

The Relationship between Death Depression and Death Anxiety among Cancer Patients  
in Saudi Arabia

by

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## **Dedication**

I dedicate this paper to my family who has ever been so supportive throughout my academic years. I would not have been able to achieve my academic goals without their help and encouragement. To my mother who has always been there for me and her selfless support, has always been with me throughout my academic career. To my father, who has always encouraged me to work harder and achieve my dreams; he has been an inspiration for me. Without my parents, I would not have been able to carry out this great responsibility that will determine my career ahead. To my sister Walaa, who was always there beside me and provided me with all the emotional and moral support that she could offer. It means a lot to me. To my husband Sultan Rajeh Almarri who is my absolute support and strength which encouraged me to overcome all the obstacles that came in my way through this time.

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## Table of Contents

List of Tables .....	iii
Abstract.....	iv
Chapter I: Introduction.....	1
Problem Statement.....	3
Research Questions.....	3
Definition of Terms.....	4
Significance to Nursing .....	4
Chapter II: Review of Literature.....	7
Death depression.....	7
Death anxiety .....	11
Summary.....	17
Chapter III: Methods.....	19
Setting and Sample .....	19
Instruments.....	20
The Arabic Scale of Death Anxiety .....	20
Reliability.....	20
Validity .....	20
The Death Depression scale-Revised .....	20
Reliability.....	21
Validity .....	21
Demographic Data Form.....	21
Procedures.....	21
Data Analysis .....	22
Chapter IV: Results, Discussion, and Conclusions.....	23
Results.....	23
Demographic Data .....	23
Death anxiety .....	23
Death depression.....	25
Correlations.....	25
Discussion.....	29
Demographic Data .....	29
Death anxiety .....	29

Death Depression .....	32
Correlation .....	35
Differences in gender scores .....	36
Type of cancer and death anxiety and death depression.....	37
Conclusions.....	38
Limitations and recommendation. ....	38
References .....	40
Appendices .....	44
Appendix A: The Arabic Scale of Death Anxiety .....	45
Appendix B: Death Depression scale-Revised .....	47
Appendix C: Demographic Data Form .....	49
Appendix D: Informed consent.....	50

### **List of Tables**

Table 1: Frequency and Percent of Participants' Gender and Type of cancer.....	24
Table 2: Mean and Slandered Deviations death depression total and death anxiety total.....	25
Table 3: Means and Standard Deviations of items of death anxiety.....	26
Table 4: Means and Standard Deviations of items of death depression .....	27
Table 5: Independent t-test comparison of men and women in their scores in their levels of death depression and death anxiety.....	28
Table 6: Independent t-test comparisons between death depression and death anxiety by type of cancer .....	29

## **Abstract**

Cancer is one of the main public health problems in the world. People diagnosed with cancer may become depressed and fearful of dying. This causes them to question treatments and sometimes avoid treatment altogether. Cancer may change the person's life and the lives of others around them. The current study focused on the psychosocial impact of impending death for cancer patients in Saudi Arabia. Currently, the relationship between the death anxiety and death depression in persons with cancer in Saudi Arabia is not yet clear. Added to that, little research has been conducted with Muslim cancer patients and their emotional needs.

This study explored the relationship between death anxiety and death depression among cancer patients in Saudi Arabia. The study sample consisted of 100 Saudi cancer patients, 50 male and 50 female, ranging in age from 18 to 85 with a mean age of 45.5. All participants completed a survey questionnaire that included three parts: the first part contained a demographic data form; the second part consisted of 20 statements to measure death anxiety using the Arabic Death Anxiety Scale; the third part was a 21-item, questionnaire designed to measure depression about impending death using the Death Depression scale-Revised Arabic version.

The results of this study revealed statistically significant correlation between death anxiety and death depression ( $r = .85, p < .001$ ). The total ASDA mean was out of a possible 20-100 52.3 (SD=22.3) and total DDS mean was 54 (SD=21.7) out of a possible

21-105. The result showed that, there were significant differences ( $p = .001$ ) in gender between death anxiety and death depression. Moreover, Hematological malignancies obtained higher levels of death anxiety ( $p = .026$ ) and death depression ( $p = .001$ ) than solid tumor.

In addition, in Saudi Arabia health care providers target cancer symptoms and barely address the psychosocial issues. This may be due to a lack of communication between patients and health care providers. On the other hand, providers lack the time to spend with patients and have to treat to great number of patients.

Therefore, the results of this study suggest that the health care providers should spend some time with each patient discussing feelings with no boundaries, and try to understand the patients' feelings, and involve them in decision making

Death depression and death anxiety are universal feelings and should not be neglected. Consequently, this research may expand the knowledge base about death anxiety and death depression in Saudi Arabia that might lead to intervention that would help to improve patients' quality of life.

## **Chapter I. Introduction**

Cancer is known to be a difficult disease affecting patients and their families both physically and emotionally (Tavoli, Montazeri, Roshan, Tavoli, & Omidvari, 2007). According to the World Health Organization (2011) report, there were approximately 7.6 million deaths in 2008 all over the world and in 2030 that number is expected to rise to 13.1 million (World Health Organization, 2012). According to the latest report from to Saudi Cancer Registry (2007, SCR), the total number of cancer incident cases reported was 12,309, but the true numbers are yet known due to lack of medical record availability in the hospitals. Further, the cancer mortality rates in Saudi Arabia are expected to rise but the data are not available for the reason that of logistical issue (Saudi Cancer Registry, 2007).

All Saudi patients are receiving free health care services unlike other regions in the world (Almalik, Fitzgerald & Clark, 2011). Despite the availability of professional oncologists and treatments in Saudi Arabia, the majority of Saudi cancer people who seek medical help present with late stage of cancer, which makes their disease incurable. This late diagnosis may be associated with low level of knowledge and awareness in the Saudi community (Ravichandran, Al-Hamdan & Mohamed, 2011).

However, cancer diagnosis is traumatic for any patient to hear .When physicians inform patients they have cancer, individuals can react in a myriad of ways. There is no

right or wrong way to assimilate information that no one ever wants to hear. The patient's routine may be disrupted along with ensuing financial upheaval, health insurance coverage problems, and caregiver issues, while roles and duties inside the family may change (Foster & McLellan, 2000).

A common denominator of cancer patients is their fear of death, regardless of personal characteristics, religious beliefs or cultural background. Although Muslims believe in life after death, fear of death exists in the culture even though it is a natural human experience. When patients are diagnosed with cancer, as opposed to other diseases, patients may have a greater fear of death. The cancer patient might be unique in the fact that the fear might come from the meaning that the patients attach to the word cancer and its association with death (Vilhuer, 2008).

Vilhuer also states that most patients have a fear of the unknown. Once the diagnosis of cancer has been made, patients start to experience feelings of fear, stress, depression, and worry of what the future holds for their lives. Researchers suggest that cancer and depression are related (Rodgers, Martin, Morse, Kendall, & Verrill, 2005). Death distress and anxiety level are associated with depression (Chibnall, Videen, Duckro, & Miller, 2002). This constant fear creates anxiety and depression which can affect day –to- day life and can become very distressing.

Pasquini and Biondi (2007) concluded that depression causes complications in the course of cancer and its treatment. It is not only the diagnosis of cancer that is related to the depression rate, but also the amount of pain the cancer patient feels, the socio-economic issues, the religious beliefs or cultural attitudes toward the disease, and the ability to follow through on treatments that can all lead the patients to face this kind of

stress (Vilhuer, 2008). Among people who have been diagnosed with cancer, patients with high levels of pain have much higher rates of depression than those with little or no pain (Tavoli, Montezeri, Rasook, Tavoli, & Mahdiyeh, 2008).

The majority of cancer patients have similar fears; fear of pain, death, loss of control and function. These fears may lead to suffering and depression; it is easy to understand the difficulty faced by cancer patients when they have to live their lives with the threat of their impending death always present (Sigal et al., 2008).

### **Problem Statement**

People diagnosed with cancer may become depressed and fearful of dying. This causes them to question treatments and sometimes avoid treatment altogether. There are few studies related to fear of death among cancer patients. Most of the published studies are focused on the terminally ill, so it is not clear what patients experience in the earlier stages of their illness (McClain-Jacobson, et al.,2004; Mystakidou et al.,2005; Tsai, Wu, Chiu, Hu, & Chen, 2005; Vilhauer, 2008). In addition, in Saudi Arabia, there is limited of data regarding presence of death depression and anxiety in cancer patients. Therefore, the purpose of this research was to examine the presence and relationship between death depression, and death anxiety among cancer patients in Saudi Arabia.

### **Research Questions**

The following questions are addressed in this study:

1. What is the level of death anxiety in patients with cancer in Saudi Arabia?
2. What is the level of death depression in patients with cancer in Saudi Arabia?
3. What is the relationship between death depression and death anxiety among Saudi cancer patients?

4. Are there significant differences in men and women in their scores on death anxiety and death depression?
5. What is the relationship between of cancer among and either death anxiety or death depression and type Saudi cancer patients?

### **Definitions of Terms**

For the purpose of this study the following terms are defined

*Death anxiety:* anxiety about possible impending death (Kubler-Ross, 1969).

*Death Depression:* related to experiencing distress, depression about impending death, the death of significant others, or death in general (Templer et al. 2001).

### **Significance to Nursing**

This study focuses on the psychosocial impact of impending death for cancer patients in Saudi Arabia. Currently, with increasing numbers of cancer patients in Saudi Arabia, physicians and nurses rarely address the psychosocial issues. There are many factors that can affect these psychosocial issues. There may be some miscommunication between the health care providers and patients. Added to that, in the Saudi culture, the family has a great influence on the patients' decision making (Younge, Moreau, Ezzat, Garry, 1997). That means that patients may not have decision-making power during the process.

Many times the physicians and care takers are expected to withhold certain information because there is a common perception that the patients are already fragile and shaken due to their conditions; it is also believed that their psyche might not be able to deal with shocking news that could even lead them to an early depression. In sum, the family wishes to spare the patients from more suffering. Thus, telling the truth to the

patients as individuals is still controversial in the Saudi culture .The physicians are facing an ethical dilemma because of the family request to hide the truth from the patients (Aljubran, 2010; Al-Amir, 2009). This inability to discuss impending death may lead to a communication gap between physicians and patients, with the situation preventing professionals from discussing the patients' feelings about what they are going through. In fact, health care providers in Saudi Arabia avoid discussing and explaining the cancer to their patients. Physicians are afraid or do not know how to break the bad news (Aljubran, 2010).

However, because nurses are usually the first to approach and discuss the feelings of fear of death with the patients, nurses should be aware of their patients' state of mind. This information is important because the patients can have fear of dying and/or depression that may affect their treatments and outcomes. Nurses should be proactive and educate their patients and their families when a diagnosis is first given to a patient. If education about fear of death is discussed early in their treatments, then more patients and families might become more comfortable with the issues, and the entire family may be able to be more supportive during the initial highly stressful diagnostic phase (Watson, 2001).

Further, most of the treatment in Saudi Arabia targets symptom management. However, if the health care providers referred patients to psychiatric services more often, and made use of the psycho-therapeutic resources available, patients' quality of life might significantly increase by reducing depression, anxiety and fear, as well as helping the process of adaptation to coping with this new phase of life (Aljubran, 2010; Al-Amir, 2009). Death depression and death anxiety are universal phenomena. These feelings are

often not discussed. This may be due to a lack of communication and embarrassment to share feelings with others. This research may expand the knowledge base about death anxiety and death depression in Saudi Arabia that might help improving patients' quality of life.

## **Chapter II. Review of the Literature**

This chapter presents the review of literature relevant to depression, death depression, and death anxiety in cancer patients. First is a review of the depression literature, followed by a review of death anxiety, and finally a brief summary of the literature.

### **Death Depression**

Little research has been conducted with Muslim cancer patients and their emotional needs. Research about death depression also is very limited and there are only two instruments that measure death depression. One of them is Templer's Death Depression scale which is 17- items, and the other one is the Death Depression scale-Revised (Templer et al. 2001). However, studies of depression in cancer patients in other cultures have been conducted and their findings could lead to further investigation in the Muslim culture.

Alvarado, Templer, Bresler, and Thomas-Dobson (1995) conducted a study to investigate the relationships of religious variables to death anxiety and death depression. Their sample included 200 people, male and female, from the general heterogeneous population. The subject had mean age of 31.5 years, and included different religious groups, 46 % were Catholic, 23% Protestant, 5% Jewish, 3% non-believers, and 24% other. All subjects completed Death Anxiety and Death Depression Scales, and the

religious inventory. The result indicated that the lower death depression score and death anxiety are associated with belief in God and greater belief in afterlife.

Harville, Stokes, Templer, and Rienzi (2003-2004) also found that the individuals who experienced less depression had a greater strength of conviction and greater belief in afterlife. This study took place among 500 adults from undergraduate and graduate college students, work setting, church group, and community organizations. The participants were given three different scales which were the Death Depression Scale-Revised, Life attitude Profile-Revised, and Brief Religious Inventory. Afterlife belief and believing in God was negatively correlated with depression.

A similar study by Roshdieh, Templer, Cannon, and Canfield (1998–99) was conducted to determine the relationship of death anxiety and death depression of Iranian Muslims to war-related events during the 1980-1988. In addition, the study also aimed to examine the relationship of religious variables to death anxiety and death depression in individuals who were both Muslims and Iranian. A total of 1176 Iranian students participated in the study.

Participants completed four scales that included Death Anxiety and Death Depression Scale, the religious inventory regarding war-related experience, and inventory modification for Muslims. The study findings show that those who had uncertain religious beliefs and did not believe in life after death, experienced higher death anxiety and death depression levels. The study suggested that there is a strong relationship between death anxiety and death depression ( Roshdieh et al., 1998–99).

According to Templer, Lavoie, Chalgujian, & Thomas-Dobson (1990) perception of death and thinking about death, and loss of loved ones might bring feelings of sadness,

sorrow, and depression. Moreover, depression is one of the most common psychological disorders among cancer patients in general and has been examined in several studies.

Goodwin, Dong, and Ostir (2004), studied the consequences of depression on the diagnosis, treatment, and survival of geriatric females with breast cancer. Overall, 24,696 women aged 67 to 90, diagnosed with breast cancer were included in this study. The findings revealed that there was less probability of women being diagnosed with depression while obtaining treatment. Depression was shown to affect survival rate.

In 2006, the effects of cognitive behavioral therapy (CBT) were the focus of a study by Osborn, Demoncada, and Feuerstein that focused on stress management and problem solving. The study also looked closely at patient education (PE) that included aspects such as, depression, anxiety, pain, physical functioning, and quality of life (QOL) issues. The study was conducted with 1,492 cancer survivors with types of cancer. A total of 709 patients were selected for the interventions; the other 702 were assigned to the control group. The results showed that CBT has a great effect in short and long term management of depression, anxiety, and QOL. The study also provided evidence to those group settings was less beneficial than individual interventions. Where CBT failed to help patients manage pain, PE helped individuals effectively manage their pain for up to eight-months. However, it is important to note that these two approaches must be used in combination for effective pain management in cancer survivors.

Ell and colleagues (2005) studied depression in low income, ethnic minority women with breast or gynecological cancer. Subjects numbered 472 and all had been diagnosed with either breast (Stage 0-III) or gynecological cancers. All

subjects were in the process of receiving follow-up care. The women were mostly single Latinas with a mean age of 50. Primary language among them was Spanish and most did not have an educational level past the ninth grade. Individuals were interviewed in either English or Spanish language by telephone interview. The patient Health Questionnaire (PHQ) was used to help diagnose major depression. In addition, subjects were screened and also given baseline questionnaires at the time they were receiving active treatment or during active follow up treatment. The study found that neither the cancer stage nor treatment status was correlated with depression. Ell et al. (2005) theorized that age and low income led to depression which, in turn, led to barriers and lack of understanding of treatment recommendations. If addressed and treated regularly, depression disorders may become less common among that particular population. The study suggests the need to integrate depression care within the oncology care plan.

A similar study by Lloyd-Williams and Friedman (2001) examined the relationship between age, history of psychiatric illness, and social support with the incidence of depression in the advanced cancer patients and also assessed the undetected depression rate. The sample size consisted of 100 patients ranging in age from 18 to 70 with advanced metastatic cancer receiving palliative care. Patients were interviewed using the Present State Examination interview (PSE) and semi-structured interview. The investigators asked in the interviews whether the patients had social support. The results showed that there was no correlation between the depression incidence and the history of social support. In this study the

result of the depression incidence rate was 22% according to PSE. The study concluded that the older patients have the highest rate of emotional distress.

A study by Tavoli and colleagues (2008) involved 142 adult cancer patients who had been hospitalized with gastrointestinal cancer diagnosed within the last 12 months. This study analyzed the relationship between pain beliefs, depression, and QOL. Ninety-eight of these individuals reported pain while 44 reported not experiencing significant pain. The Hospital Anxiety and Depression Scale, consisting of 14 items, was used to determine rate of depression. The European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC-QLQ-C30) was used to measure the QOL. Pain Beliefs and Perceptions Inventory (PBPI), was used to measure pain perception. All the instruments were to be used by the psychologist in the direct meeting interview.

Results showed that QOL and emotional function were significantly lower for patients experiencing pain than patients who had not reported pain. The lower QOL contributed to greater depression in those individuals experiencing pain. Another important factor included religious and personal beliefs, which affected beliefs about pain (Tavoli at al., 2008).

### **Death Anxiety**

Death is a normal expected fact in the process of life. Perhaps what most people fear is not the certainty that life will end one day, but the uncertainty of what comes after death. They wonder if there is Hell or Heaven, whether there any something else! It is still uncertain why people fear and worry about death. In 2002, Abdulkhalek tried to answer the question “Why do we fear of death?” He studied 307 undergraduate college

students from Egypt, Lebanon, Kuwait, and Saudi Arabia who were mostly Muslim college students. All the chosen participants were asked to answer questions from eight different scales including the Reason for Fear of Death scale, The Death Anxiety Scale, The Death Depression Scale, The Death Obsession Scale, and The Arabic Scale of Death Anxiety, the trait subscale of the State-Trait Anxiety Inventory, and the Kuwait University Anxiety Scale.

All the instruments were identified as reliable and valid to be used in the Arabic version. Results showed that some of the reasons for death anxiety were the fear of leaving the world and invoking God's punishment along with the fear of dying alone and being separated from loved ones. This study highlights the strong relationship between religious beliefs and fear of death among young people. However, the result cannot be generalized since the findings of this study were only from undergraduate college students. (Abdulkhalek, 2002)

Another study conducted to by Suhail and Akram (2002) examined death anxiety in Pakistan. A total of 132 male and female Pakistani adults participated in the study. Participants were interviewed using the Templer Death Depression Scale and the Collett-Lester Fear of Death Scale. All samples selected were divided into four groups, with half of each gender belonging to a younger group and the other half belonging to an older group.

The results showed that greater death anxiety was found among women, less religious people, and older people. The study confirmed that high levels of death anxiety correlated with gender, age, and religiosity (Suhail & Akram, 2002)

A cross-sectional recent study by Tang , Chiou , Lin , Wang , and Liand (2011)

conducted on 219 cancer patients male and female who were aware of their advanced cancer conditions. The purpose of this study was to explore the correlation of death anxiety between Taiwanese cancer patients. Participants were asked to answer three questionnaires that included: a demographic questionnaire, Purpose in Life scale, and Templer Death Anxiety Scale.

Data was analyzed by using the stepwise multiple regression analysis. The result demonstrated that average score of death anxiety was 44.79 that indicated that the fear of cancer and relapse had a great effect on level of death anxiety. Stage of initial diagnoses was highly associated with anxiety and indicated that people who were newly diagnosed with cancer had greater fear of death than other cancer patients (Tang et al., 2011).

A study was done by McClain-Jacobson and colleagues (2004) on 276 terminally ill cancer patients to examine whether the belief in life after death could affect the level of distress. The findings revealed that there was a correlation between believing in life after death and lower levels of hopelessness, thoughts about suicide, but there was no significant relation in regards to anxiety or depression level.

An exploratory study reported by Sigal et al. (2008) aimed to determine how cancer patients in different stages of the illness can deal and cope with the three death anxieties: fear of pain and suffering, loneliness, and the unknown. The authors hypothesized that the patients in the late stages of cancer would have the greatest level of death anxiety. The study was conducted on two groups of patients; group one consisting of 50 patients with mean age 53.3, who were in stage I or II of the disease. Group two consisted of fifty-four advanced stage cancer patients with a mean age of 55. All the participants were asked to answer and complete the French version questionnaire as the

study was conducted in Canada. Death anxiety was measured by the Death Anxiety Questionnaire. Coping lifestyle, life anticipation, and their spiritual values were also assessed. Pearson correlation coefficient was used in this study to determine the relationships between the variables.

Although there are no significant differences in the results between the two groups, the results showed that group one (less advanced) had a correlation ( $p < .001$ ) in all three death anxieties, and group two (more advanced) reported the correlation between the fear of loneliness and unknown. The most unexpected result in the study was because, although group two had a more advanced type of cancer, it was more familiar with the cycle of treatment and had learned that the pains did not mean that were becoming worse (Sigal et al., 2008)

Fear of death and a good death was studied by Tsai, Wu, Chiu, Hu, and Chen (2005). The researchers evaluated whether fear of death is a common characteristic among terminally ill cancer patients. By studying two different age groups of patients with terminal cancer, the study investigated the differences in the degree of death fear and the relationship between good death and death fear in these two groups in Taiwan. The sample consisted of different types of cancer patients, all terminally ill who were admitted to the palliative care unit in the National Taiwan University Hospital. They were divided into two groups; the elderly group and the non-elderly group. The data was collected by assessing patient's fear of death at the points of admission, one week after admission and two days before death, and by assessing good death, or accepting death, at two days before death.

The good death assessment consisted of five factors that include awareness of death, accepting death, arranging will, death timing and degree of physical comfort three days before death. After each patient's death, a score from 0-15 determined the extent to which it was a good death. The death fear assessment consisted of a five- point scale( 1= very little fear, peaceful and happy; 2= little fear but can be managed and no company required; 3= fear and company is required but the fear can be managed; 4= extreme fear, company required, and fear of sleeping at night; 5= insanity and confusion, losing autonomy, and rejecting help from others (Tsai et al., 2005).

The study showed that the score of death fear among the elderly group was significantly higher than the score of the non-elderly group at the time of two days before death. In addition, they found that the level of death fear decreased in both groups after being admitted. As for the good death scale, the study showed no significant differences between the two groups. However, a significant negative correlation was found between death fear and good death in the non-elderly group.

The analysis of the data in this study showed that the elderly group exhibited a higher degree of death fear at two days before death more than the non-elderly. Also, it showed that the degree of death fear decreased under comprehensive palliative care. Lastly, in both groups, patients who had a lower level of death fear scored higher on the good death scale. These study findings show that if a patient's death fear level has been reduced it might improve the quality of life. Accordingly, elderly terminally ill cancer patients are in need of spiritual and psychological care (Tsai et al., 2005).

A recent study conducted by Shinn and colleagues (2009) examined the quality of life of women with ovarian cancer felt and what they were concerned about regarding

their own lives. This study evaluated 245 ovarian cancer patients, with a mean age of 59, who were just starting a chemotherapy course. The QOL of patients diagnosed with ovarian cancer was measured by the Functional Assessment of Cancer Therapy–Ovarian (FACT-O). This scale consists of a 38 -item questionnaire with four subscales which includes; physical, social, functional, and emotional well-being. Results showed that 55%, or the majority of patients, have a fear of death and 31.6% admitted to loss of hope.

The study confirmed that a high number of patients had a fear of dying, and this feeling still existed regardless of the stage or progress of the disease. The authors emphasized the importance of being aware of a patient’s emotional health, as this can affect their treatments and outcomes (Shinn et al., 2009).

A diagnosis of breast cancer can seriously affect women and their emotional well-being. Body image and sexuality are issues that worry breast cancer patients. In a qualitative study, Vilhauer (2008) interviewed 14 Caucasian women with metastatic breast cancer who were all involved in online support groups. The mean age of the women was 51.6 years. The study aimed to assess the experiences of women diagnosed with metastatic breast cancer. A 30-90 minute recorded interview was done by phone, using open-ended questions to encourage the patients to talk about what they felt. The result showed that 71% of patients reported having fear of death. The women’s fear came from the stress of worrying about dying, the fear of the disease progression, the loss of their future, and practical concerns such as fear of being dependent, and not able to do normal daily activity.

Mystakidou et al., (2005) conducted a focused study with cancer patients receiving palliative care. The study concerned the desire of either hastening death, or

desire for death. Researchers approached their study by assessing the relationships between depression, anxiety, pain and desire for hastened death in a group of 120 Greek adult patients who were terminally ill. All 120 patients who participated in the study were over 18 years old, diagnosed with advanced cancer and able to participate and communicate with the palliative care research team.

The study started with short interviews to elicit medical history, demographic data, previous mental health and present condition. It was followed by a 20-item true/false measure of the desire for hastened death from the Greek version of the Schedule for Attitudes toward Hastened Death (G-SAHD). According to the G-SAHD scale, patients who score seven or higher are classified as having a high level of desire for death and patients who score 11 or higher are classified as having a strong desire for death. In addition, a Greek version of the Brief Pain Inventory (G-BPI) assessment was used to measure the patient's level of pain intensity using simple numeric rating scales from 0 to 10. The study's results showed that 8.3% of the patients had a high desire for death while an additional 5% of patients had a strong desire. This result was comparable with those from the American and Canadian palliative care studies that examined end of life despair among terminally ill cancer patients. This led to emphasize the importance of mental health care for palliative care patients around the world (Mystakidou et al., 2005).

### **Summary**

In summarizing the review of literature, there is a gap in research in the area of death anxiety and death depression in cancer patients. Early research suggested that depression and anxiety are common problems among cancer patients. However, until

recently there were limited studies and information about the relationship between death anxiety and death depression.

With the diagnosis of cancer, it has been found that these particular patients have high rates of depression (Goodwin, Dong, & Ostir, 2004; Osborn, Demoncada, & Feuerstein, 2005; Kathleen et al 2005; Lloyd-Williams & Friedmant, 2001; Tavoli et al., 2008). Level of death anxiety varies among the cancer stages but there are not many studies about fear of death and death anxiety among patients in early stages of cancer, and most of the studies that exist focused on the terminally ill at late stages of the disease (McClain-Jacobson, et al., 2004; Mystakidou et al., 2005; Tsai, Wu, Chiu, Hu, & Chen, 2005; Vilhauer, 2008).

Death anxiety and death depression are worldwide phenomena. However, the Saudi Muslims patients live in a homogenous society where all have the same belief of life after death and the creation of soul and body. Research suggested that lower levels of death anxiety and death depression are correlated with increased spirituality (Alvarado et al., 1995; Harville et al., 2003-2004; Roshdieh et al., 1998–99).

However, more research is needed to further explore this relationship. Thus, the relationship between the death anxiety and death depression in persons with cancer in Saudi Arabia remains unclear.

### **Chapter III. Methods**

This study involves the secondary analysis of de-identified data collected in Saudi Arabia. This chapter describes the research methods and procedures used in this study. First, the sample and setting selection are described. Second, the instruments included in the study are discussed. Third, research procedures are described including the data collection methods, and finally, the data analysis plan is discussed.

#### **Setting and Sample**

The data was collected in the outpatient clinic of a comprehensive cancer center in Saudi Arabia. The target population was male and female adult cancer patients who met the eligibility criteria and consent to participate in the study. The participants were included regardless type or stage of cancer. Eligibility criteria included: (1) being an adult over the age of 16, (2) being able to speak and read the Arabic language, (2) willingness to participate in the study.

Exclusion criteria: (1) Patients with history of psychiatric illnesses or who were recently diagnosed with depression, (2) Debilitated, comatose, or actively dying patients who may not have the ability to provide consent or answer the research questionnaires. Target sample was 100 patients.

## **Instruments.**

Three Instruments were used for this study. They were: (1) The Arabic Scale of Death Anxiety (ASDA), (2) Death Depression scale-Revised (DDS), and (3) a Demographic Data Form.

**The Arabic Scale of Death Anxiety .**The Arabic Scale of Death Anxiety (ASDA) consists of 20 statements on a summated rating scale. Each item is answered on a 5-point intensity scale [1 = no and 5 = very much) (Appendix A). This instrument was tested on a healthy sample of undergraduate college students and has never been used in cancer patient populations before. Four factors of the ASDA were analyzed for construct validity (Fear of Dead People and Tombs, Fear of Post Mortem Events, Fear of Lethal Disease, and Death Preoccupation). The ASDA has Arabic and English comparable versions (Abdel-Khalek, 2004).

***Reliability and Validity:*** The scale has good reliability and internal consistency, Cronbach's alpha reliability ranged from 0.88 to 0.93, and item-remainder correlations ranged between 0.27 and 0.74 ( in three Arabic countries). The correlations between the ASDA and other scales such as Templer's Death anxiety Scale ranged from 0.60 to 0.74; this correlation supports good convergent validity of the ASDA. A limitation of this instrument is its generalizability. The instrument needs to be tested on cancer patients, different age groups, and more diverse ethnic groups (Abdel-Khalek, 2004).

**Death Depression scale-Revised .**The Death Depression scale-Revised (DDS) was chosen to measure death depression (Appendix B). It consists of a 21-item, summated rating scale designed to measure depression about impending death or death in

general. Items are scored from 1 (Strongly disagree) to 5 (strongly agree). Further, the DDS-Revised had been translated to the Arabic language which makes it suitable for use in the targeted population of this study. The DDS-Revised comprises four factors with eigenvalues greater than 1.0. Factor one has been classified as “death sadness” (items 6, 5, 4, 1, 2, 3, 7). Factor 2 was classified as “anergia” (items 11, 12, 13, 14). Factor 3 was classified as “existential vacuum” (items 15, 16, 17). Factor 4 was classified “anhedonia” (items 8, 9, 10) (Templer et al. 2001).

***Reliability and Validity:*** The scale has good reliability and internal consistency. Cronbach’s alpha reliability was 0.92, and .85,  $P < .001$  for the Likert –type and true-false formast respectively, since they were both tested (the DDS-Revised and the original Death depression Scale). Templer and colleagues (2001) found moderate correlations between the DDS –Revised and the Death Anxiety Scale ( $r = .50$ ). The investigator found significant intercorrelations between the DDS-Revised and other scales such as Death anxiety, general depression, and general anxiety. It was found that the DDS correlates more highly with the general anxiety than the general depression. These positive significant correlations support good convergent validity of DDS-Revised (Templer et al.)

**Demographic Data Form.** The demographic and personal characteristics of the subjects were collected using a Demographic Data Form (Appendix C). The data included in this form are: age, gender, ethnicity, educational background, marital status, employment status, underlying cancer diagnosis, stage of their cancer, and history of depression.

## **Procedures**

Research permission was obtained from the National Guard Hospital's Scientific Review Committee; written consents were taken from each patient, and patients received a copy of the consent form to keep. The procedures and purpose of the study were explained to the patient and the researcher was available to answer all the participants' questions. Patients were seated in a quiet private place to answer the three questionnaires. Questionnaires were returned to the investigator when they were completed. All data and the information are highly confidential. De-identified data were made available to the present investigator, and this secondary analysis was submitted to the University Of South Florida IRB for approval prior to data analysis.

## **Data Analysis**

Descriptive statistics were used to analyze demographic data including percentages, frequencies, means, and standard deviations.

Data was analyzed with means and standard deviations to answer the following research questions:

1. What is the level of death anxiety in patients with cancer in Saudi Arabia?
2. What is the level of death depression in patients with cancer in Saudi Arabia?

To answer question 3. What is the relationship between death depression and death anxiety among cancer patients? a Pearson correlation was used.

To answer question 4. Are there differences in men and women in their scores on death anxiety and death depression? an Independent t-test was used.

To answer question 5. What is the relationship between type of cancer and either death depression or death anxiety and? an Independent t-test was used.

## Chapter IV. Results, Discussion and Conclusions

The following chapter presents the results of this study, discussion of the results and limitations of the study. Finally the chapter concludes with recommendations for further research.

### Results

**Demographic data.** The data were analyzed using SPSS version 20. A sample of 100 Saudi cancer patients, 50 male and 50 female, ranging in age from 18 to 85 with a mean age of 45.5 (SD=16.3) were recruited for this study. The majority of the participant's held a Bachelor's degree or higher. Also, the majority was married and living with family; in addition all participants were Muslims. Two types of cancer were identified in the sample; solid and Hematological cancer with majority of patients having solid tumors (75%) comparing to (25%) Hematologic tumor (Table 1)

**Death Anxiety.** To answer question 1, "what is the level of death anxiety in patients with cancer in Saudi Arabia?" The Arabic Death Anxiety Scale (ASD) was used. Total ASDA scores had a mean of 52.3 (SD=22.3) (Table 2). To further explore the issue of death anxiety, an item analysis was conducted (Table 3). Among the ASDA items "I fear the torture of the grave" obtained the highest mean score of the 20 ASDA items mean= 3.5 (SD=1.6). The item "I worry that death may deprive me of someone dear to me" was the second highest score mean= 3.2 (SD=1.5). Likewise, "I fear death whenever I

become ill” was the lowest score item mean= 2.1 (SD=1.4) and “I fear death” was the second lowest score with mean= 2.4 (SD=1.5).

Table 1

*Frequency and Percent of Participants’ Gender and Type of cancer*

	Frequency	Percent
<b>Gender</b>		
Female	50	50.0%
Male	50	50.0%
<b>Education</b>		
Elementary school	7	7.0%
High school	12	12.0%
Associate degree	19	19.0%
Bachelor	35	35.0%
Doctor	6	6.0%
Other	21	21.0 %
<b>Type of cancer</b>		
Solid tumor	75	75.0 %
Hematologic	25	25.0 %

Table 2

*Mean and standard Deviations death depression total and death anxiety total*

Scale	Mean	SD
ASDA total	52.3	22.4
DDS total	54.0	21.7

**Death Depression.** To answer questions 2, “what is the level of death depression in patients with cancer in Saudi Arabia?” The Death Depression scale-Revised (DDS) was administrated. Total DDS mean score was 54 (SD=21.7) (Table 2). To further explore the issue of death anxiety, an item analysis was conducted (Table 4). The highest scoring item of DDS-revised scale was “Dying must always be an unhappy process” (mean= 3.4; SD=1.4), in addition, item “The process of dying is sure to be the saddest time in my life” was the second highest score (mean = 3.2; SD=1.3). Further, “The thought of death saps my energy” obtained the lowest mean score (mean= 2; SD=1).

**Correlation.** A Pearson correlation was used to answer question 3, “what is the relationship between death depression and death anxiety among cancer patients?” The result indicated a strong positive significant relationship between the two variables ( $r=.85, p < .001$ ).

Table 3

*Means and standard Deviations of items of death anxiety*

The Scale Item	M	SD
1-I fear death whenever become ill.	2.1	1.3
2. I fear looking at the dead.	2.5	1.5
3. I fear visiting graves.	2.3	1.4
4. The possibility of having a surgical operation terrifies me.	2.7	1.2
5. I am afraid of suffering a heart attack.	2.4	1.4
6. I worry that death may deprive me of someone dear to me	3.1	4.1
7. I am apprehensive of unknown things after death.	2.9	1.5
8. I am afraid of looking at a corpse.	2.7	1.7
9. I fear the torture of the grave.	3.4	1.5
10. I fear getting a serious disease.	2.5	1.3
11. Witnessing the burial procedure terrifies me.	2.5	1.4
12. I dread walking in graveyards.	2.3	1.4
13. I am preoccupied with thinking about what will happen after death	2.6	1.4
14. I am afraid of sleeping and not waking up again	2.3	1.3
15. The pain accompanying death terrifies me.	2.6	1.3
16. I get upset by witnessing a funeral	2.3	1.3
17. The sight of a dying person frightens me.	2.8	1.3
18. Talking about death upsets me.	2.2	1.3
19. I am afraid of cancer	2.7	1.5
20. I fear death	2.4	1.5

Table 4

*Means and standard Deviations of items of death depression*

The Scale Item	M	SD
1. When I think about death, I feel empty	2.4	1.3
2. Thinking about death makes me tearful	2.9	1.3
3. Dying must always be an unhappy process	3.4	1.3
4. Nothing saddens me more than knowing friends and relatives will eventually die	2.8	1.3
5. The process of dying is sure to be the saddest time in my life	3.1	1.3
6. The thought of death makes me sad	2.8	1.2
7. Death is a lonely matter	2.8	1.3
8. The thought of death makes it difficult to experience pleasure	2.3	1.3
9. When I think about death, I lose interest in activities of life	2.4	1.3
10. I lose interest in caring for myself when I think about death	2.3	1.3
11. When death is on my mind, my body seems to lose energy and slow down	2.4	1.3
12. The thought of death saps my energy	2.1	1.1
13. It's hard to concentrate when death is on my mind	2.5	1.3
14. When I think about death, even the easiest of tasks becomes difficult	2.5	1.4
15. Death makes me feel discouraged about the future	2.2	1.3
16. Why try in life if you are only going to die	2.1	1.2
17. Death makes me feel hopeless	2.1	1.2
18. Wakes and funerals are depressing	2.7	1.3
19. It is impossible to ever get over the death of a loved one or close friend	2.5	1.2
20. I am terribly upset by the shortness of life	2.3	1.2
21. I dread to think of the death of friends and loved one	2.8	1.3

Independent t-tests were used to answer question 4, “Are there differences in men and women in their scores on death anxiety and death depression?” The result indicated the female group obtained higher mean scores in both the ASDA and the DDS scores than the male group (Table 5).

Table 5

*Independent t-test comparison of men and women in their levels of death depression and death anxiety*

Variables	Male		Female		t	P
	M	SD	M	SD		
ASDA total	44.9	18.9	59.3	23.5	- 3.27	.001
DDS total	47.1	19.9	61.9	21.5	-3.34	.001

Table 6

*Independent t-test comparisons between death depression and death anxiety by type of cancer*

	Solid		Hematologic		t	P
	M	SD	M	SD		
ASDA total	49.2	21.5	60.9	23.3	-2.2	.026
DDS total	50.1	19.9	65.8	23	-3.2	.001

## **Discussion**

**Demographic Data.** After IRB approval from the National Guard Hospital's Scientific Review Committee where the study was conducted in Saudi Arabia, data collection began in August, 2010. A convenient sample of 100 Saudi cancer patients participated in this study. The purpose of this study was to investigate the relationship between death depression, and death anxiety among cancer patients in Saudi Arabia. Arabic Death Anxiety Scale (ASD) and The Death Depression scale-Revised (DDS) were incorporated in this study. The current study appears to be one of the first studies assessing death anxiety and death depression in Saudi patients.

Equal numbers of men and women were strength of this study, making gender comparisons possible. The sample was a relatively well educated group, with the majority having at least a bachelor's degree. This highly educated sample may not be representative of the majority of Saudi citizens. The fact that all patients in the sample were Muslim probably made them more representative of the majority of cancer patients in Saudi Arabia, a country where Islam is the national religion.

**Death Anxiety.** Death anxiety was assessed using the Arabic Death Anxiety Scale (ASDA). The mean score on the ASDA was 52.3 out of a possible 20-100 (SD=22.3). The level of death anxiety found in this study was actually below than the mid-point but some patients had much higher scores that indicated possible death anxiety among Saudi cancer patients. Explanations for this could be related to the different bearing on the individuals. These scores may be caused by a variety of factors. First, Muslims believe in life after death; thus, some patients might have found confidence in that hop, while others were fearful. Further, some patients who were earlier in the disease

process might have had few symptoms, making it more possible for them to use the psychological defense mechanism of denial.

These results might be affected by the fact that how the individuals in the Saudi society see death and their perception of death on the basis of their religious belief might be a factor affecting the responses of the individuals to this scale thus affecting the overall results of the study.

Moreover, patient's responses may be built more on emotional characteristics of the participants, since ASDA scale items are based on questions regarding serious illness like cancer, death, and death experience that provoke the death anxiety level, such as "I fear death, I fear death whenever I become ill, I fear getting a serious disease etc". Since the study was conducted on cancer patients, it might be deduced that these cancer patients scored high in ASDA owing to the pain of their illness, fear, and suffering caused to them by their disease. In addition, cancer patients may be afraid of death since they had realized that they may be leaving the world without completing their tasks and leaving their family and loved ones behind. This also could have contributed to the feeling of anxiety that these patients had.

"I fear the torture of the grave" was the highest score on the ASDA scale and "I worry that death may deprive me of someone dear to me" was the second highest on the scale. The origin of the patients, that they all belonged to the same Saudi society and were of same faith, contributed in the more or less same anxiety levels shown by the participants. The Islamic teachings that strongly foretell of the afterlife and belief in afterlife are considered to be cornerstone of Islam. After death, there is a life when the soul and body resurrect and this afterlife starts from the burial in the grave. Based on the

deeds, a person might go to paradise or hell. In other words, if a person had done more wrong deeds, he/she will be approaching hell afterwards, for which Azab Al Qabr takes place within the grave. In Islam, Azab Al Qabr is known as agonies or “Torture of the grave”. Quran teaches the followers to be very careful in every move that they take in the world, thus, well known among Muslims, the punishment for the wrong deeds starts immediately after death. According to the teachings, the deceased is questioned on the first night in the grave. In regards to the high scores of death anxiety and the torture of the grave, this may be premised on their religious beliefs based on the teachings of the Quran. Thus, responses of Muslims could be emotionally negative (Hossain & Siddique, 2008; Abdulkhalek, 2004).

Therefore, Patients may fear the unknown more than the known and understand that this is not the end yet just the beginning of a new life. According to Islam, death is just the beginning of new life and grave is the gateway to either hell or paradise. God informed people in the Quran that people belong to God and that we will return to God. “To Allah we belong and to Him we shall return.” (Surah Al Baqarah 2:156). This led to, “I fear death whenever become ill” and “I fear death” to be the lowest scores. Accordingly, people who are sinful perhaps show higher levels of anxiety as compared to the ones who lead their lives according to the teachings of the Holy Quran. Patients may not be really afraid of the moment of death or dying; but rather may fear the illness and pain combined with death and the unpredictable circumstances that surround it (Abdulkhalek & Al-Sabwah, 2006).

Another explanation for the above findings could be the social-desirability response bias. Since Saudi society is a Muslim community in general, the responses of

the patients could be biased since they might want to prove themselves true and faithful Muslims who are not afraid of death at all. This could lead them to base their answers on false representation of themselves just to avoid any criticism which could affect the overall results of the study.

**Death Depression.** Death depression was measured using The Death Depression scale-Revised (DDS) with a total DDS mean score of 54 (SD=21.7) out of a possible 21-105 putting the mean slightly below the mid-point. However, some patients had scores that were much higher. The items for death depression are measured on a five-point scale and are mostly associated with depression mode. Most of the items on the scale use the word “death” for example, “When I think about death, I feel empty”; “Thinking about death makes me tearful”; “The thought of death makes me sad”; “The thought of death makes it difficult to experience pleasure.”

The above findings may correlate to the indirect relation of the subject of death with cancer. A cancer diagnosis may involve being informed of a time limit for survival. During the remaining life span, the individual may assume this may be the last birthday celebration mode, or this is the last summer, and the last holiday with the family. These thoughts and experiences may lead to a change in patient’s moods, and thus correlate to a higher level of death depression. Cancer patients might be punched with deep depression, forcing them unconsciously to answer the questionnaire. The subject of death could bring feelings of melancholy, unrest, mental distress that may result in depression. After patients are diagnosed with cancer and know about their stage and type of treatment, their level of depression can be increased (Mhaidat et al., 2009 & Tavoli et al., 2008). The hardest moment in cancer patients’ lives could be when living life with the fear of facing

death every day leads to feeling depressed about death. It is the end of life, and time is running out but no one ever wants to die before enjoying hobbies, leisure activities or spending time with friends and family. These feelings might affect the patients' responses on the death depression scale.

The items that scored high on the DDS-revised scale were "Dying must always be an unhappy process" and "The process of dying is sure to be the saddest time in my life". According to the responses on the depression scale, most of the patients agreed that the process of dying is an unhappy process. An explanation of the above may associate with the fact that cancer diagnoses could affect emotional feelings of patients. This is an emotional pain as well as a physical pain, leading to what may be the saddest time in their lives. Death can occur suddenly and at any time; no one can predict when exactly it will happen. However, patients may worry about the moment of death and have concern about what will happen when death is approaching. On the other hand, when patients, friends and family members make plans for the future, the cancer patient may see death is near and may not be there to join in. This tendency to isolate oneself from others during the process of dying can also indicate a possible relationship to death depression.

Thinking of death and the thought of leaving the loved ones behind may be the factor that generates feelings of sorrow, sadness, pain and pessimism in such patients. As death approaches physical and emotional changes occur, besides losing independence and becoming dependent on others as the medical condition progresses can be difficult; adjustments have to be made that all lead to a sense of losing independence and the approaching of the saddest time in life. The realization that the person may be experiencing the last event in life can be very difficult to process, resulting in sadness and

feelings of depression about impending death. Patients might start evaluating themselves, their gains and losses throughout their life span, by recalling their memories and pondering upon their deeds and acts.

Patients with life threatening illnesses generally experience a lot of pain and emotional distress, but do not express their feelings of fear, anger, and denial to others, thus, a lack of feeling connected and openly sharing can also led to depression. Patients may like to share feelings with their relatives and friends, but may be afraid because of the pain that this emotional pain may cause to a loved one. That may force them to face the death alone. These feelings often lead to higher levels of depression about impending death (Tavoli et al., 2008; Vilhuer, 2008; Sigal et al., 2008). Family members should continue to seek the advice of the patient and continue to involve the patient in everyday routines as tolerated. Offering choices to the patients would allow them to feel a sense of control over the situation.

Further, the item “The thought of death saps my energy” and “Why try in life if you are only going to die” obtained the lowest scores among the scale items, since death can happen anytime to anyone and no one knows exactly when they will die. Most of the patients believed that it was unnecessary to spend time thinking on something that was unknown (Hossain & Siddique, 2008). The reason for this could be the fact that these patients already had their disease diagnosed and were unsure of their death, but this did not affect them in any way. The low scores on the scale for these items may relate also to that the patients were hopeful about their recovery from cancer. Also, it could be that the patients had hopes of living and wanted to cope with their disease. Family and loved ones can be one of the reasons for getting out of their illness and striving to cope with their

disease, which might elevate their energy levels and give them hope to live on. Another factor could be their strong religious beliefs that they were to meet their Creator after death, and death was the start of an eternal life. As the patients were nominally Muslims, this factor can be the most influential, since it is a basic Islamic teaching that death is the start of an eternal and peaceful life

**Correlation between death anxiety and death depression scales.** The findings indicated that there is a significant, strong relationship between death anxiety and death depression among cancer patients in Saudi Arabia. Nevertheless, the high correlation of .85 between Death Anxiety Scale and Death Depression Scale indicated that both instruments complement each other. That correlation may indicate overlap with identity relation. It appears that Death Depression Scale items are more related to death sadness and death preoccupation. Similarly in the Death Anxiety Scale includes more thought of death and shortness of life. In other words, preoccupation of death is congruent in both scales. Consequently, the two scales are asking mainly about death, death process, pain, and feeling empty that may perhaps enhance the relationship between the separate instruments.

Further, although from different authors, both scales measure mostly death attitude and have similar negative emotion stimulants overlapping on the death issue. Nonetheless, this thought can be painful and increase the anxiety and depression unconsciously (Pyszczynski, Greenberg, & Solomon, 1999).

As result, death anxiety and death depression among cancer patients increased simultaneously. These findings suggest that more people are anxious about death, the more they feel depressed about it (Roschdieh et al., 1998-99).

**Difference in gender scores.** The results of the study show that women experienced higher death anxiety and death depression as compared to men. The fact that women more easily show their emotions and culturally thought to be physically and emotionally weaker than men, could be the reason why women expressed more death anxiety and death depression as compared to men in this study. On the other hand, men are less likely to show their emotions and tend to have difficulty expressing their worries and fears.

An explanation for this emotional deception by men could be the social and cultural factors, since men are expected to be psychologically strong and are raised as such. They are expected to hide their inner feelings and emotions, which may lead their death anxiety and death depression not to be recognized. Also, men might try to present themselves as confident, that is, strong and fearless, which might affect the overall results of this study. The cultural factor cannot be neglected since in a Muslim household, a man is considered the head and responsible for looking after his family, which might be the reason for men to curtail their emotions and present themselves as strong so that family or others under his leadership are not affected.

In contrast, in a Saudi society, women are considered fragile and tender, and they are raised with great care and love, therefore, whenever they confront any problem, they are more likely to panic and undergo a lot of fears. Besides, women in Saudi society are more involved in household chores and caring for their children. As a mother and a wife, a woman may have higher anxiety than a man due to the sense of obligation to the family. The mother directly cares for children emotionally and physically. Her anxiety may be projected towards others more than the anticipated fear of pain and discomfort from her

illness. They might worry about leaving their children behind and be more concerned about their care. Further, they might be frightened that they may be leaving their children and loved ones behind and may never be able to spend time with them again.

**Relation between type of cancer and death anxiety and death depression.** The finding shows that patients with hematological malignancies exhibited higher levels of death anxiety and death depression than patients with solid tumors. Many factors such as cancer site, disease stage, age, cancer treatment, and time from diagnosis of the disease may affect the results of this study. Diagnosis of any type of cancer, whether solid or hematological malignancies, is a very traumatic experience itself for the patient. The patients face many stresses, pain, and fear of facing death. Rationalization for the above finding may be associated with the fact that patients who have a solid tumors might be in a better state of mind, as a surgical option, removal of the cancer, has a viable and somewhat predictable outcome. Prognoses for most solid tumor malignancies, especially if diagnosed early, are much better than in hematological cancers (Mukherjee, 2010).

Hematologic cancers, such as leukemias, are often diagnosed by accident, during routine blood work or because the patient is generally not feeling well; fatigue often sends them to seek medical help. Leukemia, especially acute leukemia, in adults does not have a good prognosis (Bernadette, 1995). Long-term treatments of hematologic malignancies mean undergoing therapy or treatment and confronting the pains associated with these treatments, change in body shape which may cause acute stress on the patient, thus resulting in anxiety and depression.

## **Conclusions**

This study explored the relationship between death anxiety and death depression among cancer patients in Saudi Arabia. The highlight findings of this study are: there was a strong relationship between death anxiety and death depression; the higher the anxiety level of the patients, the more they were depressed about death; further, there were significant differences between men and women for both between death anxiety and death depression; hematological malignancies produced higher levels of death anxiety and death depression than on patients with solid tumors.

However, the problem remains that two concepts have not yet been addressed by health care providers in Saudi Arabia. Death anxiety and death depression should be assessed routinely among patients by health care providers. Nursing interventions are really important. In addition, nurses should be aware of the patients' fears and worries, and they need to communicate with patients. Establishing support programs that include the family and referring patients to psychiatric services, if needed, would help patients to express their fears and cope with their anxiety and depression levels. That may increase quality of life and effect of the treatment.

**Limitations and recommendation.** This study cannot be generalized for all cancer patients because it is focused mainly on Arabic Muslim cancer patients. In spite of the convenient sample size of patients, findings were drawn solely from Muslims, Arab participants and do not include a specific cancer diagnosis making it difficult to generalize to all cancer patients. Further studies should include a larger sample size and a more ethnically, economically and religiously diverse group. In addition one of the instruments was developed in a population of healthy undergraduate students and had

never been used on cancer patients before, thus its appropriateness should be examined by further testing. Further research should be conducted and should include diverse cultures and beliefs.

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## **Appendices**

**Appendix A: The Arabic Scale of Death Anxiety (ASDA):**

*Instructions:*

Read the following statements, and then decide to what extent each one describes your feelings, behavior, and opinions. Show how far it does, or does not, apply to you in general by circling the appropriate number after each statement.

	<b>no</b>	<b>A little</b>	<b>Affair amount</b>	<b>Much</b>	<b>Very Much</b>
1-I fear death whenever become ill.	1	2	3	4	5
2-I fear looking at the dead.	1	2	3	4	5
3- I fear visiting graves.	1	2	3	4	5
4-The possibility of having a surgical operation terrifies me.	1	2	3	4	5
5- I am afraid of suffering a heart attack.	1	2	3	4	5
6- I worry that death may deprive me of someone dear to me.	1	2	3	4	5
7-I am apprehensive of unknown things after death.	1	2	3	4	5
8- I am afraid of looking at a corpse.	1	2	3	4	5
9- I fear the torture of the grave.	1	2	3	4	5
10- I fear getting a serious disease.	1	2	3	4	5
11- Witnessing the burial procedure terrifies me.	1	2	3	4	5
12- I dread walking in graveyards.	1	2	3	4	5
13- I am preoccupied with thinking about what will happen after death.	1	2	3	4	5

14- I am afraid of sleeping and not waking up again.	1	2	3	4	5
15- The pain accompanying death terrifies me.	1	2	3	4	5
16- I get upset by witnessing a funeral.	1	2	3	4	5
17- The sight of a dying person frightens me.	1	2	3	4	5
18- Talking about death upsets me.	1	2	3	4	5
19- I am afraid of cancer	1	2	3	4	5
20- I fear death.	1	2	3	4	5

**Appendix B: Death Depression Scale-Revised:**

*Instruction:*

Read the following statements, and then decide to what extent each one describes your feelings, behaviour, and opinions. Show how far it does, or does not; apply to you in general by circling the appropriate number after each statement.

	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Strongly Agree</b>
1. When I think about death, I feel empty.	1	2	3	4	5
2. Thinking about death makes me tearful.	1	2	3	4	5
3. Dying must always be an unhappy process.	1	2	3	4	5
4. Nothing saddens me more than knowing my friends and relatives will eventually die.	1	2	3	4	5
5. The process of dying is sure to be the saddest time in my life.	1	2	3	4	5
6. The thought of death makes me sad.	1	2	3	4	5
7. Death is a lonely matter.	1	2	3	4	5
8. The thought of death makes it difficult to experience pleasure.	1	2	3	4	5
9. When I think about death, I lose interest in activities of life.	1	2	3	4	5
10. I lose interest in caring	1	2	3	4	5

for myself when I think about death.					
11. When death is on my mind, my body seems to lose energy and slow down.	1	2	3	4	5
12. The thought of death saps my energy.	1	2	3	4	5
13. It's hard to concentrate when death is on my mind.	1	2	3	4	5
14. When I think about death, even the easiest of tasks becomes difficult.	1	2	3	4	5
15. Death makes me feel discouraged about the future.	1	2	3	4	5
16. Why try in life if you are only going to die.	1	2	3	4	5
17. Death makes me feel hopeless.	1	2	3	4	5
18. Wakes and funerals are depressing.	1	2	3	4	5
20. I am terribly upset by the shortness of life	1	2	3	4	5
21. I dread to think of the death of friends and loved ones.	1	2	3	4	5

***Appendix C: Demographic Data Form***

1. Age: What is your age?

2. Gender:  Male  
 Female

3- Marital status (check one).

single  
 married  
 divorced  
 separated  
 widowed

4- Have you ever been diagnosed with depression before cancer?

*Answer will be collected From Patient chart*

5- What type of cancer are you being treated for (breast, colon, lymphoma, etc.)

*Answer will be collected From Patient chart* \_\_\_\_\_

6- Educational levels:

Elementary School  
 High school graduate  
 Associate Degree  
 Bachelor  
 Master  
 Doctorate  
 Other: Specify

6-Who lives with you? (Check one or more answers below)

I live alone.  
 I live with my spouse.  
 I live with at least one family member who is not my spouse.  
 Other: Specify

7- What is your job/occupation?

*Appendix D: Informed Consent*

***Informed Consent Agreement***

**TITLE OF STUDY:** The Relationship between Death Depression and Death Anxiety among Cancer Patients in Saudi Arabia

**Please read this consent agreement carefully before you decide to participate in the study.**

**Introduction and Purpose of the research study:**

My name is Doaa Almostadi, a student pursuing a Master's Degree at the Oncology/Education Nursing Program. I am intending to conduct a study that focuses on the psychosocial impact of impending death for cancer patients in Saudi Arabia. Currently, with increasing numbers of cancer patients in Saudi Arabia, physicians and nurses rarely address the psychosocial issues. People diagnosed with cancer may become depressed and fearful of dying. This causes them to question treatments and sometimes avoid treatment altogether. There are few studies related to fear of death among cancer patients. Most of the published studies are focused on the terminally ill, so it is not clear what patients experience in the earlier stages of their illness. The purpose of this research is to examine the relationship between death depression, and death anxiety among cancer patients in Saudi Arabia You are invited to participate in this study.

**What you will do in the study:**

If you decide to participate in this study, you will be required to complete a questionnaire with survey interviewer. The survey questionnaire includes three parts: The first part contains a demographic data form; the second part consists of 20 statements to measure **death anxiety**. Each item is answered on a 5-point intensity scale [1 = no and 5 = very much], and the third part is a 21-item, questionnaire designed to measure depression about impending death or death in general.

**Time required:**

It will take approximately about 30 to 45 minutes to complete the survey.

**Risks:**

There are no anticipated risks to you in this study. If for any reason, a question causes an emotional response, the interview may be stopped if you wish, and participant help and counseling services will be offered.

**Benefits:**

There are no direct benefits to you for participating in this research study other than furthering the project and sharing your knowledge and experience. No promise or guarantee of benefits is being made to encourage participation. The survey is constructed to assist in determining the needs and perceptions of the study population and to examine the relationship between death depression, and death anxiety among cancer patients in Saudi Arabia.

**Confidentiality:**

The information in this study will be handled confidentially. All identifying information obtained data will be coded and will be kept in a locked file. Upon completion of the study, and data analysis, this identifying information will be destroyed. Your identifying information will not be used in any report. No one outside the project team will have access to the interviews. The information that you give in the study will be anonymous.

**Voluntary participation:**

Your participation in the study is completely voluntary. If you decide not to participate, there will be no penalty.

**Right to withdraw from the study:**

You have the right to withdraw from the study at any time without penalty.

**How to withdraw from the study:**

As a participant in this research, you are free to withdraw at any time without penalty. If you choose to withdraw, tell the interviewer to stop the interview.

**Payment:**

You will receive no payment for participating in the study.

## Agreement

I have read and understand this consent form and conditions of participation. I understand what is being asked of me. My questions have been answered. I freely agree to participate and have not been coerced into participation. I understand that participation is voluntary and that I may withdraw at any time without penalty.

Participant/ (Print Name) \_\_\_\_\_ Signature \_\_\_\_\_ Date \_\_\_\_\_

### You will receive a copy of this form

**Contact:**

**Principal Investigator:** *Doaa Almostadi, BSN, RN*

Oncology Nurse Practitioner Student.

Email: 

**Co-Investigator:** *Professor Susan C McMillan, PhD RN FAAN*

Distinguished University Health Professor

Thompson Professor of Oncology Nursing

Program evaluation, instrument development and testing.

(University of South Florida)

**Other Co-Investigator:** Dr. Amani Babgi, PhD, RN

Associate Dean & Assistant Prof. CON-J, King Saud Bin Abdulaziz University for Health Sciences

Palliative Care Coordinator, Princess Noorah Oncology Center

King Abdulaziz Medical City KAMC-WR 