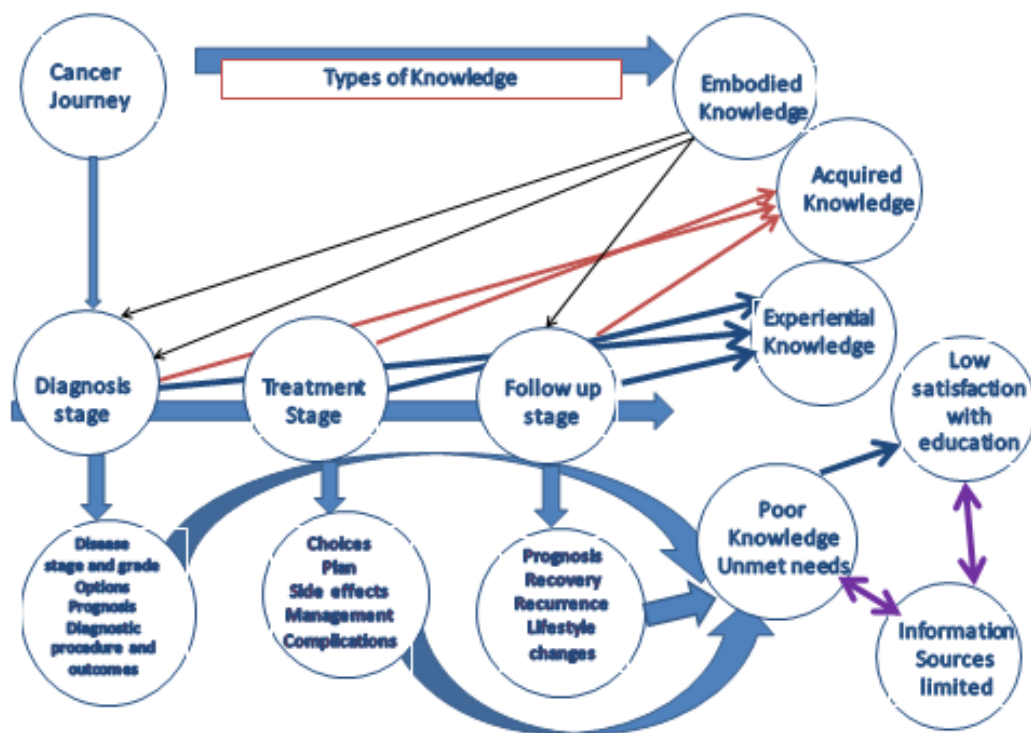


Figure 6. Thematic Map

7. Conclusion

This study has shown that there were differences in the level of knowledge and the sources of their knowledge throughout the three stages among most patients. Also patients have identified lots of areas that were considered to be gaps in their knowledge and in the information provided to them. The most obvious gap in knowledge was reported in the third stage of the cancer continuum. Patients started their journey with some existing or what can be named as embodied knowledge about cancer and its treatment, The more the patients have advanced with their journeys the more they learned about their conditions, their treatment plan and treatment options, side effects and management in general. Nevertheless, they mostly ended up their journey with many unanswered questions, but with very limited knowledge about their follow up plan and prognosis. Patients wanted to know about plans rather than about the process of diagnosis. Also patients fear about prognosis and success of treatment was a concern from the beginning of the journey.

It was concluded from the study that information needs have changed throughout the cancer journey and as patients progressed with their journey more education and knowledge needs have emerged and some remained as unmet informational needs. These needs and the transition of education needs were also mainly similar among most of the patients over the three identified stages of the cancer journey continuum. This area will be discussed in details in the discussion chapter.

Patients have shown some preferences on what and how to learn. Many have stated that having an educator and a well-planned education program would have helped them more during their journey. Some have suggested that having survivors involved in providing them with education. Also some have preferred to be given the information gradually and at the right time. The study findings suggest that formal and well planned education can change people's beliefs, misconceptions and knowledge. Moreover, the cervical cancer patients' experiences suggest that having a multidisciplinary team can improve patients' knowledge throughout the three stages leading to less educational needs. In addition, the patients' accounts have demonstrated that awareness campaigns, screening and education programs have improved people's breast cancer literacy in comparison to other cancers.

Patients have displayed great interest in knowing causes of cancer and how to prevent recurrence. Some patients stated that they were ready to go for a prophylactic surgery to prevent recurrence, or to use other alternative therapies and faith based preventive measures to ensure that cancer will not recur.

Many sources of information were identified to be used by patients in Tawam and that could be particular to the region also their information seeking behaviour could be also particular to UAE as cultural and religious factors have affected the knowledge seeking behaviour. The patients' experiences and account have identified different interpretations for the patients seeking behaviours. For example, fear and anxiety may stimulate patients desire to learn more and at the same time they may also discourage patients from seeking information about their disease and journey; younger and educated patients seek more knowledge; breast cancer patients seek more knowledge and have more unmet educational needs although breast cancer patients have more existential knowledge and tend to learn more during the journey.

Other themes that have been emerged from this study and need further exploration in future studies include that UAE nationals exhibited more fear and anxiety; western patients seek more knowledge outside the health care field; and Muslim patients rely on faith and belief to cope with their condition and show more fatalistic views to cancer. These findings cannot be exclusive and cannot be generalised due to the small sample size and the nature of the study, however, it is definitely worth exploring in future studies.

Finally, this study suggests that no matter what the patients' age, background, culture and education, there is always a need to know more. Also the study suggests that there is always fear and uncertainty among cancer patients about survivorship and about the future post cancer treatment no matter what is the condition and the stage.

Chapter Five

Discussion

In the past chapter, findings of patients' current knowledge and information needs at each stage of the cancer continuum were described. This chapter will discuss these findings in relation to the available literature and within the UAE. The structure of this chapter is based on the study objectives that explore the patients' needs along the cancer trajectory, how these needs might change over time and what factors shape cancer patients' needs within the UAE.

The intended goals of the study include the following:

- Assess patient knowledge and information needs upon diagnosis of cancer.
- Explore changes of cancer patient knowledge and information needs during the process of their treatment through to the follow-up stage.
- Determine the sources of information that cancer patients seek during their cancer journey.
- Identify the facilitators and barriers that can influence cancer patient literacy during their cancer journey.
- Identify patients' different educational needs to optimize best treatment during their cancer journey.

The chapter is divided into five major sections, as per the objectives. In each section the findings are summarised, contrasted with the literature and then a short recommendation is provided.

The main objective behind this study was to identify the current knowledge of cancer patients and their accounted information needs during their cancer journey at the three identified cancer stages. Therefore, the first section discusses the findings about current knowledge and information needs of the interviewed patients during the three phases of the cancer continuum. The second objective was to find out about transition of knowledge and information needs of patients. The second section of this chapter discusses how this knowledge has changed and evolved, as shown by the findings. A comparison between the

findings in the UAE with other international studies is provided. The third section includes a discussion on the patients' sources of information as identified by the study and related to the study objectives. The fourth section discusses the barriers and facilitators that determine cancer literacy in the UAE. This section discusses the factors that affect the information seeking behaviour among patients, how their knowledge has evolved and how cancer literacy affected their participation in the decision making process. The last section of this chapter discusses participants' satisfaction with information received and the best identified education method preferences. Finally, the summary includes recommendations based on the findings.

1. Objective one:

Current knowledge and information needs at each stage

This study explored knowledge patients have about their disease, treatment and follow-up stages, and did not aim at measuring the level of knowledge as described by DeJong and Hessler (1996) who set some measures for the knowledge level. This study never aimed at measuring the knowledge level, it was intended to find what the patients knew about their condition, treatment and prognosis.

Below is an illustration of the cancer patient's journey, including topics of information that patients' knowledge and information needs were assessed for during their three stages. The interviews discussed patients' knowledge and information needs in regards to the topics included at each stage as illustrated in (Figure. 7).

In this study, almost all patients have shown certain levels of knowledge about their disease, treatment and side effects, but they have also indicated more information needs about these topics. Also, most have indicated information needs in regards to prognosis, recurrence, prevention and follow-up routine. Most patients continuously indicated a need for more information about specific topics. At each stage there was information needs specific to the stage and to certain topics, as identified above.

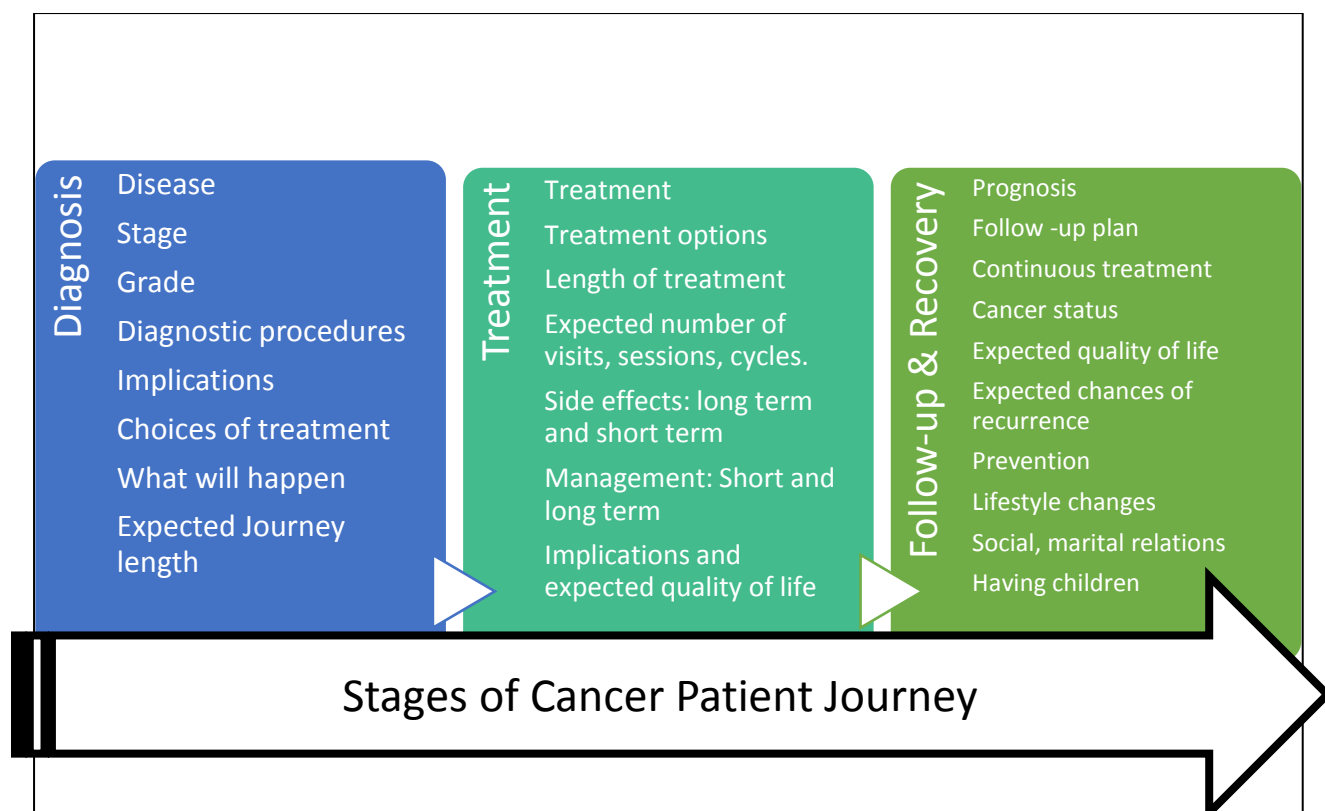


Figure 7. Topics and information during the three stages

a. Knowledge and information needs at the diagnosis stage

Contrary to the common belief that diagnosis disclosure is a problem in the Gulf as shown in (AlAmri, 2009), almost all patients in this study knew about their diagnosis, except for one patient who was not sure, Akram. He comes from an Iranian background and has lived in the UAE his entire life. His uncertainty about his diagnosis knowledge can be interpreted either by his limited education, his old age, or because his daughter and wife (who are the main caregivers) did not disclose the diagnosis with him. Nevertheless, knowing about their diagnosis does not mean that they have comprehensive knowledge about their condition (stage, grade and prognosis) and treatment.

For most patients at the diagnosis stage, general procedures such as biopsies and radiological examinations were known. Although patients wanted to know more about the implications of the procedure, they still displayed some knowledge. Tadmouri (2012) indicated that UAE patients, even those with limited educations, can understand, without difficulty, the diagnosis and tests required, as well as the treatment plan. New diagnostic techniques (specifically for

breast cancer patients), such as fluorescence in situ hybridization (FISH) and Oncotype DX, were not known and were difficult to understand for breast cancer patients. This could be interpreted as lack of community knowledge and because these new techniques are not discussed by many media outlets. Even educated patients and those with medical backgrounds, such as Mariana, did not know much about these tests and they had to ask questions and research more about them. For Mariana, knowing about the tests and their indication enabled her to make the decision about her treatment, as she decided not to take chemotherapy due to her results of her Oncotype test.

Most patients did not know much about their disease (stage, grade and type). Knowing about the grade and the stage of the disease was not a concern for most patients as much as knowing what will happen as a result of their stage and whether they will survive the prognosis. Glazer et al. (2002); Nagler et al. (2010) and Matsuyama et al. (2011) all agreed that even patients who were told about the stage and grade needed a further explanation. Rutten et al. (2005, 2006) reported that patients were more interested in knowing what will happen and the indication of the diagnosis, rather than finding out about more specific scientific information. In this study, patients who were asked about their stage and grade said that they knew that this information existed in their reports and that doctors might have mentioned it, yet they did not go back to the reports to find out about their disease stage and grade, except for one patient whose native language was English. Medical reports are usually issued in English and that could have been a reason that some patients do not make proper use of them as a source of knowledge. Patients, in general, were more interested in knowing the outcome, rather than the mean, as reported in other studies such as (Rutten et al., 2005; Squiers et al., 2005).

In this study, information about the disease, cause of the disease, diagnostic procedures and implications, possible side effects, and the meaning of the stage and the grade of the disease were very important to most patients. There was lack of information and information needs about these topics. Patients were not interested in the procedures themselves; however, they were interested in the impact of these procedures of their daily lives and on their disease progression. One of the most common needs identified was in regards to the prognosis and recovery from the first stage. Many studies have reported similar findings; patients wanting

disease related information (Derdiarian, 1987; Feldman, 1978; Galloway et al., 1997; Graydon et al., 1997; Luker et al., 1995; Mages & Mendelsohn, 1979; Matsuyama et al., 2013; Rutten et al., 2005).

Research has reported that patients want to know, at the diagnosis stage, about the spread of the disease, its impact on the body, prognosis and chances of cure (Adams, 1991; Crossen, 1984; Derdiarian, 1987; Galloway et al., 1997; Luker et al., 1995; Matsuyama et al., 2013; Rutten et al., 2005). Information on tests, as well as investigative and diagnostic procedures, were reported by (Derdiarian, 1987; Galloway et al., 1997).

Moreover, most of the patients interviewed did not know much about their treatment plan at the diagnosis stage. However, their knowledge about the treatment plan has improved when they started their actual treatment at the treatment stage. The bulk of patients' knowledge was at the diagnosis stage, which can be explained by the fact that a new diagnosis will trigger people to research their condition through different means and to look for other treatment options (Matsuyama et al., 2013; Molisani et al., 2014; Rutten et al., 2005; van Mossel et al., 2012, 2014). Also having more knowledge at the diagnosis stage could be interpreted by the emotional distress that a cancer diagnosis creates.

Cancer is usually equated to fear and death (Pinnock et al. 1998). Chemotherapy is always associated with hair loss, poor quality of life, fatigue, change in physical appearance and psycho-social problems (Leydon et al., 2000). Another explanation could be that health care professionals at this stage may be more empathetic and considerate to patient needs, so they provide more support at this stage, including providing more information to the patient. Molisani et al. (2014) found that there is a big difference between what the health care providers perceive to be needed by the patient and what information the patient's actually desire. Finally, the presence of a supportive family, friend, or an ex-patient who helps other patients by searching for the right information could be another interpretation for the high level of knowledge at the diagnosis stage in comparison to other stages (Rozmovitz & Ziebland, 2004).

b. Knowledge and information needs at the treatment stage

In this study, for some patients, knowledge at the diagnosis stage was much better in comparison to that of the treatment stage, whereas others' knowledge remained constant, even when they moved to the treatment stage. Patient knowledge was not only limited to the types of treatments they were offered, but also with potential side effects and management of certain complications, such as severe nausea, vomiting, or mouth ulcers. This knowledge also has shown similar fluctuation and improvements with time.

Patients were not interested in knowing why side effects happen, but were more interested in knowing how to manage them. This was also identified by (Adam, 1991; Leydon, 1999; Mistry et al., 2010; Molisani et al., 2014; Rutten et al., 2005; Squiers et al., 2005; van Mossel et al., 2012). For example, patients knew that neutropenia might happen but did not care why, they were more interested in knowing what to do if it happened. Most patients knew that if they should develop fever they must seek medical attention, but did not know why or what should be done.

Matsuyama et al. (2013) reported that patient information needs are highest near diagnosis and change throughout the course of their treatment, but remains high. They suggested that patients will always need new information once they understand the relevant information. Galloway et al. (1997); Graydon et al. (1997); Matsuyama et al. (2011); Molisani et al. (2014); Rutten et al. (2005) and Squiers et al. (2005); all have reported high and specific information needs for patients at the treatment stage. Rutten et al. (2005) categorised the most common treatment information needs reported by patients in various research from 1980-2003 in regards to information about treatments and treatment options, information about side effects of treatment and the risks and benefits of treatment, cancer-specific information and rehabilitation information. In this study, patients reported high needs in knowing about treatment side effects rather than treatment options; they reported high needs to know about the side effects and management, routine of the treatment, possible implications or benefits and the effectiveness of the treatment in preventing recurrence.

It was found that many patients wanted to know about specific side effect management and preventive measures, such oral hygiene, dietary recommendation and the use of alternative

therapies. Other studies have reported similar information needs, including treatment options, side effects and management, diet, oral hygiene and physical care. (Derdiarian,1987; Degner et al., 1997; Galloway et al., 1997; Juvonen & Lauri, 1996; Luker et al., 1995; Matsuyama et al., 2013; Mills & Sullivan, 1999; Rutten et al., 2005).

Most breast cancer patients in this study knew that chemotherapy and radiation therapy are common treatments for patients with breast cancer. As for hormonal and targeted therapy, it was not common knowledge for most of the breast cancer patients. Some knew at the diagnosis stage that they were going to take hormones because their cancer was receptive to hormones; however, it was not clear for many until they started their treatment that they were supposed to take hormonal therapy and why they should take it. This was similar for patients who were receiving, or due to receive, targeted therapy. Patients have identified targeted therapy as a smart drug or “the smart injection”. Almost all patients who were receiving targeted therapy “Herceptin” did not know the name of the drug and did not show interest to know its name. Also, they did not show interest to know about its efficacy; however, they showed interest in knowing if it might cause side effects like chemotherapy and what types of precautions they could take. This finding supports other findings by (Mills & Sullivan, 1999; Rutten et al., 2005; Vogel, Bengel & Helmes, 2008).

In general, patient information needs at this stage was fluctuating with introducing new treatment modality (refer to Figure.5 in the findings chapter). Matsuyama et al. (2013) identified a similar pattern in the treatment phase, where patient knowledge and information needs stabilise, then tend to increase with the introduction of a new treatment modality or therapy. Patients in this study have shown similar fluctuations, most were satisfied at the end of each stage with information about their treatment. Most of them became anxious and needed more information when they were receiving a new treatment modality.

c. Knowledge and information needs at the follow-up/recovery stage

At the last stage, almost all patients lacked knowledge about lifestyle changes and prevention. In contrary to my findings, most of the literature reported that the first two phases are the most important and patients need more information at these phases (Matsuyama et al., 2013; Molisani et al., 2014). Rutten et al. (2005) reported that most of the studies included in their

systematic review, research regarding information needs of cancer patients in the first two stages. Their findings suggest that there is very limited knowledge about information needs of cancer patients at the recovery, or follow-up, stage. Rutten et al. (2005) have labelled this stage as the post-treatment stage and found that patients at this stage want more information about prevention and recovery.

According to the review from Mills and Sullivan (1999) the most relevant information for cancer patients is information on treatment and side effects, extent of the disease, prognosis and self-care. This was also reported later by Rutten et al. (2005) in their more recent review which concluded that the most requested information from cancer patients are treatment related information, cancer specific information and rehabilitation information. In this study, patient information needs was high in all stages and became much higher in the last stage. Patients wanted to know whether recurrence is an option. Prevention and changes in lifestyle were also important at this stage. Survivorship and the dilemma of recurrence were very significant. At this stage, almost all patients had unmet information needs and poor knowledge about the future prognosis, follow-up and further treatment. Rutten et al. (2005) recommended that more attention should be given to the education needs for patients at the third stage, post treatment, at recurrence and at the end-of-life stage.

Capiello et al. (2007) recommended that following treatment, breast cancer patients need more support as this is a very critical stage while. The IOM (2008) highly recommends continuity in education and strong support system for patients during all stages, especially post treatment.

Education, support and appropriate resources are very important at this stage. Patients will encounter a new dilemma at this stage with fear of recurrence and fear of a similar experience. Prevention and lifestyle change was identified as being most important for the patient. As mentioned before, I did not follow the patients beyond two months after their treatment finished; one of the study limitations. I cannot definitely determine the continuity of high information needs in the follow-up period; however, other research, such as Molisani et al. (2014) argued that survivors needs continue to be high, even beyond nine months to one year after their treatment ended.

Rosmovits and Ziebland (2004) reinforced the importance of support and giving information at this stage, especially as patients want to know how to best aid their recovery with a healthier lifestyle and diet. Most of the patients in this study have reported that there was lack of information and advice from their health care team about this stage and about prevention, which was also identified by (Rosmovits & Ziebland, 2004).

Pascal et al. (2014) studied the psychosocial care of cancer patients in the rural communities of Australia and found that there is a need to implement a model of care for support services to help patients entering the survivorship stage.

In conclusion, the findings about knowledge and information needs of patients at all stages suggest that patients are told about their diagnosis, but lack information about the diagnostic procedures, treatment plan and routine, and prognosis. Patients in the UAE, at this stage, need to understand how cancer occurs and what the main causes of cancer are, as there is mixed feelings and misinterpretations leading to feelings of guilt and blame. At this stage, patients should be informed about the scientific etiology of cancer in simplistic terms. Patients need to be informed about diagnostic procedures ahead of time, also information sources and booklets should be provided to the patients instead of depending on opportunistic leanings. Patient routine and expected follow-up plans have to be clarified.

At the treatment stage, patients need to know about specific treatment efficacy, side effects and management, and possible long-term and short-term complications. Patients want to know about preventative measures that can reduce complications and side effects. Patients are also in need to be informed about dealing with their treatment, as there are misconceptions that might negatively affect the patients' treatment and could aggravate their side effects instead of helping them. Patients also are in need of continuous support and education, especially at the last stage as there is very limited knowledge and education at this stage. Moreover, patients are in need of support and education at the follow-up stage to help restore their life and to help regain a better quality of life. Patients have expressed their need to know about preventive measures and ways to lead a healthy lifestyle to prevent recurrence. Education programs should be tailored to meet the patients' needs at each stage. Health professionals need to be educated, as Johnson (2014b) suggests as measure to improve health

literacy, as patients have shown in this study that they have very limited cancer literacy and have identified their need to know about different cancer related information, prevention and ways to become healthy.

Fear of recurrence is an important area that needs to be addressed by health professionals in the UAE as it is an important factor that might hinder patients recovery and coping with the disease. Based on each patient's stage, patients have to know what their expected prognosis is. Support from survivors and educators are highly recommended.

2. Objective two:

Knowledge and information needs transition

This study has explored current patients' knowledge and their unmet educational needs. Therefore, in the following section patients' knowledge transition and their information needs evolution during the three cancer journey stages is presented.

Throughout the three stages, patients interviewed were consistent in showing their desire to know more. Their information needs can be considered as an indicator to their limited knowledge and to their satisfaction with their knowledge. Overall, knowledge in the first two phases of the journey (diagnosis and treatment) was limited, but better than the last stage. At the third stage, there were many unanswered questions and even more unmet information needs. This was not different from other international studies which also indicate the high information needs, especially in the first two stages and among survivors (Leydon, 2000; Mills & Sullivan, 1999; Molisani et al., 2014; Rutten et al., 2005, 2006; Squires et al., 2005; van Mossel et al., 2012).

An important finding of this study was the fluctuation of knowledge during the treatment phase. This was also identified by (Vogel, Bengel & Helmes, 2008) and explained by van Mossel et al. (2014) suggesting that patients will want information at a time that works for them. They need to understand the information about each treatment to make decisions at the time of the treatment, which explains this fluctuation identified by this study as demonstrated in Figure. 5.

Cancer treatment may include one or a combination of many treatment options, either at the same time or at different stages during the treatment course of the cancer journey. Patient knowledge was clearly fluctuating with the change of the treatment modality. Upon receiving a new treatment, patients have shown very limited knowledge about the new treatment; however, their knowledge showed improvement with time, especially after they started on treatment. In this study, patients had some knowledge at the start of their journey about cancer and the treatment expected. Their knowledge about each stage was stronger by the end of each stage, although some of them had unclear information and knowledge about a stage after they moved to another stage or through the all stages. Vogel, Bengel and Helmes (2008) also reported the decrease in information needs with the advancement of the treatment course.

The overall results showed that their knowledge kept improving with moving along the cancer journey in some areas, but stayed deficient in others until the end of the journey. Squiers et al. (2005) and Rutten et al. (2005) reported that usually patient' interests are influenced by their stage in the cancer care continuum. This was clear in the study, in each stage the patient's knowledge kept improving with their progress in the journey and in moving from one stage to another, showing that they were building more knowledge at each stage depending on their needs.

Overall, patients had a variety of information; however, we cannot say that all of them had the same information about each particular phase. Not all patients had similar knowledge when it came to certain topics, such as cancer specific information (stage, diagnostic tests, etc.) even for patients with the same diagnosis and same stage. Knowledge was not similar in each of the phases and there was a lot of information about particular issues that were known to some patients and unknown to others at both the diagnosis and treatment stage. The only common knowledge was their knowledge about diagnosis, while they all lacked information about their prognosis at the follow-up stage.

Patient's knowledge is built on experience, by living each stage and through the education and information received through various channels. This was also reported by Matsuyama et al. (2011); Mills and Sullivan (1999); Rutten et al. (2005) and Vogel, Bengel and Helmes (2008).

Literature has reported that there is a high need of information at the diagnosis and treatment stage among different cancer patients (Matsuyama et al., 2011; Mills & Sullivan, 1999; Molisani et al., 201; Rutten et al., 2006; Squiers et al., 2005). In this study, patients reported high information needs at the beginning of these stages, dropping slightly only toward the end of each stage and increasing again at the follow-up stage. Patients in this study needed more information at the beginning of each stage. Their information needs were similar to Villaire and Mayer (2007) who suggested that patients need continuous information related to diagnosis, treatment, side effects, self-care needs and effects on daily life.

An important finding of this study was a high information needs at the follow-up/recovery stage which did not decrease as there was always the fear of recurrence. This was also described by (Matsuyama et al., 2011; Molisani et al., 2014; Vogel, Bengel & Helmes, 2008).

Vogel, Bengel and Helmes et al. (2008) reinforced that patients post-treatment still wanted information regarding recovery, but also wanted more information about medical tests and follow-up routine. In this study, information needs about recurrence (including diagnostic tests, etc.) were high among the patients interviewed. Information needs about prevention and how to adjust lifestyle to prevent recurrence was significantly high among most patients. Diet was a very important area of knowledge that patients requested in their quest to know about possible prevention methods, as this was also identified in other studies (Dediarian, 1987; Degner et al., 1997; Galloway et al., 1997; Juvonen & Lauri, 1996; Luker et al., 1995; Matsuyama et al., 2013; Rosmovits & Ziebland, 2004; Vogel, Bengel & Helmes, 2008).

Overall, the change in information needs throughout the three stages among cancer patients in the UAE did not differ greatly from other parts of the world such as the USA, UK, Norway, Sweden, Canada and Australia (Jenkins et al., 2001; Matsuyama et al., 2013; Mistry et al., 2010; Molisani et al., 2014; Raupach & Hiller, 2002; Rutten et al., 2005; van der Molem et al., 1999; Wallberg et al., 2000). It was similar to findings from a study conducted recently in Jordan (AlQadire, 2014). Patients wanted to have cancer specific information, including the cause of the disease. They wanted to find treatment specific information, prognosis and recurrence. This was seen also described by Raupach and Hiller (2002) with breast cancer in

Australia, who found that 94% of study participants reported high level of information needs regarding recurrence and chances of cure.

The findings in this study suggest that there must be continuity in the patient education process. Patient education needs and knowledge changes and vary throughout the cancer journey with many factors that may play a role. Support and education are needed to meet the patient needs during the cancer journey. An educator or a support person who is available to provide the patient with certain education at all stages (a clinical health educator or a survivor) or patient educators, as suggested by (IMO, 2008; Lager et al., 2010; Redman, 2007; Rankin, London & Stallings, 2004; Skalla et al., 2004; WHO, 2006, 2007) as very important to patient education needs. Another suggestion is using group education therapy, as identified by Sutherland et al. (2008) as a better way in supporting patients during their cancer journey with education and emotional support. Improving health care provider knowledge regarding education components is also an important measure that needs to be taken to meet the patient education needs (IMO, 2008; Johnson, 2014b). Finally, activities and programs that can improve health literacy encourage a “health literate organisation”, as described by Johnson (2014b) and are highly recommended to help meet patient information and education needs. Administrative support and policy maker support is also needed to ensure the implementation of programs in patient education and to improve the health literacy culture in the organisation (Tawam) and in the UAE.

3. Objective three:

Sources of information

In this study most patients relied on their health care professionals for information, some relied on reading from the internet and scientific books, but most did not try to look for additional information at all. The sources of information of the studied sample were not different from other studies (Matsuyamu et al., 2013; Mills & Sullivan, 1999; Molisani et al., 2014; Rutten et al., 2005; van Mossel et al., 2012, 2014); however, many patients in this study have depended mostly on their support person, family and friends to learn more about their condition.

This study confirms results reported by these other studies that indicated that doctors and health professionals, in addition to reading materials and internet based information, were the most common sources of information for cancer patients during their cancer journey (Adams, 1991; AlQadire, 2014; Bilodeau & Degner, 1996; Raupach & Hiller, 2001; Rosmovits & Ziebland, 2004; Rutten et al., 2005; Talosig-Garcia & Davis, 2005).

Raupach and Hiller (2002) found that the most frequently used source of information for breast cancer are surgeons, followed closely by friends, then TV, newspaper and books. Rozmovits and Ziebman (2004) reported that patients often trust consultants, as they feel they receive adequate information from them. Leydon et al. (2000) found that three factors affected the information seeking behaviour: trust in the health care professionals, hope and belief that they are better than others.

Most patients in this study indicated that they did not receive printed material and were not provided with any audio-visual education materials during their treatment. However, most of them indicated that they would have preferred to receive written and visual information to take home and review at their leisure. According to most patients in this study, educational materials were rarely available from the hospital or in the community. They had to look for information online and from other sources readings from other sources. The internet was reported to be the main source of information, after health care professionals among most patients in this study. The availability of educational material would have been helpful as some patients have verbalised and many indicated that they were looking for information wherever possible, including sources from outside the country and different organisations in the region. Printed materials are proven to reinforce information received by the health care team and others (Walsh et al., 2010).

Johnson et al. (2008) have concluded that a combination of verbal and written information is highly recommended during communication with patients about their health care issues, as this will improve the patient's knowledge and satisfaction. Other studies have looked at sources such as the internet. For example, Ziebland (2004) found that information that cancer patient's access through the internet might improve their knowledge. In this study, patients have indicated that they used the internet to find information; however, only a few indicated

that they used known cancer information websites such as the Australian Cancer Council, the American Cancer Society and National Cancer Institute. Others indicated that they searched the internet and read from any source available. This raises a concern that was also voiced by Mcleod (1998) about the quality of information patients' encounter. Many of the patients in this study have indicated that they could not find many Arabic language resources that they were able to trust. Other patients, whose native language was not Arabic or English, also indicated some difficulties in research via the internet.

In this study, sources of information can be classified in two categories, the first ones are formal sources (health care team and printed educational materials), and all patients received education from the health care team. The second form of information sources are informal sources and are represented by support people with medical background, family and relatives, survivors, friends and websites. Both types of information sources were trusted by patients and families. Health care team members (specifically the doctor) and the support person in this study appeared to be the most trusted. This was also identified in many studies before, such as (AlQadire et al., 2014; Leydon et al., 2000; Rutten et al., 2005). Trust in doctors and health care teams are high among patients in the Middle East, including the UAE (Silbermann et al., 2012). This could be explained by cultural factors and by the existing paternalistic health care system (Silbermann et al., 2012, 2013).

It was noted in this study that Arabic speaking women depended more on the health care team and their support person for information. English speaking patients used a combination of sources, including more use of the internet, possibly because of the abundance of information in English or for other reasons that were not investigated in this study. Further research and investigation is needed to identify the factors behind this observation.

Older patients depended mainly on their health care team and their family members and had less information needs, which is a common occurrence as identified by (Ankem, 2006; Matsuyama et al., 2013; Vogel, Bengel & Helmes, 2008). Patients with higher educational background used different sources from those with lower educational background and have shown higher educational needs. Ankem (2006); Matsuyama et al. (2013) and Vogel, Bengel and Helmes (2008) found similar results in their studies.

Furthermore, patients in this study depended on both formal and informal sources for information and were seeking knowledge through these sources. Carlsson (2009) argues that most of the information that patients receive about cancer and treatment is provided by health care professionals. However, Mayer and Villaire (2004) and Villaire and Mayer (2007) reported that patients also obtain information from non-medical sources, as a coping mechanism for some patients. Patients try to cope by finding information from various sources, including formal channels (doctors and nurses), informal channels (friends and neighbours) and media (newspapers, television and internet) when available, also reported by (Tian & Robinson, 2008). Chen et al. (2001) argued that patients will always seek additional information about their cancer from other sources, even if they are satisfied with their medical care. This was also reported by (Manfredi et al., 1993; Rutten et al., 2005).

Eysenbach et al. (2002) and Cline et al. (2001) pointed to the growing quantity of health-related information available through the internet and other media sources. Unfortunately, not all internet sources are credible. According to Fallowfield and Jenkins (1999) patients are also exposed repeatedly to misleading and inaccurate information on television programmes and other media sources regarding cancer, which does more harm than good. Some patients tend to try some of the “miracle cures” for cancer posted on the internet and some of them might choose to not use traditional medical treatment. This is also the case in the Arab world and, specifically, in the UAE. It is important to provide patients with information through trusted channels to decrease false and misleading information from untrusted sources that spread wrong information (Al-Huziah et al., 2009).

Many of the patients in this study relied on a support person with a medical background or from a survivor to get their information. In this study, the support person was either a family member or a friend. Ziebland (2004) have discussed the importance of a trusted expert or previous experiences from other patients who can provide information to the cancer patient. Ziebland (2004) found that people tend to learn from the internet through socialising with such survivors or the support persons. This was also suggested by some of the patients in this study who have said that they would learn better if there was a survivor available for them to provide education and support when needed.

The sample in this study did not use any audio-visuals to learn about their treatment. Patients were not aware of any audio-visual resources or web based information available to them through the hospital; however, some of the patients were aware of certain Arabic websites available in the UAE and other resources available such as the Friends of Cancer Society (FOCS). Non-Arabic speaking patients were able to identify cancer information websites that are known internationally or in their countries.

The unavailability of a cancer hotline or cancer websites in Arabic (and other native languages) that can provide comprehensive information and answer patients' questions and concerns, and provide emotional support, makes it hard for patients in the UAE to make full use of the internet as an educational resource. Only educated patients indicated that they were utilizing the internet to further their education. Squiers et al. (2005) have reported high use of helplines among patients during their cancer treatment. The presence of a cancer helpline for UAE cancer patients could be very useful in improving cancer literacy among patients and families, as well as providing appropriate information to patients.

Carlsson (2009) reported that internet research increased in 2008 as compared to 1998. The author explained that the increase in internet access and in confidence in the internet as a resource makes the internet a reliable source of information. Lee et al. (2012) reported in their study that education levels were strongly associated with internet use, more than with the use of other sources, regardless of topic. In this study, patients with higher educational backgrounds indicated that they used the internet as a source for their information, or their caregivers have used the internet to educate themselves. This also suggests that the availability of information via the internet in different languages for patients being treated at Tawam Hospital is very useful and will help in providing patients with trusted sources of information. This was also suggested by some patients as a way to improve education at Tawam Hospital.

Patients in the UAE and in the Arab world in general, are more social learners and they prefer to ask others and to learn from others, even in the waiting area (Tadmouri & AlSharahan, 2012). Information in Arabic is not as abundant as it is in English, especially on the internet and in books. For many patients, international sites (mainly in English language) have better

reputations and are more trustworthy, which limits education resources to those who are not fluent in English. Participants who had a family member researching information and those who had volunteers that provided them with information without asking received more information, were more knowledgeable and had less unmet educational needs. The presence of a son or a daughter who was researching and seeking information for parents was a very important source of information for many patients. These patients felt more comfortable and relaxed because they felt secure knowing that there is someone who can do the research when needed and from reputable sources. These patients showed more trust and less anxiety and fear.

The study findings suggest that patients are in need for more trusted sources of information, they need health-literate health professionals, which is also suggested by Johnson (2014a, 2014b) as they are the most trusted source of information. Patients need printed educational provided by the hospital and they need internet sites that provide them with correct information and preferably in their native language, preferably through the Tawam Hospital website or through links provided by Tawam Hospital.

4. Objective four:

Factors that facilitate learning and knowledge seeking behaviour in the decision making process

In this section, I will discuss the findings regarding the factors that play a role in developing UAE patient cancer literacy. The types of knowledge that shape patient knowledge and information needs will be discussed. Information seeking behaviour and the involvement in the decision making process are also discussed in this section.

Johnson (2014a) explains that health literacy is achieved with numerical and oral skills, as well as the ability to interpret information and to communicate effectively. Johnson (2014b) explains that health literacy is considered an important component of a successful patient-centred care (PCC). This study was concerned with identifying the needs of the patients to achieve the ultimate goal of a successful PCC. The findings suggest that there are many factors that may affect patient health literacy, specifically, cancer literacy in the UAE. These

include patient readiness, motivation and abilities, previous knowledge, experience, availability of resources and support people, and communication skills. Other factors, such as values, beliefs and language also play an important role in developing patient cancer literacy. Below, I am discuss the knowledge that patients have displayed and developed during their journey, as well as how this knowledge has shaped, and can shape, patient cancer literacy. This section will also discuss information seeking behaviour of patients and their decision making involvement in their treatment process.

a. Types of knowledge:

The study showed that patients interviewed had the three types of knowledge discussed in the literature review chapter: the embodied, the experiential and the acquired knowledge.

i. Embodied knowledge

Embodied knowledge refers to the knowledge that every patient has at the baseline, which is the diagnosis stage. This type of knowledge includes many topics related to cancer, from beliefs and perceptions about cancer, to knowledge about possible types of treatment and their side effects, early detection (mammography or pap test for example) and possible risk factors of cancer (smoking, unhealthy diet, stress, etc.). Research has shown that patients start with baseline knowledge and display high information needs (Matsuyama et al., 2011; Molisani et al., 2014; Rutten et al., 2005; Squiers et al., 2005).

Patients have shown mixed emotions and various amounts of knowledge in regards to cancer at the diagnosis stage. Most knew that chemotherapy was the hardest treatment on their bodies, as it might cause a change in their body, self-image and quality of life. This has been a continuous dilemma for cancer patients, as identified by (Donnelly et al., 2013; Fallowfield, 1990; Pinnock, O'Brien & Marshall, 1998).

Almost all patients associated cancer with the loss of life at one stage or another. Usually cancer patients, including Arabs, associate between cancer and death among (Donnelly et al., 2013; Mellon et al., 2013). Many patients perceive cancer as a deadly disease and carry a stereotype that cancer is a disabling disease that will cause disruption to quality of life (Cohen & Lazarus, 1979; Fallowfield et al., 1999; IMO, 2008; Skalla et al., 2004). The fear

of hair loss and/or body part loss was identified by patients interviewed at the diagnosis stage. The question of “Why me?” and “What is the cause of my disease?” stood out among all patients. There was confusion about the cause of cancer. Some blamed their lifestyle for the disease, while others could not believe that they had cancer as they thought they were living a healthy life. For some, the cause of their disease was interpreted by their faith and spirituality, believing that this disease is a test of their faith and their patience will help them clear their sins and lead them to heaven.

Cultural and religious beliefs impact patient perception and understanding of cancer, and the impact of cancer on life. It has also impacted some patients’ decisions in regards to their treatment. This type of embodied knowledge that is based on cultural and religious beliefs was very strong among most patients. Ferguson and Kasper (2000) referred to the role of sociocultural beliefs and practices in shaping beliefs about breast cancer. Silbermann et al. (2012) argues that Arabic countries are still in need of strong research and education programs to change people’s views about cancer and its treatment, as well as removing the stigma surrounding cancer. These findings suggest that cancer literacy is, in general, poor in the UAE. More research is needed to identify ways that can improve cancer literacy, taking into consideration embodied knowledge, cultural values and beliefs that shape embodied knowledge.

This type of knowledge influences the second type of knowledge identified in this study, experiential knowledge.

ii. Experiential knowledge

Experiential knowledge refers to knowledge patients have developed from their experience with the disease during their journey, from the point of their diagnosis until the end of their journey. Patients learn from their experiences, this was clear with most of the patients who learned about specific treatment types, side-effects and how to manage side-effects after experiencing them. This knowledge might not be necessarily from patient experiences, but also may be developed as patients move along the continuum, through their interactions with other patients who have experienced a similar journey.

Matsuyama et al. (2013) reported that patients develop knowledge with experience, which then decreases information needs. Patients in this study learn from their experiences with the disease and with the diagnostic procedures at the diagnosis stage. They also learn from interactions with other patients, support people and from their health care providers. Their experience, at the treatment phase, was the main source of their knowledge, although they did learn from other patients and survivors. This was the strongest knowledge type patients displayed in this study.

This type of knowledge acquired during the cancer journey suggests that there must be properly planned education programs that can assist this experience. Programs are needed to regulate misconceptions and misunderstandings that patients might develop from an unfortunate experience, such as severe complications due to certain treatment or from other people's experiences and views. This type of knowledge highlights the importance of making correct information available for all patients throughout the continuum. There is a shortage in available resources for these patients. The presence of a trusted person with trusted knowledge in the hospital can also improve the learning experience and will help in improving the patients' knowledge and meeting their information needs. Cancer literacy is shaped by patients' previous and embodied knowledge and by the persons' experience with the disease. The findings suggest that education programs should start in the community to improve patients understanding about cancer, to decrease fear and the social stigma that is attached to cancer and to develop better understanding in how to cope with the disease.

iii. -Acquired knowledge

Acquired, or learned, knowledge differs from experiential knowledge. Patients will develop this knowledge through reading, asking questions, communicating with experts and through receiving education from legitimate sources, such as health care providers (doctors, nurses, pharmacists, dietitians, etc.) or through survivors.

Cancer patients in this study reported that acquired knowledge was limited as there was very limited resource access. Their main education sources were their health care team members and their own personal efforts to acquire knowledge.

Patients who had a support person providing them with trusted information were the most satisfied and had less information needs than the rest of the patients. Those who received education from a multidisciplinary team displayed more acquired knowledge, more satisfaction and less information needs than those who received education only from their doctors. These findings suggest that patients need to have a trusted source within the hospital to ensure the patient has credible information. Support groups can also be a good source, as long as patients with positive attitudes are involved.

Patients who had a support person showed more confidence and displayed less stress, especially with new treatment. This reinforces the importance of having educational resources available for patients all through their cancer journey. Helplines and support persons, such as survivors or educators, can help in improving patient cancer literacy and will help give them appropriate information at the right time.

All three types of knowledge have shape patient cancer literacy in this study. Patients have shown previous knowledge that was constructed throughout their lives about cancer, before becoming patients themselves. This embodied knowledge, as described by Fosket (2000) is the way patients' experience and deal with their disease. Patients in this study use embodied knowledge to experience their illness. Some of them use this knowledge throughout the journey. Fear of death and recurrence are both good examples that show how patients' embodied knowledge affected their experience. For others, their own personal experience (acquired knowledge) changed their embodied knowledge. Then the author argues that most of the learning is acquired via experiential knowledge. In her study, Mackenzie (2010) reports that a cancer experience may lead the patient to change their behaviour; suggesting that the patient experience is an important method of knowledge creation. Many patients were looking for ways to prevent recurrence. Health education is also considered an important way to develop knowledge and cancer literacy as it may change people's behaviour and beliefs. Direct education is an essential building block for knowledge construction among patients in this study.

In conclusion, patient knowledge is a mixture of the three types of knowledge, as identified above. The study findings suggest that cancer literacy is limited among patients in the UAE;

especially patient knowledge developed mainly from embodied and experiential knowledge rather than acquired knowledge.

There is a need to improve cancer literacy among patients and health care professionals in the UAE. To improve cancer literacy, there must be program that targets all three channels of knowledge acquisition. There should be more effort through campaigns and education programs to improve embodied knowledge surrounding cancer in the community. There must be some changes in perceptions and attitudes of people toward cancer to reduce the stigma associated with this disease. Bener et al. (2002); ElObeid et al. (2014) and Silbermann et al. (2012) all recommend that there must be more community campaigns and efforts to improve community awareness about cancer prevention and to clear misconceptions about cancer.

Patient's experiences with cancer treatment should be made easier through proper educational programs that can reduce patients stress and improve patient response to treatment. Patients need trusted persons to provide them with credible information at the right time. Complications and unfortunate experiences may lead to misconceptions and may affect patient decisions in regards to their treatment. It is recommended, as suggested by Johnson (2014b) to improve cancer literacy among health care providers and to ensure that policies and programs are available to support cancer literacy for patients.

By examining the themes, the map provided on page 188 (Figure. 6) illustrate that patients' knowledge were mostly embodied and experiential rather than acquired and learnt. Patients' general satisfaction with education services were poor and the lack of resources and the poor knowledge and the unmet educational needs make it mandatory to identify measures to improve the learning and knowledge acquisition for cancer patients in the UAE.

b. Factors that affect patient information needs and information seeking behaviour

Factors affecting information seeking behaviour in this study can be placed in two main categories. The first one is the personal factor, including age, sex, ethnicity, personality type, type of cancer and stage. The second one is the psychosocial factor, including education, socioeconomic status, availability of resources, family and friend support, psychological

status, spiritual belief, cultural barriers and customs, doctor/patient relationship, social stigma and acceptance level for the disease.

i. Personal factors

Personality type, age, sex and ethnicity can be factors that affect information seeking behaviour (Czaja, 2003; Leydon et al., 2000; Matsuyama et al., 2013; Molisani et al., 2014; Moynihan, 2002; Squiers et al., 2005). Information seeking is usually motivated by the need to understand the disease, the treatment and the amount and nature of information needed (Manfredi et al., 1993). Information seeking behaviour in cancer patients and their families is an important aspect of their coping mechanism and a sense of support to reduce fears and concerns (Darrow et al., 1998; Degner & Sloan, 1992; Fallowfield et al., 2001).

This study interviewed patients of different ethnicity, race, age and personality type. Older patients had less information needs and less knowledge. Literature has shown that older patients have less information needs and tend to ask fewer questions (Ankem, 2006). In this study, most of the older people depend more on their caregivers, who could explain their basic information needs. Older people have shown less interest in learning. Ankem (2006) argued that older patients had less information needs and displayed less knowledge in comparison to younger patients because of the lack of confidence and the feelings of inhibition. In this sample, some older patients displayed this feeling of inhibition during the interviews. Older patients in this study depended mainly on their caregivers and did not display high information needs. Further investigations among older patients in the UAE are needed to improve information seeking among this group of patients and to improve their knowledge about the disease.

Younger females with higher education background, Western and Arab patients knew more about their condition, diagnosis, stage related information and diagnostic procedures in this study. Patients of Arabic background had more questions and more information needs compared to people from India and the Philippines. Language can be considered a barrier for information needs, rather than ethnicity, in this study. On the other hand, patient awareness of limited access to patient education information and resources can also explain this issue among non-Arabs. Westerners were more knowledgeable, had better access to information

and were able to communicate their information needs better during the interview. Patients whose mother tongue was not English or Arabic had more difficulties during the interview in communicating their information needs. More probing was used with these patients. It must be noted that patients do not receive interpreting services in Tawam; this may also play a role in their low literacy and in their less information needs.

Education, age, access to a support person and knowing English were important factors in the patient looking for more information. Patients who were inquisitive found answers with their physician, which confirms that doctors are more likely to provide education when requested (Leydon et al., 2000; Vogel, Bengel & Helmes, 2008). It is possible that due to time limitations, cultural barriers to provide further information, the physicians may give very limited information (AlAmri, 2009).

Molisani et al. (2014) argues that “the rate of information received does differ due to certain participant characteristics of disease, physical, psychosocial and total information”. They reported that the amount, level and rate of disease information decreases faster over time, as the education of a participant increases and varies with age, education and gender, and possibly race.

Personality characteristics are also considered one of the factors that affect information seeking behaviour (Leydon et al., 2000); however, no conclusion can be made in this regard from this study as I did not explore any patient personality factors or personality types.

Moynihan (2002) argued that gender determines the patient’s experience with cancer. The sample in our study was considerably small and the majority of the participants were females. This makes it hard to come up with any conclusion or to determine whether gender played a significant role in knowledge seeking behaviour and information needs throughout the stages.

Most of the patients interviewed in this study were females, which was one of the limitations of this study. Only three males were included in the study. A possible rationale for this discrepancy could be that male patients in the UAE prefer to seek treatment outside the country (as stated by the one of doctors in Tawam). Another possible explanation is that

females may accept participation in research studies in the UAE more than males. Many of the male patients I approached refused to participate in the study. More research is needed to investigate this phenomenon that can be particular to cultural values and a gender related issue.

In summary, patients with higher educational backgrounds and younger in age have shown increased knowledge, greater ability to find information when needed and had shown more interest to increase their knowledge in this study. Patients with language barriers have shown less knowledge and had less interest to further their understanding. This concludes that language, age and education play an important role in information seeking behaviour and affects learning and information needs among patients in the UAE. Further studies are needed to investigate these factors and to develop programs that improve the learning experiences of cancer patients in the country.

ii. *Psychosocial and cultural factors*

Psychosocial factors include socioeconomic status, language and religion/spirituality. It also includes social support (i.e. support groups, family support, etc.), psychological wellbeing, patient/doctor relationship and communication, as well as paternalistic and autonomous approach of communication and decision making.

Cancer type also played a role in information seeking behaviour in this study. Studies conducted with breast cancer patients (Cappiello et al., 2007; Denger et al., 1997; Girgis et al., 2013; Raupach & Hiller, 2002) reported high needs for information following primary treatment (the follow-up period), in which patients wanted to know as much as possible. Hypotheses of these researchers include physical and psychological statuses of women post-treatment, such as feelings of anger, depression, fear of physical pain and recurrence, body image and sexual difficulties. Vogel, Bengel and Helmes (2008) also reinforced that patients post-treatment still wanted information regarding recovery, but also wanted more information regarding medical tests and the follow-up routine. Mustayama et al. (2011) argue that patient information needs decrease when the patient develops a strong information ground regarding the topic and then increases again with the need to know about new treatment or topics. Fear of a new treatment may indicate an increase in information needs at the time of the start of

the new treatment. This study has identified the same findings and suggests that patients need extensive education at the beginning of each stage, as well as throughout the stages, and more information and education should be given with the introduction of new topics and new treatments. Some of the patients in this study suggested that information and education should be given to them gradually and upon need, also at the beginning of every stage and every treatment

Literature has indicated that there is a positive relationship between factors such as age, gender, socioeconomic status, education, patient knowledge, information seeking behaviour and involvement in decision making (Ankem, 2006; Kaur, 2014; Keating, 2002; Rutten et al., 2005). In a recent publication, Kaur (2014) argued that poverty was strongly associated with lack of resources, information and knowledge, as well as distrust of the health care system. Squiers et al. (2005) also showed that patient interest in information was not only limited to the stage they were in, but also to their age, education level and income, among others. Access to information and resources was also connected to the education level and background of the patient.

Another factor that might play a role in information seeking behaviour among patients is lack of support. High information needs found in this study from the diagnosis stage to the follow-up stage can be explained by lack of educational, social and emotional support available in the country for people with cancer at diagnosis, pre- and post-treatment, and in the community. Lee et al. (2012) reported that there is a gap in cancer information seeking behaviour between high socioeconomic status (SES) cancer patients and low SES cancer patients. This study did not explore the socioeconomic background of patients, therefore it is not possible to discuss this factor; however, it is recommended that future studies investigate this important factor.

Villaire and Mayer (2007) reported that inadequate health literacy and other barriers, such as language and culture, are major challenges to providing effective patient education. This study is in agreement with their findings and can conclude that barriers such as language, culture, education level, and existential and embodied knowledge are important factors in patient experience with learning and information needs.

Patients who had family or friends with a medical background who were supporting the patient during their journey knew more about the diagnosis and treatment phase and appeared less anxious and more relaxed about the information they had or might need. This finding also supports findings of other studies, which confirm that family and friends education and support improves patient knowledge and helps them cope better (Ankem, 2006; Rutten et al., 2005; van Mossel et al., 2012, 2014). This study has shown that there are differences in patients' knowledge needs and involvement in decision making. As stated by (Eapen & Revesz, 2003; Shetty et al., 1997) patients that lack support with their cancer diagnosis are more likely than others to pass through various stages of shock, self-denial and depression, leading to poor coping.

Revesz et al. (1990) and Tadmouri and AlSharhan (2008) have stated that family attitudes and perceptions are integral parts of patients self-esteem. They argue that family members usually modify their coping to help patients cope better with the progress of their disease and treatment, or death. They refer to this process to the five stage process of adaptation. These stages start with confronting treatment, this leads to efforts to protect family members (known as family integrity), followed by a support process, then maintenance of their emotional wellbeing, and ends with searching for spiritual meaning. Tadmouri and AlShrahan (2008, p.61) argued that people in the Gulf region, with their different philosophical approaches to life and death, accept diagnosis and treatment. The authors believe that with this process, most people come to accept their diagnosis and treatment of cancer with less anxiety, especially as many cancers are now curable (Eapen & Revesz, 2003).

The issue of rehabilitation and attending support groups was not much of a concern for most patients, although a few patients who had a support person in the family with a medical background showed less information needs. Similarly, patients who had a survivor in their families or among their friends have shown less information needs and reported that they use them as a source for information and knowledge when needed. In general, support services and support groups were not as important for patients in the UAE. Findings in other studies have reported that family and friends' education and support improves patient knowledge and

helps them cope better. This was also indicated in other research by (Ankem, 2006; Rutten et al., 2005; van Mossel et al., 2012, 2014). Patients with cancer and their families are more likely than others to pass through various stages of shock, self-denial and depression, leading to poor coping (Eapen & Revesz, 2003; Tadmouri & Alsharhan, 2012).

This study cannot generalise results in the UAE, as this is the only study that looked at information needs of cancer patients. It is difficult to generalise in other areas of the world too, as Rutten et al. (2005, 2006) argue, results of information needs of cancer patients, in relation to cancer type, socioeconomic status and age, have limited homogenous study groups of cancer patients. They argued that as breast cancer is the most commonly studied group of patients and it has the largest base of research literature, it is hard to generalise on other populations of cancer patients (Bilodeau & Degner, 1996; Degner et al., 1997; Rutten et al., 2005, 2006).

Some of the patients had concerns about their social life and how to manage work and life issues. Sexuality and intimate relationship were not a concern for them. From my previous experience with cancer patients in the Gulf, spouse relationship and sexuality were important issues for most breast cancer patients, which is different from this current study finding. This finding can be interpreted in two ways, it could be that the availability of information and the acceptability of breast cancer among people in the Gulf, as the number of cases has increased, have improved the knowledge of patients and families about this topic (Tadmouri & AlSharhan, 2008). It is also possible that patients did not disclose their fears about this issue to me, as a researcher, especially as the issues of sexuality and intimate relationships are still considered very private and taboo in the region.

Interestingly, complications (i.e. Lymphoedema management) were also not much of a concern. This could be because patients were seen by physical therapists in the hospital and they were given information about management. Also, it could be because patients did not have any lymphedema symptoms and they did not display any information needs at this stage. In general, most patients have shown an increase in information needs with the emergence of a new problem, symptom, or side-effect, including that of pain.

Patients interviewed were open about their cancer and their disease. They stated that they informed their family and friends, which showed that the stereotype of cancer was not a concern for these patients, contrary to AlAmri's (2009) results and the common belief that cancer has a disease of stigma in the Arab world, especially in the Gulf region (Tadmouri & Nair, 2012). The presence of support people with medical background and survivors to provide some patients with needed information could explain patient openness to the disease. The presence of a support person was an important factor that affected information seeking behaviour. Those who had a support person or a survivor tended not to ask as many questions and showed less information needs, these patients showed satisfaction with their information and were more relaxed throughout their interviews.

In this study, the type of cancer was a significant factor behind information needs and the type and quality of information some patients had. There were a few significant differences between patients with different types of cancer. Breast cancer patients constituted more than half of the sample; middle-aged females were the majority. Gynaecological cancers, such as breast, cervical, ovarian and uterine, were most represented among the participants. Studies done in different parts of the world have singled out gynaecological cancers and have reported that these particular patients have high information needs especially in the survivorship stage (Farquhar et al., 2005; Kim, 2009).

Breast cancer patients displayed more information needs and more knowledge at the same time. It was reported in another research studies that that breast cancer and prostate cancer patients wanted to know more information than colorectal patients (Nagler et al., 2010; Rozmovitz & Ziebland, 2004). Many researchers have reported high information needs in breast cancer patients in particular (Raupach & Hiller, 2001; Talosig-Garcia & Davis, 2005; Vogel, Bengel & Helmes, 2008). Breast cancer patients had better knowledge about cancer and treatment at the early beginning of their journey, possibly because of their previous knowledge exposure and previous work, or social experience and exposure to breast cancer cases. At the same time, breast cancer patients have shown higher information needs and a tendency to ask more and to be involved in the decision making process.

Moynihan (2002) argues that gender and sex may determine patient experience with cancer and medical institutions might be contributing to that experience. This argument may provide an explanation to the differences between female and male patients' knowledge and information needs. Gender can be a possible explanation for the differences stated above; however, the type of cancer may have affected also the transition of knowledge and information needs between patients in this study. Further studies are needed to explore the gender and type of cancer relationship with knowledge seeking and knowledge needs.

Another clear finding was the concept of spirituality; the studied patients manifested their use of their spiritual beliefs to cope. Spiritual care is obviously needed with cancer patients, especially for those who had social problems and complicated cases. Even with no spiritual support provided in the hospital, these patients', and even patients not receiving spiritual care in the hospital, spirituality, faith and beliefs helped them in their coping. For Muslim patients, the acceptability of fate and destiny, and the belief that cancer is going to shed their sins, helped them to cope. This important factor must be investigated further within the UAE to explore how to improve patient care and to help improve information seeking amongst these patients.

The use of alternative therapies, including the use of Ruqya or spiritual healing (reading verses from the holy book and prayers), and alternative cultural treatments such as cupping, herbal supplements, honey, black seed and holy water from Mecca was also identified as being used by some of the Muslim patients interviewed in this study. This also calls for further studies that explore the advantages and disadvantages of these practices, as well as being part of the embodied knowledge of most UAE Muslim patients, which might lead to more possibilities that patients will use it throughout their cancer journey (Elbarazi & Grivna, 2015).

Again, coping mechanisms and styles were not an objective in my study, but patients have shown different types of coping mechanisms. Some coped by not seeking out any information and some coped by asking family, friends and other patients for more information.

Finally, an interesting observation that is worth exploring in the future is related to the time delay between time of referral to an oncologist and the start of treatment. I noticed a delay between the first visit and the start of the first medical treatment. Diagnosis time seemed to take longer, either because the patient had to repeat tests done outside Tawam Hospital, insurance approval issues, or lack of money to cover diagnostic tests, causing to delays to tests and treatment. A delay between the first signs of symptoms and seeing a doctor was explored by El-Obaid (2014) in the UAE and by Ozmen et al. (2014) in Turkey but nothing has been done about this issue in the UAE or in the Arab world so far to improve the time of delay to treatment .

iii. *Shared Decision making*

This study found that some patients were involved in the decision making process, while others refrained from making decisions. Some patients expressed their need to be involved and showed unhappiness when they were not given the ability to be involved. This informs us that differences in patient personality, opportunity and knowledge can influence the decision making process, as (Leydon, 2000; Rutten et al., 2005, 2006; van Mossel et al., 2012, 2014) indicated in their research studies.

Czaja, Manfredi and Pierce (2003) reported that the desire for information and the desire for involvement in medical care decisions were independent factors among patients investigated in her study. Some patients had a strong desire for both information and involvement in making health care decisions and they were actively involved in their treatment plans, while others wanted to be informed about their disease and treatment but preferred to delegate most decision-making to their physicians. Ankem (2006) argued that younger cancer patients want more information and seek more involvement in the decision making process. The author argues that patients who preferred active roles in treatment decisions expressed a greater need for information. Patients who had higher education levels and who were more involved in the decision making process trigger doctors and professionals to provide more information. This was observed with some patients in this study who were very inquisitive and pushed their doctors to give them more information, they were strongly involved in the decision making process related to their treatment choices. Empowering patients with knowledge and improving their self-confidence is a very important tool that could be utilized to change the

health care team's perspective and behaviour, and can improve the patient education process in the future.

Patients' involvement and desire to participate in decision making was very much related to the patient education background, as well as their age. Patients with higher educational backgrounds wanted to know more and wanted to be more involved in the decision making process. Westerners and those who were fluent in Arabic and English showed more willingness to learn more and be involved in the decision making process. The type of cancer might be also an indicator for more involvement in decision making as breast cancer patients showed more interest in educating themselves and were very involved in the decision making process. Patients who showed religious acceptance did not ask as many questions and did not show much involvement in the decision making process. AlAmri (2009) and Silbermann et al. (2012) argue that culture and religious beliefs play an important role in information seeking behaviour amongst cancer patients in Arabic countries.

The findings about decision making involvement amongst the patients studied cannot be conclusive due to many reasons. First, the sample was too small. Second, the study did not use any scales that measured patient willingness and involvement in decision making. Nevertheless, the findings indicate that there are differences and some patients are willing to participate in the decision making process if they are given the opportunity.

This study suggests that there must be more research to study ways to improve patient-doctor communication skills in the UAE. More education programs are needed to produce health literate staff and organisations, as suggested by (Johnson 2014a, 2014b). More programs that use the principle of health promotion and health education are needed to empower patients in making decisions about their health are needed to meet the goals of patient-centred care.

5. Objective five:

Patient satisfaction with education and suggestions to improve patient experience with receiving appropriate information

Patients expressed slight satisfaction with the patient education process, but in general, they wanted better access to education and support programs. The need for health education

programs, clinical health education and specific chronic disease teaching will improve disease management as have been discussed profusely in various literatures (Green et al., 2015; Rankin & Stallings, 2007; Redman, 2007).

The UAE is one of the leading countries in terms of increasing in obesity, diabetes, cardiovascular and cancer disease trends. Proper management of these cases in the hospital will decrease the cost on the health care system, which is mainly insurance based. Health care has a great potential to decrease side effects and complications of these (IHME, 2013).

The importance of health education programs arise from patient recommendations and from literature that has proved its effectiveness. Al-Nohair (2013) has proven the effectiveness of health education with diabetic patients. Al-Nohair (2013) also argued that improving the quality of health education in primary health care centers, by designing health education programs and involving health educators, will improve the awareness and practices among the greater population and among patients with diabetes mellitus.

Lagger et al. (2010) reported improvement of patient outcomes due to Therapeutic Patient Education (TPE). A review of literature with detailed descriptions of educational interventions, as well as those who report multidimensional and multidisciplinary educational interventions, has shown many benefits of TPE and this could improve patient outcomes. They recommended health care professionals training based on a patient centred model and interactive learning methods to improve their ability to deliver effective patient education.

Also having a support person who can help patients in answering their questions and comforting their fears has proven successful. Moreover, Support groups and cancer specific support groups are important, as well as a multidisciplinary efforts to improve education. In fact, Rutten et al. (2005, 2006) have reported that research by (Krasuska & Stanislawek, 2003; Weis, 2003) that cancer patients have focused on one specific source, such as support groups or the internet as reported also by (Anderson & Klemm, 2008; Ziebland et al., 2004). Therefore, the availability of support groups, or support people, and resources is essential to improving the patient education process. Kreps et al. (2007) reinforced the use of cancer information services as a good source for patient and professional education, and

improvement in the knowledge gap that may arise. While Glazer et al. (2002) has called for more research to identify successful methods for educating and communicating with patients who have limited health literacy. In the context of UAE, definitely more studies are needed to identify patients' preferences taking into consideration the diversity in culture and languages among the UAE population.

Evaluations of group-based programs, such as the "I Can Cope Program" in the United States, its derivatives "Learning to Live with Cancer" in the United Kingdom and Europe, and the "Living with Cancer Education Program" (LWCEP) in Australia, have found high levels of participants' satisfaction, as well as positive effects on knowledge, coping, communication abilities and relationships with health professionals (Carlsson, 2009; Roberts, Black & Todd, 2002; Speca et al., 2012; Sutherland et al., 2008; Todd, Roberts & Black, 2002; van der Molem & Hutchison, 1999). Such programs if available will positively influence on patients satisfaction and coping in UAE.

Nagler et al. (2010) argued that to participate effectively in the decision making process, patients require information on diagnosis, prognosis and treatment options. They undoubtedly receive such information from their doctors, but the demands on physician time may limit the extent to which they can address all of their patients information needs. Therefore, the help of a multidisciplinary team in providing, reinforcing and answering patient information needs will improve the process of the patient education process.

Family, spouse and friend support was one of the major findings of this study. It was very strong amongst these patients, no matter their nationality, and clearly this support was a big help for these patients. The use of the support figure and involving him/her in patient education could be a very useful tool to improve patient information seeking behaviour and to improve knowledge amongst patients in the UAE. Further investigation based on this study could be very helpful and might add to a better patient education process.

Patients have identified different ways they prefer to learn, they asked for more resources and for more education in the hospital. They suggested that an educator or survivor can provide great help for patients and would be a great source of information and support. Patients need a well-rounded interdisciplinary program that is continuous and that employs different

methods of teachings. Some patients indicated that they would prefer education in groups; others indicated that they would prefer one-on-one teachings. One patient suggested a helpline, while the others indicated printed and audio-visual materials, including internet based information, would be useful.

This study confirms Mayer and Villaire (2007) suggestions that patients need planned patient education that includes a variety of teaching strategies and written materials; this would contribute to better patient outcomes. In conclusion, patients are in need of health-literate health professional that can provide them with needed information at the right time

6. Conclusion

In summary, the study has shown similar findings to international literature in terms of patient information needs transition through the major cancer stages. The study findings suggest that patients in the UAE have continuous information needs throughout the three stages identified for this study. Also the study findings suggest that although patient information needs and knowledge transition does not differ greatly from international findings, however, cultural and language specific needs have to be considered to meet the information needs of cancer patients in the UAE. Patients' information and information needs have shown fluctuation throughout the stages and have continued to be high at the follow up/recovery stage. Patients have lots of uncertainties and fears of recurrence that suggest that patients in the UAE need lots education and support at all stages and specifically at the last stage: follow up/recovery stage. In the follow-up stage, most patients had information needs that were not answered and remained vague for most of them. Fear of recurrence and possibly the unavailability of rehabilitation programs, support groups and services were other findings that call for action to improve cancer patient experiences, misunderstanding and misconceptions were also very common.

Patients had very limited sources of information in this study. The findings suggest that more efforts are needed in the hospital, where patients were interviewed and in the UAE health care services in general, to provide resources and reliable cancer information for patients and their families as well as for the community via different channels that meet patients preferred educational needs.

Moreover, the study have identified certain emerging themes like information seeking behaviour and factors that affect patients learning such as type of knowledge and how knowledge about cancer is constructed in the UAE . From the findings, a call for more research and efforts to understand the sociocultural impact of cancer, education and different treatment approaches on patients' behaviours, coping and acceptance of cancer and related treatment.

The study findings suggest that patients with breast cancer have better knowledge although high education needs is present no matter what was the patients type of cancer or stage. Certain social and economic problem might affect patients education needs, being more educated and younger appeared to be a factor that affect patients' education needs making them in need of more information. Language was identified as a major hindrance for learning among cancer patients interviewed strongly suggesting that the hospital need to out in place strategies and programs that provide patients with education in their own language and that meet their cultural and religious needs. Also the study findings suggest that patients' spirituality and acceptance of destiny might affect patient information seeking behaviour negatively. However, more studies are needed to establish a relationship and to find out the effect of religion and beliefs on cancer patients information needs and behavioural seeking.

Finally, these study findings suggest that patients are still not fully satisfied with education taking place in the hospital and community. This study suggest that there must be an immediate action to improve patients satisfaction with education to help cancer patients pass through their journey with less complications and for better health outcomes as suggested by other literature.

This study confirms with other studies that cancer patient information needs emphasises the importance of understanding how patient needs change throughout their cancer journey. The transition of knowledge of the patients interviewed has stressed the importance of follow-up information, continuous care and education for cancer patients, even after treatment. The study confirms that more structured education, following a systematic and scientific approach, is recommended for better patient education and care.

Chapter Six

Translation of Research into Practice

This chapter presents some suggestions on how to make use of the current research, the goal of which was to identify possible ways to improve patients' learning experience during the cancer journey. Recommendations for an information dissemination plan with some key actions will be provided.

This study has identified the ways in which knowledge and information needs of patients on the road to recovery change during the cancer journey. Below is a short summary of the findings:

- Cancer patients in UAE are in need of planned education programs that meet their knowledge and information needs.
- Patients' information needs continue through all the three identified cancer journey stages but change with patients' individual experiences and according to different types of and stages of cancer.
- Patients' cancer journey may start with certain existing knowledge about cancer that might affect the whole journey either positively and negatively depending on their knowledge.
- Patients need extensive education at the diagnosis stage regarding the cause of the disease, the treatment and expected routine plan and the possible prognosis.
- During the treatment stage patients' knowledge changes with experience and with education provided or gained. Patients' knowledge and information needs fluctuate with different treatment modalities and with patients' individual experiences. Patients at this stage need tailored education on certain topics and especially on the management of short term and long term side effects. The treatment routine and its expected length and potential success are important topics that patients wish to understand. Diet and changing lifestyle are also important topics that need to be addressed at this stage.
- Patients' information needs increase at the last follow up stage with more uncertainties and fear of recurrence emerging. Patients at this stage need comprehensive education about how to get back into the normal life routine following

the completion of their treatment. To assist them to return to normal life, they need to be empowered with more knowledge about healthy lifestyle and preventive measures. Due to the many misconceptions and non-evidence base or mixed information that are being circulated among the public that might impact on the patients' quality of life, patients are in need of a well-planned education program and support. Education and support at this stage may help relieve the patient's fear and anxiety induced by fear of recurrence and death that usually increase at this stage.

- Patients in the UAE have expressed their needs for better planned education delivered by qualified educators and survivors, as well as the needs for more educational resources to be available for them in their own languages.
- Finally the study suggests that cancer literacy among patients in the UAE is still limited. Therefore, more research is needed to identify level of cancer literacy in UAE, including the factors that affect cancer patients' literacy.

1. Recommendations

The results of this study suggest that there is a need to address the issue of cancer education for patients and families. The study recommendations include developing measures and policies in UAE to improve patients' experiences in learning to meet their educational needs and to improve health literacy as well as cancer literacy. Such actions may include the adoption of the health promoting hospitals initiative in health care facilities as well as patient centred care approach in primary care services. As explained by Johnson (2014b) health literacy is crucial for the success of patient centred care which is an important component for primary health care reform. Also, HPH are an important initiative that can improve patients' experiences with health care services leading to better health literacy. Johnson (2014a, 2014b) also has identified many benefits of health literacy from the literature including decreasing rates of hospitalisation and readmissions and death, and preventing longer stays in hospital. Gazmararian et al. (2003) demonstrated that there is a link between lower health literacy and decreased capacity to manage chronic disease. As stated before, UAE, there are no health promoting hospitals yet. Also patient centred care is not yet adopted as a policy or an approach in health care services (UA-UAE business council, 2014). Importantly, then this study may be a step forward for UAE hospitals to start adopting the HPH initiative.

Taking into consideration the complexity of the health care system in UAE (US-UAE business, 2014) this study may help to develop a role model health care service that can provide patients with much needed cancer education. Specifically, this study may provide suggestions to help in improving patient education and patient in Tawam hospital and other tertiary hospitals.

To improve patient education practices a patient centred approach is needed in health care services in the UAE. A patient centred approach was proven to help in the management of chronic disease, improved health statuses and outcomes, and increased the efficiency of care by reducing diagnostic tests and referrals (Barry & Egdman-Levitan, 2012; Cooper et al., 2003; IOM, 2008; Picker Institute, 1993; Stewart et al., 2000). To employ the study findings, I present three main strategies with key actions that I will use to disseminate the study results with the aim of improving patient education in Tawam and more broadly can be implemented later in other UAE hospitals hoping that there will be in the future policies that improve delivery of patient education in health care services, hence, improving patients experiences. In addition to disseminating the findings to Tawam, I will send some recommendations to the ambulatory care services in SEHA in Abu Dhabi that summarise the findings and that provide suggestions on how to improve cancer patients experiences in terms of learning and gaining knowledge about their conditions. I am hoping that these recommendations will be taken into consideration to initiate some patient education and health literacy research in the ambulatory care services (AHS) in SEHA in UAE. Also I am hoping that the recommendations will be taken into consideration to further direct patients care services in the (AHS) to be patient centred care.

a- First Strategy

The findings will be used to inform key persons in Tawam hospital of the challenges that are facing cancer patients in terms of needed information and their preferred ways of learning about their disease during their cancer journey. Therefore, key persons in Tawam hospital will receive the findings through a written report. The report will be provided to the ethics committee in Tawam, to the oncology department head and to the nursing administration as well as the health education department in the hospital. A consumer advocacy approach will be used through sending a written report, then a meeting with each department head or with persons in charge of health or patient education in each department will be set to discuss the

findings and to engage them in writing some recommendations or a proposal to improve patient education services in the hospital.

Key actions will include:

- Writing a report that identified key findings of the study
- Send the report to identified key persons in charge of cancer education in the oncology department and in the hospital
- Set a meeting with the persons in charge in all concerned department to discuss the actions that can be taken on the basis of the findings
- Identify collaborative measures that can help to improving patient education
- Run some workshops and focus group discussions with various staff (nurses and doctors, dietitians and clinical pharmacists) to discuss steps to improve the patient education measures.
- Introduce administrators, quality managers and health education staff to the HPH concept, the Flinders chronic disease management plan as an example for patient centred care plan.
- Suggest for health education department developing a multidisciplinary committee for patient education in the hospital or to oncology department a multidisciplinary committee for cancer education
- Prepare a report that Tawam hospital can send to policy makers in HAAD to suggest policies that may improve patient education in SEHA hospitals and services.

b- Second strategy: Initiate more research

The second strategy that is recommended is to ensure proper dissemination of study findings and to make the appropriate changes needed in terms of patient education in the UAE, is to further explore measures on how to improve cancer literacy in the UAE among patients and in the community. Also to identify specific needs of different cultures as UAE is a multicultural society.

This strategy is essential to help make use of these research findings, to initiate more research in the area of patient education and cancer education in the UAE. This study findings recommend that there must be more research on how to improve patients' learning

experiences and it sets the ground for the importance for more research on how to improve cancer literacy in the UAE. It also calls for more research that will identify cancer patients' education needs and preferred method. Also the findings of this study suggest there must be more research related to the efficiency of different health education methods and resources that will improve concordance. In addition research related to factors that might affect patients' involvement in the decision making and in settings treatment goals and how to overcome barriers that might hinder patients' participation are also needed.

Key actions:

- Initiate a research team from different disciplines (clinical, academic and administrators) that is able to conduct research into improving cancer literacy in different health care services especially in the (AHS) and in different emirates.
- Start a collaborative research with the identified team that will help identify needs of cancer patients' information needs in different emirates like Dubai and in different health care services (private and public).
- Conduct research on health literacy and on cancer literacy, including cancer prevention and screening. A research that might identify different needs among different cancer types is also needed.

c- Third strategy: Publish findings

This study was done in one of the major tertiary hospitals in UAE that is considered to be a role model for different health care services in UAE and in the region. Tawam is a reputable hospital especially in cancer care in the whole region including EMR (Eastern Mediterranean region) and MENA (Middle East and North Africa) regions. The oncology centre in Tawam provides clinical, research and training services (Tawam newsletter, 2015). Therefore, any action that will be taken in terms of patient education is presumably going to be followed and used as an example by other health care services.

Aim: Prepare and publish scientific publications to disseminate the findings of this study. Also prepare publications of possible strategies and recommendations based on this study and other future studies on how to improve cancer education in the UAE. Publishing findings and recommendations will allowing for other researchers in the country and the surrounding

regions to engage with this much needed area of research and providing guidance and models of patient education care for other health care services to improve cancer education process.

Key Actions

- Publish the findings in peer reviewed journals and in hospital reports
- Present the findings at conferences and to public and private health care sector
- Advocate with policy makers through workshops and through scientific and collaborative work related meetings
- Advocate for health promoting hospital initiatives

Finally, publish recommendations to improve patient education in UAE hospital taking into consideration cultural and language barriers as this study findings suggest that education and communication can be hindered by some cultural and language difficulties leading to a breakage in the learning process . As I am working in the public sector, I will use my network to set up meetings and to work with other public health specialists, staffs and academics to advocate for planning health education and promotion programs in UAE hospitals.

This study is the first of its own in the UAE. I am hoping that it will create some interests among other researchers and public health specialists to further investigate this area of research considering the big gap in knowledge. Also taking into consideration the risk transition in the UAE population that have shifted diseases and public health priorities toward chronic diseases prevention and management, I am hoping that study will instigate increased interest among researchers, administrators and policy makers to define appropriate measures, that value the importance of patient education and giving appropriate information for patients, to improve chronic disease management practices in the UAE.

2. Conclusion

This study suggests that patients in UAE are in continuous need for education and support during their cancer journey. Patients' experiences explored in this study indicate that cancer patients in UAE have high information needs that start with their cancer diagnosis and

continue throughout their treatment stage and to stay elevated at the follow-up/recovery stage. Information needs of cancer patients during the cancer journey in UAE increase and sometimes remain high during the recovery and follow-up period. Importantly, this need does not stop with the end of their treatment. These findings were consistent with research done around the world and with a research done in Jordan by (AlQadire, 2014). In this study, uncertainties, fear of death and recurrence of the cancer were the main concerns of patients throughout their cancer journey. These concerns did not ease with the end of the treatment or at the recovery stage. Support and education programs that help patients survive with less fear and anxiety and that improve the patients experience with cancer treatment are therefore highly needed. Unfortunately, however, these study findings indicate that cancer literacy is still limited among cancer patients in the UAE.

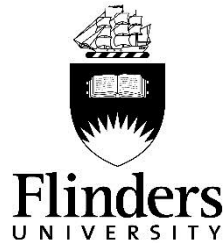
Moreover, this study suggests that due to the reported low satisfaction among cancer patients interviewed regarding education efforts and programs available for cancer patients, cancer patients are in urgent need of more education and support in Tawam hospital and most probably in other health care services in UAE. Efforts are therefore needed to improve cancer literacy among patients, health care professionals and the community. A health literate organisation that provide cancer education program will help in improving patients' literacy, and will decrease patients' tension and dissatisfaction with cancer education. An overall conclusion of this study indicates that cancer patients in UAE are in more and urgent needs for more education and support at hospitals. More research, however, is needed to determine cancer literacy in the UAE community, to identify public and individual misconceptions and to find ways to improve cancer literacy for patients and their families, communities and health care providers. This study has employed a qualitative approach that explored patients' experiences. There is also a need for more research in this area using different approaches and study designs including a quantitative approach that measures patients' cancer literacy and information needs in larger samples.

These study findings indicate a need for an urgent action on the level of ambulatory care services to improve patients' experiences in gaining information. The findings also call for more research to explore patients' learning inhibiting factors as well as gaps in the system. More research will help identify key strategies for improving patients' experiences in

learning and gaining knowledge for better health outcomes. The findings suggest that there must be more available educational resources for cancer patients that will address their educational needs at each stage. Planned education sessions preferably following a structured plan that will be provided by health care professionals, who are trained in health education, are also needed.

Health care team members are highly encouraged to involve patients in the decision making process as this will ease for patients the experience and the journey and will give them the power to make appropriate choices for their conditions. A multidisciplinary team who provides a detailed, continuous and systematic education and support with concordance to be the foundation of the education process is advisable as it has been shown in the literature to be effective in chronic disease management. Finally, factors that might improve education, learning, involvement in decision making and the provision of information needs should be researched more thoroughly taking into consideration the cultural and linguistic diversity among cancer patients in the UAE.

APPENDICES



Appendix One- Flinders Ethics Approval

FINAL APPROVAL NOTICE

Project No.: **5981**

Project Title: Exploring knowledge and information need changes among cancer patients during their cancer treatment journey

Principal Researcher: Mrs Iffat Elbarazi

Email: elda0002@flinders.edu.au

Address: PO Box 101

Moreland VIC 3058

Approval Date: 2 May 2013 Ethics Approval Expiry

Date: **31 January 2014**

The above proposed project has been **approved** on the basis of the information contained in the application, its attachments and the information subsequently provided with the addition of the following comment:

Additional information required following commencement of research:

1. Provision of a copy of the ethics approval notice from the Tawam Ethics Committee *on receipt*. Please note that data collection should not commence until the researcher has received the relevant ethics committee approvals (item G1 and Conditional approval response – numbers 5 and 9).

RESPONSIBILITIES OF RESEARCHERS AND SUPERVISORS

1. Participant Documentation

Please note that it is the responsibility of researchers and supervisors, in the case of student projects, to ensure that:

all participant documents are checked for spelling, grammatical, numbering and formatting errors. The Committee does not accept any responsibility for the above mentioned errors.

the Flinders University logo is included on all participant documentation (e.g., letters of Introduction, information Sheets, consent forms, debriefing information and questionnaires – with the exception of purchased research tools) and the current

Flinders University letterhead is included in the header of all letters of introduction. The Flinders University international logo/letterhead should be used and documentation should contain international dialling codes for all telephone and fax numbers listed for all research to be conducted overseas

the SBREC contact details, listed below, are included in the footer of all letters of introduction and information sheets.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number 'INSERT PROJECT No. here following approval'). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au.

2. Annual Progress / Final Reports

In order to comply with the monitoring requirements of the *National Statement on Ethical Conduct in Human Research (March 2007)* an annual progress report must be submitted each year on the **2 May** (approval anniversary date) for the duration of the ethics approval using the annual progress / final report pro forma. *Please retain this notice for reference when completing annual progress or final reports.*

If the project is completed *before* ethics approval has expired please ensure a final report is submitted immediately. If ethics approval for your project expires please submit either (1) a final report; or (2) an extension of time request and an annual report.

Your first report is due on **2 May 2014** or on completion of the project, whichever is the earliest.

3. Modifications to Project

Modifications to the project must not proceed until approval has been obtained from the Ethics Committee. Such matters include:

- proposed changes to the research protocol;
- proposed changes to participant recruitment methods;
- amendments to participant documentation and/or research tools;
- change of project title;
- extension of ethics approval expiry date; and
- changes to the research team (addition, removals, supervisor changes).

To notify the Committee of any proposed modifications to the project please submit a Modification Request Form to the Executive Officer. Download the form from the website every time a new modification request is submitted to ensure that the most recent form is used. Please note that extension of time requests should be submitted prior to the Ethics Approval Expiry Date listed on this notice.

Change of Contact Details

Please ensure that you notify the Committee if either your mailing or email address

changes to ensure that correspondence relating to this project can be sent to you. A modification request is not required to change your contact details.

4. Adverse Events and/or Complaints

Researchers should advise the Executive Officer of the Ethics Committee on 08 8201-3116 or human.researchethics@flinders.edu.au immediately if:

- any complaints regarding the research are received;
- a serious or unexpected adverse event occurs that effects participants;
- an unforeseen event occurs that may affect the ethical acceptability of the project.

Andrea Fiegert

Executive Officer

Social and Behavioural Research Ethics Committee

c.c Prof John Coveney

Andrea Fiegert

Executive Officer, Social and Behavioural Research Ethics Committee

Research Services Office |Union Building Basement

Appendix 2- Tawam Ethics

UAEU College of Medicine
and Health Sciences



26th June 2013

Iffat Elbarazi
Public Health Department
Flinders University

Dear Iffat:

Re: Al Ain Medical District Human Research Ethics Committee - Protocol No. 13/53 (CRD 253/13) – Exploring knowledge and information need changes of breast cancer/ and colorectal cancer patients during their cancer treatment journey.

Thank you very much for submitting your application to the Ethics Committee.

Your submitted documents were reviewed by the committee and I am pleased to provide you ethical approval of your project.

May I reiterate, should there be any ethical concern arising from the study in due course the Committee should be informed.

Annual reports plus a terminal report are necessary and the Committee would appreciate receiving copies of abstracts and publications should they arise.

I wish to take this opportunity to wish you success with this important study.

This Ethics Committee is an approved organization of Federal Wide Assurance (FWA) and compliant with ICH/GCP standards.

With kind regards,

Yours sincerely,

Dr. Fawaz Torab



Chair, Al Ain Medical District Human Research Ethics Committee

Appendix Three: Interview Guide

First and Second Interview

<p>1. Demographic questions</p>	<ul style="list-style-type: none"> ✓ Age ✓ Nationality ✓ City of residence ✓ For how long have you been in the country ✓ Where did you get diagnosed 	
<p>2. Disease and condition Information</p>	<p>2. Can you tell me about your disease and diagnosis process</p>	<p>2.a. How did you find about your disease?</p> <p>2. b. What symptoms did you have?</p> <p>2.c .Who advised you to seek medical help?</p> <p>2.d. Where did you go and how did you start your treatment at Tawam Hospital?</p> <p>2.e. What do you know about your condition?</p> <p>2.f. Did you have anyone supporting you during the diagnosis process?</p> <p>Tell me more about your</p>

		information without asking? To what extent do you think you have enough knowledge about your disease
4. Knowledge about treatment plan?	4.Tell me what do you know about your treatment	<p>4.a. What type of treatment are you receiving?</p> <p>4.b How many chemotherapy sessions/Radiation therapy sessions/ are you going to receive</p> <p>4.c. How long is your treatment going to last</p> <p>4.d. Who provided you with the information about your treatment?</p> <p>4.e. When did you receive information about your treatment, plan of treatment, time of treatment and expected outcomes?</p> <p>4.f. Did you try to look for information from different sources, can you explain what did you do?</p> <p>4.g. Can you discuss the type of \ information you received from each source.</p> <p>4.h. How did you receive the education?</p>
	Probe	

		<p>Did you receive the education through a formal education</p> <p>Did you ask for the information or you were provided with the information without asking??To what extent do you think you have enough knowledge about your treatment</p>
<p>5.Knowledge about side effects and management</p>	<p>5.Tell me what do you know about your side effects and how to manage side effects</p>	<p>5.a. What are the expected side effects of your treatment?</p> <p>5.b What are the precautions that you need to take during your treatment?</p> <p>5.c What are the management steps you have to take if you starting developing side these side effects?</p> <p>5.d. How did you learn about your treatment side effects and management?</p> <p>5.e. Did you get any education about treatment side effects, and who provided you with the education and when?</p> <p>5.f. Do you think you received enough or did you</p>

	<p>Probe</p>	<p>try to look for information from different sources? 5.g. State the information you received from each source. 5.h. To what extent do you think you have enough knowledge about your treatment side effects.</p> <ul style="list-style-type: none"> • What will you do if you started having severe nausea and vomiting? • What will you do if you developed diarrhea and constipation • What will you do if you started developing mouth ulcers and sores • What will you do if you developed high fever ? • Did you ask for the information or you were provided with the information without asking? To what extent do you think you have enough knowledge about your treatment
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<p>6. Knowledge about quality of life and life changes</p>	<p>6. Tell me what do you know about expected life changes during your treatment and how would you try to maintain a good quality of life?</p> <p>Probe:</p>	<p>6.a. To what extent did you receive education about your expected life changes and quality of life?</p> <p>6.b. Elaborate on what you know and how did you know about your life changes and quality of life.</p> <p>6.c. Explain what and how you learned about your life changes and how to improve your quality of life).</p> <p>6.d. To what extent do you think you have enough about life changes and quality of life.</p> <p>I mean did you ask for the information or you were provided with the information without asking?? To what extent do you think you have enough knowledge about your treatment</p>
<p>7. Knowledge about surgery (If applicable)?</p>	<p>7. Tell me what do you know about your surgery?</p>	<p>7.a What type of surgery you will have or you had?</p> <p>7.b Why is the surgery important in your condition?</p> <p>7.c Will the surgery impact your health or your life in general?</p>

	<p>Probe</p>	<p>7.d. What information did you receive about your surgery</p> <p>7.e. Who provided you with the information</p> <p>7.f. Did you look for information from different sources</p> <p>Do you believe that you were provided with enough information about your surgery</p>
<p>8. Information needs</p>	<p>What do you think are yours and your family's information needs regarding your condition?</p> <p>Probe</p>	<p>8.a. What do you think you and your family want to know at this stage of your disease?</p> <p>8.b. Are you feeling satisfied with the information that doctors and staff have given you? Prompts: too much/too little? Was is easy to understand</p> <p>8.c. How do you like to learn about your disease, treatment and prevention, state your best sources of information and why?</p> <p>8.d. To what extent did you find the information given to you were and the information you learned matching with the</p>

		<p>experience?</p> <ul style="list-style-type: none"> • What do you think a patient with your similar condition would like to know from his first day until the end of treatment and until he/she is discharged home • Did you ask for information? Were you given an answer? • Did you try to look for any information? Did you find it? • Do you think you have enough knowledge about your disease/treatment/prognosis/ life changes and cancer prevention?
<p>9.Views on clinical health education/ patient and family education</p>	<p>9. What is your definition of patient education programs and how would you describe a successful program</p>	<p>9.a.What are your suggestions to improve patients' knowledge and literacy during cancer treatment journey?</p> <p>9.b.What are your</p>

		<p>suggestions regarding planning and implementing clinical patients and family education programs in hospital</p> <p>9.c. How do you think we can improve cancer patients experience through education</p> <p>9.d. Do you think education and improving health knowledge and literacy can have an impact on patients life, explain.</p>
10. Comments		

These questions will be used in the last interview

Knowledge about surgery (If applicable)?	<p>Tell me what do you know about your surgery , complications and management</p> <p>Probe</p>	<ul style="list-style-type: none"> • What information did you receive about your surgery and about any expected complications • How will you manage these complications • Who provided you with the information • Did you look for information from different sources <p>Do you believe that you were provided with enough</p>
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		information about your surgery
Knowledge about prevention and lifestyle change	<p>Tell me what do you know about prevention measures and lifestyle changes post cancer treatment</p> <p>Probe:</p>	<ul style="list-style-type: none"> • Please explain the preventive measures needed during your treatment and lifestyle changes. Elaborate on treatment side effects and preventive measures and on the sources of your education and information. • Explain where did you learn about your treatment plan, prevention measures, how to prevent complication and what to do in case of any side effects and lifestyle changes? <p>I mean did you ask for the information or you were provided with the information without asking? To what extent do you think you have enough knowledge about your treatment.</p>



Appendix Four-Letter of Introduction

English and Arabic

LETTER OF INTRODUCTION

Dear Sir or Madam,

This letter is to introduce Ms. Iffat Elbarazi who is a student in the Discipline of Public Health at this University. She will produce her student card, which carries a photograph, as proof of identity.

She is undertaking research leading to the production of a dissertation or other publications on the subject of patients' information and support needs during the different stages of cancer diagnosis and treatment.

She would be most grateful if you would volunteer to assist in this project, by granting an interview which covers certain aspects of this topic. No more than one hour would be required.

Be assured that any information provided will be treated in the strictest confidence and none of the participants will be individually identifiable in the resulting thesis, report or other publications. You are, of course, entirely free to discontinue your participation at any time or to decline to answer particular questions.

Since she intends to make a tape recording of the interview, she will seek your consent, on the attached form, to record the interview, to use the recording or a transcription in preparing the thesis, report or other publications, on condition that your name or identity is not revealed, and to make the recording available to other researchers on the same conditions.

Any enquiries you may have concerning this project should be directed to me at the address given above or by telephone on +61 87221 8419 or +61 87221 8458.

Thank you for your attention and assistance.

Yours sincerely 

Professor John Coveney

Discipline of Public Health

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project N.5981). For more information regarding ethical approval of the project the Secretary of the Committee can be contacted by telephone on 8201 5962, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au



Flinders
UNIVERSITY

خطاب تعريف

إلى من يهمة الامر

هذا الخطاب يقوم بتقديم السيدة عفت البرازي وهي طالبة دكتوراة في قسم الصحة العامة في جامعة فلندرز في استراليا. ستقوم السيدة عفت بابرار بطاقتها التعريفية والتي تحمل صورتها كبرهان على هويتها وانتمائها للجامعة. تقوم السيدة عفت حاليا باجراء دراسة من اجل تحضير رسالة دكتورا خطية وغيرها من المطبوعات كالمقالات العلمية وذلك عن المعلومات التي يحتاجها المرضى ممن يعانون من مرض السرطان وعن احتياجاتهم المعلوماتية خلال فترة العلاج.

سنكون شاكرين وممنونين لكم لو تطوعت للمشاركة في هذه الدراسة عبر اجراء مقابلات معك تتناول المواضيع المطروحة اعلاه وتاكد اننا لن نحتاج من وقتك الثمين اكثر من ساعة لاجراء المقابلة الواحدة. نود التاكيد لك ان المعلومات التي ستقومون بتقديمها ستعامل بالسرية التامة ولن نقوم بالتعريف عنكم باي شكل في رسالة الدكتوراة وفي اي المطبوعات الاخرى وتقارير العلمية. نود التاكيد لك انه لديك كامل الحرية بايقاف المقابلة في اي وقت وكما لديك كامل الحرية بعدم الاجابة على اي سؤال قد يسبب لك الحرج او المضايقة.

بما ان السيدة عفت ستقوم بتسجيل صوتك خلال المقابلة سوف نحتاج لتوقيعك على ورقة الموافقة المرفقة والتي تشمل موافقتك على تسجيل صوتك وموافقتك على استعمال التسجيلات لنقلها وتحليل المعلومات المطلوبة لرسالة الدكتوراه ولأي تقارير علمية اخرى ضامنين لك عدم ذكر اسمك باي منها وبانه لن يتمكن اي باحث اخر من الحصول على هذه التسجيلات يمكنكم بالاستفسار عن هذه الدراسة عبر الاتصال مباشرة باحد الارقام المذكورة ادناه . +61 87221 8419 or +61 87221 8458.

شاكرين لكم حسن انتباهكم وتعاونكم

البوفسور جون كوفني

قسم الصحة العامة

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number 5981) For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au.

INFORMATION SHEET

Title: Exploring knowledge and information need changes of breast cancer and colorectal cancer patients during their cancer treatment journey

Investigators:

Mrs Iffat Elbarazi

Public Health Department

Flinders University

Ph: 0559067601

Description of the study:

This study is part of the project entitled ‘Exploring knowledge and information need changes of breast cancer and colorectal cancer patients during their cancer treatment journey’. This project will investigate patient knowledge and information needs upon diagnosis with breast cancer /colorectal cancer and how this information need change during their treatment journey..This project is supported by Flinders University Public Health department. Please be advised that your participation in this study is completely voluntary and if you not to participate in this study your treatment process and caring will not be affected at all

Purpose of the study:

This project aims to identify patients information need and will determine the importance of the implementation of evidence based patient and family education programs for cancer patients in UAE to meet their information need and to improve their health literacy for a better cancer experience.

What will I be asked to do?

You are invited to attend three face to face interviews with a Doctorate student during your treatment. The researcher will ask you a few questions about your disease, treatment and

prevention of cancer knowledge, your source of information, your information needed and what do you need to know about your cancer at each stage of your treatment journey. You will be interviewed firstly before you receive your first treatment, then after you start your treatment and then after 2 months toward the end of your treatment. Each interview will take about 30-45 minutes. The interview will be recorded using a digital voice recorder. Once recorded, the interview will be transcribed (typed-up) and stored as a computer file and then destroyed once the results have been finalised. This study is voluntary and will not interfere at all with your treatment and care process.

What benefit will I gain from being involved in this study?

The sharing of your experiences will confirm the importance on planning evidence based patient and family education programs for cancer patients and will improve the planning and delivery of these programs. We are very keen to deliver a service and resources which are as useful as possible to people.

Will I be identifiable by being involved in this study?

We do not need your name and you will be anonymous. Once the interviews have been typed-up and saved as a file, the voice file will then be destroyed. Any identifying information will be removed and the typed-up file stored on a password protected computer that only the coordinator (Mrs Iffat Elbarazi) will have access to. Your comments will not be linked directly to you.

Are there any risks or discomforts if I am involved?

Other group members may be able to identify your contributions even though they will not be directly attributed to you.

There will be no risk from your involvement in this study. If you have any concerns regarding anticipated or actual risks or discomforts, please raise them with the investigator.

How do I agree to participate?

Participation is voluntary. You may answer 'no comment' or refuse to answer any questions and you are free to withdraw from the interview at any time without effect or consequences.

A consent form accompanies this information sheet. If you agree to participate please read and sign the form or you can call me on 0559067601.

How will I receive feedback?

Outcomes from the project will be summarised and given to you by the investigator if you would like to see them.

Thank you for taking the time to read this information sheet and we hope that you will accept our invitation to be involved.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number 5981). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au

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ورقة معلومات

عنوان الدراسة:

استكشاف المعرفة والمعلومات التي يحتاجها مرضى سرطان الثدي وسرطان القولون والمستقيم خلال رحلة العلاج

الباحثون:

السيدة عفت البرازي

إدارة الصحة العامة

جامعة فلندرز

تلفون: 0559067601

وصف الدراسة:

هذه الدراسة هي جزء من مشروع بحث بعنوان "استكشاف المعرفة و المعلومات التي يحتاجها مرضى سرطان الثدي وسرطان القولون والمستقيم خلال رحلة العلاج". يبحث هذا الموضوع اهمية المعرفة والمعلومات لدى مرضى سرطان الثدي والقولون ويقوم باستكشاف معلوماتهم الصحية عند التشخيص وكيف تتطور هذه المعلومات والمعرفة الصحية خلال رحلة العلاج. ويدعم هذا المشروع من قبل جامعة فلندرز إدارة الصحة العامة في استراليا

الغرض من هذه الدراسة:

يهدف هذا المشروع إلى تحديد المعلومات التي يحتاجها مرضى سرطان الثدي والقولون حيث تهدف الدراسة الى تسليط الضوء على اهمية التخطيط ووضع البرامج التثقيفية لهؤلاء المرضى في الامارات العربية المتحدة لتحسين جودة الحياة لديهم خلال فترة العلاج ولتحسين المعلومات ومحو الأمية في مجال الصحة للحصول على تجربة أفضل السرطان.

ماذا سيطلب مني؟

انتم مدعوون لحضور مقابلات مع طالبة الدكتوراه الباحث الرئيسي في هذه الدراسة ثلاث مرات على الاقل خلال فترة علاجكم . سوف تطرح الباحثة عليكم بعض الأسئلة حول العلاج والمرض والوقاية من السرطان وستسالكم ما هو مصدر المعلومات لديكم، وما هي المعلومات التي تحتاجونها وماذا تحتاجون معرفته حول مرض السرطان في كل مرحلة من رحلة العلاج. سوف تتم مقابلتكم أولاً قبل تلقي العلاج الخاص بكم ، ثم مرتين خلال فترة ال6 اشهر المقبلة. وسوف تاخذ كل مقابلة حوالي 30-45 دقيقة. سيتم تسجيل المقابلة باستخدام جهاز تسجيل صوتي رقمي للمساعدة على استخراج النتائج و سيتم نسخ المقابلة وتخزينها كملف كمبيوتر وسوف تدمر بمجرد الانتهاء من استخراج النتائج. هذا البحث طوعي كلياً.

ماذا ساستفيد من مشاركتي بهذا البحث؟

أن تبادلك معنا للخبرات الخاصة بك ستؤكد على اهمية التخطيط لبرامج تثقيف صحي مبنية على الادلة والبراهين لمرضى السرطان. ونحن حريصون جدا على تقديم الخدمات التي ستفيد الناس بشكل واسع.

هل سيتم التعرف على اسمي من خلال مشاركتي؟

نحن لسنا بحاجة لاسمك وسوف تبقى هويتك مجهولة. وبمجرد أن يتم طبع المقابلات ونسخها وحفظها كملف الكتروني سوف يتم تدمير الملف الصوتي. سوف يتم إزالة أي معلومات تعرف عن المشاركين وستم حماية الملف الالكتروني بكلمة مرور لا يعرفها سوى الباحثة الاساسية (السيدة عفت البرازي). لن يتم ربط معلوماتك بما ستعطينا من معلومات.

هل ساتعرض بسبب مشاركتي بالدراسة لاي اذى او مضايقات؟

سيستطيع بعض المشاركين التعرف الى تعليقاتك ولكن لن يستطيعوا ربطها بك مباشرة. لن يكون هناك اي خطر من مشاركتكم في هذه الدراسة. إذا كان لديك أية مخاوف بشأن المخاطر المتوقعة أو الفعلية أو المضايقات، يرجى مناقشتها مع الباحث الرئيس في هذه الدراسة.

كيف أوافق على المشاركة؟

ان المشاركة في هذه الدراسة طوعي. بإمكانك ان تجيب ب "لا تعليق" أو ترفض الإجابة عن أي أسئلة وأنت حر في الانسحاب من المقابلة في أي وقت دون اي تأثير أو عواقب. مرفق مع هذه الورقة نموذج موافقة ت. إذا كنت توافق على المشاركة يرجى قراءة وتوقيع النموذج أو يمكنك الاتصال بالباحث الرئيسي على 0559067601.

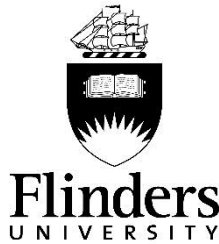
كيف يمكنني تلقي المعلومات عن الدراسة بعد انتهائها؟

يمكن الحصول على تلخيص النتائج من المشروع إذا كنت ترغب في رؤيتها وذلك عبر الباحث الرئيسي

نشكركم على أخذ الوقت لقراءة ورقة المعلومات هذه ونأمل بأن تقبل دعوتنا للمشاركة

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number 5981). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au

Appendix Five: Consent Form -Arabic/ English



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CONSENT FORM FOR PARTICIPATION IN RESEARCH

(by interview)

Exploring knowledge and information need changes of breast cancer and colorectal cancer patients during their cancer treatment journey

I

being over the age of 18 years hereby consent to participate as requested in the Interviews for the research project on health education and patient educational needs.

1. I have read the information provided.
2. I agree to audio recording of my information and participation.
3. I am aware that I should retain a copy of the Information Sheet and Consent Form for future reference.
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.

- Whether I participate or not, or withdraw after participating, will have no effect on my treatment process.
 - I may ask that the recording/observation be stopped at any time, and that I may withdraw at any time from the session or the research without disadvantage.
5. I agree/do not agree* to the tape/transcript* being made available to other researchers who are not members of this research team, but who are judged by the research team to be doing related research, on condition that my identity is not revealed.
- 6 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 volunteer and consider that she/he understands what is involved and freely consents to participation.

Researcher's name: Iffat Elbarazi (mobile:0559067601)

Researcher's signature.....Date.....

Witness name.....

Witness signature-.....Date.....

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee.(Project N.5981) For more information regarding ethical approval of the project the Secretary of the Committee can be contacted by telephone on 8201 5962, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au

استمارة موافقة للمشاركة في بحث

(عن طريق المقابلة)

استكشاف المعرفة ومدى الاحتياج للمعلومات لدى مرضى سرطان الثدي وسرطان القولون
والمستقيم خلال رحلة العلاج

- أنا----- بما اني
فوق سن ال 18 عاما وافق على المشاركة على اجراء مقابلات معي حول بحث التنقيف الصحي واحتياجات المرضى
التعليمية.

1- لقد قرأت المعلومات المقدمة لي.

2- وافق على التسجيل الصوتي لمشاركتي والمعلومات التي ساقدمها

3- وأنا أدرك أنني يجب أن احتفظ بنسخة من ورقة المعلومات ونموذج الموافقة للرجوع إليها مستقبلا

4- و أفهم أنني:

- قد لا استفيد مباشرة من المشاركة في هذا البحث.
- حر في الانسحاب من المشروع في أي وقت، وأنا حر في أن ارفض الإجابة عن أسئلة معينة.
- في حال سيتم نشر المعلومات المكتسبة في هذه الدراسة كما هو موضح، لن يذكر اسمي والمعلومات الفردية ستبقى سرية.
- في حال مشاركتي أم لا، أو في حال انسحابي بعد المشاركة، فان هذا لن يؤثر على أي علاج أو اي خدمة تقدم لي
- في حال مشاركتي أم لا، أو في حال انسحابي بعد المشاركة، فانه لن يكون هناك تأثير على علاجي

انه يمكنني الانسحاب في اي وقت وانه يمكنني طلب ازالة المعلومات عن الشريط ومحوه في اي وقت من دون اي تاثير سلبي علي.

5. أنا أوافق / لا أوافق على تسجيل كلامي او نقل كلامي و إتاحتة للباحثين الآخرين الذين ليسوا أعضاء في فريق البحث هذا، او يقوم فريق اعضاء البحث بالحكم على بحوثهم المشابهة على شرط أن لا تكشف هويتي .
6. وقد أتيتحت لي الفرصة لمناقشة المشاركة في هذا البحث مع أفراد العائلة أو الأصدقاء.

توقيع المشارك تاريخ

أشهد بأنني أوضحت الدراسة إلى المتطوعين وأنها / أنه يفهم ما يجري و يوافق بحرية على المشاركة.

اسم الباحث ... عفت البرازي- تلفون 0559067601 .

توقيع الباحث تاريخ

اسم الشاهد

توقيع الشاهد تاريخ

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee.(Project N.5981) For more information regarding ethical approval of the project the Secretary of the Committee can be contacted by telephone on 8201 5962, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au

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