Aim of the Study

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The aim of the present study is two folds:

1. Identify caregiving burden and psychological health status of caregivers caring for older adults with cancer.
2. Assess the relationship between caregiving burden and psychological health status of caregivers caring for older adults with cancer.

Research questions

1. What is the caregiving burden and psychological health status of caregivers caring for older adults with cancer?
2. What is the relationship between caregiving burden and psychological health status of caregivers caring for older adults with cancer?

Review of Literature

Review of Literature

This chapter presents an overview of the literature on certain aspect of cancer caregiving for older adults. The chapter discusses cancer as a health problem affect older adults, most common types of cancer in older adults, treatment of cancer and nursing management. Thereafter, the chapter explains family caregiving and caregiver burden in cancer which include definition of terms, , roles and challenges of the family caregiver, the impacts of cancer caregiving on caregivers' quality of life and factors associated with caregiving burden. Psychological health status of family caregivers has been also explained and include introduction, caregivers at increased risk for anxiety and depression, caregiver's psychological distress by phases of cancer and the relationship between caregiver burden and psychological health status. Finally, interventions for family caregivers caring for older adults with cancer also have been discussed.

Cancer in older adults

The world health organization defines cancer as "a group of diseases involving abnormal cell growth with the potential to invade or spread to other parts of the body". One defining feature of cancer is the rapid creation of abnormal cells that grow beyond their usual boundaries, and which can then invade adjoining parts of the body and spread to other organs. This process is referred to as metastasis. Metastases are the major cause of death from cancer **(WHO, 2014).**

The proportion of people aged over 60 years is growing faster than any other age group in almost every country, as a result of both longer life expectancy and declining fertility rates **(WHO, 2013).** In Egypt, older adults population aged 65 years or more increased from 3.4% in 1996 to 3.7% in 2006 to 4.2% in 2011**(The Egyptian Central Agency for Public Mobilization and Statistics, 2012)** and to 4.8% in 2014**.** With the improvement of health care systems, life expectancy of the Egyptians is expected to rise markedly to 8% in 2030. Currently, life expectancy of Egyptian males and females at birth is 70.82 years and 76.2 years, respectively **(The Central Intelligence Agency, 2014)**. It is expected that people aged 60 years or more will increase from 4.6 million in 2000 to 23.7 million in 2050 **(Population Reference Bureau, 2012)**.

The risk of being diagnosed with cancer increases with age, most cases occur in adults who are middle aged or older and about 77% of all cancers are diagnosed in people 55 years of age and older **(WHO, 2012)**. It is estimated that global cancer burden has doubled over the last 25 years and is set to double again before 2030. Not only have the incidence and the mortality both increased, but with more and more patients alive within five years of diagnosis, the prevalence has been growing at an even quicker rate **(International Prevention Research Institute, 2013).**

The incidence and prevalence of cancers differs by age and is categorized to four age groups including children (below the age of 15), young adults (15 to 44), middle age (45 to 64) and the elderly (65 and older). Cancer in the older adults has become an increasingly common problem in the world due to the ageing of the population; the sharp increase in the life expectancy and the presence of the changes in the clinical behavior of certain neoplasms with age. Over 60% of all cancers are diagnosed after the age of 65, and the risk of cancer development in persons over 65 years of age is ten to eleven times higher than those observed in the people younger than 65 years. It is estimated that by 2030, 70% of patients with cancer will be over 65. Moreover more than 67% of cancer deaths occur in older groups **(Somi et al., 2009).**

In Egypt, based upon results of National Cancer Registry Program (NCRP), the crude incidence rates (CIR) of cancer per 100,000 were 113.1 (both sexes), 115.7 (males), and 110.3 (females). Age-standardized incidence rates (ASRs) per 100,000 were 166.6 (both sexes), 175.9 (males), and 157.0 (females). The age-specific rates are represented graphically in Figure (1) in which the CIR of cancer per 100,000 for males 793.5 (aged 60–64 years), 840.2 (aged 65–69 years), 1096.1(aged 70–74 years), and 1335.6 (aged 75+ years) and for females 633.7 (aged 60–64), 665.8 (aged 65–69 years), 715.9 (aged 70–74 years), and 850.5 (aged 75+ years). By 2050, a 3-fold increase in incident cancer relative to 2013 was estimated **(Ibrahim et al, 2014)**.

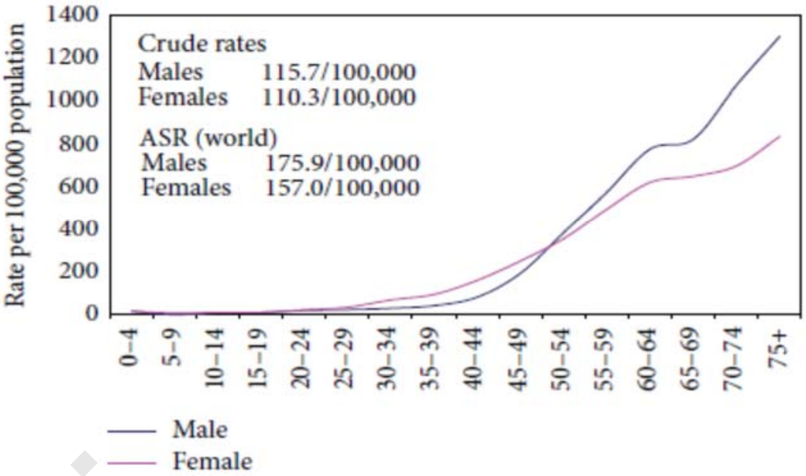


Figure (1): Calculated age specific incidence rates for Egypt 2008–2011.

Most common types of cancer in older adults

Certain cancers are more prevalent among older individuals, among them breast, prostate, colorectal, and lung cancers, non-Hodgkin's lymphoma and chronic lymphocytic leukemia

1-Breast cancer

Breast cancer is a malignant tumor that starts in the cells of the breast. A malignant tumor is a group of cancer cells that can grow into (invade) surrounding tissues or spread (metastasize) to distant areas of the body (**American Cancer Society, 2013)**. Breast cancer is a disease of aging with an average age at diagnosis 61 years and average age at death is 68 years **(Jemal et al., 2010)** and with incidence rate of 82.2 new patients per 100,000 in women younger than age 65 years versus 403.8 per 100,000 for those age 65 years and older **(Altekruse et al., 2010)**. Moreover, in 2011 there were an estimated 230,480 cases of invasive breast cancer in the United States and a total 39,520 deaths among women with the diagnosis. Of those diagnosed with breast cancer, 98,080 cases or forty three (43) percent were among elderly women over the age of sixty-five who also accounted for 22,660 deaths **(Walker, 2013).**

In Egypt, recent study showed that out of 6078 breast cancers, 12% were elderly breast cancers (EBCs). Between 1999 and 2007, the crude incidence rate (CIR, per 100,000 populations) of EBC increased from 47 to 71 and that of non EBC increased from 16 to 17. This study also revealed that the Egyptian EBC patients present with a more advanced disease and are less likely to receive curative therapies as surgery, radiotherapy or chemotherapy than younger patients (**Zeeneldin et al., 2013**).

2-Prostate Cancer

Prostate cancer, a disease of aging men, is the most frequently diagnosed cancer in males and second leading cause of cancer death. Prostate cancer incidence is rare in men before the age of 50 years and increase with age particularly after age 50 years. In general, all men are at risk for prostate cancer. However, there are specific risk factors that increase the likelihood that certain men develop the disease. **(Kamel et al., 2006).**

The single most significant risk factor for prostate cancer is advanced age. While men who are younger than 40 have a one in 10,000 chance of developing prostate cancer, this risk increases to one in seven by the age of 60 **(American Cancer Society, 2009).** The relationship of prostate cancer to advanced age reflects the interplay of environmental, physiological, and molecular influences with normal consequences of aging that presumably exacerbate the effects of these influences **(Shen and Abate-Shen, 2010).** Recent study in Egypt showed that the mean age of the patients at the diagnosis of prostate cancer was 66.2±7 years (range 52-85) and at disease presentation 90 % of patients were 60 years or above **(Ali, 2011)**.

3- Colorectal cancer (CRC):

Colorectal cancer is predominately a disease of older persons. Despite this, elderly populations are either excluded or underrepresented in clinical trials. However, elderly tend to have major comorbidities that may significantly limit life expectancy and potentially reduce treatment benefits (**Muss et al., 2007).**

The median age at diagnosis of CRC is 71 and approximately 70 % of cases develop it over the age of 65; 40 % are 75 years or older. The United States Census bureau projects expected that by the year 2030 the number of Americans over age 65 will double. As a result, the number of patients over the age of 70 presenting for colorectal cancer care is expected to rise **(Sanoff, 2014).** In Egypt, CRC was the 6th cancer in 2012, representing 4% of the total cancers and 53% of GIT cancers. The median age in diagnosis was 53 years with male predominance. Colon cancers were more common than rectal cancers **(Zeeneldin et al 2012)**.

4- Lung Cancer

Lung cancer is a proliferation of malignant cells arising in the airways or tissues of the lung. Ninety-five percent of lung malignancies are either non-small cell lung cancer (NSCLC) or small cell carcinoma. Small cell lung cancer and NSCLC are managed differently **(Pacific Northwest EPC, 2013).**

Lung cancer is the leading cause of cancer mortality with the median age of incidence being 69 years in males and 67 years in females **(Casas et al., 2009)**.In Egypt, NSCLC constitutes approximately 80% of all cases of lung cancer. More than 50% of advanced NSCLC occurs in people aged >65 years, with median age at diagnosis of 70 years **(El-Shenshawy et al., 2012).**

5- Non-Hodgkin's lymphoma (NHL)

The Non-Hodgkin's lymphomas (NHLs) are a heterogeneous group of lymphoproliferative malignancies with differing patterns of behavior and responses to treatment. Like Hodgkin lymphoma, NHL usually originates in lymphoid tissues and can spread to other organs **(Shankland et al., 2012).** Non-Hodgkin lymphoma (NHL) is one of the most common cancers in the United States, accounting for about 4% of all cancers. While NHL can occur at any age, about half of patients are older than 65 and the risk of developing NHL increases throughout life **(American Cancer Society, 2013).**

In Egypt, the incidence of NHLs is very high according to Middle East Cancer Consortium (MECC) , the NHLs age standardized incidence rates (ASRs) are (16.3/ 100.000 person) while this incidence in US according to SEER (Surveillance, Epidemiology, and End Results) are 15.3/100,000 only in 2006. This very high incidence makes NHLs the third most common cancer in Egyptian males and the second most common cancer in females, for 10.9% of all cancer in Egypt diagnosed every year **(Aly et al., 2008).**

6- Chronic lymphocytic leukemia (CLL)

Chronic lymphocytic leukemia (CLL) is dramatically increased in patients above the age of 65 years up to an incidence rate of 22-30/100 000. Although elderly patients represent the largest group of CLL patients they are clearly underrepresented in clinical trials **(Eichhorst et al., 2009).**

In chronic lymphocytic leukemia (CLL), the most prevalent lymphoid malignancy in western countries, patients have a median age at diagnosis of 72 years. An important prognostic factor in the elderly is the burden of co morbidity. Therefore, not only age but several age-related conditions including social environment also determine the choice of treatment of older patient **(Molica et al., 2013).**

Treatment of Cancer in Older Adults:

Treatment for cancer varies, depending on its extent and severity. It takes the following forms: surgery to remove the cancer, chemotherapy by infusing medication into the blood to kill the cancerous cells, radiotherapy for directing radiation to the cancerous tissues, and molecular targeted therapy which are medicines that specifically home in on cancer cells that have a particular marker. The treatment plan for cancer in an elderly patient depends on the type of cancer, the stage of disease and the general health status of the patient **(Kanesvaran, 2013).** Also, Palliative care is given in addition to cancer treatment **(National Cancer Institute, 2010).**

1- Surgery

Surgery is the oldest treatment for cancer and until recently was the only therapy that could cure cancer patients. Advances in surgical techniques and a better understanding of the patterns of spread of individual cancers have led to more successful operations, and the development of alternate and adjunct treatment strategies has led to less extensive surgery. Age is not an independent risk factor for surgery. The determinants of surgical risk include the status of the heart, lungs, kidneys, brain, liver, hematopoietic, and endocrine systems as well as nutritional status and presence of diseases such as diabetes. An elderly patient who is healthy can withstand surgery as well as a young person by using newer methods of anesthesia and postoperative monitoring **(Freedman & Nierodzik, 2007).**

2- Chemotherapy

Chemotherapy is the use of medicines or drugs to treat a disease, such as cancer. Many times this treatment is just called chemo. Surgery and radiation therapy remove, kill, or damage cancer cells in a certain area, but chemo can work throughout the whole body. Chemo can kill cancer cells that have metastasized or spread to parts of the body far away from the primary (original) tumor **(American Cancer Society, 2014)**. Elderly patients are at higher risk of chemotherapy-related side effects, due to altered physiology that may contribute to changes in the tolerability of chemotherapy **(Turner et al., 2013)**.

With increased age, total body water decreases, leading to a decreased volume of distribution for water-soluble medications, and total body fat increases, altering distribution of fat-soluble drugs. Additionally, decreased creatinine clearance often leads to decreased clearance of renally excreted medications. There are conflicting data regarding changes in liver and biliary metabolism with age. Other than pharmacokinetic alterations, aging is associated with a reduced normal tissue tolerance to chemotherapy, such that older patients are at higher risk of both hematological and non-hematological toxicity, including cardiac and neurological toxicity. Furthermore, the presence of co morbidities, polypharmacy and functional dependency, all of which may impact on the tolerability of chemotherapy, are of particular importance in elderly cancer **(Turner et al., 2013)**. For this, chemotherapy toxicity is common in older adults, with 53% experiencing at least one grade 3 to 5 toxicity and among these, 2% experienced treatment related mortality **(Hurria et al., 2011)**.

3- Radiation therapy:

Radiation therapy is a cancer modality that can be an excellent option for the elderly because of its limited systemic toxicities. Radiation therapy is a local cancer treatment that can be effective for curative, prophylactic, control, or palliative purposes **(Haas, 2004)**. If a tumor is radiosensitive, radiotherapy may be appropriate and have positive results for older patients in good health. The more commonly seen radiation side effects that occur in elderly subjects are predicated on preexisting conditions; thus, radiation to emphysematous lungs will increase dyspnea, and irradiation of the mediastinum will impair declining left ventricular function. Compliance with radiotherapy in elderly subjects is additionally hampered by multiple visits and traveling. The use of split fraction does reduces the toxicity and is essential in the treatment of many tumors in older patients (**Fillit, 2010**).

4- Targeted therapy

Targeted cancer therapies are drugs or other substances that block the growth and spread of cancer by interfering with specific molecules ("molecular targets") that are involved in the growth, progression, and spread of cancer. Targeted cancer therapies are sometimes called "molecularly targeted drugs," "molecularly targeted therapies," "precision medicines," or similar names. Targeted therapies differ from standard chemotherapy in several ways: First, targeted therapies act on specific molecular targets that are associated with cancer, whereas most standard chemotherapies act on all rapidly dividing normal and cancerous cells. Second, targeted therapies are deliberately chosen or designed to interact with their target, whereas many standard chemotherapies were identified because they kill cells. Third,targeted therapies are often cytostatic (that is, they block tumor cell proliferation), whereas standard chemotherapy agents are cytotoxic (that is, they kill tumor cells) **(National Cancer Institute, 2014)**.

Targeted agents provide effective and less toxic therapy while at the same time allowing elderly patients maintain their functional independence. Furthermore, targeted agents have similar efficacy and tolerability in elderly fit patients when compared with younger ones, provided caution is exercised in specific high-risk sub-groups. Until then, use of molecular targeted therapies in the elderly population should be exercised with caution and assessed on an individual basis taking into consideration the risks, benefits and prognosis of patients **(Gonsalves & Ganti, 2011 and Kyriakou et al., 2011)**.

5- Palliative care

Palliative care is patient- and family-centered care that focuses on effective management of pain and other distressing symptoms, while incorporating psychosocial and spiritual care according to patient and family needs, values, beliefs, and cultures **(Levy et al., 2009)**. A recent study shows that including palliative care along with standard treatment can improve quality of life, help people with cancer live longer, reported less depression, anxiety, pain and nausea. They also scored higher on measures of mobility and other quality of life aspects **(Ness, 2013).**

Elderly patients would be able to benefit from palliative care in an early stage of their disease and positively influencing older cancer patients and families. Palliative care is beneficial in meeting the family's needs in a timely and adequate manner, improving quality of life, increasing caregiver satisfaction and communication, possibly delay institutionalization of the older patient, and may ultimately impact bereavement **(Wittenberg-Lyles & Sanchez-Reilly, 2008).** Palliative care for older patients relates particularly to multiple treatments for various conditions. However, elderly who need palliative care are frequently disregarded as individuals and may experience discrimination because of their age **(Brighi et al., 2014).**

Nursing Management for older adults with cancer

Caring of older adults with cancer is a nearly inescapable aspect of gerontological nurse. Older adults with cancer must undergo a thorough assessment of their physiologic, mental and psychosocial support status. If time and personnel constraints are not prohibitive, a full comprehensive geriatric assessment (CGA) is ideal. When time does not permit a full CGA, using one or a combination of the brief assessment tools will be enough for most individuals. In addition to assessing the physical and mental status, nurses should initiate a discussion of the goals of therapy both from the perspective of the oncology medical team and the patient and family. Determination of patient values, quality of life and treatment preferences will help both the patient and medical team to determine an individualized and appropriate treatment plan. **(Oncology Nursing Society, 2007)**.

Nurses play an important role in patient education. Providing older cancer patients with adequate treatment information is important for patients' health, well-being and satisfaction. Older people have more difficulties processing and remembering information than younger ones. A trustful environment appears to be a prerequisite for reflection of older patients on the information provided and individualized information is essential to enhance memory of information. Clear, concise and understandable information is especially important when dealing with the elderly. Information may have to be repeated multiple times and the nurse should anticipate telephone or written follow-up to clarify information discussed in the clinic setting. Providing written as well as verbal information and avoid use of technical verbs. Sensitive communication is important, e.g. showing empathy and emotional support, throughout the continuum of cancer care. Moreover, engaging the patients' relatives and encouraging elderly patients and relatives to ask questions (**Posma et al., 2009**).

Nurses can improve outcomes in elderly patients by assuring that less-aggressive treatment or dosing is truly indicated, based on thorough patient assessment, not on a generalization that all elderly people need a modified chemotherapy dose. Aggressive supportive care should be undertaken in the treatment of all older adults with cancer regardless of the goal of treatment. It is recommended that nurses consult evidence-based guidelines or recommendations for supportive care of the older adult during treatment for cancer. **(Hood, 2003).**

Ageist attitudes in cancer care still exist. Maintaining an awareness of these discriminatory attitudes is an important part of the nurse’s role in assuring safe and effective care for aging population. Moreover, caregiver support must be assessed before and during cancer treatment. If found to be less than optimal, close monitoring by a home health nurse may be required in order to prevent exacerbation of side effects such as burden or psychological stress **(Ehrenberger et al., 2003).**

As the population ages, so the burden of caring for people with cancer increases. Promoting the benefits of nursing research in older people, providing age-sensitive assessment, counseling and education, designing supportive care measures to lessen treatment side effects that are often exacerbated by increasing age, and keeping a watchful presence toward ageist attitudes can help to reduce the burden of disease and increase quality of life for older adults **(Meniscus Educational Institute, 2010).**

Family caregiving and caregiver burden in cancer

Definition of Terms

A family is two or more people who have come together for a self- defined common purpose. That purpose may be procreation or it may be simple companionship, but the persons involved view themselves as family with the bonds and responsibilities one expects from a family of origin or blood relationship. The caregiver and the cared-for are an irreducible whole. If one is cut, the other bleeds **(Blum & Sherman, 2010)**

A caregiver is defined as ‘‘anybody who provides unpaid help, or arranges for help, to a relative or friend because they have an illness or disability. Family members are generally considered to be the most important and frequent providers of informal care **(Bevan & Sparks, 2011).**

Family caregiver is broadly defined and refers to any relative, partner, friend, or neighbor who has a significant personal relationship with and provides a broad range of assistance for a person with a chronic or disabling condition. These persons may be primary or secondary caregivers and live with or separately from the person receiving care **(Blum, 2010)**.

The National Family Caregivers Association defines Family caregiving as "assisting someone you care about who is chronically ill or disabled and who is no longer able to care for themselves'. The Hartford Institute for Geriatric Nursing defines it as "the wide range of unpaid care provided in response to illness or functional impairment to a chronically ill or functionally impaired older family member, partner, friend, or neighbor that exceeds the support usually provided in family relationship" **(Eckman, 2011).**

Roles and Challenges of Family Caregivers

Over the past few years, demographic changes and constraints in health-care system costs contribute to the crisis of traditional models of care for elderly patients. Shortened hospital stays have led to an increase in the use of home-care models with an important role of patients' families (**Locatelli et al., 2010**). Caregivers have many roles and these roles change as the patient's needs change during and after cancer treatment. Caregivers serve as home health aides and companions **(American Cancer Society, 2014).** Family caregivers of cancer patients are expected to function broadly, providing direct care, assistance with activities of daily living, case management, emotional support, companionship, and medication supervision **(National Alliance for Caregiving, 2005)**. Caregivers of elderly cancer patients face an increasingly complex set of challenges created by the patient's pre-existing co morbid conditions combined with more aggressive treatment and prolonged survival after diagnosis **(Given & Sherwood, 2006).**

Caregiving activities are varied and numerous, including personal care, mobility, transportation, communication, housework; management and coordination of medical care, administration of medications and therapies, emotional support, assisting with personal care, organizing appointments, social services, assistance with social activities, managing money; ambulating, transferring, incontinence care, shopping, housework, meal preparation, telephone calls and managing finances **(Girgis et al., 2013).** Caregivers of cancer older adults generally undertake multifaceted responsibilities for tasks such as the following **(Glajchen, 2009):**

- Administrative tasks (case management, management of insurance claims, bill payment).
- Instrumental tasks (accompanying the cancer patient to medical appointments; running personal errands; managing cooking, cleaning, and other housekeeping tasks).
- Navigation tasks (seeking information that may be difficult to find, finding a doctor).
- Social support activities (providing companionship, socializing).

Girgis & Lambert (2009) reported that among a mixed group of caregivers of cancer survivors, common caregiving tasks included household tasks (daily 68.5%), emotional support (daily 39.9%), and managing money (daily 22.7%). Furthermore, **Yabroff and Kim (2009)** found that caregivers participating in the American Cancer Society's Study of Cancer Survivors provided care for 8.3 hours per day for 13.7 months over the first 2 years after diagnosis. Caregivers of patients with lung cancer, ovarian cancer or non-hodgkin lymphoma spent the most hours per day caregiving (>10 hours), and caregivers of patients with breast and bladder cancer, melanoma of the skin, or uterine cancer spent the fewest hours per day (>7 hours). Another study reported comparable levels of caregiving and burden across cancer and dementia caregivers; however, both of these groups provided more hours of care per week, assisted with a greater number of daily activities, and reported greater levels of physical burden and psychological distress than caregivers of individuals with diabetes or frail elderly **(Kim and Schulz, 2008)**.

Decision Maker

The caregiver faces an overwhelming array of decisions during the course of a patient's illness. Decisions about treatment options, role changes, and finances generally are made by the patient-family unit. Even in the context of a strong doctor-patient relationship, caregivers may be more open to receiving information from other sources, both informal (family, friends) and formal (the Internet, Cancer Information Service, support groups). Families may make erroneous decisions based on biased information found in the media and on the Internet **(National Cancer Institute, 2014).** Decision making can be complicated by serious gaps in recall and understanding that can occur during psychological and physical health crises and by differences in the communication styles of patients, family caregivers, and health care professionals (**Siminoff et al., 2006**).

Advocate

Family caregivers often become advocates for the patient with cancer. This role may include administrative tasks such as the following: Seeking information, managing insurance claims, paying bills, renewing prescription medication, requesting symptom relief, incorporating lifestyle changes, exercising increased vigilance over the patient, reporting new symptoms or side effects, encouraging treatment compliance, and promoting healthy behaviors by the patient. **(Bowman et al., 2005 & Glajchen, 2009)**

Communicator

An important goal for the oncology nurses is to improve the ability of patients to understand symptoms and treatment decisions and communicate their ongoing needs and preferences for support. However, communication problems can arise within certain patient groups, including older patients, patients with lower levels of education, and culturally disparate groups **(Rose et al., 2008)**.The family caregiver will often undertake the role of communicator for the patient. For both patients and caregivers, communication is affected by the family members' health information processing style and ability to manage sometimes threatening health information **(Rose et al., 2008)**.

Communication with providers, physicians, nurses, social workers, pharmacists, specialty pharmacies, or home care agencies may be problematic for family caregivers.

This communication is often mentioned as top challenge. Caregivers report not receiving quality information about their family member's care from providers and many caregivers are unsure how to interpret and use the information they receive **(Stenberg et al., 2010).**

Hands-on Care Provider

Pain and symptom management is a major focus of the caregiver's role. Family caregivers frequently dispense pain medication or remind the patient to take a scheduled dose, which requires making decisions about which medication to give, when to give it, and what dose to give. It often falls to the caregiver to keep records and control the technical aspects of managing pain and other symptoms.If the patient is homebound or unable to move around with ease, the caregiver will often fill and refill medication prescriptions, try to follow medical instructions, and anticipate the need for medication refills ahead of time. In addition to managing the patient's treatment regimen, the caregiver is expected to identify and report treatment side effects or new symptoms **(Glajchen, 2004)**.

As they move along the disease trajectory, cancer patients may face an array of other side effects and symptoms:

- Fatigue, drowsiness, and sleep problems have been reported in 51% to 68% of cancer patients
- Nausea, vomiting, anorexia, and cachexia have been reported in 10% to 40% of patients.
- Reports of anxiety, mood disorder, and depression are documented in 25% to 50% of cancer patients.

Management of these complicated side effects frequently falls to the family caregiver. **(Hickok et al., 2005)**.

Social Support

Family members who care for the elderly cancer patient (caregivers) play an important role in supporting their loved ones and helping them to adjust to the new life situation **(Giacalone et al.,2009).** Family cargivers were increasingly seen as a source of social support for patients with potential influence on patient's coping, morbidity and mortality. Family members carry financial, professional and social burdens, they may be able to support patients emotionally, to provide nursing tasks and to help patients in making treatment decisions; they, therefore, could act as a “guaranty of stability” in times of changes. Social support is known to be one of the most important determinants of psychological well being and health of patients (**Baider et al., 2004)**. Cancer patients who perceive their social support positively are more efficient in coping with illness related stress, show less anxiety and depression and better adaptation, including longer survival time **(Hann et al., 2002)**.

Social support in elderly cancer patients combined with psychopharmacological treatment has an effect on increasing the quality of life of elderly patients. Adequate support by the partner, characterized by empathy and a low tendency to withdraw, has a stronger impact on the patients’ well being than adequate support by others. These individuals cannot compensate the support of a partner. For the elderly, trust in a supportive person seems to be more important than the opportunity to disclose negative feelings. The latter seems to be more significant in younger adults. Elderly patients may be more sensitive to the potential self destabilizing aspects of receiving social support due to their age related decrease in physical and psychological fitness. This increases problems among family members to find an adequate form of supporting the elderly patients **(Kotkamp-Mothes et al., 2005).**

Impacts of cancer caregiving on caregivers' quality of life:

Caring for older adults may affect negatively the physical, psychological, spiritual, social, and financial health of her/his informal caregiver **(Van Durme et al ., 2012).**

1- Impact on Physical Health

The health of family caregivers and their elderly care receivers is a major concern. Indeed, there is not only evidence of the positive impact of caregiving on the health of caregivers and care receivers (i.e. quality of relationships, feelings of accomplishment and meaning of the caregivers’ role); but also there is evidence of a negative impact on their health **(Farfan-Portet et al., 2007 and Carbonneau et al., 2010)**.

Caregiving is considered a risk factor for physical health, because it may set stress responses through activation of the hypothalamic-pituitaryadrenal axis and the sympathetic adrenomedullary axis, involving humoral, immunologic, cardiovascular, and metabolic alterations. Caregiving strain has been reported as an independent risk factor for mortality among elderly spousal caregivers. As regards the cardiovascular risk factors, caregivers, mostly when elderly show higher systolic blood pressure and increased risk for hypertension over time, compared with non caregivers. Risk of cardiovascular alterations can be associated with sleep disorders and can be modulated by the caregiver's emotional state, quality of the relationship between caregiver and care recipient, care demands, and perceived social support. **(Corà et al., 2012**)

Cancer patients require varying levels of practical assistance during the course of their illness. Cumulative sleep disruption and fatigue are common among caregivers who are on duty 24 hours a day or only during nighttime hours. Behaviors such as not getting enough rest or exercise and neglecting their own health can mimic depression in caregivers but can also contribute to the impairment of their health and quality of life (**Travis et al., 2004)**.Throughout the illness experience, the physical demands of caregiving can predispose caregivers themselves to medical illness and a greater risk of mortality **(Family Caregiver Alliance, 2006).**

A recent study of family caregivers **by Lambert et al., 2012** shown that more than half reported that caregiving had directly affected their overall physical health, including tiredness and exhaustion (54.5%); back, neck, and shoulder problems (33.8%); blood pressure and/or heart problems (12.6%); arthritis (10%); stress-related illnesses (6.6%); being physically unfit and weight problems (5.5%); digestion and bowel problems (4.6%); and leg and foot problems (4.6%).Furthermore a recent review found that the most prevalent physical problems reported by caregivers included sleep disturbance, fatigue, pain, loss of physical strength, loss of appetite, and weight loss **(Stenberg et al., 2010)**.

Cancer caregiving also has a negative impact on health-related activities. A study done in Australia found that 42% of caregivers of people diagnosed with ovarian cancer reported decreasing their physical activity since their family member was diagnosed with cancer, and slightly more than one third gained weight to a level that exceeded their healthy body mass index range. Although most caregivers did not report a change in their fruit and vegetable consumption, 12% increased their alcohol intake **(Beesley et al., 2011)**.

2- Impact on Psychological Health

The impact of caregiving on the caregivers' physical health is inconclusive; while the effect of burden on psychological wellbeing of the caregivers is also well known **(Borneman et al., 2003)**. Depressive symptoms, anxiety, and distress are common. Higher levels of anxiety were reported in caregivers of patients with cancer than in other patients **(Given et al., 2004).** Emotionally, caregivers often become demoralized and exhausted and may need to be treated for psychiatric problems. Family caregivers often abandon their own activities, which create stress on themselves, and the family as a unit **(Sherman et al., 2014).**

Among the numerous psychiatric disorders seen among family caregivers, depression was reported to be one of the first symptoms experienced and also the most enduring psychological outcome for this group. Anxiety disorders are also commonly seen among the caregivers especially panic attacks, phobias and generalized anxiety disorders. Other psychiatric disorders that may be seen among this group of people include substance and alcohol use disorders and chronic sleep disturbances **(Okewole et al, 2011).**For instance, a study done by **Lambert et al., (2013**) found that more than one third of caregivers reported borderline or clinical levels of anxiety, and almost 17% reported borderline or clinical depression, with most depressed caregivers also reporting anxiety, at 6 and 12 months after patient diagnosis**.** Moreover, **Price et al (2010)** reported significantly higher prevalence of borderline or clinical anxiety and depression among caregivers of women with invasive ovarian cancer compared with patients' rates and community norms. Studies looking at post-traumatic stress disorder (PTSD) in caregivers and partners of people with cancer reported that, 4% of caregivers experienced PTSD, (**Vanderwerker et al., 2005)** and one third of partners experienced traumatic symptoms (**Butler et al., 2005).**

Despite the significant psychological impact of caring, caregivers might not seek required treatment, with the study of Vanderwerker et al (2005) reporting that almost half of cancer caregivers who met diagnostic criteria for a psychiatric condition did not seek treatment for it **(Vanderwerker et al ., 2005)** . Furthermore, review done by

Kotkamp-Mothes et al., (2005) for elderly patients with cancer and their caregivers found illness-related stress to be even higher among caregivers than among patients. Similar to other findings, the predominant psychological symptoms of relatives of elderly patients with cancer were feelings of anxiety, unassertiveness, depressive reactions, hopelessness and feelings of guilt (**Kotkamp-Mothes et al., 2005)**.

3- Impact on Spiritual Health

Positive associations between spirituality and mental health have been reported in a few studies of family caregivers **(Vallurupalli et al., 2012).** Family caregivers may use spirituality as a way of coping, to lower their level of depression **(Son et al., 2012).** Family caregivers who had spiritual support through the trajectory of illness had better well-being. Those who had higher spirituality had lower psychological stress **(Colgrove et al., 2007)**. Spirituality among caregivers is seldom determined by the health care team. Kim et al., 2011 study showed that caregivers had high levels of spirituality at 2 years after spousal diagnosis with cancer and reported personal growth and increased importance of meaning. Moreover, anxiety and depression were correlated with negative spiritual health **(Kim et al., 2011)**.

4- Impact on Social Activities and Relationships

The two basic types of family system in current society include Nuclear family system and Joint family system. Regardless of the family type, lack of social support from a caregiver's family also leads to stress and loneliness. In caring for the patient or elderly person, caregivers often find themselves isolated from the society. Little time is available to maintain social contacts. This social isolation further increases with the progress of cancer since higher levels of care-giving consume more time **(Ansari & Qureshi, 2013).** Moreover, caregiving disrupts social connectedness and activities as caregivers' energy and time are focused on the patient and their recovery **(Stenberg et al., 2010)**. The caregivers of people with cancer who have limited social networks and more restrictions in their daily activities are more likely to report caregiver burden **(Goldstein et al., 2004).** An Australian study found that lower social support was a predictor of both anxiety and depression for caregivers of women with ovarian cancer **(Price et al., 2010)**.

Caregivers often report trying to participate in social activities but giving up as a result of concern for the patient while they are absent. Even high-functioning couples may struggle to manage the stress and challenges of cancer, as well as changes in their relationships brought on by the cancer diagnosis. Such stress might lead to tension and conflict within the couple **(Fergus et al., 2009).** In an interviews with relatives (mainly spouses) living with a person suffering from a serious chronic illness, that caregivers seemed to live a shrinking life, had lost the joy that the relationship with friends and social activities brought them, their personal freedom to live and act as they had in the past no longer existed, and their own needs and interests had lost secondary to the caregiving role **(Öhman and Söderberg, 2004)**. In caring elderly with cancer, negative social consequences of caregiving that may occur; less socialization and a deep sense of interpersonal loss **(Haley, 2003)**.

Caregiver abuse may be occurred as a result of stresses and challenges of caregiving. An Australian study reported that 5% to 13% of elderly people experience psychological, physical, or financial abuse perpetrated mostly by people in a caregiving relationship (**Girgis et al., 2013).** Another study found that 26% of care recipients living in the community were exposed to potentially harmful caregiver behavior. Risk factors for caregiver abuse include greater levels of patients' needs in activities of daily living, being a spousal caregiver, greater caregiver cognitive impairment, physical symptoms, and depression symptoms. Abuse of patients may be occurring but not be evident as a result of the stigma of reporting abuse and the secluded lives of patients **(Beach et al., 2005**).

5- Impact on Financial and Work Status

Caregiving affects a family caregiver's work and family financials, such as balancing a job and providing care to family members and creates a financial burden for family members, both in outright expenses and in lost income **(Haddock et al., 2006)**. The finances of family caregivers can be affected by the daily costs of caregiving such as transportation, nonprescription medications, medical supplies, prescription medications, equipment, and homemaking supplies **(Hollander et al., 2009)**. Recent study in Canada indicated that 40.3% of the family caregivers of older adults agreed that caregiving for the care receiver was causing them to dip into savings. Again, 40% of the family caregivers indicated that they and their families could not afford those little extras because of the expenses to care for the care receiver. Over a third (38.5%) indicated that their family or they had to give up necessities because of the expense to provide care. Another similar proportion (36.8%) of the caregivers indicated that caring for the older adult was too expensive **(Lai, 2012)**.

Caregiving also appears to reduce a person's chance of being employed, and many caregivers are unable to work, need to take leave without pay, have fewer work hours, are in lower paid jobs, or work from home to manage the caregiver demands **(Fergus &Gray, 2009)**. Some researchers note that the time required to competently care for a frail elderly relative often amounts to a full-time job. Compared with coworkers who are not caregivers, family caregivers had to take more time off work, were interrupted at work more often regarding family matters, missed more days at work, took more time off without pay, and ultimately worked fewer hours than desired **(Schulz et al., 2003)**.

6- Positive Impact of Care Giving (Benefits of Caregiving)

Much of the caregiving research and literature to date has focused on the negative aspects of caregiving; however, the experience of caregiving can be gratifying and meaningful to the family caregivers. Caregiver benefit refers to the positive aspects associated with the caregiver role, such as gratification, satisfaction, personal growth, and enhanced self-esteem. Positive effects of providing care have also been reported such as rewards, self-esteem, support, uplifts, and satisfaction, which may provide a buffer to the residual negative effects of caregiving. Caregivers report life changes, appreciation of life, acceptance, reprioritization of values, increased self-confidence, stronger interpersonal relationships, and strengthened spirituality **(Given et al., 2011).**

Caregiving benefits/gains can also include feeling more useful, feeling needed, learning new skills, and adding meaning to one's sense of self. They also may include gaining a sense of fulfillment for meeting a duty/obligation and enjoyment derived from caregiving itself or from companionship with the care recipient **(Koerner et al., 2009)**. There is also evidence that negative and positive outcomes often co-exist within the same caregiver. For example, some researchers had found that a large proportion of caregivers (70– 80%) experience both positive and negative emotions as a result of their caregiving role **(Sanders, 2005 & Cohen et al., 2002)**.

While caregivers report experiencing surprise, shock, disbelief, anger, distress, fear, and depression in response to a cancer diagnosis, they also felt that caring for a person with cancer is an experience that can produce positive emotions. In an Australian, 60% of caregivers were able to identify positive aspects of their role **(Hudson, 2004).** It has been suggested that caring for the patient may help caregivers to accept the death of the patient and work through their grief **(Stajduhar, 2003)**.

Caregivers assume their tasks for reasons that include a sense of familial obligation and loyalty and altruism in the face of their loved one's suffering; more practical reasons include lack of paid help and lack of insurance coverage for services. Other positive rewards of caregiving include the following: discovery of personal strength through adversity, improved sense of self-worth, deepening of the relationship with the cancer patient, and sense of personal growth **(Feinberg et al., 2006)**.

Moreover, caring for a patient with cancer has rewards such as satisfaction, closeness with the cancer patient, and a sense of fulfilling an obligation. Positive aspects of caregiving are associated with psychological well-being and the caregiver's willingness to continue providing care **(Balducci et al., 2008).** Those caregivers who derive benefit from the role have fewer depressive symptoms and better self-assessed health than caregivers who only identify the costs or burden of caregiving **(Habermann & Davis, 2005).**

Factors associated with caregiving burden

Caregiving burden, a negative reaction, is a multidimensional concept that stems from the imbalance between the social, psychological, and economic consequences permeating a care situation and the caregivers' coping strategies to meet the demands of patient care. Caregivers who are unable to apply effective coping strategies to care demands may develop burden, which, if sustained, may lead to depression **(Given et al., 2012).**

Two types of burden have been distinguished: objective and subjective. Objective burden refers to the costs for the family and includes aspects such as household routine, family relations and leisure time. Subjective burden refers to the distress experienced as a result of caring such as guilt, anger and feelings of loss **(Ivarsson et al., 2004).**

The level of burden family caregivers experience is dependent on a variety of factors associated with both the caregiver and the care receiver. For instance, the primary caregiver is more vulnerable to burden than those who do not play a primary role in providing care **(Greenberger & Litwin, 2003)**. The demographic characteristics of the caregiver such as sex, marital status, and religion also play a role. Correlates of increased vulnerability to a higher level of burden have been identified. These include being younger, being a woman, being unmarried, having a religion, and being an immigrant **(Kim et al., 2006**; **Choi & Bohman, 2007 and Knight et al., 2007)**.

Variables associated with care receivers are also contribute to caregiver burden. These variables include the types of health problems that the care receivers have, and the type and number of caring tasks the caregiver is required to perform **(Sörensen & Pinquart, 2005).** A higher degree of mental or physical impairment in the care recipient, more behavioral problems and disabilities, and a higher level of dependency in their activities of daily living contribute to increasing the burden level of caregivers **(Lee & Kolomer, 2005).** If the care recipient had more activities of daily living with which they needed help, this was an indicator of more caregiver burden. Having to give constant attention to the care recipients for their well-being was another correlate of a higher caregiving burden **(Mendez-Luck et al., 2008)**.

Social support, coping style and strategies, or the personality type of the caregiver are also related to the caregiving burden level (**Smerglia et al., 2007)**. If the caregiver perceived the caregiving role as a responsibility as a threat, this will contribute toward a higher level of caregiving burden (**Van Den Wijngaart et al., 2007)**. Caregivers reporting a lower level of filial piety also reported a higher level of caregiving burden **(Lai, 2007)**. Caregivers who have a more positive coping style, a higher level of perceived self-efficacy, social support, and instrumental support are more likely to have a reduced level of caregiving burden (**Van Den Wijngaart et al., 2007)**.

Having to balance caregiving with other family responsibilities caused a greater level of burden for caregivers. If sacrifices had to be made to provide care to the care recipient, the level of burden was predictably higher because of the perception of sacrifice. Sacrifices can be associated with time, money, giving up luxury items, and the quality of relationships with others **(Mendez-Luck et al., 2008)**.

Psychological health status of the family caregivers

Cancer affects the quality of life of family caregivers in many ways, but takes its greatest effect on their psychological well-being. Family caregivers are expected to provide complex care in the home with little preparation or support **(Van Ryn et al., 2011)**. When the demands placed on caregivers exceed their resources, caregivers feel overwhelmed and report high stress. The stress has a negative effect initially on the caregiver's psychological wellbeing, but as the stress continues it can negatively affect their physical well-being as well. The effects of stress on the psychological domain of quality of life appear as increased emotional distress, anxiety, and/or depression; feelings of helplessness and loss of control; and difficulty in coping with caregiving roles **(Northouse et al., 2012).**

High emotional distress reported by family caregivers is a significant problem that needs to be addressed for a number of reasons. First, when family caregivers are highly distressed, it has a negative effect on the patient's long-term adjustment. Over time, a highly anxious partner can increase the anxiety experienced by the patient **(Segrin et al., 2007)** and when caregivers are distressed, it is likely that their patients are also distressed, and vice versa (Figure-2) **(Hodges et al., 2005)**. Second, distressed caregivers have more difficulty providing optimal patient care and administering medications to patients **(Lau et al., 2010)**. Third, caregivers who have high distress also have changes in their immune system that can lead to flare-ups in auto-immune diseases, worsened glucose control in the body, and increased vulnerability to cardiovascular diseases. These changes increase the likelihood that the caregiver's own health will suffer and, subsequently, hinder their capacity to provide care **(Rohleder et al., 2009).**

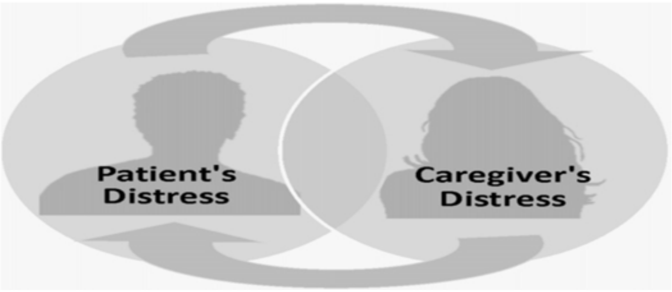


Figure (2): Reciprocal relationship between patient and caregiver emotional distress. Each one affects the other throughout all phases of illness

Risk factors for anxiety and depression in family caregivers

Caregivers at increased risk of anxiety or depression who:

- Are predominantly younger and female**.**
- Report lower socioeconomic status or education.
- Live with the patient; are the spouses, rather than the children of the patient; or report poor relationship quality with the patient.
- Are unmarried or in shorter-term marriages.
- Report high levels of unmet needs for supportive care and report comorbidities or more unhealthy behavior.
- Use avoidant coping.
- Feel less prepared for caregiving or confident in their abilities.
- Are caring for patients that are older, are at a later disease stage, have symptoms, and report poorer physical functioning.
- Have high caregiving demand and report higher intensity of care
- Report lower levels of social support **(Girgis et al., 2013)**.

Caregiver's psychological distress by phase of cancer (Psychological Repercussions)

There are many opportunities for family caregiver roles over the trajectory of cancer care from diagnosis to the end of life, considering transitions into treatment, maintenance therapy, phase of disease, disease progression, recurrence, and survivorship with late effects and residual effects (**Given et al., 2012)**. The sources of distress for patients and caregivers are briefly described for the following six phases during the cancer trajectory: 1) pre diagnosis, 2) diagnosis, 3) treatment, 4) survivorship, 5) recurrent, and 6) advanced and end of life.

1) Pre diagnosis Phase:

With advances in genetic testing, more people are learning about the possibility of hereditary cancer in their own families. Genetic testing identifies at-risk individuals and provides them with information about strategies they can use to lower their risk of developing cancer, such as risk reducing surgery and intensive surveillance **(Van Oostrom et al., 2003)**.

There are many sources of distress for families with hereditary cancer, such as learning about the risk of hereditary cancer in the family, deciding whether or not to seek genetic testing, determining whether or not to disclose test results to family members, and deciding how to manage this risk if they test positive (**Crotser & Boehmke, 2009)**. Even relatives who test negative for a deleterious mutation identified in their family, experience guilt about communicating their results to untested siblings, who may still face a 50% chance of harboring the same mutation **(Claes et al.,2003)**. Partners also experience distress when their loved ones are at greater risk for rare hereditary cancer syndromes **(Lammens et al., 2011)**.

2) Diagnosis Phase:

A number of stressors can lead to family caregiver psychological distress with the diagnosis of cancer. At this point in the trajectory, the most salient psychological outcomes revolve around fear, uncertainty, sadness and feelings of powerlessness or helplessness (**Given et al., 2006)**. Many studies have documented the emotional distress reported by cancer patients and their family caregivers following the diagnosis of cancer. Findings indicate that both patients and caregivers report shock and anxiety at the time of diagnosis **(Northouse et al., 2012).** In the study of Kim et al., 2010 who assessed the needs of three cohorts of caregivers who were 2 months, 2 years, and 5 years following cancer diagnosis, caregivers of newly diagnosed patients (i.e., 2-month cohort) had more unmet psychosocial, medical, financial, and informational needs than caregivers in the other two cohorts. Younger caregivers reported substantially more unmet needs in all domains than older caregivers **(Kim et al., 2010)**.

A major concern for caregivers during this phase is helping patients deal with emotional distress associated with their new diagnosis of cancer **(Zahlis & Lewis, 2010).** Caregivers convey that helping patients to cope with emotional distress (eg, anger, anxiety, depression, fear, and resentment) is one of their highest unmet needs following diagnosis. Family caregivers often feel unprepared to deal with the array of intense emotions surrounding the diagnosis (**Kim et al., 2010)**.

3) Treatment Phase

Just after diagnosis, patients and caregivers are confronted with new and unfamiliar treatments for the cancer. Sources of distress during this time are related to their worry about the patient's ability to tolerate the treatment, if the treatment will be effective, and if side effects and symptoms associated with the treatment will be manageable. During this phase, caregivers are more involved in providing physical care and managing treatment related symptoms. It is not surprising that during the treatment phase caregivers often report greater caregiver burden and strain than they do in some of the other phases of illness **(Van Ryn et al., 2011)**. Caregivers who reported a greater impact of caregiving on their day-today schedules and social functioning, and who felt abandoned by others, experienced more emotional distress **(Kurtz et al., 2004).**

Many other psychological outcomes become relevant as the patient undergoes cancer treatment due to a number of additional stressors that the caregiver must deal with. These additional stressors may cause intrapsychic strain, such as guilt or changes in the caregiver's self-concept **(Haley, 2003)**. For a minority of caregivers, they may meet the criteria for a psychiatric diagnosis, typically of depression or an anxiety disorder **(Pitceathly & Maguire 2003).** But for the majority, any distress they experience does not reach clinically diagnosable levels, although they may exhibit depressive symptoms **(Kim & Given, 2008)**. It remains uncertain how levels of psychological distress change with time. Some studies report that psychological distress decreases over time, but others report that it increases **(Pitceathly & Maguire, 2003).** This increase may be a result of caregivers neglecting their own needs while caring for the patient. For some, this emotional repression may lead to feelings of resentment towards the patient. At this point of the trajectory (and ongoing), caregivers may also begin to exhibit symptoms of burnout due to the increased work-burden of caring for someone with cancer. There are many physical and emotional components to burnout. Amongst the emotional components, caregivers may experience frustration, anger, depression, resentment and insecurity (**Golant & Haskins, 2008).**

4) Survivorship Phase

The survivorship phase is characterized as the time when the cancer is in remission or when the patient is considered cured. The quality of life of cancer survivors and their family caregivers become comparable to the normal population in two studies of couples who were approximately 2 years or 4 years post-diagnosis. Survivors and their family caregivers had normal levels of distress and depression rates that were consistent with community samples. Approximately 70% of the survivors and caregivers were able to identify some positive aspect associated with their cancer experience (eg, realizing how precious life is, appreciating relationships) **(Hodgkinson et al., 2007 and Kim et al., 2008).**

A universal concern during survivorship is the fear that the cancer will recur. Family caregivers often report more fear of recurrence than survivors, possibly because they interact less with health professionals than patients, and have fewer opportunities to obtain information that could lessen their fears. There is a fairly strong correlation between the levels of fear of recurrence reported by survivors and their family caregivers, suggesting that they mutually influence one another's fear **(Mellon et al., 2007)**.

5) Recurrent Phase

When the cancer returns, it is a devastating time for patients and their family caregivers. Recurrence shatters their hope that the cancer was cured, and it often requires patients to receive treatment again which in many cases is palliative rather than curative. Studies that compared the quality of life of patients with recurrent versus newly diagnosed cancer report that recurrent cancer patients have significantly lower quality of life, more pain, more role limitations, higher symptom distress, and a more negative appraisal of the illness. Their family caregivers report more uncertainty, hopelessness, adjustment problems, a lower mental quality of life, higher uncertainty and fewer sources of support than survivors **(Northouse et al., 2002).**

It is important to note that the recurrent phase of cancer can lead to very different outcomes in patients and their families over time. Some survivors experience long disease-free remissions, while others face a steady progression of their cancer, in spite of having undergone multiple unsuccessful treatments. These two scenarios can have very different effects on the quality of life and distress levels of cancer patients and their family caregivers during recurrence **(Northouse et al., 2012).**

6) Advanced and End-of-Life Phase

Advanced cancer is often characterized by high symptom distress in patients and high caregiver burden in their family members. Some patients are informed that they have advanced cancer at the time of their diagnosis, but for many patients the cancer progresses to an advanced phase over time. Researchers in one study found that caregivers of patients with a short time interval between diagnosis and death experienced more symptoms of depression **(Given et al., 2004)**.

As the end of life approaches, caregivers in some studies reported depressive symptoms that equaled or exceeded thresholds for clinical depression (Major depression) **(Given et al., 2004).**Sources of caregiver depression are related to more negative family relationships, **(Francis et al., 2010)** including a sense of abandonment, more outside demands related to their employment, and more symptom distress in patients **(Given et al., 2004)**. In one study, the majority of caregivers (71%) needed substantial help with managing the patient's symptoms, and this need remained unmet for 43% of the caregivers through the end of the patient's life. Caregivers, who had substantial unmet needs related to symptom management, and difficulty obtaining financial and community support, were more likely to report that the patient received lower quality of care at the end of life than caregivers who had fewer unmet needs **(Park et al., 2010).**

The relationship between caregiving burden and psychological health of caregivers

Even though caregiving burden is closely associated with psychological distress, previous research has demonstrated that the two are related yet different constructs. While caregiving burden is a risk factor, possibly a precursor to psychological distress, distress is the outcome of caregiving **(Brannan & Helfinger, 2002).** For example, in a longitudinal study of breast cancer patients and their primary caregivers, reported that caregiver burden is the most significant predictor of both anxiety and depression experienced by the caregivers **(Grunfeld et al., 2004)**.

Most of the research on caregiver burden outcomes has focused on psychological outcomes such as the occurrence of depression. Symptoms of loneliness and depression are widely present in family caregivers with prevalence rate up to 47% of caregiver population. Although it is indeed possible that the subjective or emotional response to caregiving will be positive because of personal reward from the act of caregiving, negative feeling of unhappiness, guilt, anger, fear and anxiety are other typical emotions expressed by distressed caregivers **(Silver &Wellman, 2002).**

Caregiver burden and depressive symptoms are the most common negative outcomes of providing care for the elderly. Caregiver burden is defined as the negative reaction to the impact of providing care on the caregiver's social, occupational, and personal roles and appears to be a precursor to depressive symptoms **(Reinhard et al., 2008).** This burden may lead the caregiver to postpone his/her own needs. The patient's close family members may experience poor psychological well-being (depression, anxiety), decreased satisfaction in relationships **(Goldberg & Rickler, 2011).**

Moreover, the most obvious signs and symptoms of caregiving burden are often psychological problems, most commonly anxiety, depression, worry and loneliness. These psychological reactions are related to the caregiver's appraisal of the experience, with those reporting more benefit and deriving more meaning from the experience feeling less stress and reporting better quality of life. The level of distress reported by many of those caring for someone with cancer can be equal to or greater than that of the cancer patient, with adult daughters seeming to have the greatest difficulties. In addition, those reporting higher levels of emotional distress also report more problems with fatigue, sleep impairment and unhealthy behaviors **(Bevans & Sternberg, 2012).** Recent study showed that cancer caregivers felt more psychological distress as they continued to fulfill their caregiver responsibilities. Other responsibilities in addition to caregiving, as well as not having enough personal time and worrying about the future resulted in more burdens and thus, more psychological distress **(Macaraeg & Smith, 2013)**.

Interventions for family caregivers caring for older adults with cancer

Cancer affects the entire family, not just the patient. In addition to causing distress to the patient, it puts financial, personal, social and health stress on family members. Stress among family caregivers ultimately affects quality of care that is being provided to the patient. This is also because they are unprepared to provide care, have inadequate knowledge about care giving along with financial burden, physical and emotional stress. Thus interventions are needed to help caregivers to strengthen their confidence in giving care and come out with better quality of care. If the burden of the caregivers is reduced, then one can expect the patient to benefit **(Kulkarni et al., 2014).**

Caregiver assessment:

Caregiver assessment is generally used to describe a systematic process of gathering information about a caregiving situation and identifying the particular problems, needs, resources, and strengths of the family caregiver. It approaches issues from the caregiver’s perspective and culture, focuses on what assistance the caregiver may need, and seeks to maintain the caregiver’s own health and well-being **(Feinberg et al., 2006).**

The family caregiver assessment is the key component to identify caregivers’ areas of needs so that they can obtain strategies and interventions that will aid the patient during and after active treatment **(Given et al., 2011)**. Caregiver assessment can identify family members most at risk for health and mental health effects and determine if she or he is eligible for additional support **(Feinberg, 2008)**.

Educational interventions

Lack of adequate information is reported as one of the most important concerns of caregivers of patients with advanced cancer. Sixty per cent of close relatives of deceased cancer patients have reported that they were not able to find out all they had wanted to know about the patient’s medical condition and how it would affect him or her. Not knowing much about the illness and fear of not knowing what to do or to expect was perceived as very stressful and led to an increase in caregiver anxiety, increasing frustration and uncertainty. Understanding details relating to the illness were reported to help caregivers cope **(Girgis et al., 2006).**

Education is an effective tool for helping cancer patients and their families understand the disease process, pain, other symptoms, and treatment options. Information about the disease trajectory, the anticipated course, and the range of emotions experienced by families helps normalize the experience and enhances the sense of control that is often absent in cancer. The most important periods along the disease course for caregivers to receive information appear to be diagnosis, period of initial hospitalization, initiation of new treatments, recurrence, and the end-of-life phase **(Glajchen, 2004).** This kind of information can relieve caregivers' distress arising from uncertainties about their ill family members' disease and treatment status and the care they may need. For example, teaching caregivers how to manage pain and other symptoms benefits both the patient and the caregiver. Caregivers who report more confidence in managing symptoms report less depression, anxiety, and fatigue **(Campbell et al., 2004).**

Although a literature review revealed few educational interventions that specifically focus on caregivers of older cancer patients, several interventions to family caregivers in general have focused on providing information to alleviate distress. For example, **Walsh and Schmidt, 2003** reported an educational intervention delivered over the phone for caregivers over the age of 50 of persons receiving hospice. Caregivers who received the intervention tended to experience less depression and disorganization with care **(Given & Sherwood, 2006).**

Psychoeducational intervention

Knowledge and psychosocial support are considered the common unmet needs of caregivers, because low social support as well as caregiving burden induced stress and anxiety in caregivers, consequently the quality of care delivered was negatively affected. To fulfill these unmet needs, alleviate caregiving burden and facilitate coping, various non-pharmacology interventions such as psychoeducational intervention and support groups have been made available. Psychoeducational intervention has been reported to improve the knowledge in disease information, such as cause, treatment and prognosis, stress coping and self-care, caregiving ability, and psychological distress of caregivers. **(Tang et al., 2014)**. Psychoeducational programs provide caregivers of cancer patients with a variety of skills, resources, and problem-solving strategies to help them cope with caregiving. For example, the problem-solving model summarized by the acronym COPE (creativity, optimism, planning, and expert information) is designed to maximize a caregiver's effectiveness, sense of efficacy, and satisfaction **(National Cancer Institute, 2014).**

Psychoeducation or psychoeducational interventions encompass a broad range of activities that combine education and other activities such as counseling and supportive interventions. Psychoeducational interventions may be delivered individually or in groups and may be tailored or standardized. This type of intervention generally includes providing patients with information about treatments, symptoms, resources, and services; training to provide care and respond to disease-related problems; and problem-solving strategies for coping with cancer. Interventions may include the use of booklets, videos, audiotapes, and computers, and formats may be interactive among healthcare professionals and patients and caregivers, self-directed via the use of CDs (compacted disks) and other materials, or delivered online or telephonically **(Oncology Nursing society, 2014)**

The majority of cancer caregiver intervention studies have used a psycho-educational intervention, which emphasizes both the provision of information and a psychological counseling component to deal with caregiver distress. **Manne et al., 2004** documented that a psycho-educational group intervention made positive contributions to spouses over age 60 through gains in the use of positive reappraisal coping and reductions in denial coping. Although changes in caregivers' psychological distress were not statistically significant, improvements in adaptive coping and psychological growth were found. In another study implemented a family-based psycho-educational program for women with breast cancer and their family members, the intervention consisted of three home visits and two phone calls over a 5-month period, and focused on open communication, mutual support, family involvement, optimistic thinking, sharing fears and negative thoughts, uncertainty reduction, symptom management, maintaining hope, dealing with stress, and coping effectiveness. This intervention led to higher reported satisfaction among participating family members **(Northouse et al., 2002)**.

Home care services for the cancer older adult's patient

Home care services for the cancer patient also give the caregiver support. State or local health departments usually have a list of licensed home care agencies. Some of the services that home care agencies provide include the following:

- Visits from nurses, aides, therapists, and social workers.
- Help with running errands, making meals, and bathing.

- Delivery of medicine.
- Use of medical equipment **(National Cancer Institute, 2014).**

In Egypt, Care with love organization which registered under the Ministry of Social Affairs in 2003 provides home services for the elderly which include: 1) Assisted Living such as personal hygiene, eating, mobility assistance, and social support, 2) Health Care such as measuring vital signs, dispensing medications, wound care, catheter care, and tube feeding **(Care with love, 2014)**.

Caregivers report high rates of satisfaction with such services and describe them as useful. At the same time, however, studies continue to show high levels of psychological morbidity and unmet needs among caregivers of cancer patients using home care services, suggesting that generic supportive nursing care does not fully meet caregiver needs **(Harding R, Higginson IJ, 2003**). In Saudi Arabia, caregivers are satisfied with the services provided by a home care support program and agreed that a home care services provided the proper healthcare-related support to the patients and improved caregivers' self-confidence in caring for their patients. The median level of satisfaction was 90%, and 73.2% of caregivers had a satisfaction score of 75% or higher **(Al-Khashan et al., 2011).**

Family Meetings

The family meeting is considered by some to be the ideal forum for eliciting caregiver concerns, providing clear information about treatment, facilitating end-of-life care decisions, and avoiding inappropriate treatment. Well-organized family meetings promote a safe setting for caregivers to process emotions and receive validation for their concerns **(Glajchen, 2012)**.

During a family meeting, the whole family talks with the health care team. Family meetings help the health care team and the caregivers connect and work together. It is important to include the family spokesperson and all caregivers. While everyone may be trying to do what they think is best for the patient, family members may disagree about what this means. During family meetings, family members can talk about how they feel or decide what kind of help they can give. Each person may have certain skills to offer. Family meetings are most helpful when:

- There is a clear list of what is going to be discussed.
- A member of the health care teams acts as the meeting leader.
- Family members and caregivers are given the chance to ask questions and discuss concerns.
- Family members and caregivers are free to talk about painful emotions and receive the help of trained professionals who care about them.
- At the end of the meeting, the health care team may go over what was decided and plan the next steps **(National cancer Institute, 2014).**

The family meeting can be extremely helpful for oncology caregivers, especially if the agenda covers both practical and psychosocial issues, more than one family member is present, consensus is reached, and different professional disciplines provide expertise that covers both the physical and psychosocial aspects of caregiving. The use of the family meeting to alleviate caregiver burden may be another fruitful area for future inquiry (**Gueguen et al., 2009**).

Respite Care:

Respite is planned, temporary relief for the primary caregiver through the provision of substitute care. There are three different types: (1) center-based day programs that offer care for a number of hours, depending on the needs of the caregiver, (2) in-home respite, and (3) institutional around the clock care used when the caregiver takes a holiday, becomes temporarily ill, or when other personal demands interfere with the care of the relative. There is no clear evidence that respite improves burden or mental health in caregivers of patients with advanced disease. This may be because respite is typically used by the most stressed caregivers only as a last resort, when the demands of caregiving become overwhelming. Respite is also often unacceptable as many caregivers are unwilling or unable to leave the patient even when respite services offered to family caregivers at no or minimal cost **(Hebert & Schulz, 2006).**

On the other hand, on systematic review of the effect of respite care on depression, burden, anger, anxiety and quality of life of family caregivers of frail elderly; pooled results show a positive effect of respite on caregiver burden after 2–3 month's follow-up and had a positive impact on caregivers' anger towards the care recipient. However, quality of life was significantly worsened after 6 to 12 months in caregivers receiving respite care. Although not statistically significant after pooling results, respite services tended to have a positive effect on depression and a negative effect on anxiety **(Shaw et al., 2009).**

Health promotion

Caregivers may forego their own health needs to focus on providing care during active treatment. Health care professionals need to encourage caregivers to return to usual activities and maintain their own physical and mental health. The prevalence of the unhealthy behaviors such as limited physical activity, poor nutrition, obesity, alcohol consumption, and smoking among family caregivers in the survivorship phase is not well established (**Given et al., 2011)**.

In one of the few studies in this area, caregivers of ovarian cancer patients were followed over approximately 3 years following their cancer diagnosis to examine current health patterns and weight changes. More than half of the caregivers did not meet physical activity guidelines, and 71% were overweight; 40% ate less than 2 servings of fruit, and 80% less than 5 servings of vegetables. The study also reported that 37% consumed alcoholic drinks and 10% were smokers, fifty-six percent reported more than one negative change in lifestyle, 42% decreased physical activity, and 35% gained weight since the patient's diagnosis. Caregivers reported more unhealthy behaviors when they had fewer years of education, were limited in daily activities, or reported high levels of depressive symptoms **(Beesley et al., 2011)**.

Nurses and other health care professionals need to encourage caregivers to adopt a healthy lifestyle to maintain their own physical and mental wellbeing. Healthy lifestyle can increase resistance to stress and strength their physical and mental health. Exercise plays a key role in preventing and reducing stress. Eating healthy diet is also critical because well-nourished bodies are in a better condition to weather the stress associated with caregiving. Finally, caregivers need to engage in cancer prevention and health screening activities (eg, cholesterol, colorectal and breast cancer screening) so that problems can be detected on a timely manner (**Yarbro et al., 2010)**.

Counseling and psychotherapy

Counseling and psychotherapy are designed to reduce distress by helping caregivers adjust psychologically to the demands of caregiving. These interventions are typically designed to enhance morale, self-esteem, coping, and sense of control while reducing anxiety and depression. Individual counseling is designed to provide caregivers with support, education, and problem-solving or coping skills. However, these interventions are expensive and may prove too time-consuming for working or highly distressed caregivers **(Wong et al., 2002).**

Multicomponent

Multicomponent interventions for caregivers incorporate various combinations of psycho-educational, supportive, psychotherapy, and respite interventions **(Sorenson et al., 2002)**. These interventions are likely to be most effective at reducing caregiver strain and burden because they use a variety of techniques to address the caregivers' needs. Multicomponent interventions in two meta-analyses had a moderate effect on reducing caregiver burden, whereas when interventions focused on a single therapeutic activity, such as supportive interventions (e.g., support groups) or psycho-educational interventions, only a small burden reduction was realized **(Sorenson et al., 2002 and Martire et al., 2004)**. Recent study in China demonstrated that the efficacy of the multicomponent intervention was demonstrated by significant improvement in the perception of positive aspects of caregiving, reduction in depressive symptoms, subjective burden, bother, and caregiving risks **(Cheung et al., 2014)**.

Evidence-based interventions to reduce emotional distress in family caregivers: meta-analysis findings

There is evidence that interventions can reduce emotional distress in patients and their caregivers. One meta-analysis examined the outcomes of 29 randomized clinical trials that delivered psychosocial interventions to cancer patients and their family caregivers, or to caregivers alone. The investigators pooled the data from these 29 studies and then analyzed it to determine if the interventions had any effects on several different caregiver outcomes. Findings from the meta-analysis indicated that the interventions had a number of positive outcomes for caregivers. They reduced caregivers' burden, increased caregivers' knowledge and perceived benefits of caregiving, enhanced caregivers' coping resources and self-efficacy, and improved many aspects of the caregiver's quality of life. Findings also indicated that the interventions significantly reduced the caregiver's emotional distress and anxiety but no significant reduction in caregiver depression. The later finding must be viewed with caution because in some studies caregivers had little depression at the start of the study, and in other studies, caregivers who were more depressed dropped out of the study **(Northouse et al., 2010)**.

The interventions reported in the 29 studies were examined for content, dose, and delivery format. The types of interventions were classified into three groups: 1) psycho-educational (57.1%); 2) skills training (25.7%); or 3) therapeutic counseling (17.1%). The dose of the interventions ranged from two to 16 sessions, with the average number being 6.7 sessions. In regard to delivery format, two thirds were delivered jointly to patients and their caregivers and one third to caregivers only. Most interventions were offered in a face-to-face format (68.6%), some were delivered by phone (20%), and only a few in a group format (11.3%). Two studies used a combination of face to- face and phone interventions. No studies used Web-based interventions **(Northouse et al., 2010)**.

Materials & Method

Materials and Method

Materials

I-Study design:

A descriptive correlational cross sectional research design was used in this study.

II-Setting:

This study was conducted in the oncology inpatient wards and outpatients clinics in the Oncology Center at Mansoura city.

III-Subjects:

A purposive sample of 157 family caregivers of the older adults diagnosed with cancer attending in the above mentioned settings within a period of three months (from 1st of January till 1st of April, 2014) and fulfilling the following criteria:

1. Aged 18 years or more.
2. Both sexes
3. Responsible for providing care for older adults included in the study.
4. Willing to participate in the study.

Exclusion criteria: Paid caregivers and caregivers who are the first time caring the older adults.

IV-Tools of data collection:

In order to collect the necessary information for the study four tools were used.

Tool I: Socio demographic and clinical data structured interview schedule (Appendix I):

It was developed by the researcher after literature reviewing and included two parts:

Part I: Data about older adults with cancer. It included item related to;

1- Socio-demographic characteristics of the patients such as age, sex, marital status, level of education, occupation, and income.

2-Health history of the older adults: type of cancer, duration of disease, and received treatment.

3-Functional status of the older adults and it included assessment of activities of daily living (ADL) and instrumental activities of daily living (IADL) through the use of the two following scales:

a- Barthel Index Scale:

The Barthel Index Scale was developed by Malhoney (1965) to measure activities of daily living of the elders. This scale was translated into Arabic by Hallaj (2007).This Arabic version was used in the present study. The reliability of this tool was tested using test retest reliability Spearman's correlation coefficient r=0.971.The scale consists of 10 questions which assess the person's abilities in the areas of feeding, moving (from wheelchair to bed and return), personal toilet, getting on and off toilet, bathing self, propelling a wheelchair, ascending and descending stairs, dressing/ undressing, and controlling bowel and bladder. A score of 0 is given when patient cannot meet criteria as defined (dependent), 1 is given when he needs help and 2 is given when he is independent. The total score of this scale is (20) and classified as:

a) 0-7= dependent

b) 8-12= independent with assistance

c) 13-20= independent

b- Lawton and Brody Scale

Lawton and Brody Scale (1969) was used to assess instrumental activities of daily living (IADLs). This scale was translated into Arabic and tested for its validity and reliability by Hallaj 2007. The scale includes eight items: ability to use the telephone, go shopping, food preparation, housekeeping, laundry, transportation, responsibility for own medication and ability to handle finances. The answers were given a score according to the response as follows:

- Able (2)
- Unable (1)

The maximum score was 16 for females and 10 for males. Six points from the maximum score were subtracted for males for gender-specific questions. The score achieved by the elder was calculated as a percentage. The degree of the elder's performance of IADL was categorized as follows:-

a) Totally dependent (0<25%)
b) Partially dependent (25<75%)
c) Independent (≥75%)

Part II: Data about older adult's caregiver. It included items related to;

1- Socio-demographic characteristics of the care giver such as age, sex, level of education, occupation, relation to elderly, marital status, number of children and income.
2- Health history of the caregiver; it include type of chronic disease such as cardiovascular diseases, liver disease, hypertension, diabetes and medication used.

Tool II : The Zarit Burden Interview (ZBI) (Appendix II):

It was developed by Zarit,et al(1980). The interview provides a global, unidimensional measure of care giving burden. 22-item rating scale measuring burden in health, psychological well-being, finances, social life, and relationship with patient .Each item on the interview is a statement which the caregiver is asked to endorse using a 5-point Likert scale. Response options range from 0 (Never) to 4 (Nearly Always). Scoring key: o to 20 = little or no burden; 21 to 40 = mild to moderate burden; 41 to 60 = moderate to severe burden; 61 to 88 = severe burden.

Tool III: Hospital Anxiety and Depression Scale (HADS) (Appendix III):

It was developed by Zigmond & Snaith (1983). HADS is a self-report questionnaire commonly used to assess levels of anxiety and depression. This scale was translated into Arabic and tested for its validity and reliability by Abd Elhameed SH, 2010. This Arabic version was used in the present study. The reliability of this tool was tested using test retest reliability Spearman's correlation coefficient r=0.861. The HADS comprises statements which the patient rates based on their experience over the past week. The 14 statements are relevant to generalized anxiety (7 statements) or 'depression' (7 statements), the latter being largely (but not entirely) composed of reflections of the state of anaerobia. Each question has 4 possible responses. Responses are scored on a scale from 3 to 0. The two subscales, anxiety (HADS-A) and depression (HADS-D), have been found to be independent measures. In its current form the HADS is now divided into four ranges: normal (0–7), mild (8–10), moderate (11–15), and severe (16–21).

Tool IV: General Health Questionnaire-12 (GHQ-12) (Appendix IV):

General Health Questionnaire-12 was developed by Goldberg in 1988. GHQ-12 is a screening tool which was used to identify the severity of psychological distress experienced by an individual within the past few weeks.GHQ-12 Arabic version was tested for its validity and reliability by Daradkeh TK, et al in 2001. The Arabic version of the GHQ-12 proved to be reliable as indicated by Cronbach alpha of .86 and was used in this study. The items of GHQ-12 focus on various aspects of respondents' psychological disposition, for example problems with sleep (Have you recently lost much sleep over worry?), strain (Have you recently felt constantly under strain?), happiness (Have you recently been feeling reasonably happy, all things considered?) or stress (Have you recently been feeling unhappy or depressed?). The questions compare how the respondents' present state differs from their usual state. For the scoring, a four-point Likert scale (0, 1, 2, and 3) was used with sum score ranging from 0 to 36. Higher score indicates lower psychological well-being. Scoring – Likert Scale 0, 1, 2, 3 from left to right.

The Likert scoring method results in a score ranging from 0–36 and it can be broken down for interpretation into five categories. A score of 1–10 indicates 'low psychological distress'; 11–12 is 'typical'; 13–15 is 'more than typical'; 16–20 shows 'evidence of psychological distress'; scores over 20 indicate 'severe distress' (Goldberg *et al.* 1997).

Method

1. An official letter was issued from the Faculty of Nursing, Mansoura University to the director of Mansoura Oncology Center to obtain his approval to carry out the study.

2. The director of the Oncology Center was informed about the purpose of the study, the date and the time of starting data collection in order to obtain his approval to interview the older adult patients and their family caregivers.

3. Necessary approval was obtained from ethical committee of the Faculty of Nursing-Mansoura University.

4. After a thorough review of literature, tool I (Socio-demographic Characteristic and Clinical Data Structured Interview Schedule) was developed by the researcher and reviewed by the supervisors.

5. Tool II (The Zarit Burden Interview) was translated by the researcher into Arabic language and tested using test – retest method .This tool was applied to 15 older adults and their caregivers selected from El Mansoura Oncology Center and reapplied 2 weeks later. The reliability was assured by means of Cronbach's alpha (r) = 0.85.

6. The Arabic versions of the study tools were used.

7. Study tools were revised by 7 experts in the fields of Gerontological Nursing, Medical Surgical Nursing, Psychiatric Nursing and Community health Medicine, as a jury to test its content validity and feasibility and necessary modification were done (Adding older adults' functional status assessment).

8. Verbal consent of the subjects was obtained after explanation of the purpose of the study.

9. Privacy of the subjects was assured and Confidentiality of the collected data was maintained.

10. A pilot study was carried out on 15 family caregivers from outpatient clinics in Mansoura Oncology Center before starting the data collection to test the feasibility

of the tools and to identify the approximate time needed for the interview. The family caregivers participated in the pilot study were excluded from the study sample. The data obtained from the pilot study was analyzed and according to the results, the recommended changes were done (a question about stage of cancer was removed because it was not applicable in the older adults patients' medical records).

11. Based on the schedule of the Mansoura Oncology Center, the researcher visited the outpatient clinics two days / week (Saturday for chemotherapy and blood diseases outpatient clinics and Monday for oncology medical and surgical outpatient clinics) and on Thursday the researcher visited medical, surgical and blood diseases inpatient wards.

12. All the family caregivers who were with their older adults' patients in these days and fulfill the study criteria were included in the study.

13. The researcher used to meet with each family caregiver in the waiting room either in inpatient wards or outpatient clinics. A face to face interview was conducted with each family caregiver who fulfilled the study criteria.

14. Each family caregiver was interviewed individually by the researcher after the researcher introducing herself and explaining the purpose of the study. Then the necessary data were collected using the study tools. Patients' medical records were reviewed to complete the part of patient's health history and the rest of questions was completed by the family caregiver.

15. The researcher started data collection based on the schedule days from 9 am to 2 pm and managed to interview from 4-6 family caregivers daily. Time taken to fill the study tools ranged from 30 to 40 minutes for each family caregiver.

16. The data collection covered a period of three months from the first of January, 2014 till the first of April, 2014.

Statistical analysis

Data were analyzed using with statistical package for social science (SPSS) version 16. The normality of data was first tested with one-sample Kolmogorov-Smirnov test. Qualitative data were described using number and percent. Association between categorical variables was tested using Chi-square test. Continuous variables were presented as mean ± SD (standard deviation). The two groups were compared with Student t test. Analysis of Variance (ANOVA test) used for comparison of means of more than two groups. Pearson correlation used for correlation between continuous data. Graphs were done for data visualization using Microsoft Excel.

Level significance:

For all above mentioned statistical tests done, the threshold of significance is fixed at 5% level (p-value).

The results were considered:

- Non-significant when the probability of error is more than 5% ($P > 0.05$).
- Significant when the probability of error is less than 5% ($P < 0.05$).
- Highly significant when the probability of error is less than 0.1% ($P < 0.001$).

The smaller the p-value obtained, the more significant are the results.

Results

Results

The results of the study will presented as following:

Part I: Characteristics of the studied older adults with cancer.

Part II: Characteristics of the studied family caregivers.

Part III: Caregiving properties.

Part V: Caregiving burden and psychological health status of the studied family caregivers.

Part IV: Relation between caregiving burden and psychological health status and the related factors.

Part I: Characteristics of the studied older adults with cancer

Table (1) shows the distribution of older adults' patients with cancer according to their socio-demographic characteristics.

The age of the studied older adults ranged from 60 to 85 years. Older adults aged 60>75 constituted 89.8% of the studied subjects,8.3% were elderly 65>85 years old, and 1.9% were 85 years and above.

Females were more prevalent in the studied older adults. They constituted 73.9%of the older adults, while 26.1% were males. Regarding the marital status, 58.6% of older adults were married and only 0.6% was single.

Concerning the level of education of older adults in this study, illiteracy was prevailing (83.4%) among of the studied subjects and 2.5% of the subjects had a university degree. Regarding older adults patients occupation before retirement, it was observed that more than two third of the studied older adults (72.0%) were housewives.

As regards to residence, the majority of them (81.5%) were residing in rural areas and 18.5% in urban areas. In relation to the economic status, 66.2% reported that their income was not enough and only 0.6% was enough and saves.

Table (1): Distribution of older adults' patients with cancer according to their socio-demographic characteristics

Socio-demographic characteristics	No (157)	% 100
Age		
60<75	141	89.8
75<85	13	8.3
85 and more	3	1.9
Sex		
Male	41	26.1
Female	116	73.9
Marital status		
Single	1	0.6
Married	92	58.6
Widow	59	37.6
Divorced	5	3.2
Education level		
Illiterate	131	83.4
Read and write	8	5.1
Secondary	14	8.9
University	4	2.5
Occupation before retirement		
Employee	10	6.4
Farmer	15	9.6
Housewife #	113	72.0
Worker craftsman	15	9.6
Driver	4	2.5
Residence		
Rural	128	81.5
Urban	29	18.5
Elderly income		
Enough	52	33.1
Not enough	104	66.2
Enough and saves	1	0.6

Only 3 females were employee and the rest were housewives

Table (2) shows the distribution of older adults' patients according to their medical history. It was found that the majority of older adults (67.5%) were not hospitalized. The duration of hospitalization stayed by the older adults' patients' varied. In relation to the previous surgery, the majority of older adults (73.2%) had no previous surgery.

It is also observed from the table that more than half of the older adults' patients (58%) reported no associated diseases with cancer. Hypertension was the most prevailing disease (26.1%) among the studied subjects and only 0.6% had psychiatric problem. Most common medications consumed by the older adults' patients were antihypertensive drugs 25.5%.

Table (2): Distribution of older adults' patients according to their medical history

Medical history	**No (157)**	**% 100**
Previous hospitalization		
No	106	67.5
Yes	51	32.5
No of previous hospitalization	**(n=51)**	
Once	43	27.4
Twice	5	3.2
Three and more	3	1.9
Previous surgery		
No	115	73.2
Yes	42	26.8
No of previous surgery	**(n=42)**	
Once	41	26.1
Twice	1	0.6
Suffering from other disease		
No	91	58.0
Yes	66	42.0
Associated disease type #	**(n=66)**	
Heart disease	9	5.7
Hypertension	41	26.1
Renal disease	4	2.5
Diabetes mellitus	39	24.8
Psychiatric problem	1	0.6
Liver disease	5	3.2
Using medication#		
Non	91	58.0
Cortisone	3	1.9
Antihypertensive drugs	40	25.5
Hypoglycemic agent	38	24.2
Heart medication	9	5.7
Liver support	5	3.2
Hemodialysis	2	1.3

 # More than one answer was given

Table (3) shows the distribution of older adults patients according to their cancer history.

Regarding the site of cancer, breast cancer was more prevailing among the studied older adults (29.9%) followed by blood cancer (14%). This was followed by lymphoma (10.8%), colon and liver cancer constituted the same percentage (9.6%). Lung and prostate cancer were constituted 5.7%, 4.5% respectively. Stomach, pancreatic, gallbladder and spleen cancer counted the same percentage 3.2%, while uterine cancer was 2.5%, brain tumor was 1.3% and only 0.6% was for rectal cancer and for tongue cancer.

Concerning duration of cancer, it was found that the majority 80.9% of the older patients reported suffering from cancer since less than 3 years and only 3.8% suffered since 10 years and more.

Regarding type of treatment used for cancer, 80.3% received chemotherapy, 48.8% done surgery, 6.4% used hormonal therapy and 3.2% received radiotherapy.

Table (3): Distribution of older adults' patients according to their cancer history and treatment used

Item	No (157)	% 100
Site of cancer #		
Lymphatic	17	10.8
Breast cancer	47	29.9
Blood cancer	22	14.0
Colon cancer	15	9.6
Stomach cancer	5	3.2
Uterine cancer	4	2.5
Lung cancer	9	5.7
Pancreatic cancer	5	3.2
Ovarian cancer	18	11.5
Rectal cancer	1	0.6
Brain tumor	2	1.3
liver cancer	15	9.6
Gall bladder cancer	5	3.2
Spleen cancer	5	3.2
Prostate cancer	7	4.5
Tongue cancer	1	0.6
Duration of cancer		
Less than 3years	127	80.9
3<5years	17	10.8
5<10years	7	4.5
10years and more	6	3.8
Type of treatment #		
Chemotherapy	126	80.3
Radiotherapy	5	3.2
Hormonal	10	6.4
Surgery	76	48.8

 # More than one answer was given

Table (4) shows the distribution of the studied older adults' patients according to their functional status. As regard activity of daily livings (ADLs) it was found that 4.5% of the older adults were totally dependent and 75.8% were independent in their ADLs. In relation to instrumental activity of daily livings (IADLs) it appeared that more than two third (68.6%) of older adults needed assistant, 31.8% were independent and no one was totally dependent in their IADLs.

Table (4): Distribution of the studied older adults' patients according to their functional status

Item	**No** **(157)**	**%** **100**
Barthel index scale for ADL		
Dependent(0-7)	7	4.5
Independent with assistance(8-12)	31	19.7
Independent(13-20)	119	75.8
Mean ± SD 15.15±4.11	**Min-Max** 1-20	
Lawten scale for IADL		
Independent with assistance (25<75%)	107	68.2
Independent (> or =75%)	50	31.8
Mean ± SD 69.06±12.63	**Min-Max** 50-100	

Part II: Characteristics of the studied family caregivers

Table (5) shows the distribution of family caregivers according to their sociodemographic characteristics. The age of the studied caregivers ranged from 18 to 65 years with a mean age 40.14±11.14. More than half of the studied caregivers (52.9%) were 30 to less than 45 years, while 20.4% were 18 to 30 years. Female subjects constituted more than two third (71.3%), compared to 28.7% of males' caregivers.

Regarding the marital status, the majority of caregivers (80.9%) were married and the minority (2.5%) were divorced. For the educational level, more than half (55.4%) had secondary education and only 0.6% had postgraduate degree.

Regarding caregivers occupation, it was observed that 40.1% were working, while 59.9% were not working. In relation to the economic status, about two third (61.1%) reported that their income was enough.

Table (5): Distribution of family caregivers according to their socio-demographic characteristics

Item	No (157)	% 100
Age		
18<30yaers	32	20.4
30<45years	83	52.9
45and more	42	26.8
Mean ± SD 40.14±11.14		
Sex		
Male	45	28.7
Female	112	71.3
Marital status		
Single	21	13.4
Married	127	80.9
Widow	5	3.2
Divorced	4	2.5
Education level		
Illiterate	30	19.1
Read and write	10	6.4
Secondary	87	55.4
University	29	18.5
Postgraduate	1	0.6
Occupation		
Working	63	40.1
Not working	**(94)**	**(59.9)**
Housewife	85	54.2
Retirement	6	3.8
Student	3	1.9
Income		
Enough	96	61.1
Not enough	61	38.9

Table (6) shows the distribution of family caregivers according to their medical history. It was observed that the majority (86%) of the studied caregivers didn't suffer from any disease. 8.3% had hypertension, 6.4% had diabetes, 1.9% had orthopedic problem, 1.3% had psychiatric disorder and only 0.6% had physical disability. In relation to medication used, antihypertensive and hypoglycemic drugs constituted 8.3%, 6.4% respectively. While analgesics counted 2.5% and antidepressant 1.3% for each.

Table (6): Distribution of family caregivers according to their medical history

Item	**No (157)**	**% 100**
Suffering from disease		
No	135	86.0
Yes	22	14
Type of disease #:	**(n=22)**	
Hypertension	13	8.3
Diabetes Mellitus	10	6.4
Orthopedic problem	3	1.9
Psychiatric disorder	2	1.3
Physical disability	1	0.6
Type of medication used #:	**(n=22)**	
Antihypertensive drug	13	8.3
Hypoglycemic agent	10	6.4
Analgesic	4	2.5
Antidepressant	2	1.3

 # More than one answer was given

Figure (1) shows the distribution of the studied caregivers and older adults according to interview place. It appears that the majority (77.7%) of the studied caregivers and older adults were interviewed in the outpatient clinics, while the rest of the study subjects (22.3%) were interviewed in the inpatient wards.

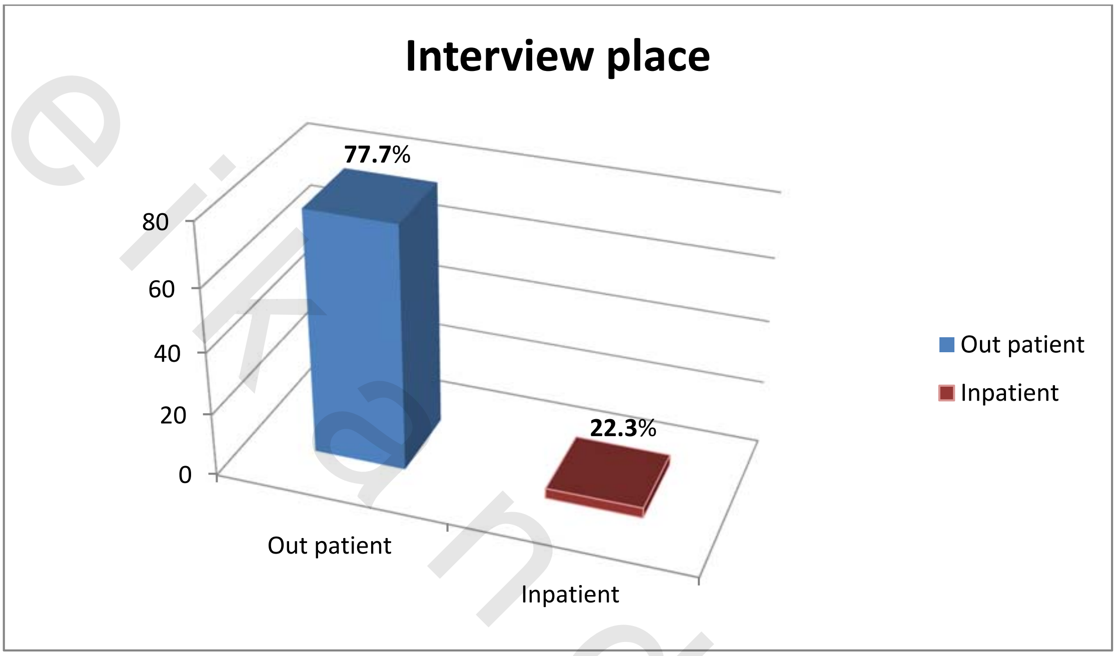


Figure (1): Distribution of the studied caregivers and older adults according to interview place

Part III: Caregiving properties.

Table (7) shows the distribution of family caregivers according to their caregiving properties. It was observed that more than half (51%) of the studied caregivers were son or daughter and 1.3% were other relatives. In relation to caregivers who live with older adults in the same house, it was noticed that more than two third (64.3%) of the studied caregivers living with older adults.

Concerning availability of secondary caregiver, the majority (78.3%) of the studied caregivers had secondary caregivers and the rest (21.7%) were the primary caregivers. Regarding period of caregiving, 42% were caring since 1 to less than 3 years and 12.1% were caring since 3years and more.

Regarding number of daily hours of caring, about half (50.3%) of the studied caregivers spend from 2 to less than 4 hours daily, while 10.2% spend 6 hours and above daily caring the older adult patients.

Table (7): Distribution of family caregivers according to their caregiving properties

Item	No (157)	% 100
Caregiver relation to older adult		
Son / daughter	80	51.0
Husband /wife	22	14.0
Son's wife	18	11.5
Brother /sister	25	15.9
Daughter of sister/brother	10	6.4
A relative	2	1.3
Living with older adult		
Yes	101	64.3
No	56	35.7
Availability of secondary caregiver		
No	34	21.7
Yes	123	78.3
Relation of the secondary caregivers to older adult (n=123)		
Son / daughter	55	35.0
Husband /wife	28	17.8
Son's wife	26	16.6
Brother /sister	9	5.7
Grandchild	2	1.3
Daughter of sister/brother	2	1.3
A relative	1	.6
Period of caregiving		
3<6month	35	22.3
6<12month	37	23.6
1<3years	66	42.0
3and more	19	12.1
Number of daily hours of caring		
2<4hours	79	50.3
4<6hours	62	39.5
6hoursandmore	16	10.2

Part V: Caregiving burden and psychological health status of the studied family caregivers.

Figure (2) shows caregiving burden of the studied caregivers**.** It is observed that more than half (52.9%) of the studied caregivers had moderate level of burden and only 0.6% had no burden. The total burden score with mean and standard deviation (Mean ± SD) 51.23±12.65 (Min-Max: 19-81).

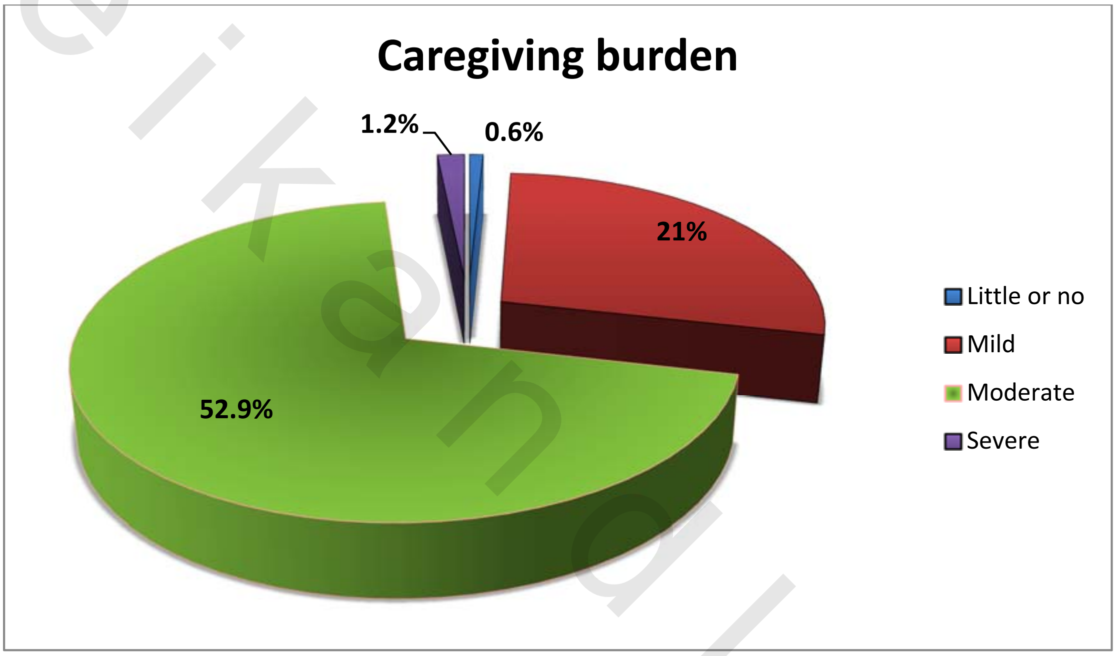


Figure (2): Caregiving burden of the studied caregivers

Table (8) shows caregivers' anxiety and depression level. It is observed that the prevalence of anxiety 85.3% in which 44.6% had moderate anxiety level, while 14.6% of the studied caregivers had a normal anxiety level (Mean ± SD11.31±3.37) & (Min-Max3-21). Moreover, the prevalence of depression was 81.5% in which 37.5% had moderate depression level and 8.9% had severe depression level (Mean ± SD10.64±3.22) & (Min-Max 4-20).

Table (8): Caregivers' anxiety and depression level

Items	**No** **157**	**%** **100**
Anxiety		
Normal(0-7)	23	14.6
Mild(8-10)	44	28.0
Moderate(11-15)	70	44.6
Severe(16-21)	20	12.7
Mean ± SD	**Min-Max**	
11.31±3.37	3-21	
Depression		
Normal(0-7)	29	18.5
Mild(8-10)	55	35.0
Moderate(11-15)	59	37.6
Severe(16-21)	14	8.9
Mean ± SD	**Min-Max**	
10.64±3.22	4-20	

Figure (3) shows caregiver general psychological health status. More than two third (68.8%) of the studied caregivers had severe psychological distress and 5.1 % were more than typical. (Mean ± SD 23.01±5.06) & (Min- Max 3-39).

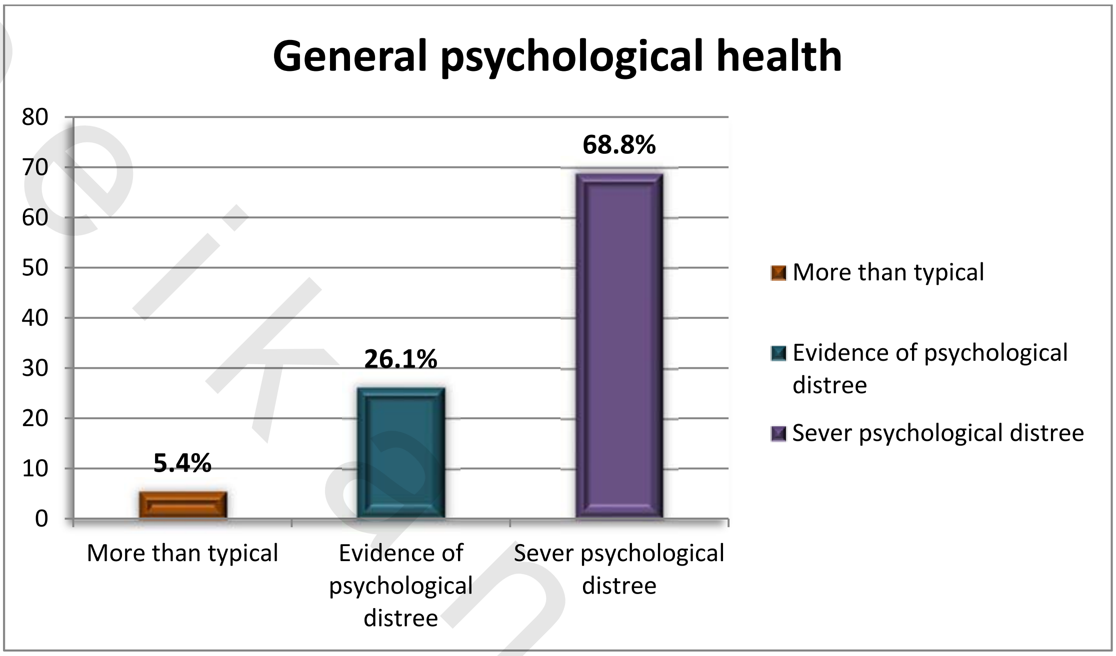


Figure (3): Caregivers' general psychological health status

Part IV: Relation between caregiving burden and psychological health status and related factors.

Table (9) represents relation between older adults' sociodemographic characteristics and mean score of total burden. The mean burden score increases with age. Older adults aged 85years and more their caregivers had higher mean burden score (X=60.00±19.28) but there is no statistical significant relation was found between age and mean score of burden (F=1.277, P=0.282).

The table also revealed that there is no statistical significant relation was found between mean burden score and older adults' sex, marital status and residence (T=0.553, F=0.627 and T=0.465 respectively) and (P=0.581, P=0.612, and P=0.643 respectively).

Moreover, level of education affects significantly the total burden score (F=3.225, P=0.024*).The lower educational level, the higher the burden on the caregivers. In relation to income, the table shows that caregivers caring for older adults who had enough income had lower burden score than those caring for older adults who had not enough income (F=7.085, P=0.001*).

Table (9): Relation between older adults' sociodemographic characteristics and caregiving burden

Sociodemographic characteristics	No.	Mean ± SD	Min-Max	Test of sig.
Age				
60<75	141	50.73±12.59	19-81	F=1.277 P=0.282
75<85	13	54.53±11.52	37-70	
85 and more	3	60.00±19.28	38-74	
Sex				
Male	41	52.17±12.22	19-74	T=0.553 P-0.581
Female	116	50.89±12.82	21-81	
Marital status				
Single	1	38.00±0.00	38-38	F=0.627 P=0.612
Married	92	51.03±12.82	19-81	
Widow	59	51.35±12.89	26-79	
Divorced	5	56.00±3.53	52-61	
Residence				
Rural	128	51.45±12.60	21-81	T=0.465 P=0.643
Urban	29	50.24±13.01	19 -73	
Educational level				
Illiterate	131	51.91±12.26	21-81	F=3.225 P=0.024*
Read and write	8	54.12±10.53	40-66	
Secondary	14	48.14±13.81	30-74	
university	4	33.75±14.86	19-84	
Elderly income				
Enough	52	46.05±12.87	19-76	F=7.085 P=0.001*
Not enough	104	53.83±11.82	21-81	
Enough and saves	1	15.00±0.00	62-62	

*Significant P≤0.05.

Table (10) shows relation between older adults' sociodemographic characteristics and psychological health of their caregivers. It was found that the total anxiety score of the caregivers not significantly correlate with older adults' age, sex, marital status, residence, and educational level (F=2.405, T=0.25, F=0.867, T=0.783, and F=1.557, respectively) and (P=0.094, P=0.980, P=0.460, P=0.435,and P=0.202, and respectively).

Regarding depression, the same table revealed that the total depression score of the caregivers not significantly correlate with older adults' age, sex, marital status, residence, and educational level (F=0.455, T=0.71, F=0.565, T=0.806,and F=0.638 respectively) and (P=0.636, P=0.479, P=0.639, P=0.421, and P=0.592 respectively).

Regarding general psychological health, it also was observed that the total psychological health score of the caregivers not significantly correlate with older adults' age, sex, marital status, residence, and educational level (F=1.902, T=0.815, F=0.529, T=1.269, and F=1.130 respectively) and (P=0.153, P=0.416, P=0.663, P=0.206 and, P=0.339 respectively).

On the other hand, there is a statistical significant relation between older adults' income and mean score of the total anxiety, depression and general psychological health (F=3.742, F=3.244, and F=3.522 respectively) and (P=0.026*, P=0.042*, P=0.032* respectively). Older adults with higher income their caregivers had lower level of anxiety, depression and psychological distress.

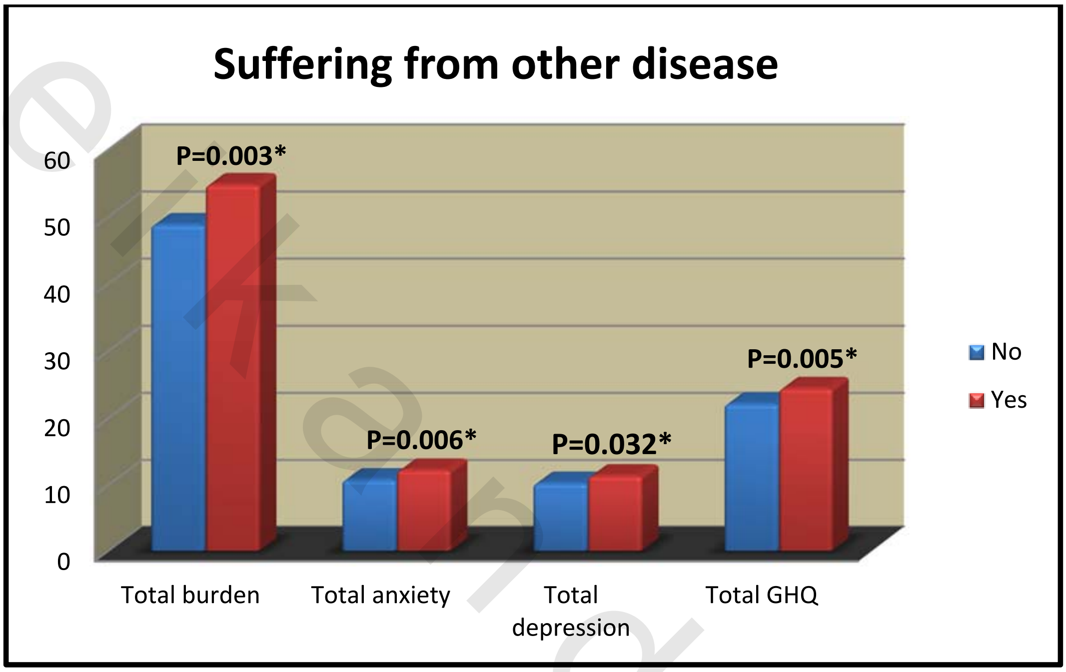
Table (10): Relation between older adults' sociodemographic characteristics and psychological health of their caregivers

Sociodemographic characteristics	No.	Total anxiety		Total depression		General psychological health	
		Mean ± SD (Min-Max)	Test of sig.	Mean ± SD (Min-Max)	Test of sig.	Mean ± SD (Min-Max)	Test of sig.
Age							
60<75	141	11.14±3.38 (3-21)	F=2.405 P=0.094	10.56±3.29 (4-20)	F=0.455 P =0.636	23.04±4.84 (13-39)	F=1.902 P =0.153
75<85	13	12.15±3.10 (8-19)		11.46±2.47 (8-16)		21.46±6.86 (3-29)	
85 and more	3	15.00±1.73 (13-16)		10.66±3.21 (7-13)		27.66±4.93 (22-31)	
Gender							
Male	41	11.31±3.25 (4-17)	T=0.025 P=0.980	10.95±3.13 (5-17)	T=0.71 P= 0.479	23.56±5.22 (15-39)	T=0.815 P =0.416
Female	116	11.30±3.42 (3-21)		10.35±3.26 (4-20)		22.81±5.01 (3-35)	
Marital status							
Single	1	16.00 (16-16)	F=0.867 P=0.460	7.00 (7-7)	F=0.565 P= 0.639	22.00 (22-22)	F=0.529 P =0.663
Married	92	11.17±3.41 (3-21)		10.76±3.28 (4-19)		23.19±5.26 (3-39)	
Widow	59	11.33±3.40 (5-20)		10.47±3.22 (5-20)		22.54±4.94 (13-35)	
Divorced	5	12.40±1.94 (9-14)		11.20±2.28 (8-14)		25.20±2.04 (23-27)	
Residence							
Rural	128	11.40±3.40 (3-21)	T=0.783 P=0.435	10.74±3.22 (4-20)	T=0.806 P =0.421	23.25±5.19 (3-39)	T=1.269 P =0.206

Urban	29	10.86±3.25 (6-19)		10.20±3.23 (5-15)		21.93±4.35 (13-29)	
Educational level							
Illiterate	131	11.38±3.38 (3-21)	F=1.557 P=0.202	10.70±3.15 (4-20)	F=0.638 P= 0.592	23.03±4.91 (3-35)	F=1.130 P =0.339
Read and write	8	11.62±3.15 (7-14)		10.37±3.70 (6-16)		22.50±4.59 (17-30)	
Secondary	14	11.85±3.43 (7-17)		10.85±3.99 (5-17)		24.21±6.63 (14-39)	
University	4	8.00±1.41 (6-9)		8.50±1.00 (7-9)		19.00±4.32 (15-25)	
Elderly income							
Enough	52	10.28±3.12 (5-18)	F=3.742 P=0.026*	9.73±3.19 (5-17)	F=3.244 P =0.042*	21.51±4.66 (14-31)	F=3.522 P =0.032*
Not enough	104	11.79±3.40 (3-21)		11.08±3.17 (4-20)		23.75±5.13 (3-39)	
Enough and saves	1	13.00 (13-13)		12.00 (12-12)		22.00 (22-22)	

*Significant P≤0.05.

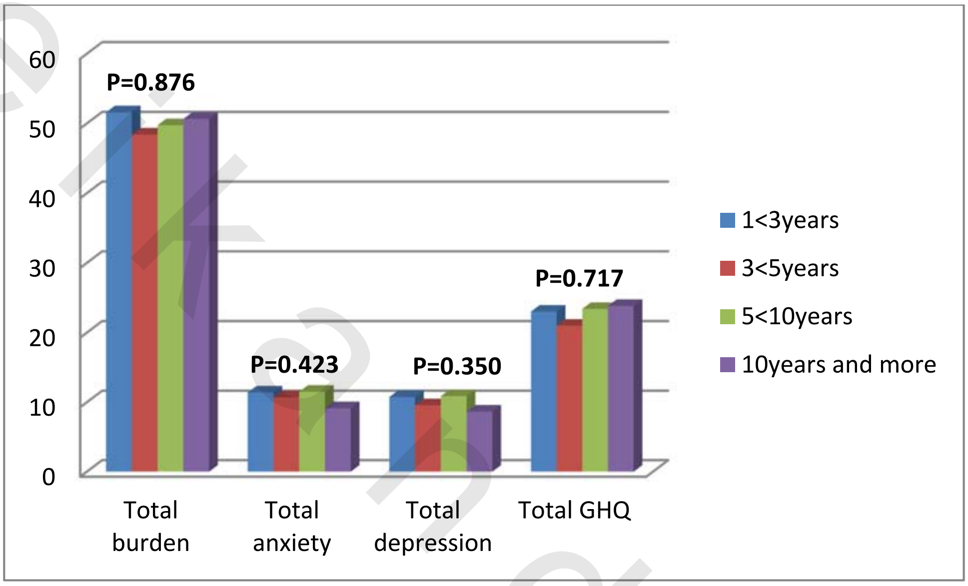
Figure (4) show relation between older adult's health history and caregiving burden and psychological health of their caregivers. There is a statistical significant difference between older adults who were suffering from other disease than cancer and mean score of total burden, anxiety, depression and general psychological health (P=0.003*, P=0.006*, P=0.032* and P=0.005* respectively).



*Significant P≤0.05.

Figure (4): Relation between older adults' health history and caregiving burden and psychological health status of their caregivers

Figure (5) show relation between duration of cancer and caregiving burden and psychological health of their caregivers. The figure shows that there is no statistical significant difference between duration of cancer and mean score of total burden, anxiety, depression and general psychological health (F=0.229, F=0.940, F=1.102, and F=0.452 respectively) and (P=0.876, P=0.423, P=0.350, P=0.717 respectively).



*Significant P≤0.05.

Figure (5): Relation between duration of cancer of older adults' and caregiving burden and psychological health status of their caregivers

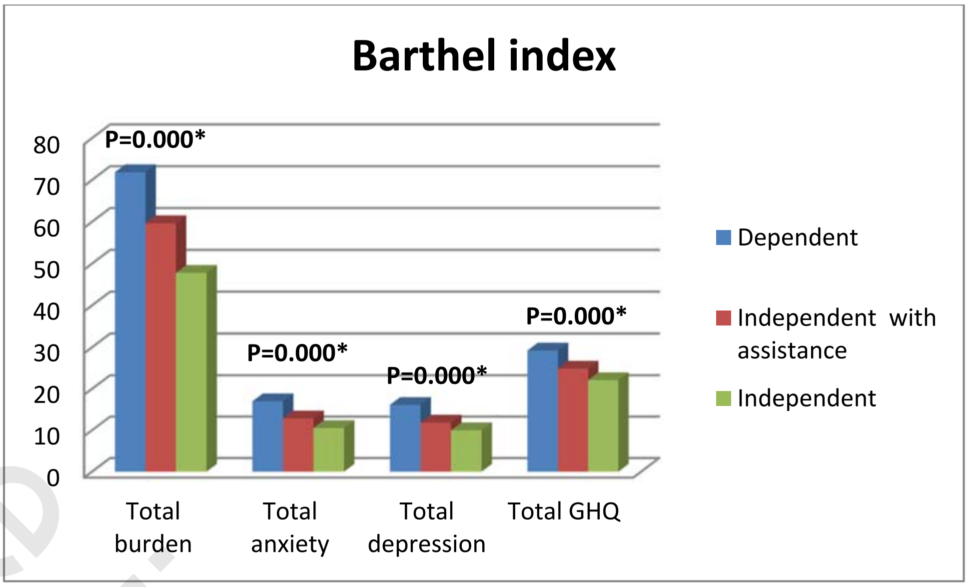
Table (11) & figure (6) show relation between older adult's functional status and caregiving burden and psychological health of their caregivers. The table shows that there is statistical significant relation between dependency in ADL and mean score of total burden, anxiety, depression and general psychological health (F=27.256, F=20.174, F=18.026, and F=10.764 respectively) and (P=0.000* for all). The total mean scores increases with increasing dependency

Moreover, there is statistical significant relation between dependency in IADL and mean score of total burden, anxiety, depression and general psychological health (T=3.544, T=3.315, T=2.833, and t=2.811 respectively) and (P=0.000*, P=0.001*, P=0.005*, P=0.006* respectively). The total mean scores increases with increasing dependency.

Table (11): Relation between older adults' functional status and caregiving burden and psychological health status of their caregivers

Items	No.	**Total burden** Mean ± SD (Min-Max)	**Total anxiety** Mean ± SD (Min-Max)	**Total depression** Mean ± SD (Min-Max)	**Total GHQ** Mean ± SD (Min-Max)
Barthel index (ADL)					
Dependent (0-7)	7	71.85±8.47 (61-81)	17.00±2.44 (13-19)	16.14±3.33 (10-20)	29.24±4.61 (21-35)
Independent with assistance(8-12)	31	59.67±10.56 (39-76)	12.87±3.54 (7-21)	11.87±2.86 (8-18)	24.90±5.70 (3-33)
Independent(13-20)	114	47.81±11.12 (19-74)	10.56±2.90 (3-17)	10.00±2.91 (4-17)	22.13±4.51 (13-39)
Test of significance		F=27.562 P=0.000*	F=20.174 P=0.000*	F=18.026 P=0.000*	F=10.764 P=0.000*
Lawton scale (IADL)					
Independent with assistance (25<75%)	107	53.58±11.95 (27-81)	11.89±3.38 (3-21)	11.13±3.21 (4-20)	23.76±4.88 (3-35)
Independent (≥75%)	50	46.18±12.73 (19-74)	10.04±3.00 (4-17)	9.60±3.01 (5-17)	21.38±5.11 (13-39)
Test of significance		T=3.544 P=0.001*	T=3.315 P=0. 001*	T=2.833 P=0 .005*	T=2.811 P=0. 006*

*Significant P≤0.05.



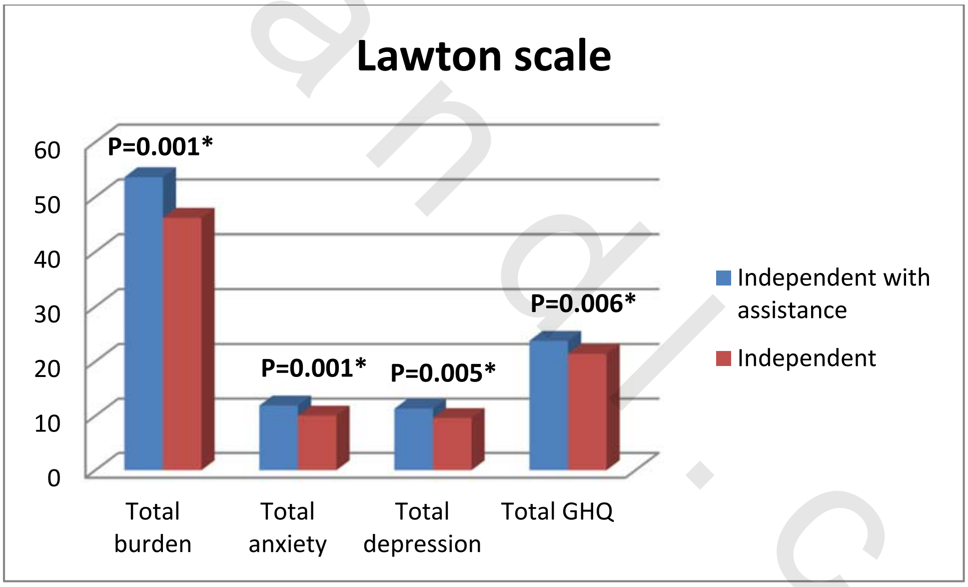


Figure (6): Relation between older adults' functional status and caregiving burden and psychological health status of their caregivers

Table (12) reveals relation between caregivers' sociodemographic characteristics and their caregiving burden and psychological health. The table shows that there is no statistical significant difference was found between different age groups regarding mean score of total burden, anxiety, depression and general psychological health (F=0.696, F=1.006, F=1.361, and F=1.059 respectively) and (P=0.778, P=0.791, P=0.423, P=0.549 respectively). Although there is increase in the mean score of total burden, and depression in female than male, yet the difference are not statistically significant (F=1.753, F=1.401 respectively) and (P=0.082, P=0.163 respectively) but there is statistical significant relation between sex and mean score of total anxiety and general psychological health (F=2.224, F=2.280 respectively) and (P=0.028*, P=0.024* respectively).

Marital status did not affect significantly mean score of total burden, anxiety, depression and general psychological health (F=1.027, F=0.907, F=1.393, and F=864 respectively) and (P=0.382, P=0.439, P=0.247, P=0.864 respectively). As regards to educational level, there is no statistical significant difference was found between different educational level and mean score of total burden, anxiety, and general psychological health (F=2.036, F=1.726, and F=0.981 respectively) and (P=0.092, P=0.174, P=0.420 respectively) while, the statistical significant relation was found with the mean score of total depression (F=2.585, P=0.024*).

Occupation was not statistically correlated to total mean score of burden, anxiety and depression (F=1.249, F=2.048 and F=1.105 respectively) and (P=0.290, P=0.132 and P=0.334 respectively).A statistically significant difference was found between occupation and general psychological health (F=3.813, P=0.024). Caregivers who were not working had lower psychological distress. It also observed from the same table that caregivers with enough income had lower mean score regarding total burden, depression and general psychological health with statistical significant difference (T=2.107, T=2.251 and T=2.417 respectively) and (P=0.04*, P=0.03* and P=0.02*). While, a statistically significant difference was not found between monthly income and mean score of total anxiety (T= 1.528, P=0.129).

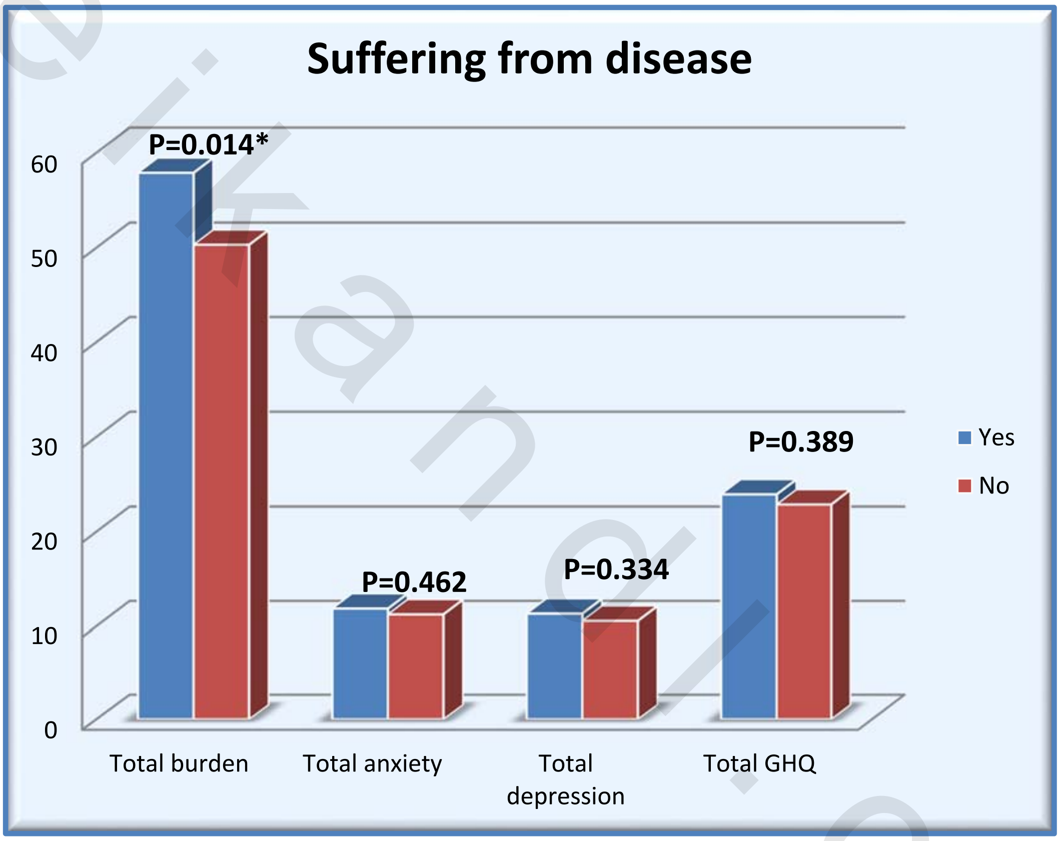
Table (12): Relation between caregiver sociodemographic characteristics and their caregiving burden and psychological health status

Sociodemographic characteristics	**No**	**Total burden** Mean ± SD (Min-Max)	**Total anxiety** Mean ± SD (Min-Max)	**Total depression** Mean ± SD (Min-Max)	**Total GHQ** Mean ± SD (Min-Max)
Age					
18<30yrs	32	48.93±13.54 (21-76)	10.68±3.44 (3-17)	10.00±3.32 (4-16)	22.09±4.48 (13-30)
30<45yrs	83	51.95±21.35 (26-81)	11. 63±3.27 (5-21)	11.02±3.03 (5-19)	23.53±5.02 (3-39)
45yrs and more	42	52.26±12.61 (19-79)	11.11±3.50 (4-18)	10.38±3.47 (5-20)	22.66±5.53 (13-35)
Test of significance		F=0.696 P=0.500	F=1.006 P=0.368	F=1.361 P=0.260	F=1.059 P=0.349
Sex					
Male	45	48. 37±11.60 (23-68)	10.35±2.70 (6-16)	10.06±2.62 (6-16)	21.53±4.10 (13-30)
Female	111	52.27±12.92 (19-81)	11. 66±3.55 (3-21)	10.86±3.43 (4-20)	23. 54±5. 29 (3-39)
Test of significance		T= 1.753 P=0.082	T= 2.224 P=0.028*	T= 1.401 P=0.163	T= 2.280 P=0.024*
Caregiver's marital status					
Single	21	47.61±15.62 (21-76)	11.475±3.34 (6-17)	10.85±3.46 (5-16)	23.28±5.88 (13-39)
Married	127	51.91±12.20 (19-81)	11.15±3.34 (3-21)	10.46±3.12 (4-20)	23.87±5.00 (3-35)
Widow	5	46.40±9.34 (34-56)	12.60±2.70 (9-16)	13.00±3.47 (7-16)	23.80±4.49 (18-28)
Divorced	4	45.50±12.34 (48-73)	13.50±4.12 (10-18)	12.25±4.03 (8-17)	24.75±4.19 (19-29)
Test of significance		F=1.027 P=0.382	F=0.907 P=0.439	F=1.393 P=0.247	F=0.246 P=0.864
Educational level					
Illiterate	30	53.36±11.92 (34-79)	11.83±3.51 (4-19)	11.20±3.14 (6-20)	24.06±4.66 (17-35)
Read& write	10	57.80±10.48 (33-70)	12.40±2.59 (7-15)	12.50±3.53 (5-16)	24.90±3.57 (16-28)
Secondary	87	50.20±12.58 (21-81)	10.81±3.30 (3-20)	10.02±3.15 (4-19)	22.44±5.40 (3-39)

University	29	49.06±13.29 (19-74)	11.65±3.47 (6-21)	11.13±3.05 (6-17)	23.00±4.77 (13-31)
Post graduate	1	73.00 (73-73)	17.00 (17-17)	15.00 (15-15)	21.00 (21-21)
Test of significance		F=2.036 P=0.092	F=1.726 P=0.147	F=2.585 P=0.039*	F=0.981 P=0.420
Occupation					
Working	63	51.71±12.60 (23-76)	11.42±3.42 (6-21)	10.66±2.98 (5-18)	22.89±4.15 (15-32)
Housewife	85	51.55±12.91 (19-81)	11.44±3.36 (3-19)	10.78±3.37 (4-20)	23.48±5.51 (3-39)
Not working	9	44.77±9.35 (35-61)	9.11±2.52 (7-15)	9.11±3.33 (5-15)	18.66±4.84 (13-26)
Test of significance		F=1.249 P=0.290	F=2.048 P=0.132	F=1.105 P=0.334	F=3.813 P=0.024*
Monthly income					
Enough	96	49.55±13.03 (19-81)	10.97±3.46 (3-21)	10.18±3.332 (4-19)	22.23±5.42 (3-39)
Not enough	61	53.86±11.62 (29-79)	11. 81±3.18 (4-19)	11.36±2.93 (5-20)	24.21±4.19 (15-35)
Test of significance		T= 2.107 P=0.04*	T= 1.528 P=0.129	T= 2.251 P=0.03*	T= 2.417 P=0.02*

*Significant P≤0.05.

Figure (7) show relation between caregivers' health status and their caregiving burden and psychological health. Caregivers who are suffering from disease had higher mean score regarding total burden than those who did not suffer with a statistical significant difference (T=2.491, P=0.014*). While there is no statistical significant relation was found between caregivers' health status and mean score of total anxiety, depression and general psychological health (T=0.738, T=0.969 and P=0.863 respectively) and (P=0.462, P=0.334 and P=0.389 respectively).



*Significant P≤0.05.

Figure (7): Relation between caregivers' health status and their caregiving burden and psychological health status

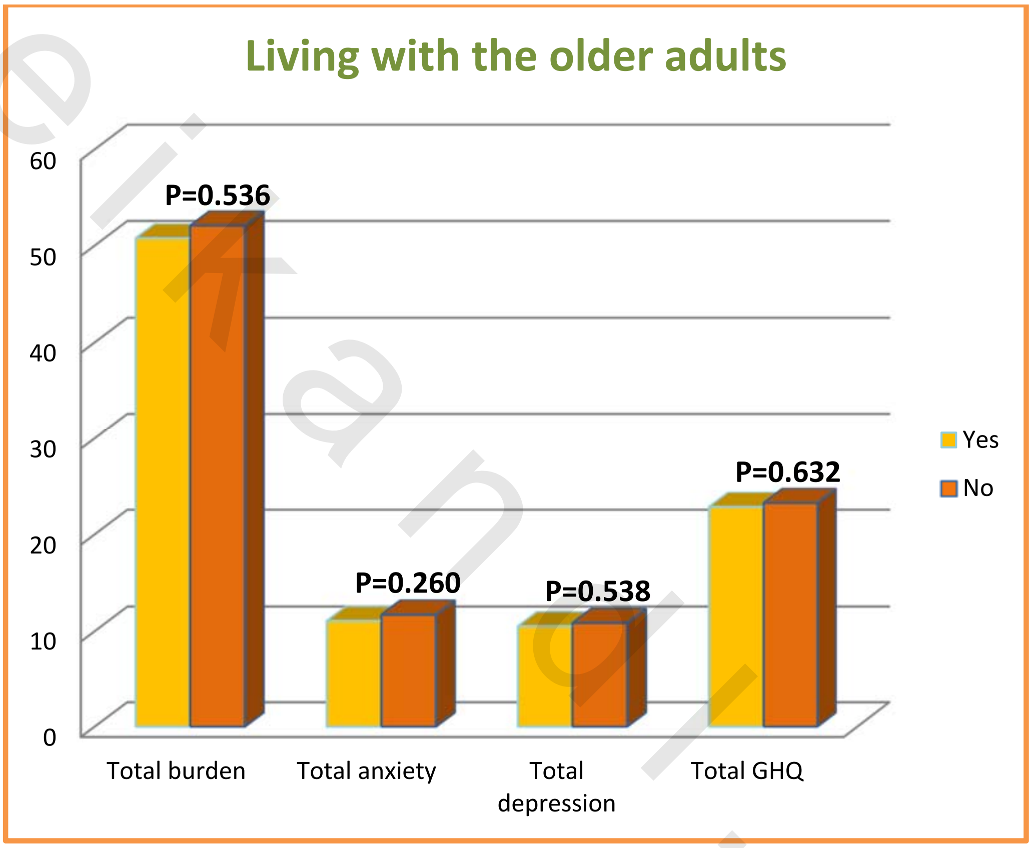
Table (13) shows relation between caregivers' relation to older adult and their caregiving burden and psychological health. The table revealed that there no statistical significant relation between caregiver relation to older adult and mean score of total burden (F=1.866, P=0.103) while, caregiver relation to older adult was significantly correlated to mean score of total anxiety, depression and general psychological health (F=5.177, F=5.184 and P=2.896 respectively) and (P=0.001*, P=0.001*and P=0.016* respectively).

Table (13): Relation between caregivers' relation to older adult and their caregiving burden and psychological health

Caregiver relation to older adults	**No.**	**Total burden** Mean ± SD (Min-Max)	**Total anxiety** Mean ± SD (Min-Max)	**Total depression** Mean ± SD (Min-Max)	**Total GHQ** Mean ± SD (Min-Max)
Son / daughter	80	52.86±12.37 (23-79)	12.32±3.15 (6-21)	11.47±2.86 (5-18)	23.76±4.76 (3-33)
Husband / housewife	22	51.45±13.87 (19-74)	11. 04±3.48 (4-17)	10.95±3.40 (5-17)	23.45±5.28 (15-33)
Son's wife	18	49.27±11.09 (29-69)	8.61±2.50 (3-11)	8.22±2.11 (4-12)	19.77±3.29 (15-25)
Brother/ sister	25	50.88±13.73 (27-81)	11.12±3.58 (7-18)	10.64±3.93 (6-26)	23.84±5.93 (13-39)
Daughter of son/brother	10	40.80±9.44 (21-55)	9.30±2.54 (7-13)	8.30±2.00 (5-12)	20.00±4.52 (13-26)
A relative	2	57.50±3.53 (55-60)	10.00±1.41 (9-11)	7.5±0.70 (7-8)	21.50±7.77 (16-27)
Test of significance		F=1.866 P=0.103	F=5.177 P=0.001*	F=5.184 P=0.001*	F=2.896 P=0.016*

*Significant P≤0.05.

Figure (8) show relation between living with older adult and caregiving burden and psychological health of the caregivers. Although there is increase in the mean score of total burden, anxiety, depression, general psychological health in caregivers who did not live with older adult than those who live, yet the difference are not statistically significant (T=0.536, T=1.131, T=0.617and T=0.632 respectively) and (P=0.536, P=0.260,P=0.538 and P=0.632 respectively) .



*Significant P≤0.05.

Figure (8): Relation between living with older adult and caregiving burden and psychological health of the caregivers

Table (14) shows relation between availability of secondary caregiver and caregiving burden and psychological health of the caregivers. It appears that, although there is increase in the mean score of total burden, anxiety depression and general psychological health in caregivers who did not have secondary caregiver than those who have, yet the difference are not statistically significant (T=0.1433, T=1.888, T=1.151and T=1.490 respectively) and (P=0.154, P=0.061, P=0.252 and P=0.138 respectively).

Table (14): Relation between availability of secondary caregiver and caregiving burden and psychological health of the caregivers

Availability of secondary caregiver	**No.**	**Total burden** Mean ± SD (Min-Max)	**Total anxiety** Mean ± SD (Min-Max)	**Total depression** Mean ± SD (Min-Max)	**Total GHQ** Mean ± SD (Min-Max)
Yes	123	50.47±12.35 (21-81)	11.04±3.11 (3-20)	10.48±3.14 (4-20)	22.69±5.07 (3-39)
No	34	53.97±13.49 (19-76)	12.26±4.09 (4-21)	11.20±3.47 (5-17)	24.14±4.94 (15-33)
Test of significance		T= 1.433 P=0.154	T= 1.888 P=0.061	T= 1.151 P=0.252	T= 1.490 P=0.138

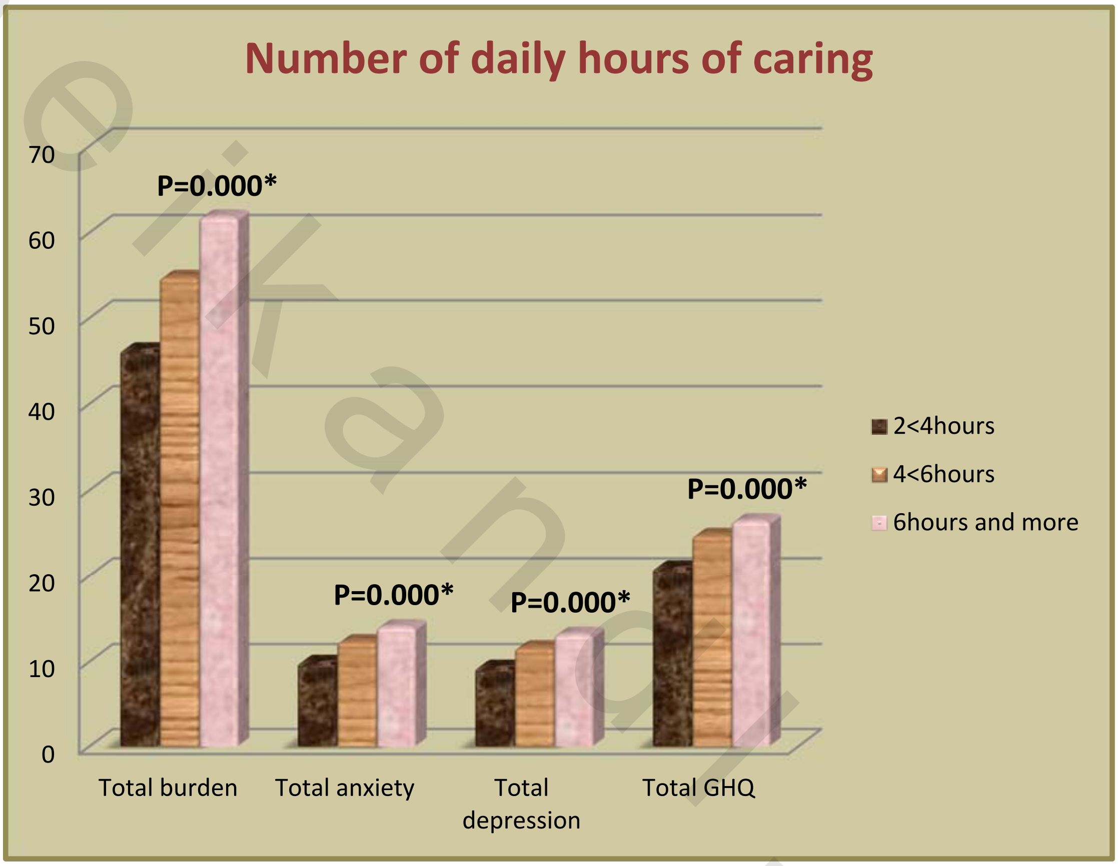
Table (15) shows relation between period of caregiving and caregiving burden and psychological health of the caregivers. The table shows that there is statistical significant relation between period of caregiving and mean score of total anxiety and general psychological health (F=3.337 and F=2.808 respectively) and (P=0.02* and P=0.04* respectively). While there is no statistical significant difference was found between period of caregiving and mean score of total burden and depression (F=1.110 and F=1.919 respectively) and (P=0.347 and P=0.129 respectively).

Table (15): Relation between period of caregiving and caregiving burden and psychological health of the caregivers

Period of caregiving	**No.**	**Total burden** Mean ± SD (Min-Max)	**Total anxiety** Mean ± SD (Min-Max)	**Total depression** Mean ± SD (Min-Max)	**Total GHQ** Mean ± SD (Min-Max)
3<6 months	35	48.17±12.64 (21-74)	10.44±3.08 (4-16)	9.71±2.62 (6-16)	21.80±4.98 (13-33)
6<12 months	37	51.78±13.75 (19-79)	11.37±3.28 (3-19)	11.10±3.41 (4-20)	23.81±4.82 (15-35)
1<3 years	65	51.63±11.75 (33-81)	11.13±3.13 (6-18)	10.56±3.27 (5-19)	22.46±4.79 (3-33)
3 years and more	20	54.25±11.95 (26-74)	13.30±4.11 (5-21)	11.65±3.42 (5-18)	25.40±5.80 (15-39)
Test of significance		F=1.110 P=0.347	F=3.337 P=0.02*	F=1.919 P=0.129	F=2.808 P=0.04*

*Significant P≤0.05.

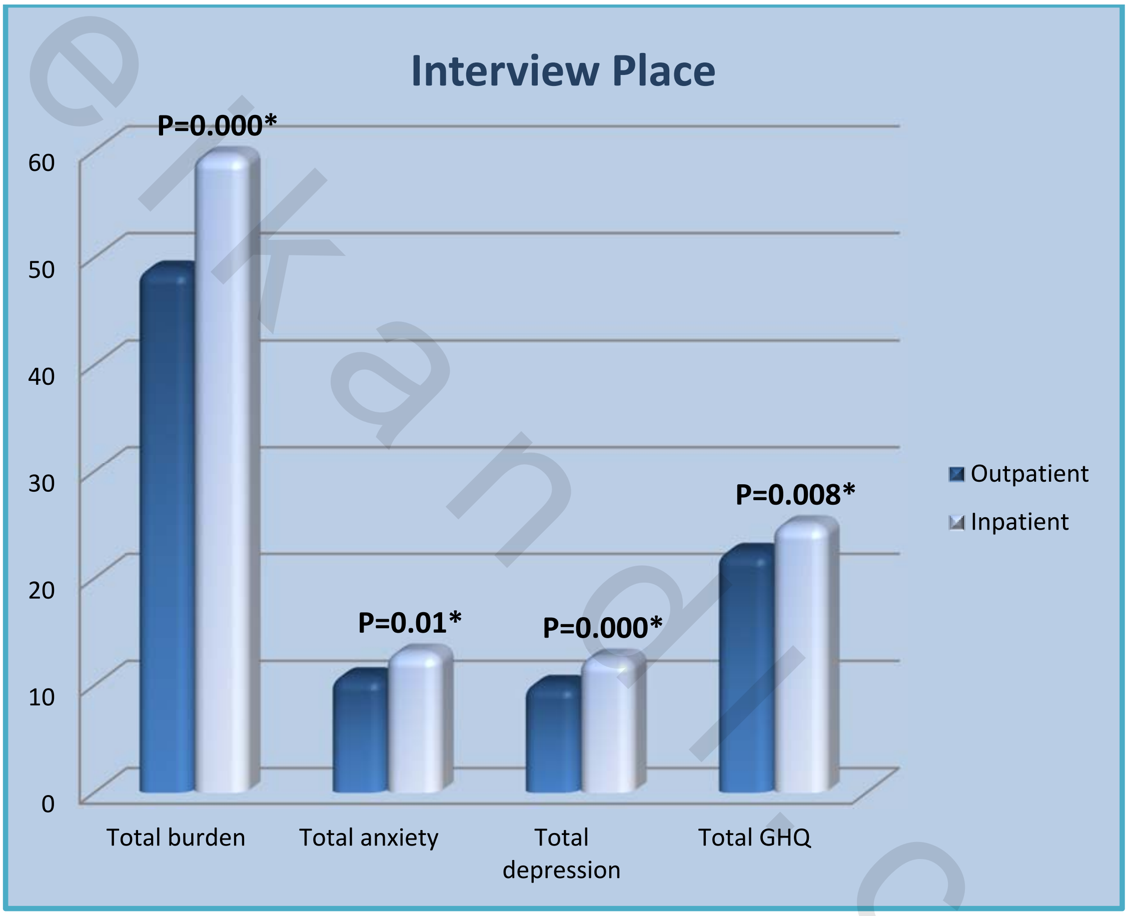
Figure (9) show relation between numbers of daily hours for caring and caregiving burden and psychological health of the caregivers. It is observed from the table that caregivers who spend more daily hours in caring had a higher mean score regarding total burden, anxiety, depression and general psychological health than those with less hours with statistical significant difference (F=16.961, F=17.963, F=17.120 and F=16.595 respectively) and (P=0.000* for all).



*Significant P≤0.05.

Figure (9): Relation between numbers of daily hours for caring and caregiving burden and psychological health of the caregivers

Figure (10) shows comparison between caregiving burden and psychological health of the caregivers according to interview place. The table reveals caregivers in the inpatient words had a higher mean score regarding total burden, anxiety, depression and general psychological health than those in the outpatient clinics with statistical significant difference (T=4.700, T=3.553, T=4.154 and T=2.694 respectively) and (P=0.000*,P=0.01*,P=0.000* and P=0.008* respectively).



*Significant P≤0.05.

Figure (10): Comparison between caregiving burden and psychological health of caregivers in outpatient and inpatient

Table (16) shows correlation between caregiving burden and psychological health status of the caregivers. The table shows strong positive correlation between caregiving burden and psychological health status of the caregivers (P=0.001* for all).

Table (16): Correlation between caregiving burden and psychological health status of the caregivers

Items	**Total burden**	
	r	**P**
Total anxiety	0.632	0.001*
Total depression	0.645	0.001*
Total GHQ	0.605	0.001*
Items	**Total anxiety**	
	r	**p**
Total depression	0.833	0.001*
Total GHQ	0.690	0.001*
Items	**Total GHQ**	
	r	**p**
Total depression	0.689	0.001*

*Significant P≤0.05.