A Dissertation on

A COMPARATIVE ANALYSIS OF CAREGIVERS' BURDEN AND MENTAL HEALTH OF PATIENTS OF DEMENTIA AND CANCER

Submitted to

THE TAMILNADU DR. M.G.R. MEDICAL UNIVERSITY

In partial fulfillment of the requirements
for the award of degree of

M.D. (PSYCHIATRY)
(Branch-XVIII)

GOVERNMENT STANLEY MEDICAL COLLEGE & HOSPITAL,
THE TAMILNADU DR. M.G.R. MEDICAL UNIVERSITY,
CHENNAI, TAMILNADU.

APRIL 2017

CERTIFICATE

This is to certify that this dissertation entitled **"A COMPARATIVE ANALYSIS OF CAREGIVERS' BURDEN AND MENTAL HEALTH OF PATIENTS OF DEMENTIA AND CANCER "** submitted by **Dr. D.PUNITHAVATHI** to the faculty of PSYCHIATRY, The Tamil Nadu Dr. M.G.R. Medical University, Chennai, in partial fulfillment of the requirements in the award of degree of M.D.(PSYCHIATRY) Branch-XVIII for the April 2017 examination is a bona-fide research work carried out by her during the period of MARCH 2015 to AUGUST 2015 at Government Stanley Medical College & Hospital, Chennai, under our direct supervision and guidance of Prof. Dr. W.J.ALEXANDER GNANADURAI., M.D., DPM., Department of Psychiatry at Government Stanley Medical College, Chennai.

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DECLARATION

I, **Dr. D.PUNITHAVATHI,** solemnly declare that the dissertation **"A COMPARATIVE ANALYSIS OF CAREGIVERS' BURDEN AND MENTAL HEALTH OF PATIENTS OF DEMENTIA AND CANCER"** is a bona- fide work done by me during the period of MARCH 2015 to AUGUST 2015 at Government Stanley Medical College and Hospital, under the expert supervision of **Prof. Dr. W.J.ALEXANDER GNANADURAI. M.D, D.P.M.,** Professor and Head of the Department of Psychiatry, Government Stanley Medical College, Chennai. This thesis is submitted to The Tamil Nadu Dr .M.G.R. Medical University in partial fulfillment of the rules and regulations for the M.D. degree examinations in Psychiatry to be held in April 2017.

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ACKNOWLEDGEMENT

I wish to thank **Dr. ISAAC CHRISTIAN MOSES MD**., Dean, Stanley Medical College and Hospital, Chennai for permitting me to carry out this study.

With sincere gratitude, I wish to acknowledge the expert guidance and suggestions of my Professor **Dr.W.J.ALEXANDER GNANADURAI MD.,DPM**. without whose guidance this study would not have been possible.

I wish to thank Associate Professor **Dr. R.SARAVANA JOTHI MD**., Department of Psychiatry, Stanley Medical College, Chennai for the able guidance, constant inspiration and continuous encouragement rendered at every stage of this study.

I am deeply indebted to and highly grateful to **Dr. M.MOHAMED ILYAS RAHMATULLAH., MD., DPM**, and **Dr. HARIHARAN MD**., Assistant Professors, Department of Psychiatry, Stanley Medical College, without whom this work would not be in the present shape.

I am highly grateful to my co-guides **Dr. GOPINATHAN,MD, D.M Neuro,** Department of Neuromedicine medicine and **Dr.VENKATAGIRI MD**. **Radiotherapy**, Department of Radiotherapy for their permission and guidance in the completion of my dissertation.

I wish to thank all my co-post graduates for helping me in this work.

I gratefully acknowledge all patients and participants who gave their consent and co-operation for this study.

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INTRODUCTION

Population ageing is an upcoming public health challenge, because of an increase in the number of older people in the global population. This is due to the direct consequence of declining ongoing global fertility transition and of declining mortality at older ages. Population ageing is expected to be among the noticeable prominent global demographic trends currently[1].

Population ageing has consequences on socioeconomic and health domains, including the increase in the elderly age dependent ratio. Older people especially who are in eighties and nineties have more prevalence of neuropsychiatric disorders. In them, many older people require assistance from other persons, even for basic activities of daily living. Dementia is a disease which is more common among older people and contributes to a significant proportion of Years Lived with Disability. Non communicable diseases like dementia which are associated with significant disability do not get adequate support and care from health care services. It remains concealed problem due to widespread low public health awareness. These are not commonly met in primary care setting though they may be extensive in the community. People with dementia generally require high level of care, which are usually cared by the family members, those are called unpaid family or informal care givers. Most of the caregivers are women, and other family members. For dementia they have to give long term care, so it is associated with significant burden to the caregiver. Care giving is associated with significant adverse impact on care giver physical and mental health. This care giver burden which was exceeding the capacity of care giver, put them more vulnerable to development of depression[2].

Similarly, on the other leading causes of morbidity and mortality in the world is cancer, with a prevalence of approximately 14 million new cases and 8.2 million cancer related deaths in 2012. The number of new cases expected to rise in next two decades is about 70%. Among men, the most common sites of cancer are lung, prostate, colorectal, stomach and liver. Among women, the most common sites of cancer are breast, colorectal, lung, cervix and stomach cancer.

Cancer causing viral infections, such as HBV/HCV and HPV which is an increasing trend nowadays are responsible for up to 20% of cancer deaths in low and middle income countries. According to WHO cancer research agency and international agency for research on cancer (IARC), ageing is another elemental factor for development of cancer. The incidence of cancer rises dramatically with age, most likely due to development of risk for specific cancer that increases with age. Due to advances in treatment modalities in cancer there are higher percentage of people living with assistance of care givers. Because of advancement in palliative care treatment which relieve, rather than cure, symptoms caused by cancer it poses a burden to care givers by providing long term care for patients' activities of daily living. In care givers it is producing definite disturbances in the physical as well as psychological well being and thereby affects the emotional and financial needs of family members and their caregivers[3].

For centuries it has been assumed that “cancer equals death”. So, the diagnosis of malignancy itself can cause significant psychological distress to both patients and the caregivers known as the sixth vital sign.

Cancer is potentially a dangerous disease, which can have definite effect in the physical as well as psychological wellbeing of the individual with the cancer an also the caregiver and thereby affects the emotional, socioeconomic needs of the caregivers. The patients who needs palliative care, which can have impact on both the patient and the caregivers’ physical and psychological wellbeing and increases the caregiver burden. This is due to the more palliative care given in home settings by the caregivers due to short hospital stay practices to decrease the cost bear for hospitalization. In early stages of cancer, the diagnosis of cancer itself and treatment of cancer is having more impact on psychological morbidity in both patient and the caregiver. In advanced stages of cancer, the physical problems concerning the seriousness of illness, duration of hours of care giving, dependency of patients to caregivers, financial concerns and low social support were causing more distress and increasing the decline the quality of life and burden to the caregivers.

REVIEW OF LITERATURE

DEFINITION OF DEMENTIA:

Dementia is defined as "A syndrome of intellectual impairment caused by brain dysfunction, usually of chronic or progressive in nature, which is acquired, which compromise three of the following domains like language, memory, visuospatial skills , personality and cognition (executive function abstraction, calculation, judgement).

Dementia causes three types of symptoms: losses in cognitive capacity, difficulties in performing basic and instrumental activities of daily living and changes in mood or personality and decline in interpersonal functioning[4].Dementia can be further divided into reversible and irreversible types[5]. Reversible dementia can be caused by factors including depression, cerebrovascular disease, reactions to medications, normal pressure hydrocephalus, brain space occupying lesions, environmental toxins, nutritional deficiencies, infections ,inflammatory illness and other metabolic disorders[5].Irreversible dementia may be caused by factors including Alzheimer's disease, vascular disease, parkinson's disease ,head trauma & inheritable background[5].The other rare causes of dementia include renal failure, chronic excessive use of alcohol or other substances, hepatic failure, and cardiopulmonary disorders[6].

The incidence of dementia in the community is often underestimated due to reasons that caregivers might mistake memory changes as part of normal ageing process and many older adults are likely to have dementia for many years prior to diagnosis[7,8] .Due to advancement in healthcare system, shorter hospital stays, greater use of outpatient treatments have put more pressures on families to take on the care giving role in home[9] . Most of the care giving was provided by family members[10] .The caregivers become motivated to provide care for reasons like a sense of duty, guilt, social pressures, and cultural practices. The caregivers provide assistance with finances, dressing, shopping, and activities of daily living. The care giving roles and responsibilities taken by the care givers of the families can often be intense and time consuming and therefore can have major impacts on care givers health and lifestyle[11,12] . Research on caregivers suggest that 6 in 10 caregivers provide care to an elderly family members for more than two years. One fifth of the caregivers provide care for dementia patients for more than five years. The care giving role and responsibilities change dramatically over time according to the severity of the disease, usually the caregiver role increases over time. According to Patterson ,family caregivers dealing with chronic illness, or entire family system, undergo a continual, cyclical, adjustment-crisis-adaptation process[13].Patients illness will have an impact on many aspects of family life of care givers, but it is unclear why some family members are more adversely affected by care giving than others[14].The caring for a family member with dementia is extremely stressful and can lead to development of both physical and psychiatric illness among caregivers[15]. Caregivers experiences to enclose strain or stress , stigma ,worry, shame and guilt and positive emotions such as caregiver satisfaction to that effort of care giving to loved ones[16].Married caregivers not only face care giving specific burdens, but also the burdens resulting from their family roles and partnership[17]. The burdens of day-day living affects markedly after the quality of life of caregivers and satisfaction with the relationship with the patient[18].

Prevalence of dementia: The prevalence of dementia worldwide currently estimated 30 million, and this is likely to double every 20 years. The annual incidence of new cases currently is 4.6 million, consequently it is expected to be 65.7 million in 2030 and 115.4 million by 2050.

REGION	STUDY	PREVALENCE RATES OF DEMENTIA (%)	REMARKS
SOUTH INDIA	Shaji et al 1996	3.39	Rural south India population in Kerala
	Rajkumar et al 1997	3.5	Rural south Indian population in Madras
	Shaji et al 2004	3.36	Urban south Indian population
NORTH INDIA	Chandra et al 1998	0.84	Rural north Indian population
	Raina et al 2010	1.83	Migrated population in Jammu region of J and K
WEST INDIA	Vas et al 2001	0.43	Urban west Inidan population in Mumbai
	Saldanha et al 2010	4.1	Urban population in Pune
EAST INDIA	Das et al 2008	0.8	Urban Kolkata
	Banerjee et al 2008	0.62	Urban Kolkata

The prevalence of dementia in India has not been researched in detail though there have been evidence of prevalence according to the 10/66 dementia study which was conducted in seven low and middle income countries in 11 sites including both rural and urban India.

INDIA	65-69 years %	70-74 years %	75-79 years %	80years %	Crude prevalence %(CI 95%)	Standardized prevalence (CI 95%)
URBAN					1.5	8.2
Men	2.9	5.5	4.5	25		
Women	5.5	7.4	8	21.2		
RURAL					10.6	8.7
Men	4.3	5.8	5.7	11		
Women	7.8	14.8	15.7	29.4		

High level of care is required by people with dementia, which are usually given by their family members. Without them people with dementia will have poor quality of life and would need hospitalisation more early and rapidly and national economies would be drive away by the advancing demographic ageing .So this support comes from a care giver at a cost of caregiver’s distress and poor quality of life.

The majority of people with dementia live in the community which accounts to 75%,for these people care is provided by family & friends(USA estimates vary between 70-81%).The majority of care giving was provided by spouses, followed by children and son in law or daughter in law, mostly females. The classic biography of dementia care giver is a middle aged or older female spouse or the children of the person with dementia. In United States of America atleast 60% of caregivers are family members especially wife, daughter, daughter in law, and other female relatives. More than 60% of people with dementia live in developing countries. The 10/66 dementia research group assessed the care arrangements of people with dementia in South East Asia, China, India, Latin America, Caribbea and Nigeria. While the classic profile of the primary care giver was similar to those in USA, the proportion of female care givers tend to be higher, spousal care givers were as common as child care givers(mean of 40%) and daughter in laws accounts for 11% of care givers overall(In India 24% of the caregivers were daughter in Laws).One of the important difference between care giving in the developed and developing countries is the living facilities, whereby persons with dementia in the developing country live mostly in the households of extended families. It has been noted in several studies that the problems that mainly affect the caregiver range from tiredness, problems at work, problems with unmet needs of the family, feelings of inadequacy and incapacity, sleeping difficulties, depression and anxiety.

SOCIODEMOGRAPHIC FACTORS AFFECTING CAREGIVERS IN DEMENTIA

The mean age of patients was about 71 years and the man age of care givers were about decade younger than patients on an average[19].In another study by Ioannis Vrettos the mean age of dementia patients were 57.4 years ± 14.6 and the mean age of caregivers were 48.9 ± 14.3.[20]

In Ioannis Vrettos study females were the major care givers which accounts for 62.7%.Most of the care givers were married which comes to 75.5% and 79.2% of the care givers were finished secondary and higher education.46% of care givers were spouses[20] . In a study by Haj Mohammed 65% of the caregivers were married and 34.6% were unmarried are divorced or widowed.46.9% were spouses, 39.2% were patient’s children, 13% were siblings and 1% were parents among them 60.8% were employed and 61.5% came under no income or less than 2000 per month. The mean duration of care giving by caregivers was 37.4 ± 9.7 months [21].

In a study by Jaishree.M, it was found that the female caregivers have affected by higher mean burden score than the male care givers.

Women and men may approach their care giving role differently[22]. Whereas men may consider it more as a task, women may consider it more as comprehensively[23,24].In a study by Pasquale De Fazio it was found that

79% of caregivers were women, most of them were above 50 years old and also children of the dementia patients. Most of them were married and completed education at secondary school[25] .

In a study by Hanan et al, female caregivers were found as more prone to worry and over involvement in care giving roles than the male caregivers. The relationship of caregivers with the patients accounting for 40% were spouses, showed a statistically significant value. Among them 70% of caregivers were women and 30% were men[17]. A total of 40% were spouses, 25% were siblings, 25% were sons and 10% were other persons like relatives, neighbours and friends to the patient. The mean age of caregivers was 49 years. Marital status of the care givers showed a statistically significant value that is 70% of caregivers were married in dementia.60% were mainly from urban areas and 40% were from rural areas.37.5% were working and 62.5% were unemployed in caregivers. The employment in caregivers can act as a buffer for feelings of helplessness and help caregiver in distracting their negative feelings.

CAREGIVER BURDEN AND DEPRESSION IN CAREGIVERS OF DEMENTIA

The care giving experiences often leads to stressors in variegated domains like physical, psychological, emotional, socioeconomical depending on the status of the dementia recipient like severity of the disease, dependency and mental status of the individual.

Caregiver burden is defined as the type of stress or strain involving physical, psychological, emotional and financial that caregivers experience related to the problems and challenges they face as a result of the repute of the care recipient.

Caregiver burden threatens the physical, psychological, emotional and functional health of caregivers.[26]. Caregiver burden is of two types. They are observable burden and subjective burden.

Observable burden is an observable, specific and tangible cost to the caregivers for taking care of the recipient. Subjective burden is the perceived cost such as the extent to which the care giver is bothered by performing these care giving task and the positive or negative feelings experienced care giving[27] . The degree of caregiver burden can be made worse by so many factors, when the caregiver involved are socially isolated, lacks knowledge about the disease progress and treatment outcome, less interpersonal skills, longstanding immature coping patterns, strain on the relationship before the condition started ,guilt feelings and unduly expressed emotions. The degree of caregiver burden may be reduced or as protective factors like participation of other family members in care giving, good problem focussed coping strategies and availability and use of support from the community. In

Tamilnadu, the womens’ role considered as caregivers to family and men seen as bread winners. It is the women duty to take care of the family at the same time they have to take care of their childrens’ need, other family members need, household chores along with that demented relative, is most often shouldered by the women usually the wife or the daughter in the daughter in law. This could be the reason for the women caregivers to experience more caregiver burden than men.

According to Zarit, Reever and Bach Peterson, caregiver burden is the state resulting from necessary caring task or restrictions of self care of the caregiver that cause discomfort for them[28].(28)

According to stuki and mulvey caregiver burden is a strain born by a person who cares for a chronically ill or elderly family members or disabled care recipients[29] .

The caregivers frequently suffer from depression, exhibit maladaptive coping strategies and most of the time express concern about the poor quality of life[30,31,32] . They suffer more physical and psychological symptoms and use more frequent prescription medications and health care services than general population.[30,33] . The main patient’s factor which increased the caregiver burden were patients’ routine functional and neuropsychiatric impairments[34] .

In a study by Marvadi et al it was found that the major predictors of the time dependent care giver burden were behavioural disturbances and disability, but the psychological burden was explained mainly by caregivers anxiety and depression[35] . A review of 93 articles on gender differences in care giving role reports that women experience more burden and use more psychiatric services than men[36,37] . The male caregivers of dementia experienced lower caregiver burden than female caregivers regardless of the severity of the disease[38] .The female caregivers of dementia had higher levels of anxiety and depression than male dementia caregivers and also caregiver burden is significantly related to depression among the caregivers[39] . Female caregivers account for 3/4th of the care giving population in dementia. The greater the burden experienced by the care giver the higher the depression[39].

In a study by Pasquale De Fazio, among the caregivers 1/3rd of them on CBI scale scored between 24 and 36 and 7% scored less than 24%, had also scored for mild depression. 55% of the caregivers scored total CBI score ≥ 36 of whom, 70% found as pathological depression according to SDS (Self Rating Depression Scale).13% of the caregivers had total CBI score from 24% to 36% of whom One third were depressed.5% of the caregiver had depression in whom CBI score was less than 24%.Hence a correlation between burden and depression was evident.[25]

In a study by Ralma al-Zahrani, higher rates of prevalence of depression which accounts for 72.8% was noted with a confidence interval of 67.87% to 77.4% among caregivers. Depression was found to be associated with family caregivers. It also revealed that the risk of psychological symptoms increased with low income, higher education, immediate relative to the patient and older age of caregivers. It also showed that approximately 8/10 care givers suffer from atleast one psychiatric disorder. Older age, low socioeconomic status and well educated care givers were recognized as being at higher risk of developing psychiatric symptoms. Of 72.8% caregivers using DASS-21 scale were found with depression. Among them 9.7% had mild depression, 22.6% had moderate depression and 8.9% had severe depression and a majority of 58.8% had extremely severe depression. Depression was less common among young caregivers of age less than 20 years, non family caregivers. The prevalence of stress was 61.5%, among them14.7% had mild stress and majority 49.3% had extremely severe stress level. Stress level was less among non family caregivers compared to family caregivers. According to multivariate analysis there is a significant increase in depression among caregivers with low monthly income than high monthly income caregivers[40].

In other studies, caregiver burden is described as burnt out. When caregivers try to do more than their ability, without getting help from others in care giving or to take care of other family needs, either physically or financially burnt out can occur. Caregivers who were experiencing burnt out found with tiredness, stress, anxiety and depression.[42]

Caregivers of dementia worried most about the difficult behaviour and symptoms related to dementia patients.[42] Several studies have found that the severity o f symptoms in patients of dementia is strongly related to their caregiver burden.[43] The factors affecting caregiver burden were severity of symptoms and duration of illness.[44] Caregiver burden is directly linked to the deficit in a patient's sphere of functioning, that is dependence but not linked to severity of psychopathological symptoms.[45,48] The caregiver burden is also linked to problems related to illness like poor living conditions, difficulties at work, the responsibility of physical caring and financial responsibilities[46]. The continuous involvement in care giving increases the caregiver burden[47].

Studies have consistently shown that approximately one- third of caregivers have greater levels of anxiety or depression, especially patients of caregivers of patients with dementia, who were mainly elderly spouses of patients[18,50]. The caregivers of patients with dementia had higher prevalence of depression compared to general population[49].

There are three phases in cancer patient's illness: the initial or acute phase, chronic phase and resolution phase.

During the acute phase, the family is shocked, stunned and frightened about patient’s illness and future prognosis. During the chronic phase, when commencing treatment has been suffered and patient has been released from the hospital, family members have to take on new and additional responsibilities. During resolution phase, the family presents and coordinate itself either survivals or the bereavement process. All three phases may lead to significant anxiety, depression, perceived burden in family members, primarily in the principal caregiver.

Factors that are associated with caregiver mental health can be divided into three categories[52].

1. Characteristics of the caregiver
2. Characteristics of the patient and
3. Characteristics of the care situation

The characteristics of the caregiver that may influence caregiver mental health include age, sex, living situation, socio economic status and type and grade of the relationship between the care recipient and the caregiver.

The characteristic of the patient that may influence caregiver outcome includes disease- related and treatment related characteristics, dependency, and physical and psychological symptoms[52].

The characteristics of the care situation which may have influence on caregiver mental health include length of care, intensity of care and divergent types of care. The more confining the care task are the less time flexible and the more disruptive they are to the care givers’ schedule, the more likely they are to create negative consequences. Personal tasks like feeding and washing the patient appeared to be more perceived as more difficult and burdensome than non personal tasks like buying the groceries.[52]

CAREGIVERS AT INCREASED RISK OF DEPRESSION

Caregivers who are

1. Predominantly younger age and female.
2. Low socio economic status and low level of education
3. Who live with the patient such as spouses rather than the children of the patient
4. Who report poor relationship status with the patient
5. Who are unmarried or in short term marriage duration
6. Who report high levels of unmet needs for supportive care
7. Who report co morbid illness or destructive behaviour
8. Who use avoidant coping
9. Who feel less prepared for care giving and confident in their abilities

10. Who are caring for patients that are older, or at a later disease stage and patient with poor physical functioning

11. Who have high care giving demand

12. Who report high intensity of care

13. Who report lower levels of social support[53] .

Care giving also appears to reduce a person's chance of being employed, many caregivers are unable to work, need to take leave without pay, fewer working hours, are in low paid jobs, or work from home to manage the caregiver demands.

PREVALENCE OF CANCER

Approximately 1.6 million new cases of malignancy are expected to be diagnosed in the US in 2016.Many patients diagnosed with cancer will finally require support from caregivers from their family. The need of caregivers will expand as the number of individuals older than 65 years increases and the mortality rate decreases.

In fact, family caregivers the foundation structure of health care system in United States, carry advances such as multimodality treatment protocols given in outpatients and home settings. Most of the studies identified cancer as one of the most common health conditions in receipt of informal care giving, with the majority of the caregivers reporting taking on the role of caring because of family responsibilities and therefore little choice or no one else to provide the care. Family caregivers provide a complex package of support task that extend across physical, psychological, and emotional domains. Most of the caregivers were women and 55 years and above. Family caregivers play an important role in the management of cancer, recruiting their cooperation and including them as the part of care from the outset are considered critical component to adequate cancer management. Most oncology teams recognise this and try to comprise family caregivers in treatment planning, decision making and implementation. Caregivers have their own emotional responses to patient’s diagnosis and prognosis and they may need coaching and emotional support separate from that given to patients. Caregiver role and burden are extremely affected by a patient’s prognosis, stage of illness, dependence to caregivers and target of care. How well a caregiver achieve that role may depend on his or her pre-existing relationship with the patient of level of harmony between caregiver and patient. If there is any lack of approval within this relationship, results in diminished quality of life.

During active treatment phase of treatment, caregivers report difficulties in performing the competing demands of providing emotional and tangible support to patients while meeting the ongoing commitment of home, work and family relationship. The demands of providing transportation, scheduling and making hospital visits, arranging for home care, may be physically and emotionally debilitating for both cancer patients and their caregivers. The post hospitalisation period may be the most insecure for caregivers, filled with placing concerns about managing patients at home while also attending to their own health. If the patient is receiving home care, the caregiver is responsible for ordering necessary medical and food supplies, managing any medical emergencies that may come and generally guiding the health care system, along with ongoing commitment of home, work and family. In the context of recurrent illness, terminal illness or the dying process, the caregiver must meet a new set of dispute in dealing with increasing functional limitations, increasing dependence of the patient and greater symptom burden. So they have been shown to experience increased emotional distress, inspite of the amount of care provided, when they are limited in their ability to participate in valued activities and interest.

Research has suggested that caregivers of cancer patients were at risk of developing a variety of psychological and physical problems including depression, anxiety, fatigability, reduced self esteem and somatic health problems. Caregivers of survivors with lung, haematological, head and neck cancer displayed the highest level of anxiety and depression. One study found that employed caregivers with parenting responsibilities reported higher levels of distress, while employed caregivers without parenting responsibilities reported an increased sense of care giving as meaningful. Given the increasing chronic nature of cancer, caregivers may find support in all of these areas wear away over time. The wish for additional help from family and friends has to be identified as an indicator of caregiver burden.

Cancer patient’s caregiver were affected by various stressors in life like psychological, social or physical health functioning. Caregiver burden is commonly used to describe multiple dimensions of distress that result from a lack of proportion between care demands and the availability of resources to meet the demands. Care giving may be only limited to physical care such as helping to toilet or eating but can also comprise, lifting, transferring, massaging and operating medical equipment. Additive sleep disturbance and tiredness are common among caregivers who are on duty 24 hours a day or only during night time hours.

Behaviours such as not getting enough rest or exercise and lack of care for their own health can mimic depression in caregivers but can also subscribe to the impairment of their health and quality of life. Care giving is time consuming and leads to feelings of social isolation. The financial impact and hidden cost of cancer like travelling and managing medical appointments, waiting with patients for appointment, missing work, getting prepared for surgery and medical procedures, neglecting their usual activities and relationships, escorting to patients who are hospitalised, may affect caregiver burden.

Caregivers confronting serious illness have been found to experience as much distress than the patient with cancer. This distress arises from the caregivers risk itself as well as seeing the patient's sufferings. A care givers quality of life affected by the cancer patient's stage of illness and goal of care.

CAREGIVER BURDEN AND DEPRESSION IN CANCER

A meta analysis of 84 studies of caregiver burden found that spouse caregivers were more distressed than other caregivers and that women were more distressed than men, because women tend to perform more personal tasks, more likely to assume the primary caregiver role, less likely to access formal help and more likely to have cultural and social pressure.

It can be measured by various scales available. One of the rating scale is Zarit Burden Interview.

Older caregivers especially are vulnerable because they may present with co morbidities, they may be living on fixed incomes, and their available social support networks may have shrivelled. They also ignore their own health needs, have less time to excercise, forget to take their own prescription medications, and become exhausted from interrupted sleep. So it is common for older caregivers to lead to poor physical health, increased mortality and depression on younger caregivers must generally balance work, their own family responsibilities and surrenders involving their social lives. Middle aged caregivers typically worry about missed workdays, discontinuivity at work, taking leave of absence and reduced productivity. Low personal and household incomes and limited financial resources may also place families at risk for treatment compliance and treatment related decisions that are made on the basis of income.

In a study by Girgis and Lambert, it was found that among mixed group of caregivers of cancer survivors, common care giving assignment included household activities (daily 68.5%), emotional support (daily 39.9%), and managing money (daily 22.7%).

Australian Bureau of Statistics: Disability, Ageing and Carers 1998 reported that frequently the caregivers themselves are aged (most primary caregivers are of age more than 65 years and caring for patients in the same age group) and have health problems that are suggestively affected by the care giving role. In an Australian study of caregivers, more than fifty percent reported the care giving had frankly affected their overall physical health, in that blood pressure or heart diseases comprise 12.6%.

In a study by Beesley VL, it was found that fatigability was reported to result in diminished ability to concentrate, decreased motivation, diminished ability to perform and negative effects on mood[56]. Mostly the female caregivers report sleep disturbance which were significantly associated with depression and anxiety[57]. In some studies, one-fifth of the patients reports clinical depression[58]. The low social support was a precursor of depression for caregivers of women with ovarian carcinoma[59]. Care giving produces a financial burden for family members, both in outright expenses and in loss of income and benefits[59].

In a study by Rhee YS: Majority of caregivers had depression score, BDI >13 about 67% and very high depression score BDI more than 21 was found in 35%.The higher scores of depression were found in caregivers like women, spouse of the patient, who were in ill health, who were feeling burden, who were unable to function normally. Depression was highly prevalent among family caregivers of Cancer patient and caregiver burden was the best foresight of depression.[60]

In a study by Boyoung Park, the prevalence of depression in family caregivers was 82.2% among them 40.4% had mild depression,25.5% had moderate depression and 16.3% reported severe depression. Family caregivers who were young, who were caring for male patients or those who had poor quality of life due to burden and financial concerns reported anxiety and depression. Family care givers who were unemployed during caregiving, being the spouse of the patient and who were having poor quality of life due to burden and financial concerns and who had problems with positive adaptation were associated with depression. Sociodemographic factors and the factors affecting quality of life were best conjecture of depression in family caregivers.[61]

A study by Nijober concluded that the mental health of the caregiver also had been defined as psychological distress, burden, depression and life satisfaction. Younger age women tend to perceive care giving as more negative in terms of stress and burden than older men and report higher levels of psychological distress like depression, even when quality of patients' health and amount of care given is controlled for. Compared with other informal caregivers, spousal caregivers are expected to bare a large proportion of the stresses and burdens that follow in the course of the cancer. Less consistent finding were reported for the correlation between socioeconomic status and caregiver outcomes compared to previous studies. Patient characteristics likely to have influence on caregivers outcomes include disease-related and treatment related dependency, physical and psychological symptoms of patients. Care characteristics like duration of care, intensity of care, different types of care which influences caregiver outcome. The more disruptive and the less time flexible the caregiver schedule, the more likely to have caregiver burden. Personal tasks like feeding, washing the patient, toileting and dressing appear to be perceived as more difficult and burdensome than non personal task. The care providing requires time, the caregivers spend less time for other essential activities like household chores, leisure and visiting family and friends, so it may worsen the already existing care giver burden. The caregiver experiences predominantly expressed as an overall measure, for example burden, stress overload.[62]

In a study by Given et al, caregivers described in 5 domains including 4 negative domains and 1 positive domain. The negative domains were disrupted schedule and daily activities, self care, family responsibilities and job activities, financial problems, poor family support and decreased physical strength. The positive domain expressed as self esteem. The level of patient’s dependency in activities of daily living appeared to be particularly important in determination of negative caregiver experiences. The indirect effect may be possible because patient’s cancer related symptoms may give rise to losses in mobility and function and more patient dependency. Caregivers who experience high levels of burden, leading to increasing levels of depression and distress.[62]

Caregiving has a significant negative effect on cells of immune systems, including T cells and natural killer cells.[67] Higher percentage of caregivers were affected by mild to moderate depression and it may be due to pre exposure sufferings from chronic disease.[63] Depression among caregivers is a specific emotional reaction to the burnt out of caregiving role.[64] In a study by Butler and Covinsky, they found that one -third to half of the caregivers had depressive symptoms meeting the diagnostic criteria.[65,66]

Younger white and Afro-american caregivers had higher levels of depression than Hispanic caregivers, because younger caregivers may have more family, job and social responsibilities and less experience to cope with the caregiver role. The caregivers of age above 65 years were more likely to be depressed. Female caregivers have high levels of depression than male caregivers in cancer patients. Caregiver burden is usually assessed by interference with personal relationship, time for themselves, relationship with family and friends under social role.[66,70,71,72]

By using Zarit Burden interview Butler et al studied the caregivers of older age adults, found that caregiver burden had high correlation with caregiver depression. The patients' ADL dependency has been found to be associated with caregiver depression.[62]In a study of terminally ill cancer patients and their caregivers by Emanuel et al found that caregivers with high care needs to the extent of basic activities of daily living and patients dependency in transportation, nursing, home making , personal care, had higher depressive symptoms.[74]

The lower social support to caregivers was significantly associated with increased care giver depression than higher social support.[52,75,76,77]

A study by Kim and Schultz reported comparable levels of caregiver burden among all cancer and dementia caregivers, however both of these groups provided more hours of care per week, assisted with increasing number of daily activities and reported greater levels of physical burden and psychological distress than caregivers of individuals with diabetes and frail elderly. Care giving activities which differs according to individuals, including personal care, mobility, transportation , home management and coordination of medical care and administration of medications and supervision, emotional support, arranging and assisting with personal care , ordering appointments , social services ,assistance with community activities, incontinence care, transferring, managing money , escorting, shopping, telephone calls, meal preparation , and managing finances. They suggested that cancer caregivers may benefit from health, social and health care policies that specifically address their physical and emotional distress.[53]
A study by Youngmee Kim and Richard Schulz about comparison of the family caregivers’ strain in cancer care giving with Dementia, Diabetes and Frail elderly caregivers, it was found that most of the caregivers were grandchildren, the socio demographic characteristics were comparable in all

the groups. Cancer and dementia caregivers had greater level of burden such as 67.3% and 64.4% respectively

Another same type of study by Richard Harding, he compared the subjective burden of caregivers of advanced cancer, Dementia and Acquired Brain Injury. He found that the caregiver burden in cancer was 13.4% and in dementia was 16.4%.

SUPPORTING CAREGIVERS OF PERSONS WITH DEMENTIA AND CANCER

Increasing incidence of dementia coerce development and upgrade of services for patients with dementia as well as their caregivers. This is best attained through community based interventions. There is unmet necessity for services for care givers of persons with dementia in our community. The perceived need of the caregiver can be felt only through a participatory approach.[78]

The prime concern of people with dementia can be different from those of caregivers and professionals when comes to construct services for them. People with dementia reported fewer demands compared with reports to their caregivers and the professionals. The need assessment must be complete and it should include not only the physical needs but the social and psychological needs also.[79]

In most developing countries older people typically live with their families in multi generous households. Here there are more people to partake in the responsibility of care and help each other. Any care programme should combine these factors for qualitative outcomes. The caregivers' health is important in deciding the care receivers' quality of life. The physical and mental wellbeing of the caregiver is the key of successful caregiving. The public health system comprehend more about these caregivers who are more at risk and the reasons behind it. We must be able to recognise the hazards of caregiving and to develop prospective improvement and solutions. Community based services based on the postulate of palliative care can be drawn for dementia also. These may also be in interrelation with professional services like memory clinics.[80]

Two thirds of people with dementia live in low and middle income countries. The accessible services are less and levels of knowledge and help seeking is low in our countries. The management of dementia should include presuming information and long term support to caregivers. The form of care can be delivered by trained primary care teams working in a collaborative care framework. Continuing care with coordination and community outreach is important in such a framework. Effective care delivery in developing countries involves coordinating dementia care with that of other chronic diseases and community support programs for the elderly and disabled.

There should be interventions to deliver successful care in dementia. This include interventions to increase needs for services through increased awareness, intervention to improve ability of health care teams, plans to improve identification and programs to increase the acceptableness and reduce the cost of treatments. These can be reached only by incorporating dementia services into primary health care.[81]

A study by Youngmee Kim and Richard Schulz about comparison of the family caregivers' strain in cancer care giving with Dementia, Diabetes and Frail elderly caregivers, it was found that most of the caregivers were grandchildren, the socio demographic characteristics were comparable in all the groups. Cancer and dementia caregivers had greater level of burden such as 67.3% and 64.4% respectively.

INDIAN STUDIES IN CAREGIVER BURDEN AND DEPRESSION IN DEMENTIA AND CANCER.

A study by Dr. Srinivasagopalan from Meenakshi Medical College, Kanchipuram, Tamilnadu about A comparative study of caregiver burden in cancer cervix and cancer breast illnesses. He concluded that male caregivers have more burden than female caregivers who were looking for breast cancer patients compared to cancer cervix caregivers. He specified the higher caregiver burden in male is due to treatment modalities in breast cancer. The closer the relationship of patient, the higher the caregiver burden was noticed in both the cancer groups. Whenever the burden scores were higher, the depression scores were also higher in both the caregivers.[89]

A study by S Lukhmana from department of community medicine, UCMS and GTB Hospital, Delhi about A Family caregiver's burden: A hospital based study in 2010 among cancer patients from Delhi. He reported that 56.5% of caregivers had no or minimal burden, 37.5% of caregivers had mild to moderate burden and nobody had moderate to severe burden, which was assessed by hindi version of Zarit Burden Interview. Also he found the vulnerability of burden on caregivers were type of family, literacy, occupation, marital status and type and mode of treatment facility.

Dr. Shaji had done extensive studies in dementia and care giver outcomes. A study by Dr.Shaji from Kerala about behavioural symptoms and caregiver burden in dementia, he revealed that the major sources of caregiver strain were behavioural problems related to dementia. The next common source noticed as incontinence care needed by patients. He used Zarit Burden Interview to measure the care giver strain. The strain was increased by lack of supportive services by local health services and lack of support, stigma and criticisms from family members. The development of sustainable, effective and low cost dementia care services should be given due significance by the health policy makers in our country.

In another study by K.S. Shaji and K Smitha in 2002 about care givers of people with Alzheimer's disease: a qualitative study from the Indian 10/66 dementia research network. The results found as, younger women formed the majority of care givers, especially daughter in laws of women with dementia. The majority of the caregivers were affected by mental health problems. So there is clear need for more awareness and support for families affected by dementia. Community services in developing countries like India should consider instructing existing domiciliary outreach services, the community based multipurpose health workers, to recognise, diagnose and assist family caregivers. [88]

With increasing life expectancy in India, probability of better health care delivery, increasing occurrence of cancer and ascending cost of medical care, more and more patients are going to depend on family caregivers for their care and management in our country. We have to keep in mind the coping mechanisms differ greatly between individuals and there is no proper way to cope with cancer care giving. The steps we can do as follows: endorse the challenges by overlooked caregivers, ask about caregiver's need periodically, as needs may alter as illness progresses. Remind them as significance of caring for themselves in order to extend to care for their loved one. Provide caregivers facts about local support resources. Remind caregivers to welcome offers of help from friends and family. Depending on caregiver’s personality and wishes, professional counselling may help healthy coping with the emotional challenges of dealing with cancer and the experiences of care giving. To sustain this ever growing pool of caregivers, counselling centre to be suggested to set up in all cancer hospitals and appropriate interventions support group be established so as to help the caregiver cope and deal with miserable multifaceted burden. In view of considerable burden on family caregivers coupled with lack of adequate number of cancer hospitals, there is a public importance to recognise this important group. All standards of health staffs in cancer hospitals in developing countries should be sensitised to the different kinds of burdens faced by family caregivers. Ironically, in the collectivist Indian society where constitute backbone of support system, family caregivers have paid little attention. This demanding issue, therefore needs to be greatly addressed by clinicians and public heath physicians in preferably unique socio-cultural country like India.[82]

AIM OF THE STUDY

- To compare the caregivers' burden and caregivers' mental health like depression in patients with Dementia and Cancer.

OBJECTIVES OF THE STUDY

1. To compare the caregivers' burden in caregivers of people suffering from Dementia and Cancer attending the Outpatient Psychiatry department, Neuromedicine department, Radiotherapy department at Government Stanley Hospital, Chennai.
2. To compare the prevalence of depressive symptoms among the caregivers of patients suffering from Dementia and Cancer.

MATERIALS AND METHODS

- Study Setting
- The study was conducted at psychiatry/ neuromedicine/ radiotherapy outpatient department at government Stanley medical college hospital, Chennai. It is a tertiary care institute where patients come northern part of Chennai, Thiruvallur District and southern districts of Andra Pradesh.
- Study population

  The sample is drawn from female or male patients and their Caregivers of these patients of these two groups such as dementia and cancer attending the Outpatient Psychiatry department, Neuro medicine department and Radiotherapy department at Government Stanley Hospital, Chennai.

- Study Design:

Cross sectional , Comparative study, including not less than 40 Caregivers of patients with Dementia and 40 Caregivers of patients with Malignancy.

- Duration of study:

  6 months.

Subjects of study

Group 1

Caregivers of patients diagnosed with dementia in psychiatry and neuromedicine department.

Group 2

Caregivers of patients of patients with any type of cancer in radiotherapy department.

INCLUSION CRITERIA

1. Caregivers of patients satisfying ICD- 10 criteria for Dementia and Caregivers of patients diagnosed to have Cancer.
2. Participants to be willing to provide informed consent for the interview and assessment.
3. Patients willing to allow Caregivers to be assessed.
4. Caregivers aged from 20- 85 yrs were taken.

EXCLUSION CRITERIA

1. Those patients and caregivers who did not give their consent.
2. Refusal to allow spouse to be evaluated.
3. Caregivers with the history of Substance abuse and with the history of suicide attempt/ attempts or previous psychiatric symptoms and interventions.
4. Caregivers with the family history of psychiatric illness.

SAMPLING

For each group, consecutive cases from respective department OPD who satisfied inclusion criteria were taken.

VARIABLES STUDIED

Socio economic variables- Age, Sex, Religion, Family type, Marital status, Education, Occupation, Monthly income.

Clinical variables- chronic illness, caregiver burden, dependence and depression.

STUDY PROCEDURE

1. After obtaining informed consent from patients and their caregivers attending the Psychiatry, Neuromedicine and Radiotherapy OPD, they will be interviewed and assessed using various scales. Data will be recorded for this purpose.
2. Information is obtained from caregivers.
3. Socio demographic and medical details will be obtained using semi structured questionnaire designed for this study.

INSTUMENTS USED

1. A semi structured pro-forma to collect the sociodemographic details, family history details and a semi structured clinical profile of Caregivers.

2. Assessment of Depression in caregivers using symptoms check list based on ICD-10 Research Diagnostic Criteria and Montgomery-Asberg Depression Rating Scale (MADRS).

3. Scale for Instrumental Activities of Daily Living in the Elderly (IADL-EDR).
4. Katz index of independence in activities of daily living scale
5. Assessment of Caregivers' burden by Zarit Burden Interview (ZBI).

ZARIT BURDEN INTERVIEW

The Zarit burden interview, is a popular caregiver self- report measure employed by many aging agencies.The original version has 29 items of questions which was evolved by Zarit in 1980. The revised version by Bedard in 2000 which contains 22 items. Each item on the interview is an expression in which the caregiver is asked to endorse using a 5 point scale. The response options range from 0(never) to 4(nearly always).The score ranges from 0 to 68. The score 0 to 21 indicates little or no burden, score 21 to 40 indicates mild to moderate burden, score 41 to 60 indicates moderate to severe burden and the score 61 to 68 indicates severe burden. It is the instrument most commonly used in dementia care giving research and by clinicians in usual practice to measure the change over time resulting from interventions aimed at decreasing the burden. The scale has two-factor model, one is personal strain and the other one is role strain. The reliability and validity of this scale was tested by Herbert, Bravo and Preville in 2000, concluded that it has good internal consistency reliability, with a cronbach's alpha coefficient of 0.92. They also concluded that the scores on this scale were unrelated to age, sex, language, locale, marital status, or employment status, indicating the measure is appropriate for use with a variety of population. Scores were also significantly positively associated with behavioral and psychological severity in the older adult patients and depression scores of the caregiver, as studied by Center for Epidemiological studies Depression Scale.[83].

MONTGOMERY ASBERG DEPRESSION RATING SCALE

It is a psychological questionnaire used by physicians and other trained personnels to assess the severity of depression among patients who were already diagnosed with depression. It is developed in1979.The score ranges from 0 to 50. It includes 10 items and scores ranges from 0 to 6.The score from 0 to 6 indicates no depression, the score7 to 29 indicates mild depression, the score 30 to 34 indicates moderate depression and the score 35 to 60 indicates severe depression. It takes 20 minutes to administer. The correlation for the MADRS was 0.71, slightly higher than for Hamilton Rating scale for Depression(0.65). The inter- rater reliability ranged from 0.89 to 0.97.[84]

INSTRUMENTAL ACTIVITIES OF DAILY LIVING SCALE:

It was designed and described by Lawton and Brody in 1969. It has two domains –biological and social. It is used to assess the physical function or instrumental activities of daily living and measures functional ability as well as declines and improvements over time in community, research and hospital settings. The scale can be administered by the clinician by getting information from patients or informants (patients' family members or caregivers) and recent records. It measures 8 realms of function, which attempt to interpret everyday functional competence in the elderly. It is used to evaluate a more complex set of activities like telephoning, laundering, food preparation, shopping, housekeeping, financial, use of transportation and medicine. Each domain measured by the scale depends on either cognitive or physical function. These skills are well thought of as more complex than the basic activities of daily living . There is a gender difference in interpreting the results. It is used both in research and clinical practice. It is scored as 0-8 for women, and 0-5 for men, excluding the activities of housekeeping, laundering and food preparation for men. The higher the score, the greater the person's independence. The score 0 means low functioning and dependent on caregivers to both men and women, the score 5 means high function and independent in men and score 8 means high functioning and independent in women. It takes 10-15 minutes to administer. The validity of Lawton IADL was measured by determining their correlation with 4 scales that measured the same domains in this scale, the correlation were significant at 0.01 or 0.05 level. The Pearson correlation of 0.87 and 0.91 was found in two previous studies. Very high six month retest reliability ranges from 0.802-0.99 has been revealed for the IADL scale. It shows inter-rater reliability between personnel from various disciplines.

KATZ INDEX OF INDEPENDENCE IN ACITIVTIES OF DAILY LIVING:

It is the most appropriate instrument to measure functional status as a measurement of the patient's ability to perform activities of daily living independently. It is used to detect the problems in doing activities of daily living and to decide treatment care accordingly. It measures the adequacy of performance in six domains such as feeding, toileting,bathing, continence, dressing and transferring. It is scored as yes or no for independence in each of the domains. A score of 6 means full function, 4 means moderate impairment, and 2 or less indicates severe functional impairment. It is effectively used among older adults in hospitals, in baseline compared to subsequent visits. The tool is extensively used as a flag signaling functional capabilities of elder adults in home and clinical settings. It is sensitive to changes in declining health status, ability to measure small increments of change in rehabilitation process.

STATISTICAL ANALYSES

Statistical analysis will be done using computerized software (SPSS-20). Descriptive statistics like frequencies, percentages, means and standard deviations will be computed. Parametric and non parametric analysis will be used appropriately depending on the data collected.

OBSERVATION AND RESULTS

RESULTS

Table 1: Gender of caregivers of Dementia and Cancer patients

Category	Dementia (n=40)	Cancer (n=40)	Total (n=80)	Chi-square value	Df	p-value
Gender						
Male	5(12.5%)	2(5.0%)	7(8.8%)	1.409	1	0.429
Female	35(87.5%)	38(95.0%)	73(91.3%)			

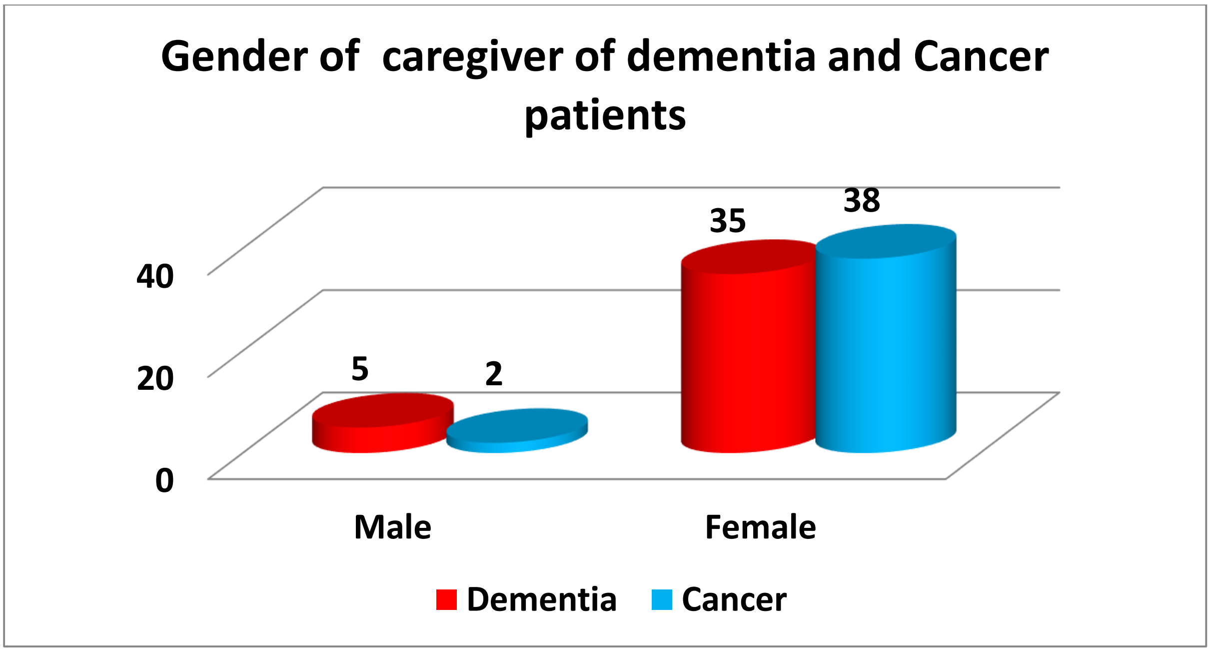
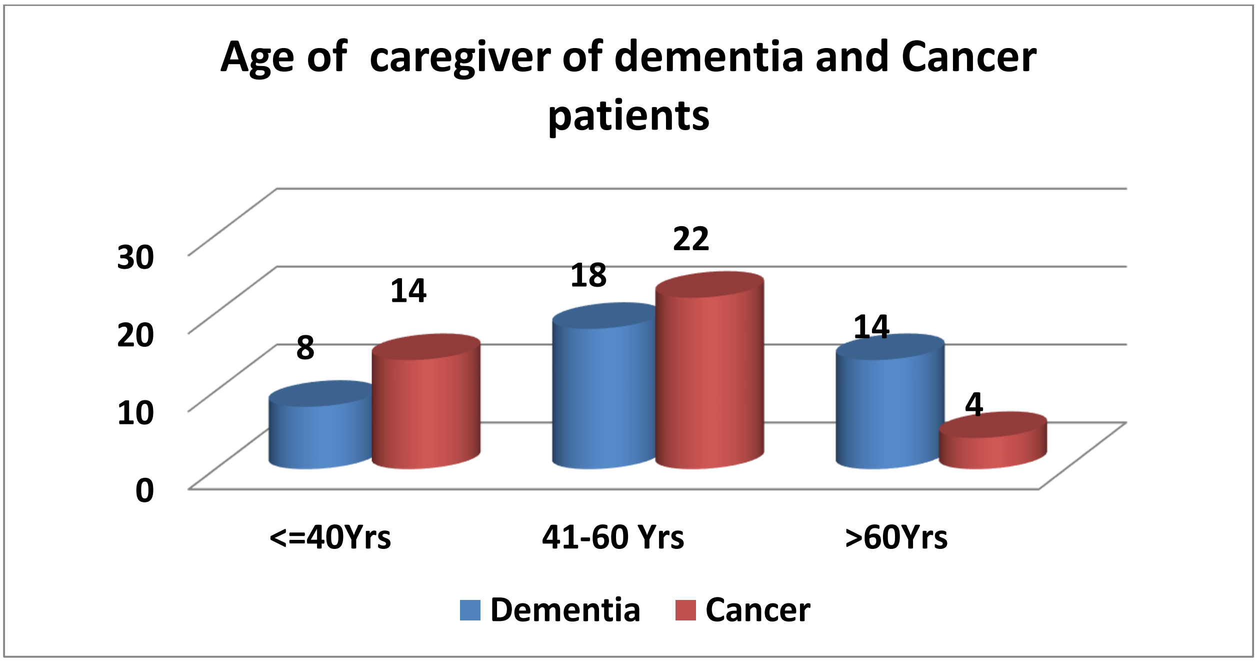


Table 1 show demographic characteristics of care giver of Dementia and Cancer patients. There were 40 dementia and cancer patients each by study design. There was 87.5 % of female patients in dementia group and 95.0% in cancer group. There were a very few male patients were found in both the group. Chi-square test shows that there is no association between gender and patient diagnosis such as Dementia and Cancer. (p=0.429).

Table 2: Age of the caregiver of Dementia and Cancer patients

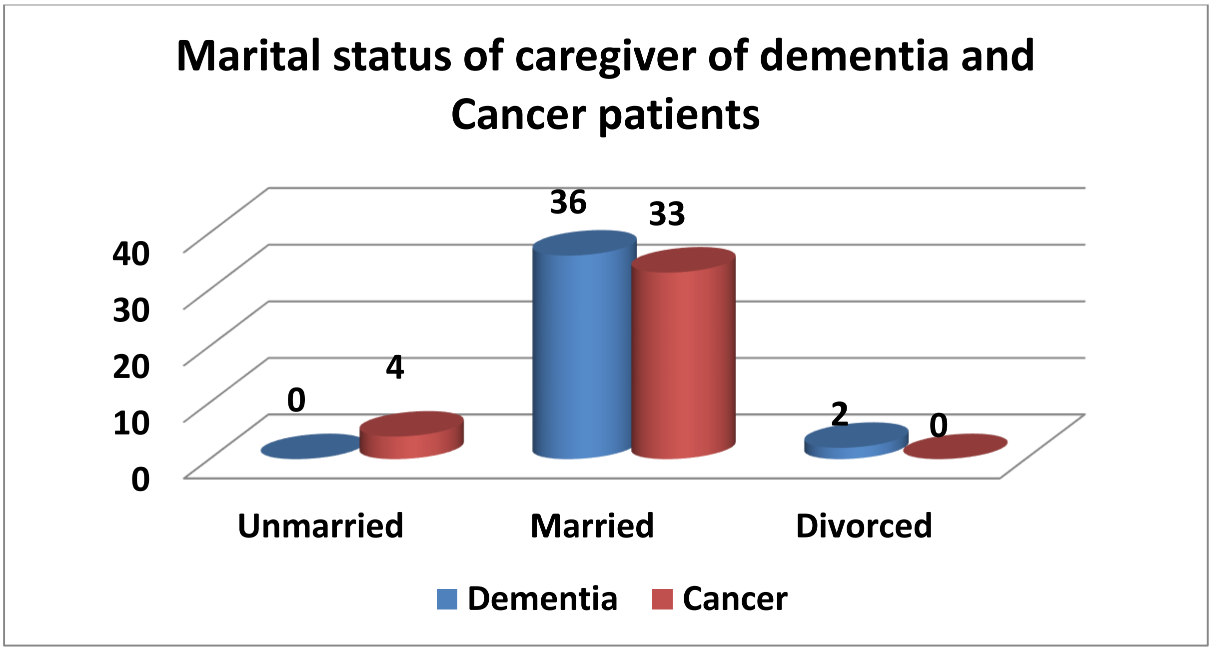
Category	Dementia (n=40)	Cancer (n=40)	Total (n=80)	Chi-square value	Df	p-value
Age of the caregiver						
≤ 40 Yrs	8(20.0%)	14(35.0%)	22(27.5%)	7.59	2	0.022
41-60 Yrs	18(45.0%)	22(55.0%)	40(50.0%)			
Above 60 Yrs	14(35.0%)	4(10.0%)	18(22.5%)			



Age of the caregiver was analysed and found that a majority were in 41-60 years age group. Among Dementia caregivers it was 45.0% and 55.0% in Cancer caregivers. Cancer caregivers were high 22(27.5%) in below 40 years while Dementia caregivers were high 14(35.0%) in 60 and above years. Chi-square test shows that there is an association between age of the caregiver and patient diagnosis.(p=0.022)

Table 3: Marital status of caregivers of Dementia and Cancer

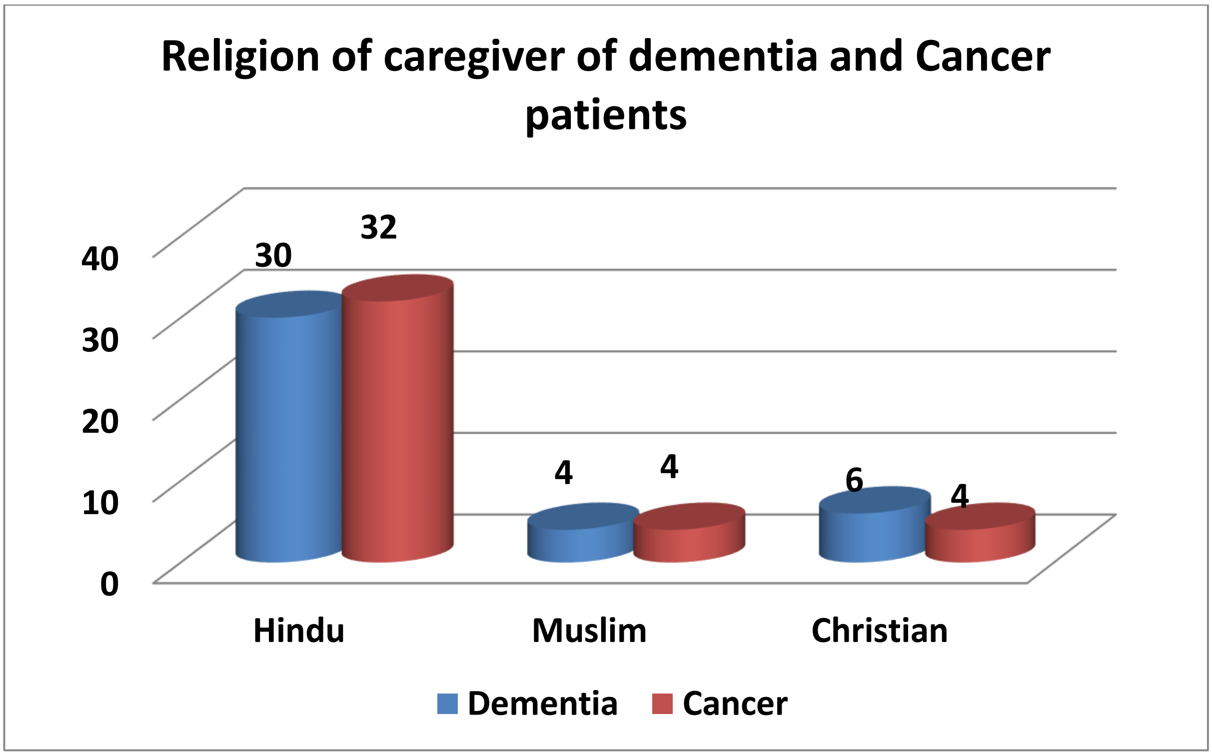
Category	Dementia (n=40)	Cancer (n=40)	Total (n=80)	Chi-square value	Df	p-value
Marital status of care givers						
Unmarried	0(0.0%)	4(10.0%)	4(5.0%)	6.33	3	0.09
Married	36(90.0%)	33(82.5%)	69(86.3%)			
Divorced	2(5.0%)	0(0.0%)	2(2.5%)			
Widowed	2(5.0%)	3(7.5%)	5(6.3%)			



Among the caregiver for Dementia patients 36(90.0%) got married and it was 33(82.5%) for caregiver to Cancer patients. A meager percent of marital status like unmarried, divorced and widowed were observed in this study. The association between marital status of caregiver and patient diagnosis was statistically not significant (p=0.09)

Table 4: Religion of caregiver of Dementia and Cancer patients

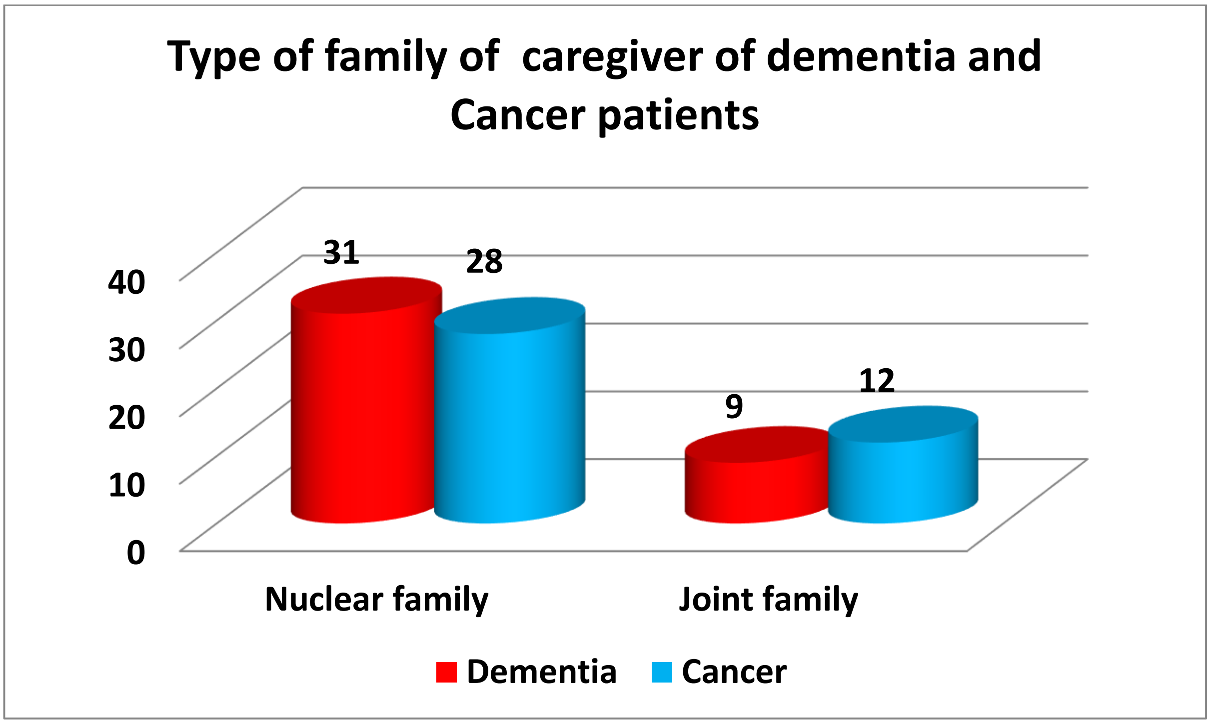
Category	Dementia (n=40)	Cancer (n=40)	Total (n=80)	Chi-square value	Df	p-value
Religion of caregiver						
Hindu	30(75.0%)	32(80.0%)	62(77.5%)	0.465	2	0.793
Muslim	4(10.0%)	4(10.0%)	8(10.0%)			
Christian	6(15.0%)	4(10.0%)	10(12.5%)			



A majority of the caregiver were Hindu in both dementia (90.0%) and cancer (82.5%) caregivers and there is no association between religion of caregiver and patient diagnosis.(p=0.793)

Table 5: Type of family of caregivers of Dementia and Cancer patients

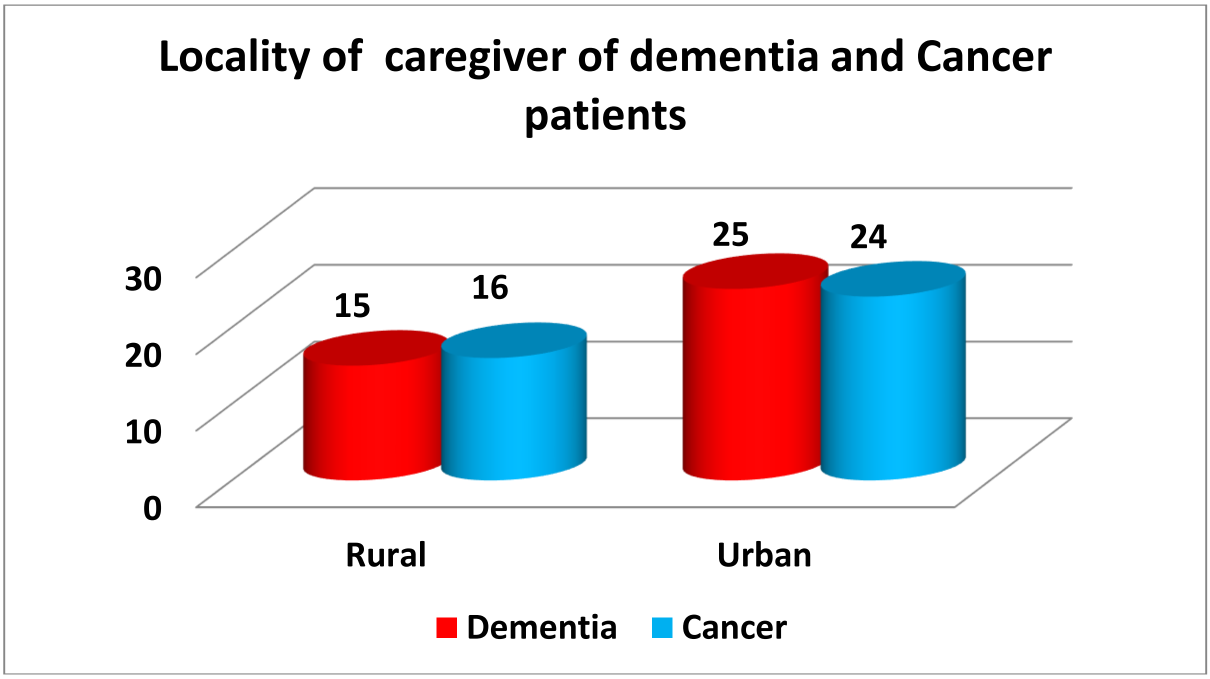
Category	Dementia (n=40)	Cancer (n=40)	Total (n=80)	Chi-square value	Df	p-value
Type of family						
Nuclear family	31(77.5%)	28(70.0%)	59(73.8%)	1.95	2	0.377
Joint family	9(22.5%)	12(30.0%)	20(26.2%)			



The study revealed 73.8% of nuclear family and 26.2% were joint family among caregiver. Nuclear family was high in caregiver of both Dementia (77.5%) and Cancer (73.8%) but the differences were statistically not significant (p=0.377).

Table 6: Locality of caregivers of Dementia and Cancer patients

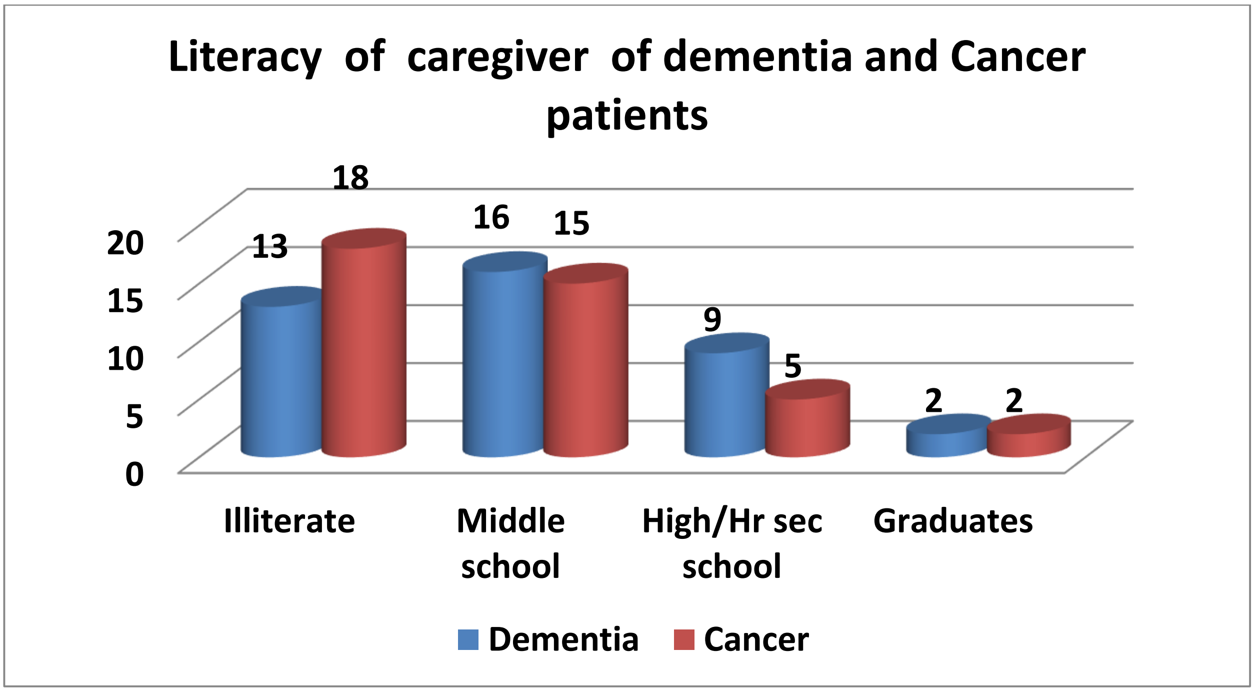
Category	Dementia (n=40)	Cancer (n=40)	Total (n=80)	Chi-square value	df	p-value
Locality						
Rural	15(37.5%)	16(40.0%)	31(38.8%)	0.053	1	0.818
Urban	25(62.5%)	24(60.0%)	49(61.3)			



Higher proportion (61.3%) caregivers were from urban and it was 38.8% for rural area. Urban Caregivers were high in both Dementia (62.5%) and Cancer (60.0%) patients , but there was no association between locality of the caregiver and patient diagnosis and it was same in both group of caregivers , it was not showing statistically significant difference in between Dementia and Cancer caregivers.(p=0.818)

Table 7: Education of care givers of Dementia and Cancer patients

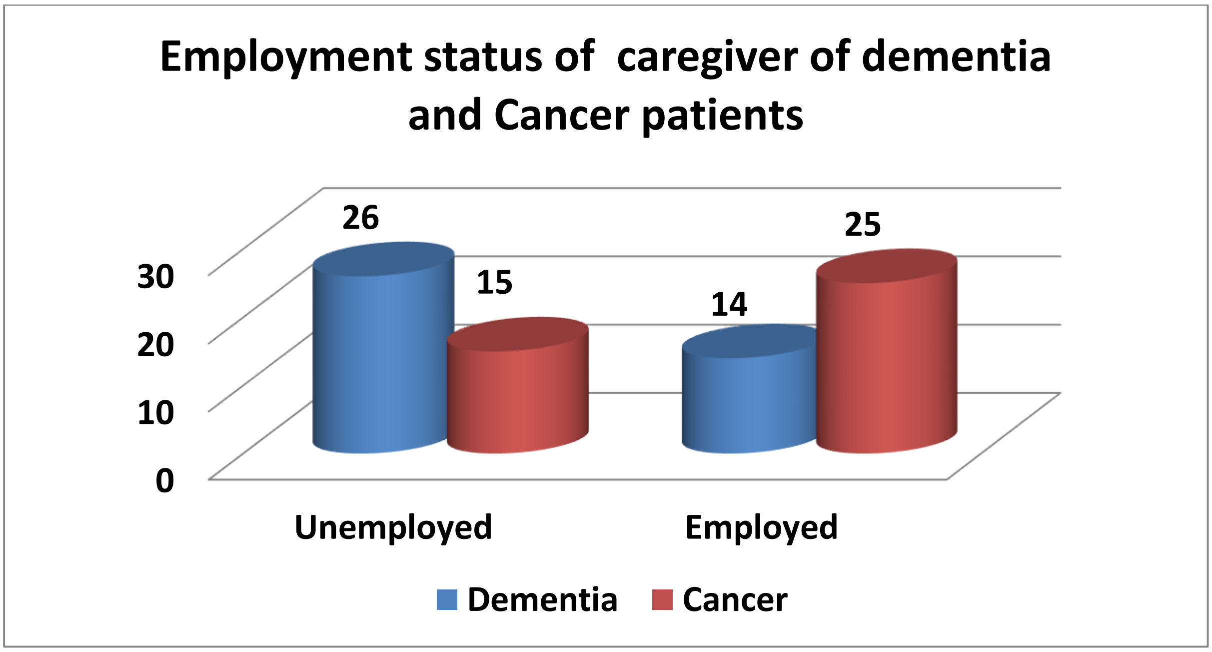
Category	Dementia (n=40)	Cancer (n=40)	Total (n=80)	Chi-square value	Df	p-value
Educational status of caregivers						
Illiterate	13(32.5%)	18(45.0%)	31(38.8%)	1.98	3	0.576
Middle school	16(40.0%)	15(37.5%)	31(38.8%)			
High/Hr sec school	9(22.5%)	5(12.5%)	14(17.5%)			
Graduates	2(5.0%)	2(5.0%)	4(5.0%)			



. The analysis on educational status of caregiver shows that illiterates were high (38.8%) among cancer caregivers compared to Dementia caregivers(32.5%). High/Higher secondary education were high in Dementia caregivers (22.5%) as compared with cancer caregivers. (12.5%). There was no association between education status of caregiver and patient diagnosis. It was not showing statistically significant difference between Dementia and Cancer caregivers. (p=0.974)

Table 8: Occupation of caregivers in Dementia and Cancer patients

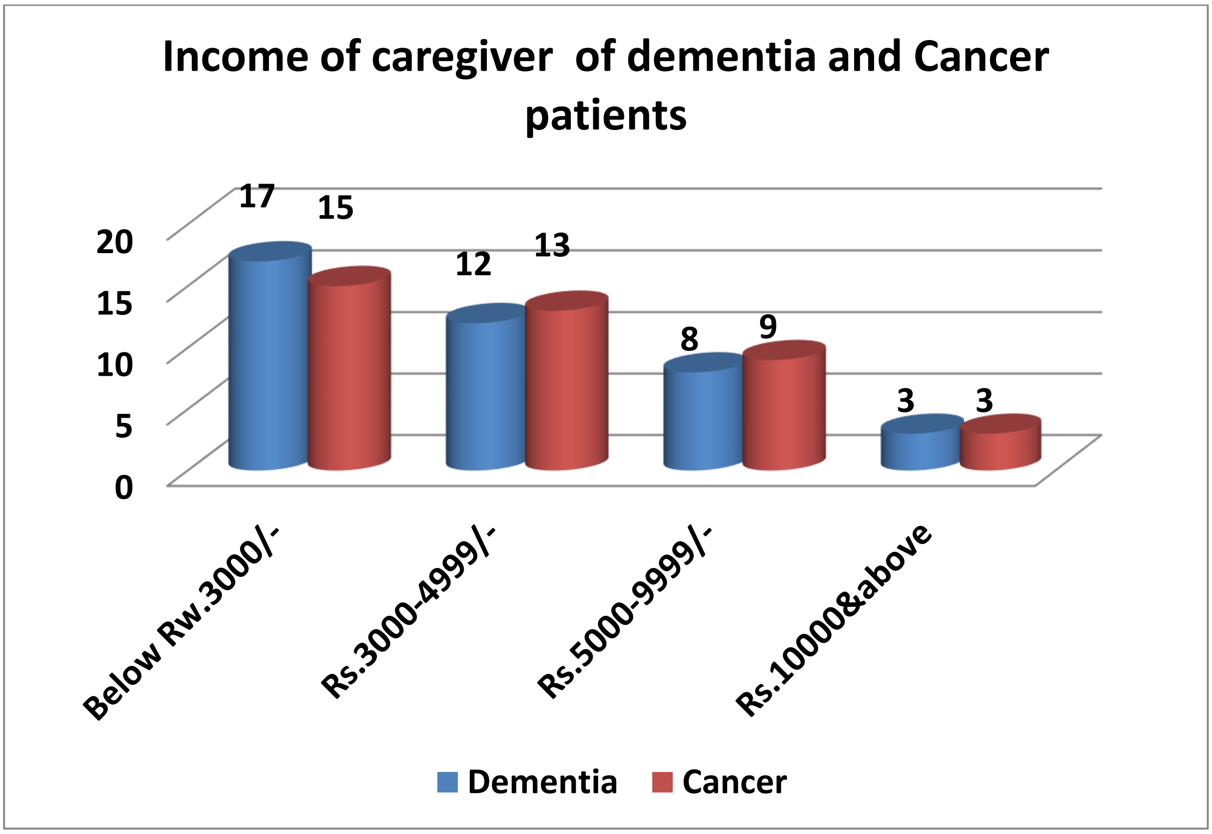
Category	Dementia (n=40)	Cancer (n=40)	Total (n=80)	Chi-square value	df	p-value
Occupation of caregiver						
Unemployed	26(65.0%)	15(37.5%)	41(51.3)	6.05	1	0.014
Employed	14(35.0%)	25(62.5%)	39(48.8%)			



A higher proportion (65.0%) of Dementia caregivers were unemployed while 62.5% of Cancer patients caregiver were employed. The differences in employment status between dementia and cancer caregivers were statistically significant (p=0.014).

Table 9: Income of care givers in dementia and cancer patients

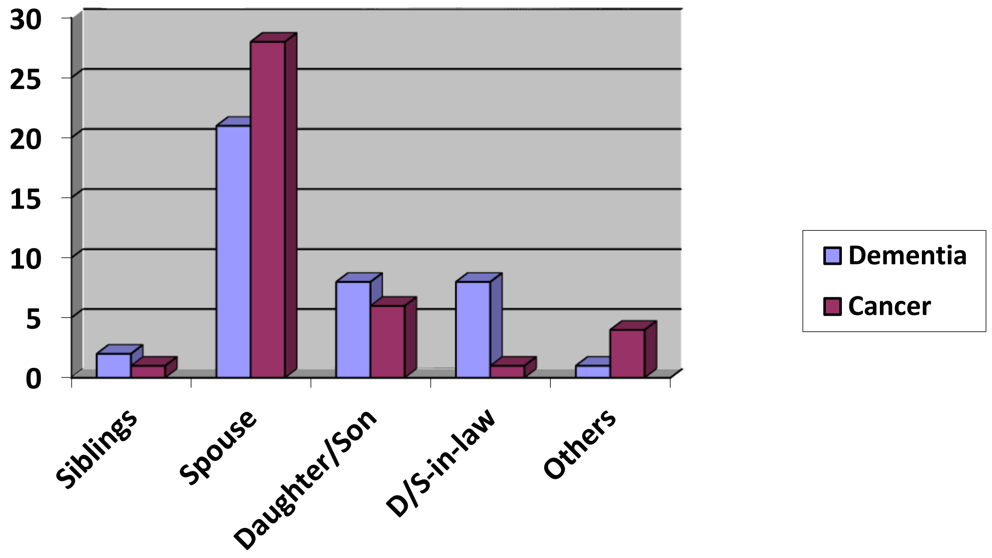
Category	Dementia (n=40)	Cancer (n=40)	Total (n=80)	Chi-square value	Df	p-value
Income						
Below Rs.3000/-	17(42.5%)	15(35.5%)	32(40.0%)	0.224	3	0.974
Rw.3000-4999	12(30.0%)	13(32.5%)	25(31.3%)			
Rs.5000-9999	8(20.0%)	9(22.5%)	17(21.3%)			
Rs.10,000 and above	3(7.5%)	3(7.5%)	6(7.5%)			



Nearly, 17(42.5%) of Dementia caregivers and 15(35.5%) of cancer caregivers' monthly income was below Rs.3000/-. The difference in proportion of monthly income in dementia and cancer caregivers were not significant (p=0.974).

Table 10: Relationship to the patients of caregivers in dementia and cancer

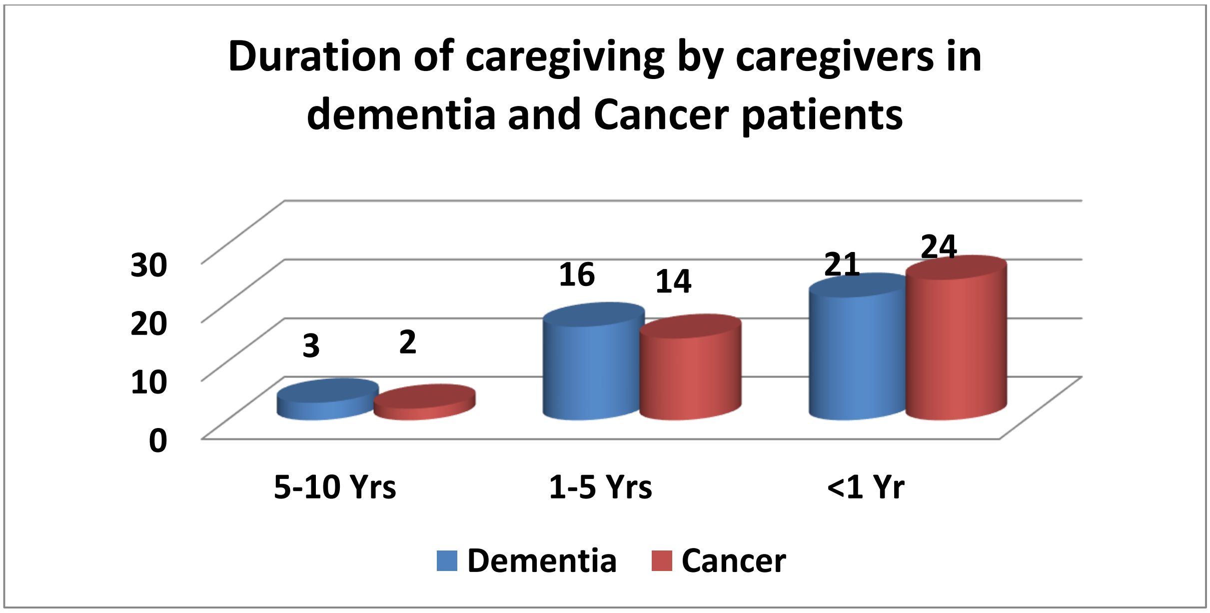
Category	Dementia (n=40)	Cancer (n=40)	Total (n=80)	Chi-square value	df	p-value
Relationship to the patients						
Siblings	2(5.0%)	1(2.5%)	3(3.8%)	8.8	4	0.065
Spouse	21(52.5%)	28(70.0%)	49(61.3%)			
Daughter/Son	8(20.0%)	6(15.0%)	14(17.5%)			
Daughter/son - in-law	8(20.0%)	1(2.5%)	9(11.3)			
Others	1(2.5%)	4(10.0%)	5(6.3%)			



The analysis of relationship of caregiver to Dementia patient shows that 70.0% were spouses and 17.5% were son/daughters. Among the caregiver of cancer patients 70.0% were spouse and 15.0% were daughter/sons. So both groups have same proportion of spousal caregivers on care giving. The differences in proportion of relationship to the patients in caregivers of dementia and cancer were statistically not significant (p=0.065).

Table11: Duration of care giving in dementia and cancer patients

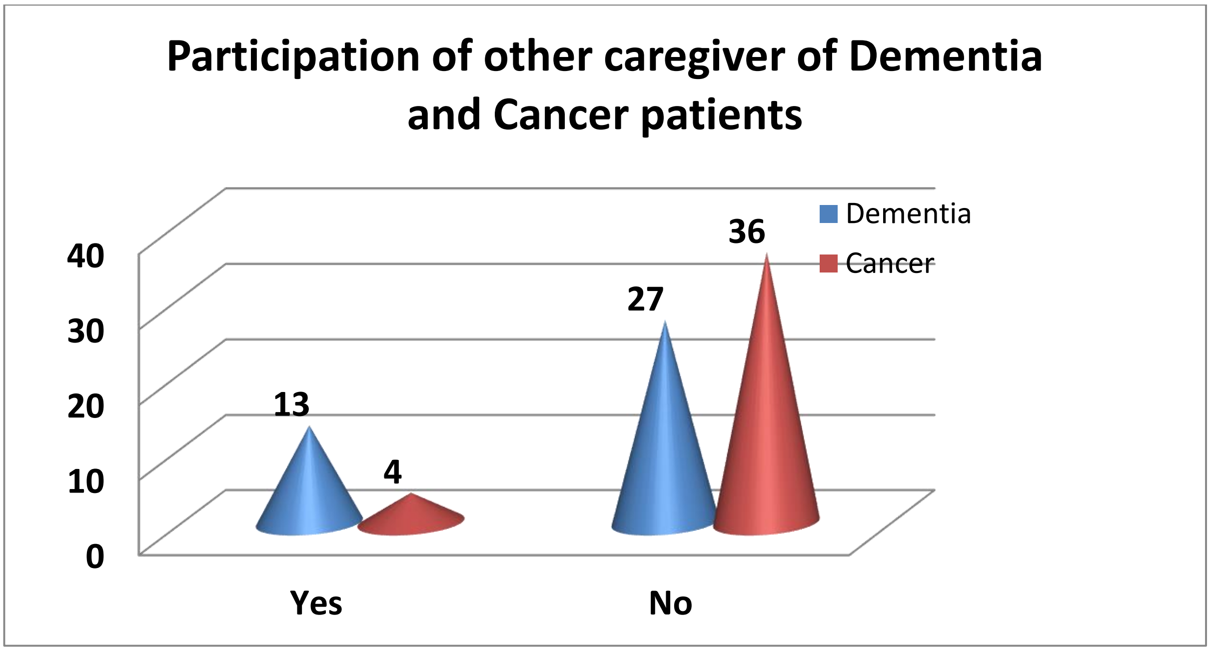
Category	Dementia (n=40)	Cancer (n=40)	Total (n=80)	Chi-square value	df	p-value
Duration of caregiver given						
5-10 years	3(7.50%)	2(5.0%)	5(6.3%)	0.533	2	0.766
1-5 years	16(40.0%)	14(35.0%)	30(37.5%)			
less than 1 year	21(52.5%)	24(60.0%)	45(56.3%)			



The proportion of duration of care giving less than one year was 52.5% and 60.0% among caregiver of dementia and cancer patients respectively. Care given in 1-5 years was 40% and35% in caregiver of dementia and cancer patients. The highest duration of care given more than 5 years was 7.5% and 5% in caregiver of dementia and cancer patients respectively. The difference between duration of care giving in dementia and cancer caregivers were not statistically significant. (p=0.766).

Table: 12 Participation of other caregivers of dementia and cancer patient

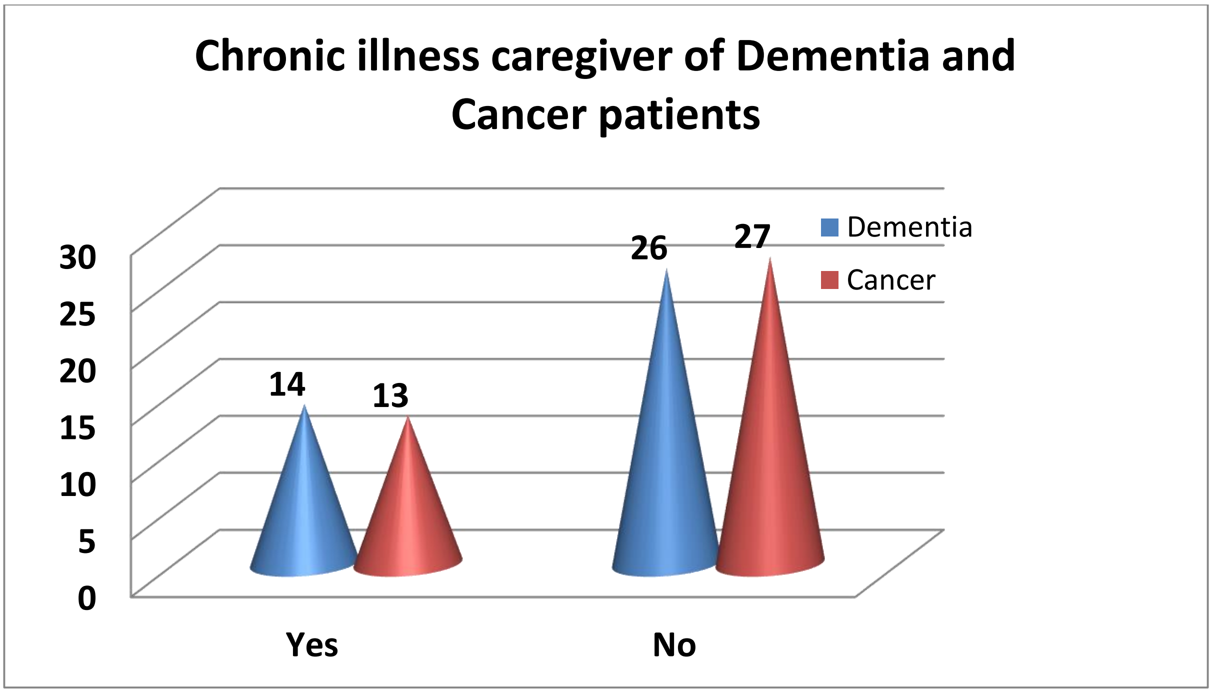
Category	Dementia (n=40)	Cancer (n=40)	Total (n=80)	Chi-square value	Df	p-value
Participation of other caregivers						
No	27(67.5%)	36(90.0%)	63(78.8%)	6.05	1	0.27
Yes	13(32.5%)	4(10.0%)	17(21.3%)			



Participation of other caregiver givers to Dementia patient was 32.5% and only 10.0% for cancer patients. The relationship between participation of other caregiver for care giving in dementia and cancer was statistically not significant (p=0.27)

Table: 13 Chronic illness of caregiver of dementia and cancer patient

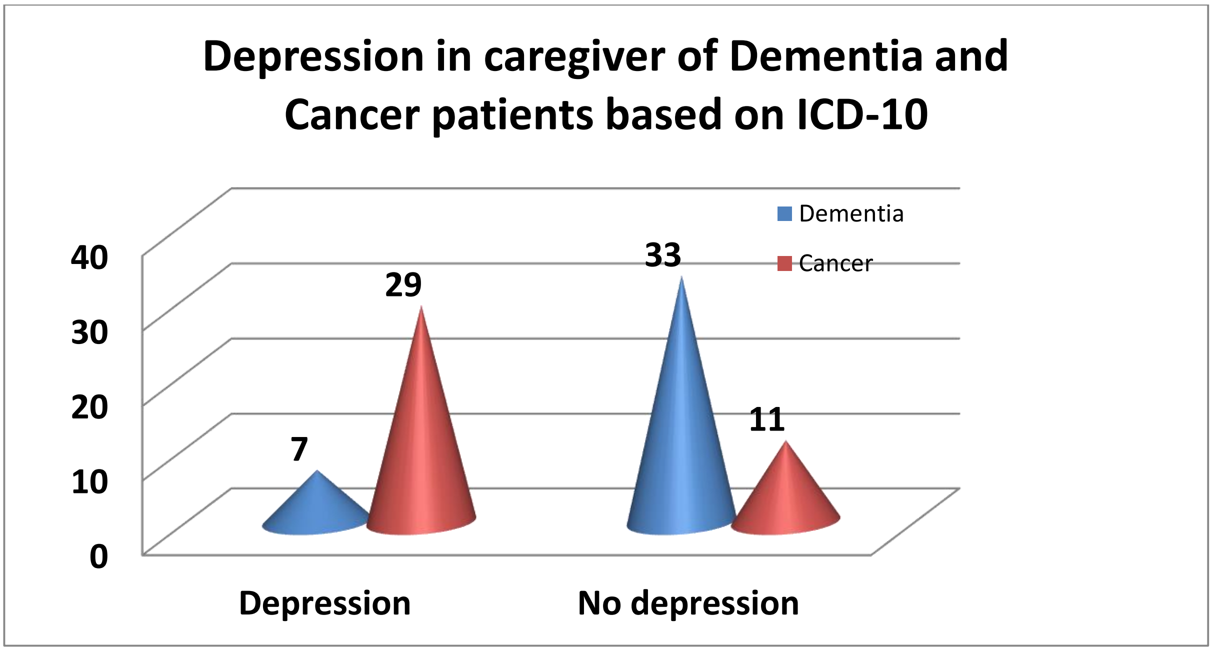
Category	Dementia (n=40)	Cancer (n=40)	Total (n=80)	Chi-square value	df	p-value
Chronic illness						
No	26(65.0%)	27(67.5%)	53(66.3%)	0.56	1	0.813
Yes	14(35.0%)	13(32.5%)	27(33.8%)			



The status of chronic illness was analysed and found that 65.0% and 67.5% of Dementia and Cancer caregivers had chronic illness respectively. The relationship of chronic illness in dementia and cancer caregivers was not significant (p=0.813)

Table : 14 Depression by ICD-10 classification in care givers of dementia and cancer

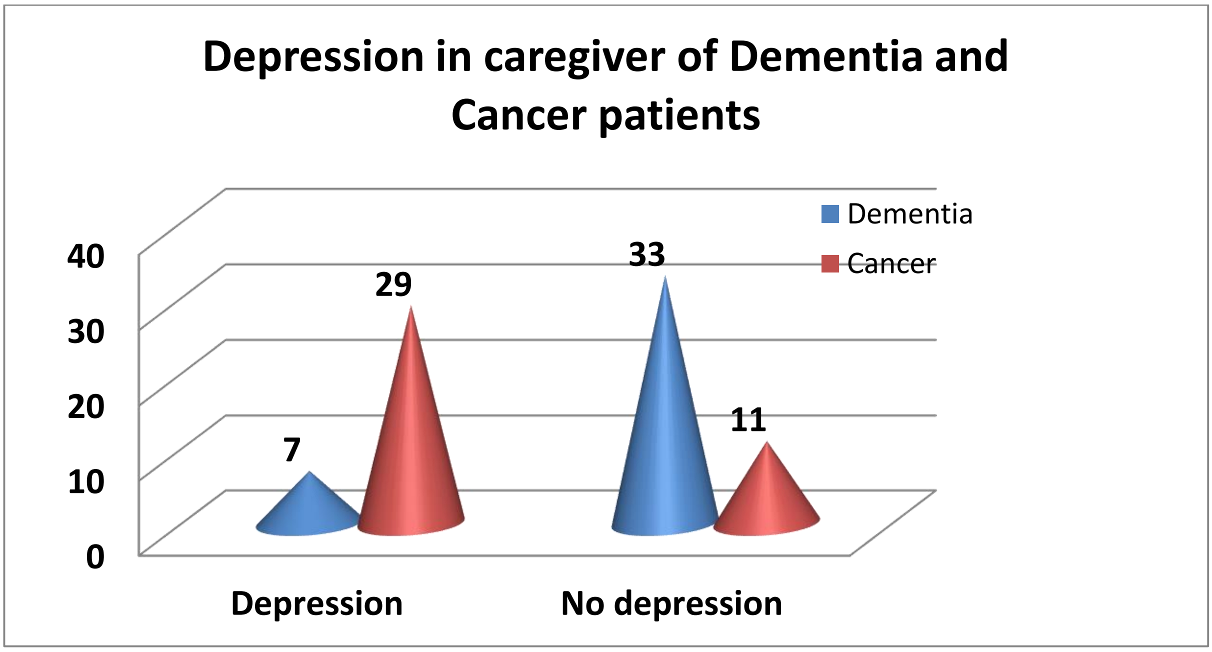
Category	Dementia (n=40)	Cancer (n=40)	Total (n=80)	Chi-square value	df	p-value
ICD-10 classification						
No depression	33(82.5%)	11(27.5%)	44(55.0%)	24.44	1	0.0001
depression	7(17.5%)	29(72.5%)	36(45.5%)			



According to ICD-10 classification, the depression was found high (72.5%) among caregivers of cancer patient compared to caregiver of dementia patients (17.5%). The difference between ICD 10 classification of depression in dementia and cancer caregivers was found statistically significant (p=0.0001)

Table :15 MADRS-Depression in caregivers of Dementia and Cancer patients

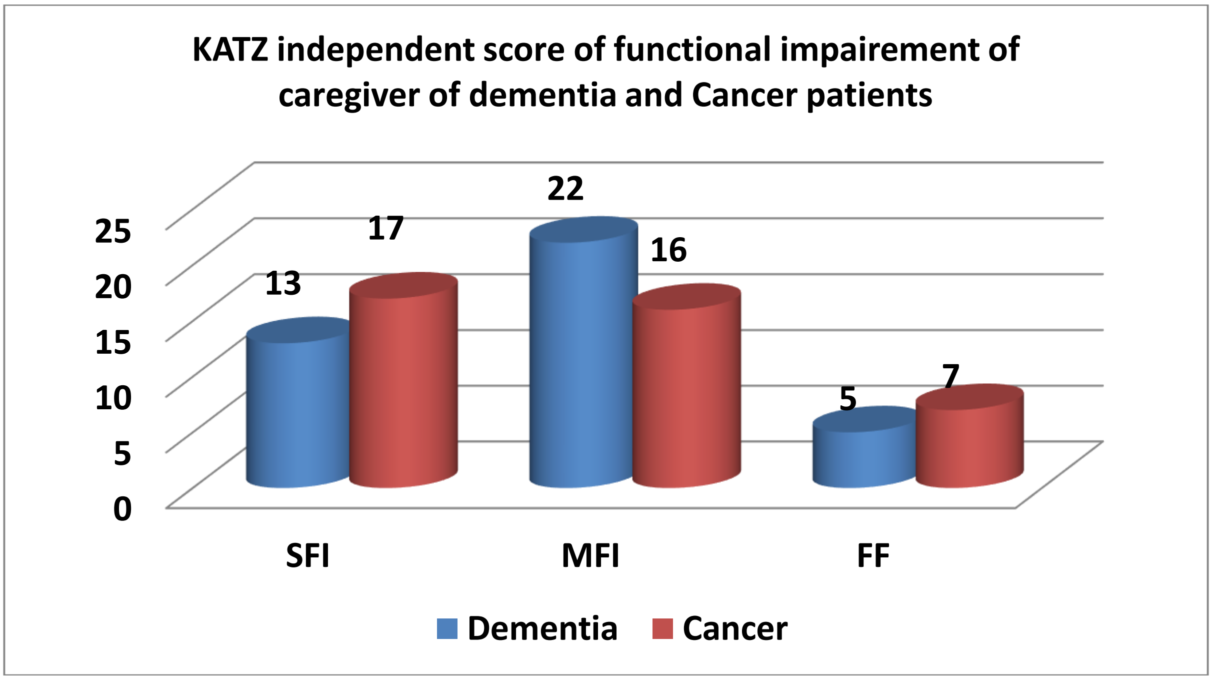
Category	Dementia (n=40)	Cancer (n=40)	Total (n=80)	Chi-square value	df	p-value
MADRS-Depression in care giver						
No	33(82.5%)	11(27.5%)	44(55.0%)	24.44	1	0.0001
Yes	7(17.5%)	29(72.5%)	36(45.0%)			

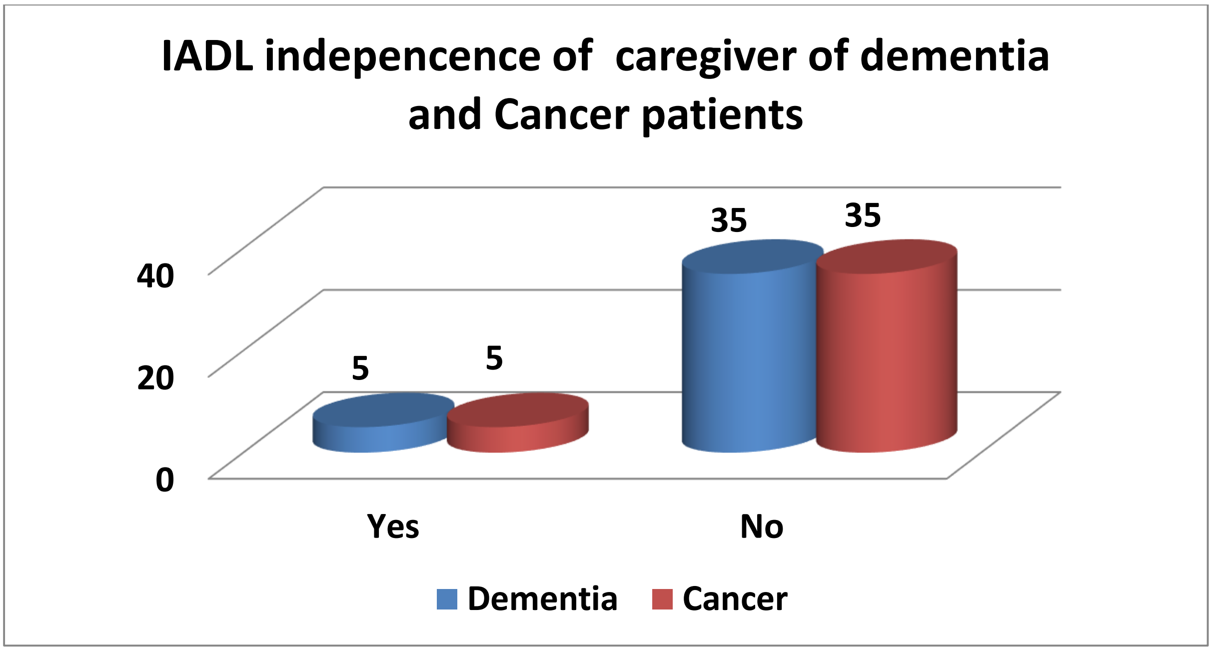


Depression was found very high among caregiver givers of cancer patient (72.5%) compared to dementia patients (17.5%). Chi-square test reveals that the difference in the proportion of depression in caregivers of dementia and cancer patients were statistically significant (p=0.0001)

Table:15 KATZ ADL & IADL score of care givers in dementia and cancer patients.

Category	Dementia (n=40)	Cancer (n=40)	Total (n=80)	Chi-square value	df	p-value
KATZ independent						
Severe functional impairment	13(32.5%)	17(42.5%)	30(37.5%)	1.8	2	0.404
Moderately functional impairment	22(55.0%)	16(40.0%	38(47.5%)			
Fully functional	5(12.5%)	7(17.5%)	12(15.0%)			
IADL independence						
No	35(87.5%)	35(87.5%)	70(87.5%)	0.00	1	1.0
Yes	5(12.5%)	5(12.5%)	10(12.5%)			



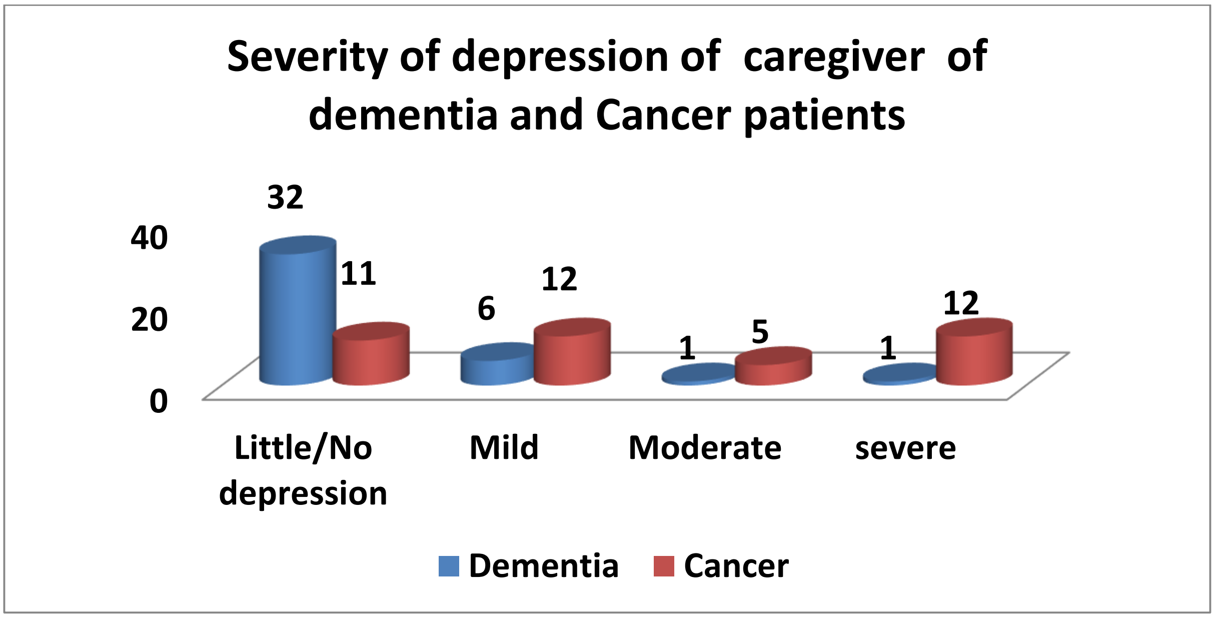


KATZ independent score shows that 12.5% of caregivers of dementia were fully functional, 50.0% had moderately functional impairment and 32.5% had severe functional impairment. Among caregivers of cancer patients, 17.5% were fully functional, 40.0% had moderately functional impairment and 42.5% had severe functional impairment.In both dementia and cancer caregivers there were similar proportion of moderate and severe functional impairment, indicator of dependence. So in KATZ independent score, the difference between the dependence to caregivers was found statistically not significant in dementia and cancer caregivers. (p=0.404).

IADL independence was present among 12.5% of caregivers of dementia patients and as well as cancer patients and hence there is no statistical significance between IADL independence in dementia and cancer caregivers . (p=1.0)

Table : 16 Severity of depression in care givers of Dementia and Cancer patients

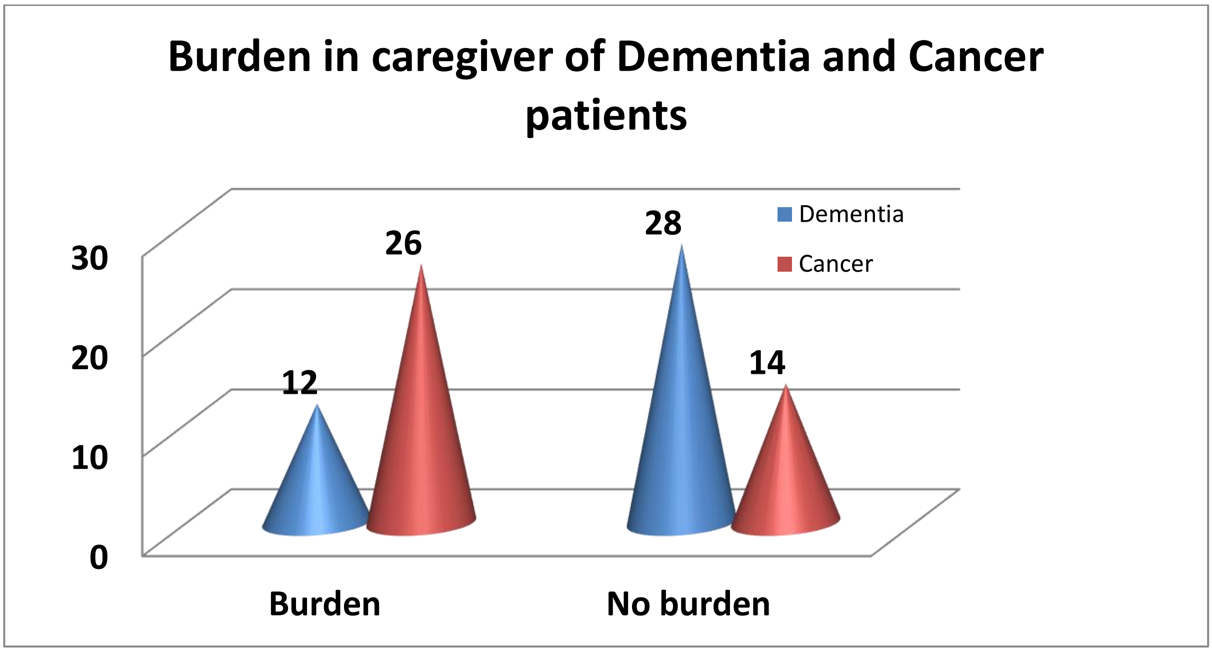
Category	Dementia (n=40)	Cancer (n=40)	Total (n=80)	Chi-square value	df	p-value
Severity of depression						
Little/No depression	32(80.0%)	11(27.5%)	43(53.8%)	24.2	3	0.000
Mild	6(15.0%)	12(30.0%)	18(22.5%)			
Moderate	1(2.5%)	5(12.5%)	6(7.5%)			
severe	1(2.5%)	12(30.0%)	13(16.3%)			



The severity of depression was measured among caregivers of dementia and cancer patients. It was found that 80.0% of the caregivers of dementia were free of depression while it was only 27.5% among caregivers of cancer patients. 30.0% of the caregiver of cancer patients had severe depression compared to that of caregivers of dementia patients (2.5%). Both mild and moderate depression was also comparatively high among caregivers of cancer patients to that of dementia patients. Chi-square test reveals that the difference in the proportion of severity of depression in caregivers of dementia and cancer patients were statistically significant (p=0.0001).

Table :17 ZBI-Burden in care givers of dementia and cancer patients

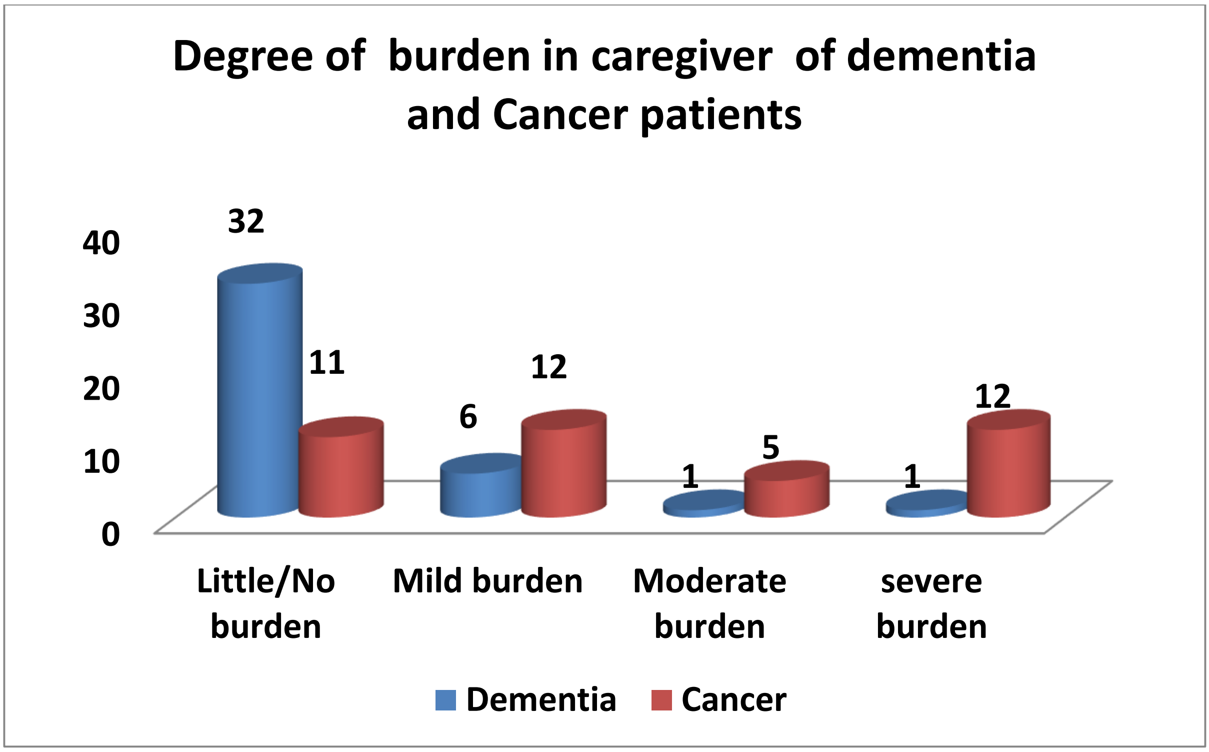
Category	Dementia (n=40)	Cancer (n=40)	Total (n=80)	Chi-square value	Df	p-value
Caregiver burden						
Burden absent	28(70.0%)	14(35.0%)	42(52.5%)	11.74	2	0.003
Burden present	12(30.0%)	26(65.0%)	38(47.5%)			



The proportion of burden among caregivers of cancer patients according to ZBI scale was high with 65.0% compared to dementia patients (30.0%). Chi-square test shows that the difference between caregiver burden in dementia and cancer caregivers was statistically significant (P=0.00).

Table : 18 Degree of burden in ZBI scale of care givers of Dementia and Cancer patients

Category	Dementia (n=40)	Cancer (n=40)	Total (n=80)	Chi-square value	df	p-value
Caregiver Degree of burden						
Little/No burden	28(70.0%)	13(32.5%)	41(51.3%)	13.10	3	0.004
Mild burden	5(12.5%)	8(20.0%)	13(16.3%)			
Moderate burden	2(5.0%)	11(27.5%)	13(16.3%)			
Severe burden	5(12.5%)	8(20.0%)	13(16.3%)			

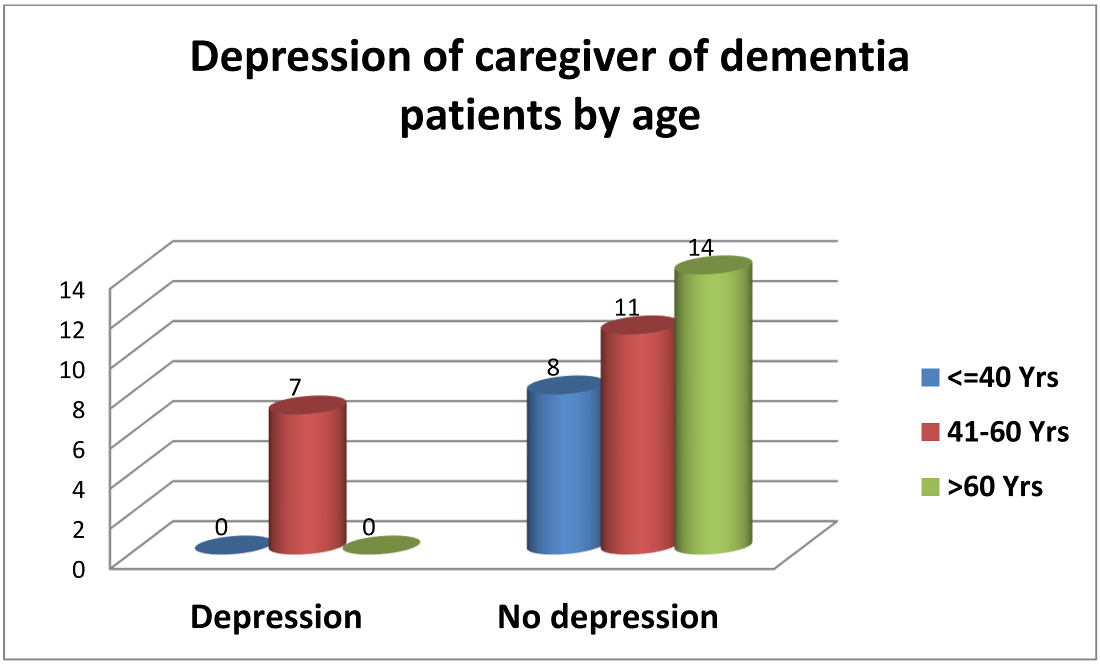


The degree of burden in ZBI scale shows that 70.0% of the caregiver of dementia patients had no burden and it was nearly one-third among caregivers of cancer patients. Severe, moderate and mild burden among caregiver of cancer patients were 20.0%, 27.5% and 20.0% respectively. It was 12.5%, 5.0% and 12.5% among caregivers of dementia patients respectively. The degree of burden among caregivers of cancer patients was high as compared to that of dementia caregivers and the difference was statistically significant (p=0.004).

ASSOCIATION BETWEEN DEPRESSION AND OTHER VARIABLES IN DEMENTIA CREGIVERS

Table:19 Depression in caregiver of dementia patients by age

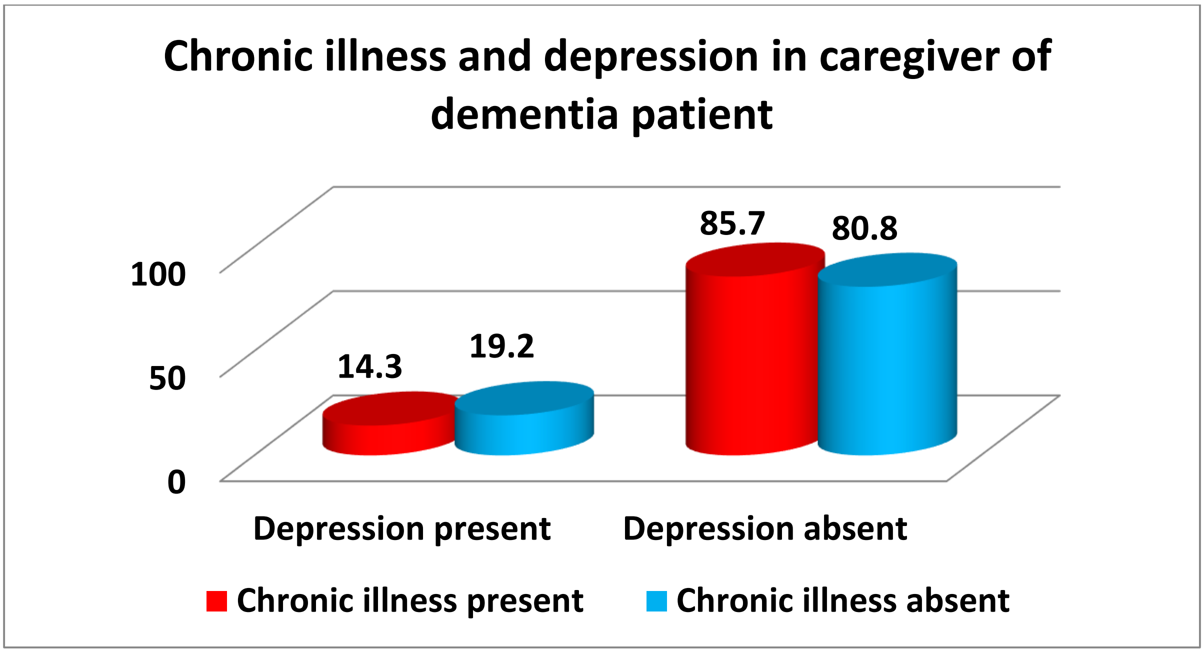
Category	Depression	No depression	Total	Chi-square value	df	p-value
Age of the caregiver (n=40)						
<=40Yrs	0(0.0%)	8(100.0%)	8(100.0%)	10.37	3	0.006
41-60 Yrs	7(38.9%)	11(61.1%)	18(100.0%)			
60 & above Yrs	0(0.0%)	14(100.0%)	14(100.0%)			



Among the caregiver of dementia patients, depression was high (38.9%) in 41-60 years of age and the rest of the age group have no depression. As the age of the caregiver giver increases, the proportion of depression was also decreases. The relationship between age of the caregiver of Dementia patients and depression was found significant (p=0.006)

Table :20 Chronic illness and depression in caregiver of dementia patient

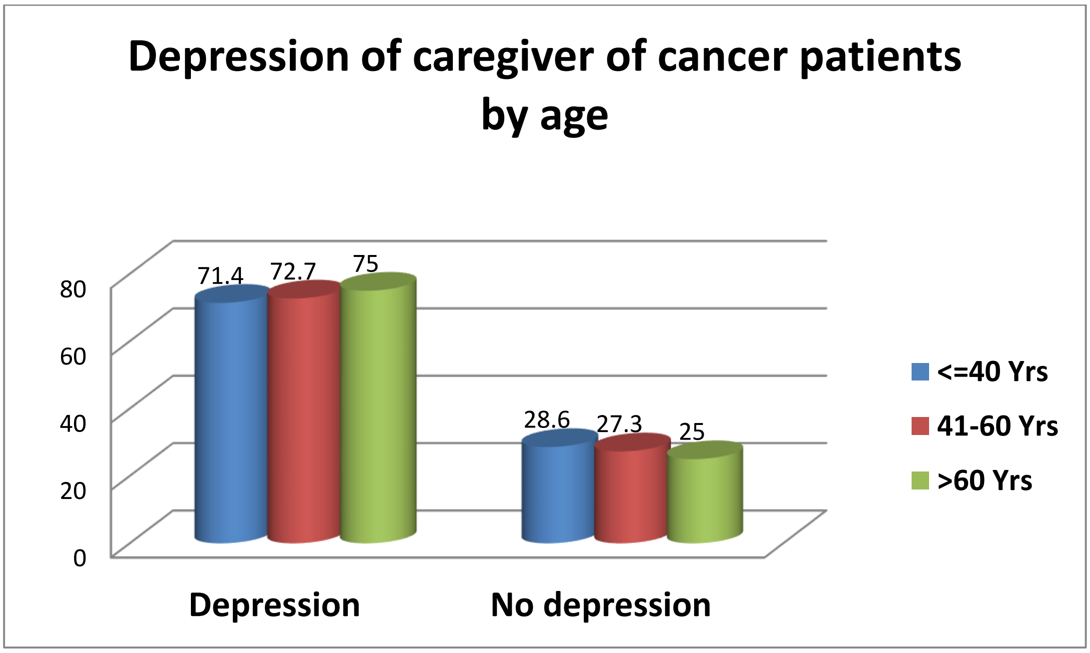
Category	Depression present	Depression absent	Total (n=80)	Chi-square value	df	p-value
Chronic illness						
Present	2(14.3%)	12(85.7%)	14(100.0%)	0.154	1	0.695
Absent	5(19.2%)	21(80.8%)	26(100.0%)			



Among the caregiver of dementia patients, depression was 14.3% and 19.2% when the patients had chronic illness or not respectively. The association between chronic illness and depression among caregiver of dementia patient was not significant (p=0.695)

Table:21 Depression of caregiver of cancer patients by age

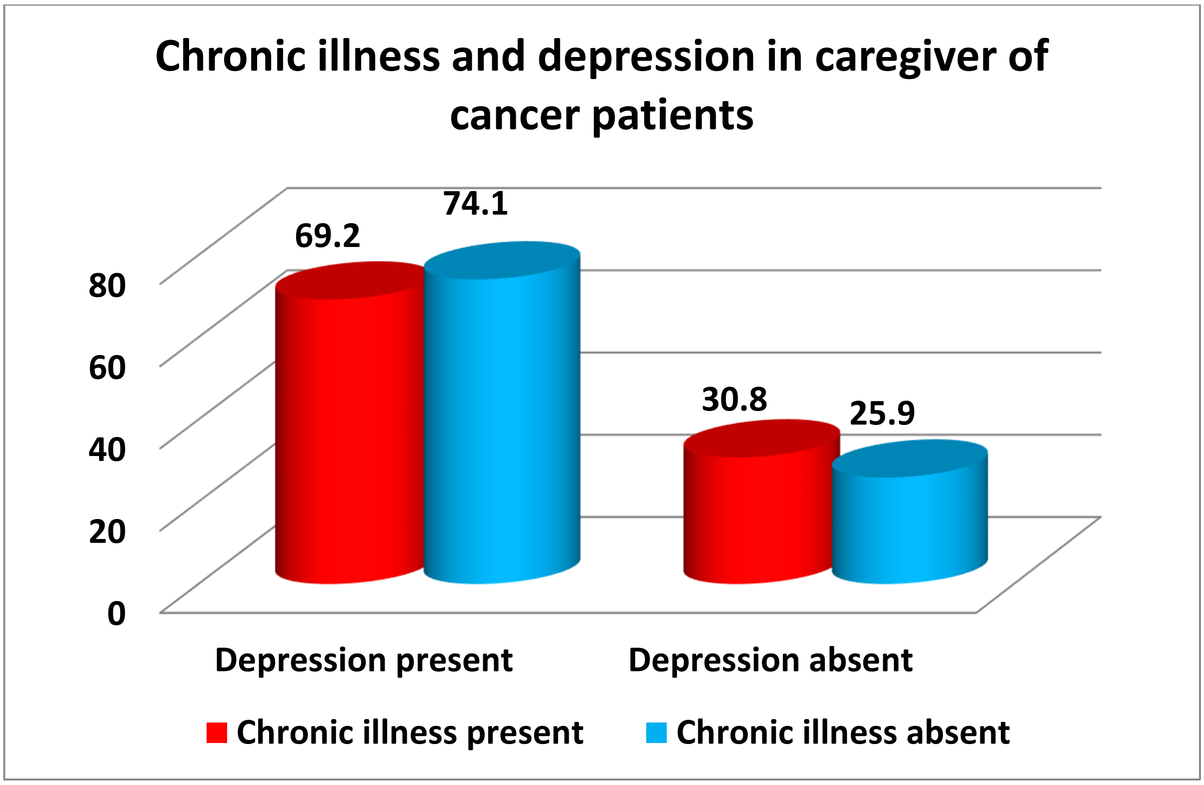
Category	Depression	No depression	Total	Chi-square value	df	p-value
Age of the caregiver (n=40)						
<=40Yrs	10(71.4%)	4(28.60%)	14(100.0%)	0.21	2	0.989
41-60 Yrs	16(72.7%)	6(27.3%)	22(100.0%)			
60 & above Yrs	3(75.0%)	1(25.0%)	4(100.0%)			



Among the caregiver of cancer patients, depression was high (75.0%) in 60 years and above, 72.7% in 41-60 years of age, 71.4% in below 40 years of age. Age of the caregiver giver increases, the proportion of depression was also increases. However, the association between age of the caregiver of cancer patients and depression was not significant (p=0.989)

Table 22: Chronic illness and depression in caregiver of cancer patient

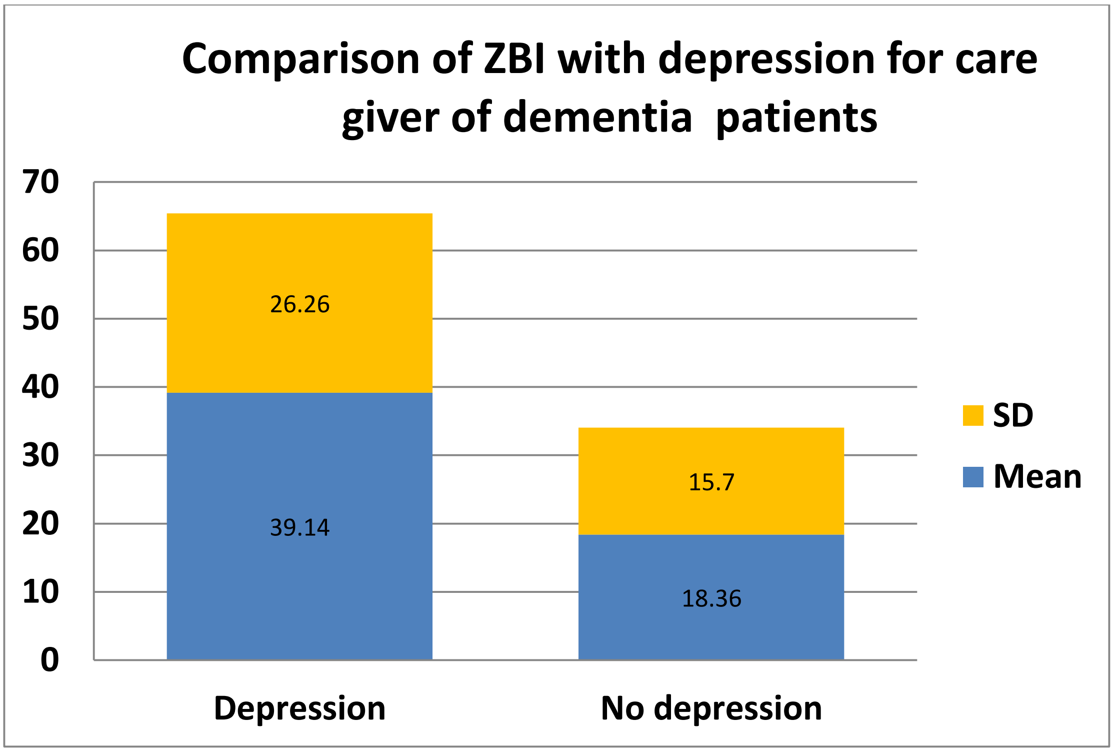
Category	Depression present	Depression absent	Total (n=80)	Chi-square value	Df	p-value
Chronic illness						
Present	9(69.2%)	4(30.8%)	27(100.0%)	0.103	1	0.748
Absent	20(74.1%)	7(25.9%)	27(100.0%)			



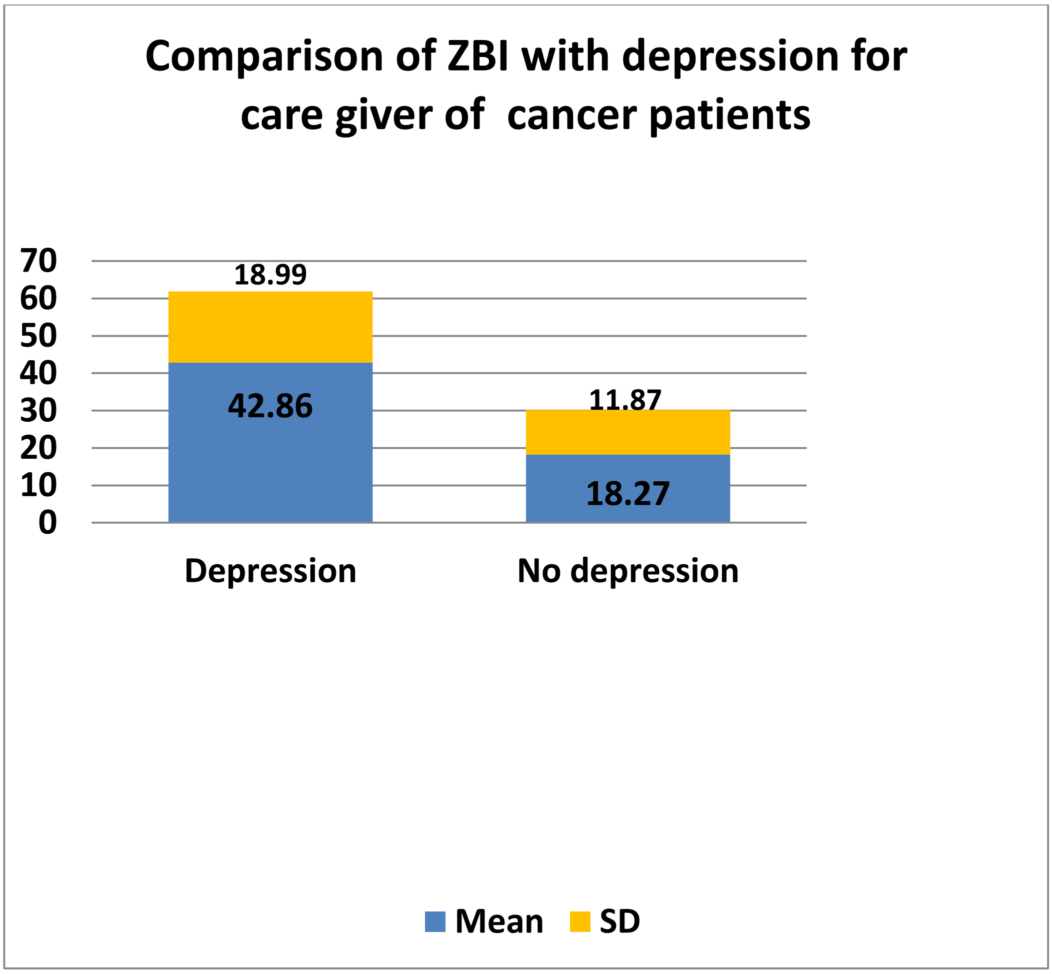
The proportion of depression was 69.2% and 74.1% when chronic illness is present or absent respectively among caregiver of cancer patients. The association between chronic illness of patients and depression among caregiver of cancer patients was not significant (p=0.748).

Table :23 Comparison of ZBI with depression for care giver of dementia and cancer patients

Variable	Mean ± SD	95% CI of difference		t-value	Df	p -value
		Lower	Upper			
Caregiver of dementia patients						
Depression	39.14 ± 26.257	7.433	20.779	2.796	38	0.008
No depression	18.36 ± 15.70					
Caregiver of cancer patients						
Depression	42.86±18.99	14.312	34.867	4.893	29	0.0001
No depression	18.27 ± 11.87					



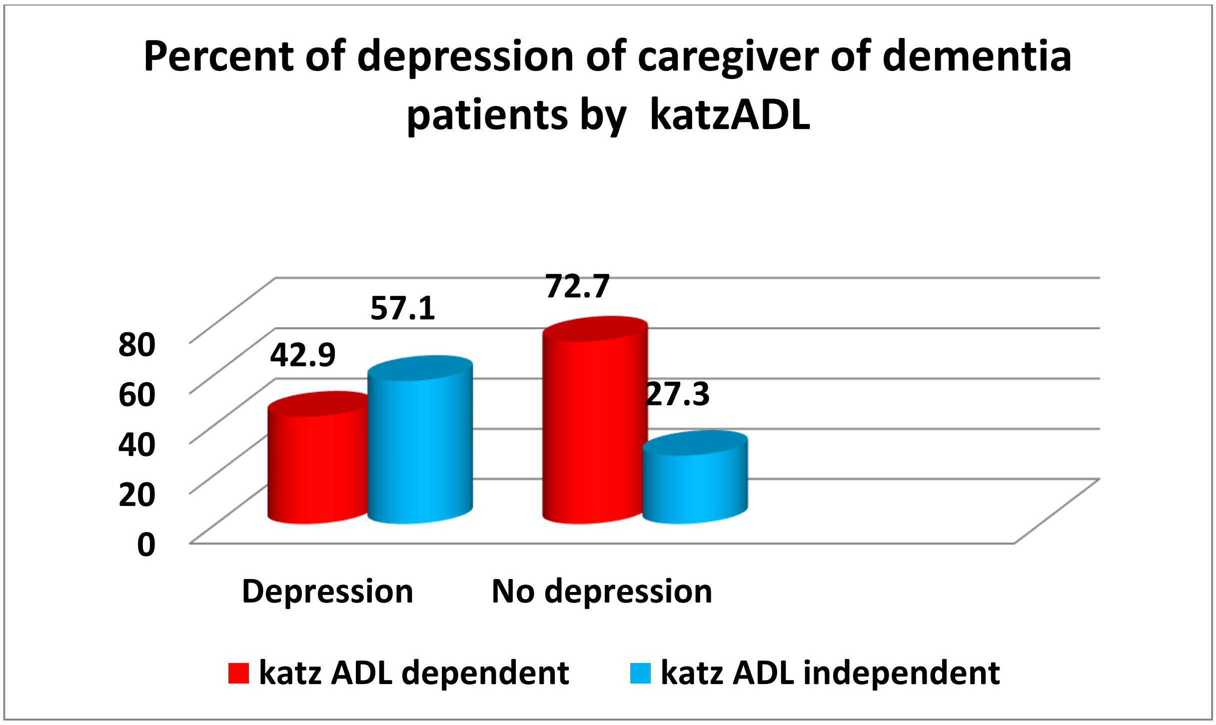
The mean ZBI score of caregiver of dementia patients had depression was 39.14±26.257 and that of no depression was 18.36±15.7. An independent sample t-test was conducted to compare the mean ZBI score between depressed and non-depressed caregiver of dementia patients and found significant [t(38)=2.79, p=0.008]



The mean ZBI score of caregiver of cancer patients had depression was 42.86±18.99 and that of no depression was 18.27±11.87. An independent sample t-test was conducted to compare the mean ZBI score between depressed and non-depressed caregiver of cancer patients and found significant [t(34)=4.89, p=0.0001]

Table:24 Depression of caregiver of dementia patients by katz ADL

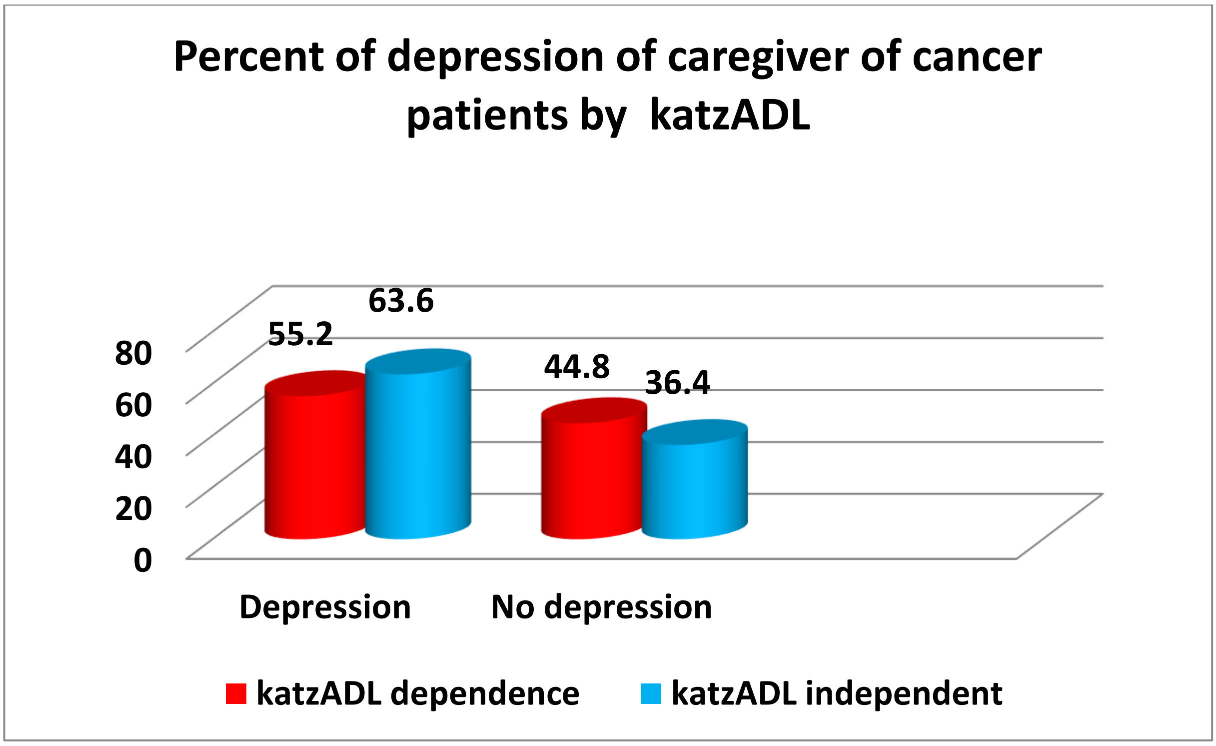
Category	Depression	No depression	Total	Chi-square value	df	p-value
Caregiver of dementia patietns (n=40)						
Katz ADL dependent	39(42.9%)	24(72.7%)	27(67.5)	2.349	1	0.125
Katz ADL independent	4(57.1%)	9(27.3%)	13(32.5%)			



Depression of caregiver of dementia patients when katz ADL was dependent was 42.9% and that was 57.1% when katz ADL was independent. The relationship between depression and dependence in katz ADL was not significant (p=0.125) among caregiver of dementia patients.

Table: 25 Depression of caregiver of cancer patients by katz ADL

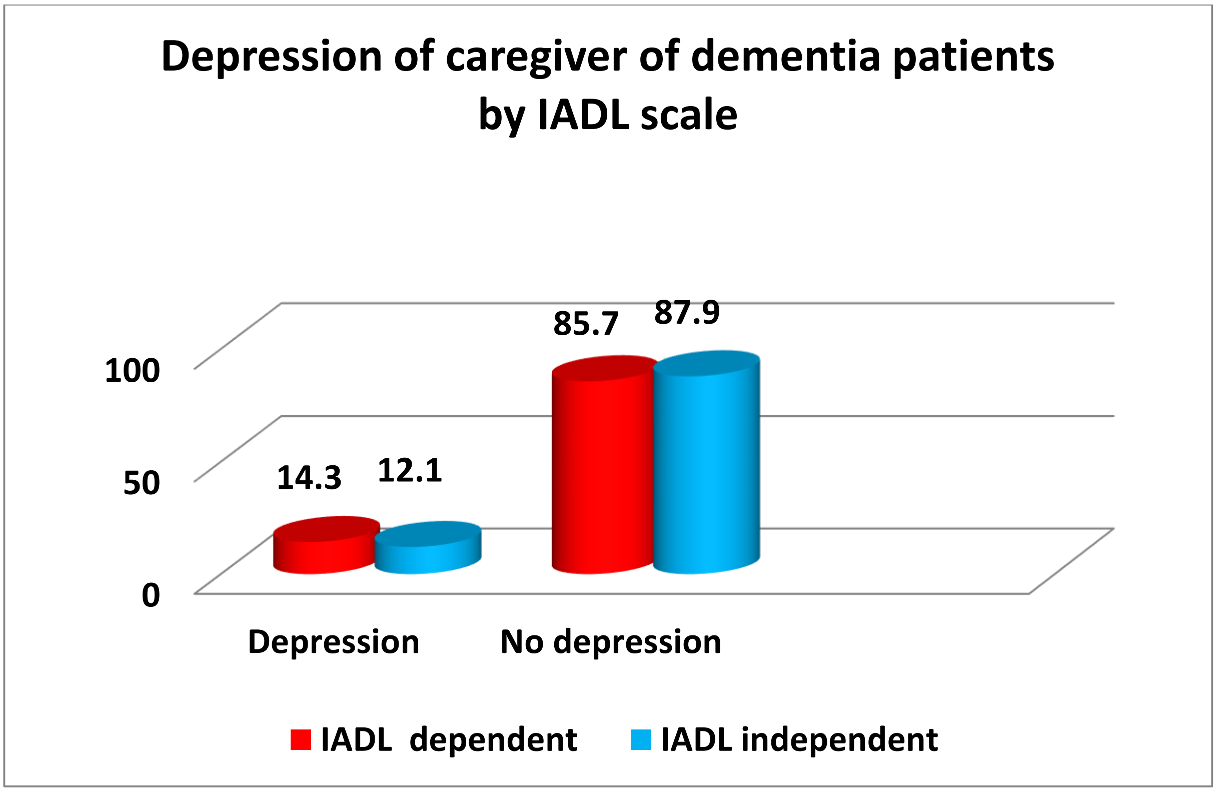
Category	Depression	No depression	Total	Chi-square value	df	p-value
Caregiver of cancer patietns (n=40)						
KatzADL dependence	16(55.2%)	7(63.6%)	23(57.5%)	0.234	1	0.629
Katz ADL independence	13(44.8%)	4(36.4%)	17(42.5%)			



Depression of caregiver of cancer patients when katzADL dependence was 55.2% and that was 63.6% for katz ADL independent. The relationship between depression and katz ADL was not significant (p=0.125) among caregiver of cancer patients.

Table:26 Depression of caregiver of dementia patients by IADL scale

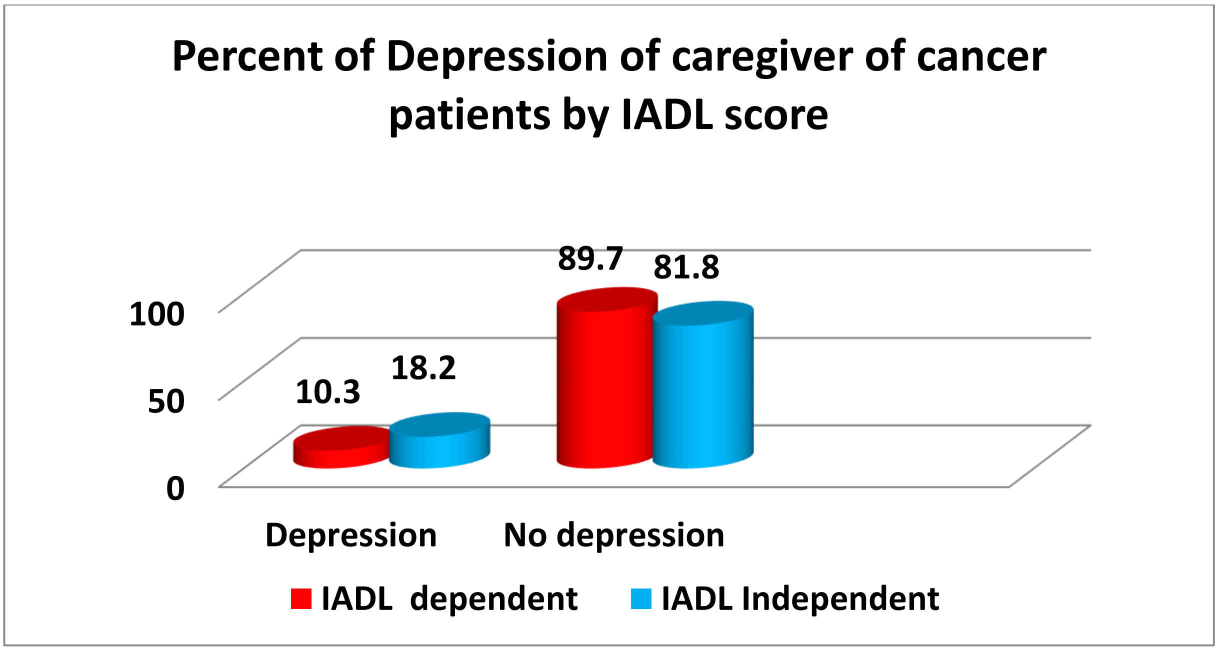
Category	Depression	No depression	Total	Chi-square value	df	p-value
Caregiver of cancer patients (n=40)						
IADL dependent	1(14.3%)	4(12.1%)	5(12.5%)	0.25	1	0..875
IADL Independent	6(85.7%)	29(87.9%)	35(87.5%)			



Depression of caregiver of cancer patients when IADL dependent was 14.3% and that was 12.1% for IADL independent. The relationship between depression and dependence in IADL was not significant (p=0.125) among caregiver of cancer patients.

Table: 27 Depression of caregiver of cancer patients by IADL score

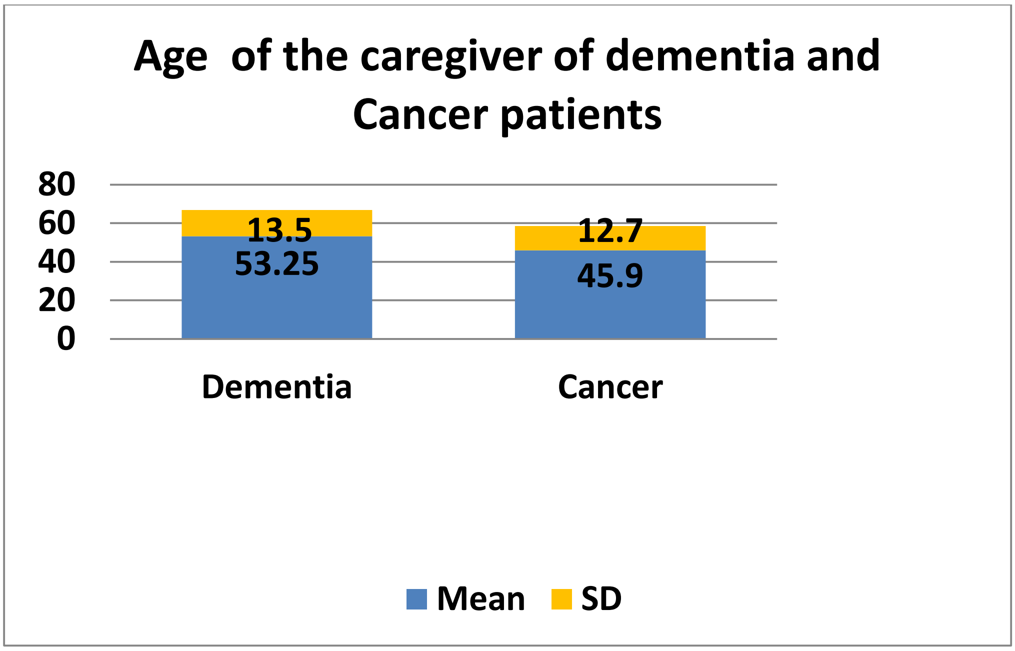
Category	Depression	No depression	Total	Chi-square value	df	p-value
Caregiver of cancer patients (n=40)						
IADL dependent	3(10.3%)	2(18.2%)	5(12.5%)	0.448	1	0.503
IADL independent	26(89.7%)	9(81.8%)	37(87.5%)			



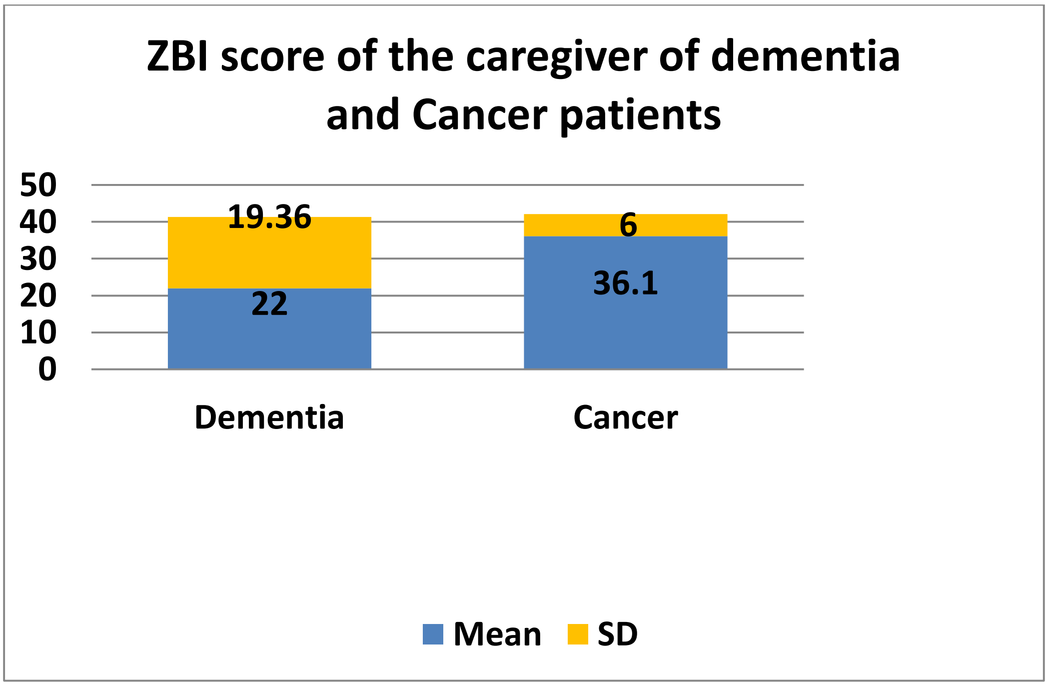
Depression of caregiver of cancer patients when IADL dependent was 10.3% and that was 18.2% when IADL independent. The relationship between depression and IADL was not significant (p=0.503) among caregiver of cancer patients.

Table : 28 Comparison of ZBI, MADRS scores and age of care giver in Dementia and Cancer patients

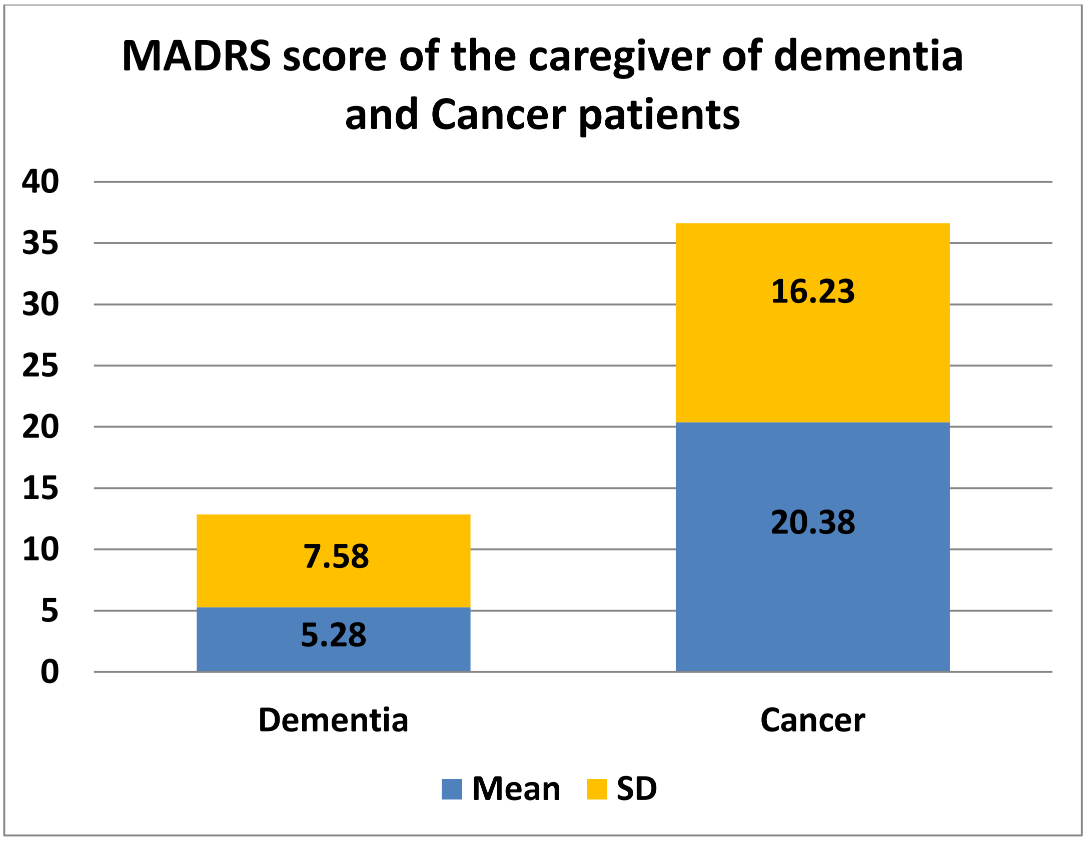
Variable	Mean±SD	95% CI of difference		t-value	Df	p –value
		Lower	Upper			
Age of the care giver						
Dementia	53.25±13.5	1.5	13.19	2.505	78	0.014
Cancer	45.9±12.7					
ZBI score						
Dementia	22.0±19.36	5.23	22.97	3.166	78	0.002
Cancer	36.1±20.46					
MADRS score						
Dementia	5.28±7.58	9.42	20.78	5.33	55.2	0.0001
Cancer	20.38±16.23					



The mean age of caregiver of dementia patients was 53.25 years and it was 45.9 years for caregiver of cancer patients. An independent sample t-test was conducted to compare the mean age of the caregiver and patient diagnose and found significant[t(78)=13.19, p=0.014]



The ZBI score of caregiver of Dementia patients was significantly higher (M=36.1, SD=20.46) than that of caregiver of Cancer patients (M=22.0, SD=19.36), t(78)=3.166, p=0.002)



The MADRS score of caregiver of Dementia patients was significantly higher (M=20.38, SD=16.23) than that of caregiver of Cancer patients (M=5.28, SD=7.58), t(55.2)=5.33, p=0.0001)

DISCUSSION

SOCIODEMOGRAPHIC FACTORS

The mean age of caregivers of dementia and cancer patients was between 41-60 years. The mean caregiver distribution was matching with previous studies done in cancer caregivers by Susan C MC Millan , the mean age of caregiver in cancer patient was 45- 54 years and in another study by Ioannis Vrettos in same group , it was 48.9±14.3 years. The mean age of caregivers found in other studies such as Covinsky et al and in Australian Bureau of Statistics: disability ageing and carers was 65 years.

The two groups – caregivers of dementia and cancer had generally similar distribution of gender, marital status, religion, family type, locality, education, all of these variables were found to be statistically not significant between the two groups, and so the groups were comparable.

Most of the dementia caregivers were unemployed in cancer caregivers, most of them were employed and difference between these two groups were statistically significant.

In these two groups, the income of the caregivers, relationship to patient, participation of other family members in care giving, chronic illness among caregivers were found to be statistically not significant, because it was approximately same in both the groups, and so the groups were comparable. These results were similar to studies done in cancer by Zyada et al and Mohammed Ali Heidari et al.

The higher percentage of depression in dementia caregivers was found in 41-60 years of age and it was low in < 40 years and > 60 years. In cancer caregivers, depression is high among 40- 60 years .It was found statistically significant association between caregiver age and depression in both dementia and cancer caregivers. There were more female caregivers than male caregivers found to be depressed, but it was not statistically significant in both these group of caregivers. The depression in dementia and cancer caregivers were found to be more among employed caregivers than unemployed, but the association was not statistically significant. Likewise the caregiver depression were higher among the both the group of caregivers who were not having other family members to care giving than who were with participation of other family members in care giving, but the association was not statistically significant.

CAREGIVER CHARACTERISTICS IN DEMENTIA AND CANCER CAREGIVERS

The chronic illness among both the group of caregiver were found to be same, such as 65.0% and 67.5% in dementia and cancer caregivers respectively, so the two groups were comparable, but the difference was not statistically significant. The duration of care giving among both the groups was approximately same and so the difference was not statistically significant.

DEPENDENCE TO CAREGIVERS AMONG DEMENTIA AND CANCER PATIENTS

According to KATZ ADL Index of independence scale, the dependence to basic activities of daily living among dementia patients, 12.5%, 50.0% and 32.5% were fully functioning, moderate functional impairment and severe functional impairment respectively. Among cancer patients, 17.5%, 40.0% and 42.5% were found fully functional, moderate functional impairment and severe functional impairment, but the difference among dementia and cancer patients' dependence to caregivers was not significant.

According to IADL scale, the dependence to instrumental activities of daily living was same (12.5%) among both dementia and cancer caregivers, so both type of patients face same type of dependence to instrumental activities, because of this, the difference among the two groups were not significant statistically.

COMPARISON OF CAREGIVER BURDEN AMONG CAREGIVERS OF DEMENTIA AND CANCER PATIENTS

The caregiver burden which was assessed by Zarit Burden Interview scale among dementia and cancer caregivers found to be 65.0% and 30.0% respectively. The difference between these two groups were statistically significant. The caregiver burden in cancer caregivers was similar to study which was done by N Haj Mohammed et al, it was 24.6%.

In dementia caregivers, the severity of burden assessed byZBI was 70.0%, 12.5%, 5% and 12.5% for little or no burden, mild, moderate and severe burden respectively. The severity of burden in ZBI Scale was 32.5%, 20.0%, 27.5% and 20.0% for little or no burden, mild, moderate and severe burden in cancer caregiver respectively. It was found statistically significant in difference among these two groups.

COMPARISON OF DEPRESSION IN CAREGIVERS OF DEMENTIA AND CANCER PATIENTS

Among dementia caregivers, 17.5% were diagnosed with depression using ICD 10 Diagnostic criteria and MADRS Scale and in cancer caregivers, 72.5% were diagnosed with depression. So the difference was statistically significant. The dementia caregiver depression findings were similar to study Lambert et al (17%). The cancer caregivers depression results were similar to the results in studies like Siew Tzuh Tang et al (75.9%) and in Rhee YS et al(67%).

In dementia caregiver, 8.0% had little or No depression, 15% had mild depression, 2.5% had moderate depression and 2.5% had severe depression. In cancer caregivers, it was 27.5%, 30.0%, 12.5% and 30.0% respectively for little or no depression, mild depression, moderate depression and severe depression. The difference between the two groups was statistically significant.

Among caregivers who were having chronic illness, the depression was about 14.3% and in caregivers who were not having chronic illness, it was 19.2%. So the association between chronic illness in caregivers and depression among was not statistically significant.(p=0.695). in cancer caregivers, the depression among caregivers with chronic illness 69.2% and who were not having chronic illness was 30.8%, so the association was not statistically significant.(p=0.748).

The association between age of the caregiver and depression was compared among these two groups were found to be statistically significant.(p=0.014). Because mean age of developing depression among these two groups were having difference of 8 to 9 years.

The association between ZBI burden and depression in both these groups was 39.14±26.25. It was found to be statistically significant. The association between dependence to basic and instrumental activities of daily living in Katz and IADL scale and depression in both these groups was not statistically significant.

SUMMARY

The patients were recruited from the psychiatry, Neuromedicine and Radiotherapy outpatient department at this tertiary care hospital. With consecutive sampling 40 caregivers of patients diagnosed with Dementia according to ICD 10 Criteria and 40 caregivers of patients who were diagnosed with any type of cancer, who were fulfilling study criteria, and consented for participation were included in the study. Sociodemographic data were collected using a self designed pro-forma. The caregiver burden among caregivers of patients with Dementia and Cancer was assessed with Zarit Burden Interview. The dependence of patients to caregivers in both these groups were assessed with Katz Index of Independence and Instrumental Activities of Daily Living scale. The depression among both these groups of caregivers diagnosed using ICD 10 Checklist and it was reassessed using Montgomery Asberg Depression Rating Scale.

In both the groups, Most of the caregivers were more than 40 years of age, female, spouse, married, hinduism, nuclear family, urban, finished middle school and less income.

Similar to this in both these groups, most of the caregivers have no participation of family members in care giving, less chronic illness and less duration of care giving.

Caregiver burden were comparatively double in cancer caregivers than dementia caregivers, but the severity differs in between these two groups of caregivers.

Depression was found to be four times higher among cancer caregivers than dementia caregivers. The severity of depression was also highest in cancer caregivers compared to dementia caregivers.

Depression was higher among 40-60 years in both the group of caregivers. As the age increase above 60 years the depression tends to increase in dementia caregivers. The severity of depression was associated with greater levels of burden to caregivers.

The depression was higher among above 60 years age caregivers in dementia and cancer caregivers. The depression was found to be higher among burdened caregivers in both these groups.

The results in our study gives information about various factors and domains of care giving role and help them to understand the challenges when caring for the patients influencing their quality of life and leads to the caregiver burden. This can help health care professionals to meet the needs of the caregiver in strain.

Psychological interventions are to be given to them to reduce their caregiver burden and depression. Counselling can be provided to dementia caregivers to help them in coping better with the stress of caregiver burden.

It also provides evidences to order to develop public policies and programmes that are targeted to meet the long term needs of dementia and cancer caregivers and prevent the psychological effects. Health care professionals need to exceed the expectations of only saving patients' lives, extending this expectation to saving their caregivers.

CONCLUSION

Dementia and cancer were the two debilitating illness worldwide, but cancer is a terminal illness, both needs long term care, which were having comparable levels of dependence to family members, especially the primary caregivers. The study was aimed at comparing the caregiver burden and depression among caregivers of dementia and cancer patients. Both these groups were comparable in terms of age, gender, education, occupation, relationship to the patient.

Most of the caregivers of cancer patients had caregiver burden, it accounts for twice the times of dementia caregivers. The severity of burden was also high among cancer caregivers than dementia caregivers.

The depression was high among cancer caregivers compared to dementia caregivers. The severity of depression was also found to be higher among cancer caregivers than dementia caregivers.

In both group of caregivers, depression was higher among middle age caregivers and burdened caregivers.

Depression has negative effects on quality of life of caregivers and also patients. So assistance, psycho education and early intervention from health care professionals is the key to improve the quality of life of caregivers and hence the patients’ quality of life.

LIMITATIONS

The caregiver sample were taken only from hospital based patients, so the sample may be an over representation of caregivers than from the general population.

Individual differences in caregivers like their personality, attitudes, cultural believes, and ethnicity were not taken into account.

The sample was of small size, it was chosen only from the hospital, not from the community.

The pre exposure coping strategies and other domains of caregivers were not taken into account.

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SOCIODEMOGRAPHIC DATA

- Patient name:
- Patient's age:
- Patient's sex:
- Caregiver Name:
- Caregiver Age:
- Caregiver sex:
- Religion:
- Education: no education to 4th std, 5th to 8th std, 9th to 12th std, undergraduate, postgraduate/ professional
- Relationship to patient: sibling, spouse, daughter/ son, daughter in law/ son in law, others
- Marital status: single/ married/ separated/ divorced/ widow
- Number of children: ≥ 3, 2, 1, 0
- Participation of other family members in care giving: yes/ no

- Family type: nuclear, joint
- Number of other adult caregivers in the family: yes/ no
- Occupation: yes/ no
- Income of caregiver: <3000, 3001- 5000, 5000- 10,000, >10,000
- Locality: urban/rural
- Caregivers' education: Illiterate/ primary/ secondary/ Higher secondary school/ College- Bachelor/ Masters/ Higher
- Any chronic illness in caregiver: hypertension /diabetes
- Duration of caregiving: <1 year, 1 to 5 year, 5to 10 year, >10 year
- Patient’s diagnosis: dementia/ cancer

The Zarit Burden Interview

0 : NEVER
1 : RARELY
2 : SOMETIMES
3 : QUITE FREQUENTLY
4 : NEARLY ALWAYS

Please circle the response the best describes how you feel.

Question		**Score**
1	Do you feel that your relative asks for more help than he/she needs?	0 1 2 3 4
2	Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0 1 2 3 4
3	Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0 1 2 3 4
4	Do you feel embarrassed over your relative's behaviour?	0 1 2 3 4
5	Do you feel angry when you are around your relative?	0 1 2 3 4
6	Do you feel that your relative currently affects our relationships with other family members or friends in a negative way?	0 1 2 3 4
7	Are you afraid what the future holds for your relative?	0 1 2 3 4
8	Do you feel your relative is dependent on you?	0 1 2 3 4
9	Do you feel strained when you are around your relative?	0 1 2 3 4
10	Do you feel your health has suffered because of your involvement with your relative?	0 1 2 3 4
11	Do you feel that you don't have as much privacy as you would like because of your relative?	0 1 2 3 4
12	Do you feel that your social life has suffered because you are caring for your relative?	0 1 2 3 4

Question	Score
13 Do you feel uncomfortable about having friends over because of your relative?	0 1 2 3 4
14 Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?	0 1 2 3 4
15 Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?	0 1 2 3 4
16 Do you feel that you will be unable to take care of your relative much longer?	0 1 2 3 4
17 Do you feel you have lost control of your life since your relative's illness?	0 1 2 3 4
18 Do you wish you could leave the care of your relative to someone else?	0 1 2 3 4
19 Do you feel uncertain about what to do about your relative?	0 1 2 3 4
20 Do you feel you should be doing more for your relative?	0 1 2 3 4
21 Do you feel you could do a better job in caring for your relative?	0 1 2 3 4
22 Overall, how burdened do you feel in caring for your relative?	0 1 2 3 4

Interpretation of Score:

0 - 21 little or no burden
21 - 40 mild to moderate burden
41 - 60 moderate to severe burden
61 - 88 severe burden

Patient last name: .... Date of birth: ..../..../........
Patient first name: .... Date: ..../..../........

Name:____ Date:________________________

Montgomery-Asberg Depression Scale (MADRS)

Instructions: The ratings should be based on a clinical interview moving from broadly phrased questions about symptoms to more detailed ones which allow a precise rating of severity. The rater must decide whether the rating lies on the defined scale steps (0, 2, 4, 6) or between them (1, 3, 5). It is important to remember that it is only rare occasions that a depressed patient is encountered who cannot be rated on the items in the scale. If definite answers cannot be elicited from the patients, all relevant clues as well as information from other sources should be used as a basis for the rating in line with customary clinical practice. This scale may be used for any time interval between ratings, be it weekly or otherwise, but this must be recorded.

1. ***Apparent Sadness***

Representing despondency, gloom and despair, (more than just ordinary transient low spirits) reflected in speech, facial expression, and posture. Rate on depth and inability to brighten up.

0 No sadness
1
2 Looks dispirited but does brighten up without difficulty.
3
4 Appears sad and unhappy most of the time.
5
6 Looks miserable all the time. Extremely despondent.

2. ***Reported Sadness***

Representing reports of depressed mood, regardless of whether it is reflected in appearance or not. Includes low spirits, despondency or feeling of being beyond help without hope. Rate according to intensity, duration and the extent to which the mood is reported to be influenced by events.

0 Occasional sadness in keeping with the circumstances.
1
2 Sad or low but brightens up without difficulty.
3
4 Pervasive feelings of sadness or gloominess. The mood is still influenced by external circumstances.
5
6 Continuous or unvarying sadness, misery or despondency.

3. ***Inner Tension***

Representing feelings of ill-defined discomfort, edginess, inner turmoil mounting to either panic, dread or anguish. Rate according to intensity, frequency, duration and the extent of reassurance called for.

0 Placid. Only reflecting inner tension.
1
2 Occasional feelings of edginess and ill-defined discomfort.
3
4 Continuous feelings of inner tension or intermittent panic which the patient can only master with some difficulty.
5
6 Unrelenting dread or anguish. Overwhelming panic.

4. ***Reduced Sleep***

Representing the experience of reduced duration or depth of sleep compared to the subject's own normal pattern when well.

0 Sleeps as usual.
1
2 Slight difficulty dropping off to sleep or slightly reduced light or fitful sleep.
3
4 Sleep reduced or broken by at least two hours.
5
6 Less than two or three hours sleep.

5. ***Reduced Appetite***

Representing the feeling of loss of appetite compared with when well. Rate by loss of desire for food or the need to force oneself to eat.

0 Normal or increased appetite.
1
2 Slightly reduced appetite.
3
4 No appetite. Food is tasteless.
5
6 Needs persuasion to eat.

6. ***Concentration Difficulties***

Representing difficulties in collecting one's thoughts mounting to incapacitating lack of concentration. Rate according to intensity, frequency, and degree of incapacity produced.

0 No difficulties in concentrating.
1
2 Occasional difficulties in collecting one's thoughts.
3
4 Difficulties in concentrating and sustaining thought which reduces ability to read or hold a conversation.
5
6 Unable to read or converse without great initiative.

7. ***Lassitude***

Representing a difficulty getting started or slowness initiating and performing everyday activities.

0 Hardly no difficulty in getting started. No sluggishness.
1
2 Difficulties in starting activities.
3
4 Difficulties in starting simple routine activities which are carried out with effort.
5
6 Complete lassitude. Unable to do anything without help.

8. ***Inability to Feel***

Representing the subjective experience of reduced interest in the surroundings, or activities that normally give pleasure. The ability to react with adequate emotion to circumstances or people is reduced.

0 Normal interest in the surroundings and in other people.
1
2 Reduced ability to enjoy usual interest.
3
4 Loss of interest in surroundings. Loss of feelings for friends and acquaintances.
5
6 The experience of being emotionally paralyzed, inability to feel anger, grief or pleasure and a complete or even painful failure to feel for close relatives and friends.

9. ***Pessimistic Thoughts***

Representing thoughts of guilt. Inferiority, self-reproach, sinfulness, remorse and ruin.

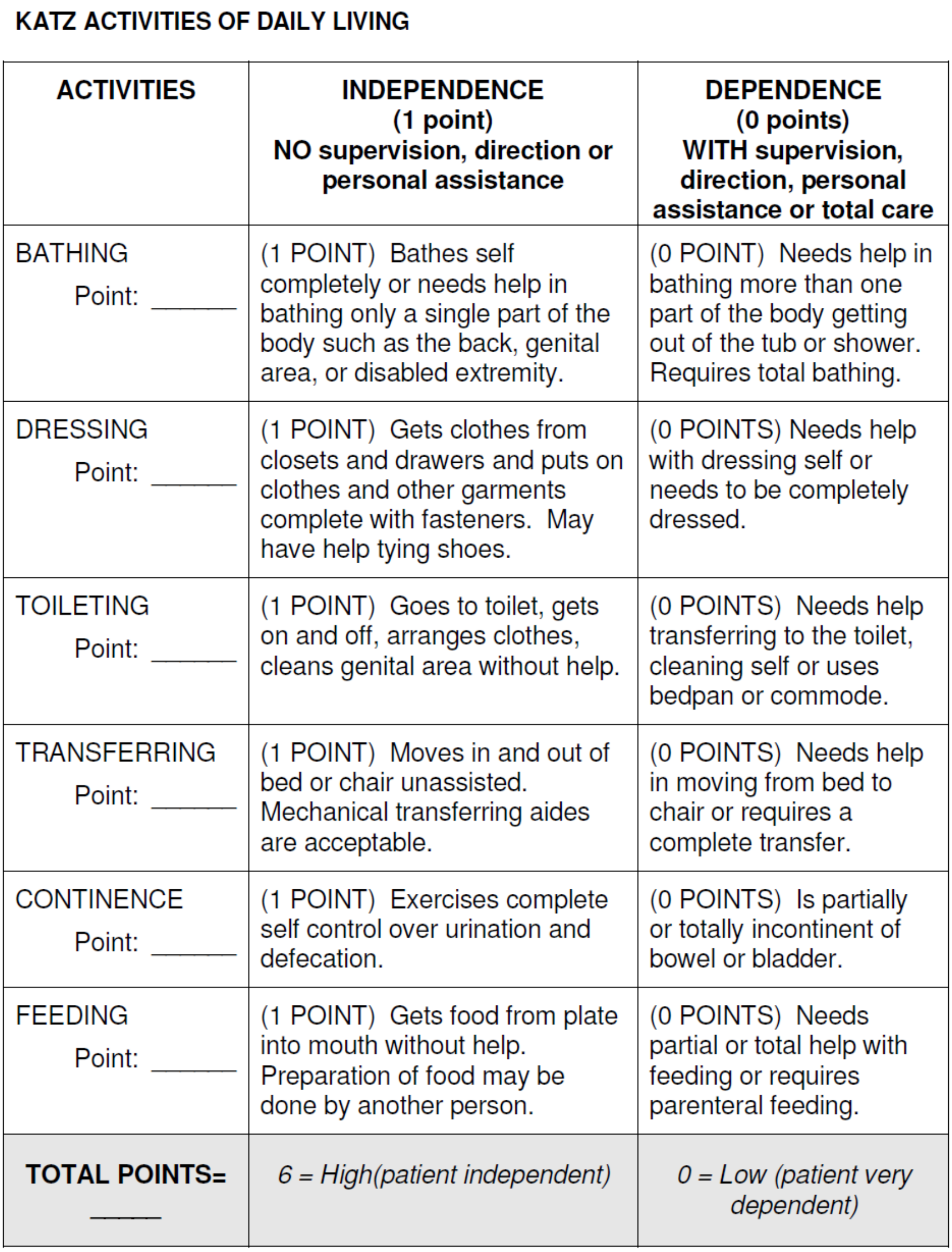
0 No pessimistic thoughts.
1
2 Fluctuating ideas of failure, self-reproach or self-depreciation.
3
4 Persistent self-accusations, or definite but still rational ideas of guilt or sin. Increasingly pessimistic about the future.
5
6 Delusions of ruin, remorse or unredeemable sin. Self-accusations which are absurd and unshakable.

10. ***Suicidal Thoughts***

Representing the feeling that life is not worth living, that a natural death would be welcome, suicidal thoughts, and the preparations for suicide. Suicidal attempts should not in themselves influence the rating.

0 Enjoys life or takes it as it comes.
1
2 Weary of life. Only fleeting suicidal thoughts.
3
4 Probably better off dead. Suicidal thoughts are common, and suicide is considered as a possible solution, but without specific plans or intention.
5
6 Explicit plans for suicide when there is an opportunity. Active preparations for suicide.

Total Score:________________



KATZ ACTIVITIES OF DAILY LIVING

ACTIVITIES	INDEPENDENCE (1 point) NO supervision, direction or personal assistance	DEPENDENCE (0 points) WITH supervision, direction, personal assistance or total care
BATHING Point: ______	(1 POINT) Bathes self completely or needs help in bathing only a single part of the body such as the back, genital area, or disabled extremity.	(0 POINT) Needs help in bathing more than one part of the body getting out of the tub or shower. Requires total bathing.
DRESSING Point: ______	(1 POINT) Gets clothes from closets and drawers and puts on clothes and other garments complete with fasteners. May have help tying shoes.	(0 POINTS) Needs help with dressing self or needs to be completely dressed.
TOILETING Point: ______	(1 POINT) Goes to toilet, gets on and off, arranges clothes, cleans genital area without help.	(0 POINTS) Needs help transferring to the toilet, cleaning self or uses bedpan or commode.
TRANSFERRING Point: ______	(1 POINT) Moves in and out of bed or chair unassisted. Mechanical transferring aides are acceptable.	(0 POINTS) Needs help in moving from bed to chair or requires a complete transfer.
CONTINENCE Point: ______	(1 POINT) Exercises complete self control over urination and defecation.	(0 POINTS) Is partially or totally incontinent of bowel or bladder.
FEEDING Point: ______	(1 POINT) Gets food from plate into mouth without help. Preparation of food may be done by another person.	(0 POINTS) Needs partial or total help with feeding or requires parenteral feeding.
TOTAL POINTS= _____	*6 = High(patient independent)*	*0 = Low (patient very dependent)*

Instrumental Activities of Daily Living (IADL)

INSTRUCTIONS: Ask the patient to describe her / his functioning in each category; then complement the description with specific questions as needed.

Ability to Telephone

1. Operates telephone on own initiative: looks up and dials number, etc.
2. Answers telephone and dials a few well-known numbers.
3. Answers telephone but does not dial.
4. Does not use telephone at all.

Shopping

1. Takes care of all shopping needs independently.
2. Shops independently for small purchases.
3. Needs to be accompanied on any shopping trip.
4. Completely unable to shop.

Food Preparation

1. Plans, prepares, and serves adequate meals independently.
2. Prepares adequate meals if supplied with ingredients.
3. Heats and serves prepared meals, or prepares meals but does not maintain adequate diet.
4. Needs to have meals prepared and served.

Housekeeping

1. Maintains house alone or with occasional assistance (e.g. heavy work done by domestic help).
2. Performs light daily tasks such as dishwashing and bed making.
3. Performs light daily tasks but cannot maintain acceptable level of cleanliness.
4. Needs help with all home maintenance tasks.
5. Does not participate in any housekeeping tasks.

Laundry

1. Does personal laundry completely
2. Launders small items; rinses socks, stockings, and so on.
3. All laundry must be done by others.

Mode of Transportation

1. Travels independently on public transportation, or drives own car.
2. Arranges own travel via taxi, but does not otherwise use public transportation.
3. Travels on public transportation when assisted or accompanied by another
4. Travel limited to taxi, automobile, or ambulette, with assistance.
5. Does not travel at all.

Responsibility for Own Medication

1. Is responsible for taking medication in correct dosages at correct time.
2. Takes responsibility if medication is prepared in advance, in separated dosages.
3. Is not capable of dispensing own medication.

Ability to Handle Finances

1. Manages financial matters independently (budgets, writes checks, pays rent and bills, goes to bank); collects and keeps track of income.
2. Manages day-to-day purchases but need help with banking, major purchases, controlled spending, and so on.
3. Incapable of handling money.

Scoring: Circle one number for each domain. Total the numbers circled. The lower the score, the more independent the older adult is. Scores are only good for individual patients. It is useful to see the score comparison over time.

ICD 10 CHECKLIST

No	Symptoms	Present/Absent
1	Low mood	
2	Loss of interest and enjoyment	
3	Reduced energy	
4	Reduced attention and concentration	
5	Reduced self esteem and self confidence	
6	Ideas of guilt and unworthiness	
7	Bleak and pessimistic views of future	
8	Ideas or acts of self harm or suicide	
9	Disturbed sleep	
10	Diminished appetite	
	Somatic Syndrome	
1	Anhedonia	
2	Lack of emotional reactivity	
3	Terminal insomnia	
4	Diurnal variation	

5	Psychomotor retardation or agitation	
6	Marked loss of appetite	
7	Loss of weight	
8	Marked loss of libido	
	Psychotic Symptoms	

Key to master chart

1. Patient sex :

Male - 0
Female – 1

2. Caregiver sex

Male - 0
Female - 1

3. Religion

Hindu – 1

Islam – 2

Christian - 3

Others - 4

4. Educational status :

No education to fourth standard	– 0
Fifth to eighth standard	- 1
Ninth to twelveth standard	- 2
Undergraduate	- 3
Postgraduate/Professional	- 4

5. Employment Status :

Not employed - 0
Employed - 1

6. Marital status :

Married - 0

Unmarried – 1
Divorced - 2
Widowed - 3

7. Number of children :

More than or equal to three children	- 1
Two children	- 2
One child	- 3
No child	

8. Net monthly income in rupees

Less than 3000- 1
3000-5000- 2
5000-10,000- 3
More than 10,000- 4

9.Relationship to patient

Sibling- 0
Spouse- 1
Daughter/ son- 2
Daughter/ son in law- 3
Others-4

10.Family type

Nuclear- 0

Joint- 1

11.Locality

Rural-1

urban-2

12. Duration of caregiving

More than 10 years- 1
5-10 years- 2
1-5 years- 3
Less than 1 year- 4

13.Participation of other family members in caregiving

No- 0

Yes-1

14.Any chronic illness
No- 1
Yes-1

15.Degree of burden
Little or no burden-0
Mild to moderate burden- 1
Moderate- severe burden- 2
Severe- very severe burden-3

16.ICD-10 Diagnosis of Depression

No Depression- 0

Depression present- 1

17. Caregiver burden present

No- 0
Yes-1

18. Depression present in MADRS

No-0
Yes-1

19. Severity of Depression in MADRS

No depression -0

Mild depression-1

Moderate depression-2

Severe depression – 3

20.Katz ADL Independence

Severe functional impairment- 0

Moderate impairment- 1

Fully functional- 2

21. IADL Independence

Dependent- 0

Independent-1

22. patient’s diagnosis

Dementia-1

Cancer-2

சுய ஒப்புதல் படிவம்

ஆய்வு செய்யப்படும் தலைப்பு

மறதி நோயாளிகள் மற்றும் புற்று நோயாளிகள் ஆகியோரின் நோயாளிகள் பராமரிப்போரின் உணர்- குடும்பச் சுமை, வாழ்க்கைத் தரம், மற்றும் மனநலப் பாதிப்புகள் பற்றிய ஓர் ஒப்பீட்டுப்-பகுப்பாய்வு.

ஆராய்ச்சி நிலையம் : மனநலப்புறநோயாளிகள் பிரிவு,
நரம்பியல் புறநோயாளிகள் பிரிவு,
கதிரியக்கச் சிகிச்சை புறநோயாளிகள் பிரிவு,
அரசு ஸ்டான்லி மருத்துவமனை,
சென்னை - 600 001.

பங்கு பெறும் நோயாளியின் பெயர் :

பங்கு பெறுபவரின் எண் :

நோயாளி / உறவினர் இதனை (✓) குறிக்கவும்

மேலே குறிப்பிட்டுள்ள மருத்துவ ஆய்வின் விவரங்கள் எனக்கு விளக்கப்பட்டது. என்னுடைய சந்தேகங்களை கேட்கவும் அதற்கான தகுந்த விளக்கங்களை பெறவும் வாய்ப்பளிக்கப்பட்டது. ☐

நான் / என் உறவினர் இவ்வாய்வில் தன்னிச்சையாக தான் பங்கேற்கிறேன். எந்த காரணத்தினாலும் எந்த கட்டத்திலும் எந்த சட்டச்சிக்கலுக்கும் உட்படாமல் நான் / என் உறவினர் இவ்வாய்வில் இருந்து விலகிக் கொள்ளலாம் என்று அறிந்து கொள்கிறேன். ☐

இந்த ஆய்வு சம்பந்தமாகவும், இதை சார்ந்த ஆய்வு மேலும் ஆய்வு மேற்கொள்ளும் போதும், இந்த ஆய்வில் பங்குபெறும் மருத்துவர் என்னுடைய மருத்துவ அறிக்கைகளைப் பார்ப்பதற்கு என் அனுமதி தேவையில்லை என அறிந்து கொள்கிறேன் நான் / என் உறவினர் ஆய்வில் விலக்கிக் கொண்டாலும் இது பொருந்தும் என அறிகிறேன். ☐

இந்த ஆய்வின் மூலம் கிடைக்கும் தகவல்களையும் பரிசோதனை முடிவுகளையும் மற்றும் சிகிச்சை தொடர்பான தகவல்களையும் மருத்துவர் மேற்கொள்ளும் ஆய்வில் பயன்படுத்திக் கொள்ளவும் ☐

அதை பிரசுரிக்கவும் / பதிப்பிக்கவும் என் முழு மனதுடன் சம்மதிக்கிறேன்.

இந்த ஆய்வில் பங்கு கொள்ள ஒப்புக் கொள்கிறேன். எனக்கு கொடுக்கப்பட்ட அறிவுரைகளின்படி நடத்து கொள்வதுடன் இந்த ஆய்வை மேற்கொள்ளும் மருத்துவ அணிக்கு உண்மையுடன் இருப்பேன் என்றும் உறுதி அளிக்கிறேன். என் உடல் நலம் பாதிக்கப்பட்டாலோ அல்லது எதிர்பாராத வழக்கத்திற்கு மாறான நோய் குறி தென்பட்டாலோ, உடனே அதனை மருத்துவ அணிக்கு தெரிவிப்பேன் என உறுதி அளிக்கிறேன். ☐

இந்த ஆய்வில் எனக்கு இரத்தம், சிறுநீர், எக்ஸ்ரே, ஸ்கேன், இ.இ.ஜி உட்பட அனைத்து பரிசோதனைகளையும் தேவையான பொழுது செய்து கொள்ள நான் முழு மனதுடன் சம்மதிக்கிறேன். ☐

நோயாளியின் / பராமரிப்போரின் கையொப்பம்

.... இடம் .... தேதி ....

கட்டை விரல் ரேகை –

பங்கேற்பவரின் காப்பாளரின் கையொப்பம்

.... இடம் .... தேதி ....

கட்டை விரல் ரேகை–

பங்கேற்பவரின் பெயர் மற்றும் விலாசம்

....

....

....

ஆய்வாளரின் கையொப்பம்

.... இடம் .... தேதி ....

ஆய்வாளரின் பெயர் ....

நோயாளியின் பெயர் ....

பாலினம் : ஆண்.......... பெண் ....

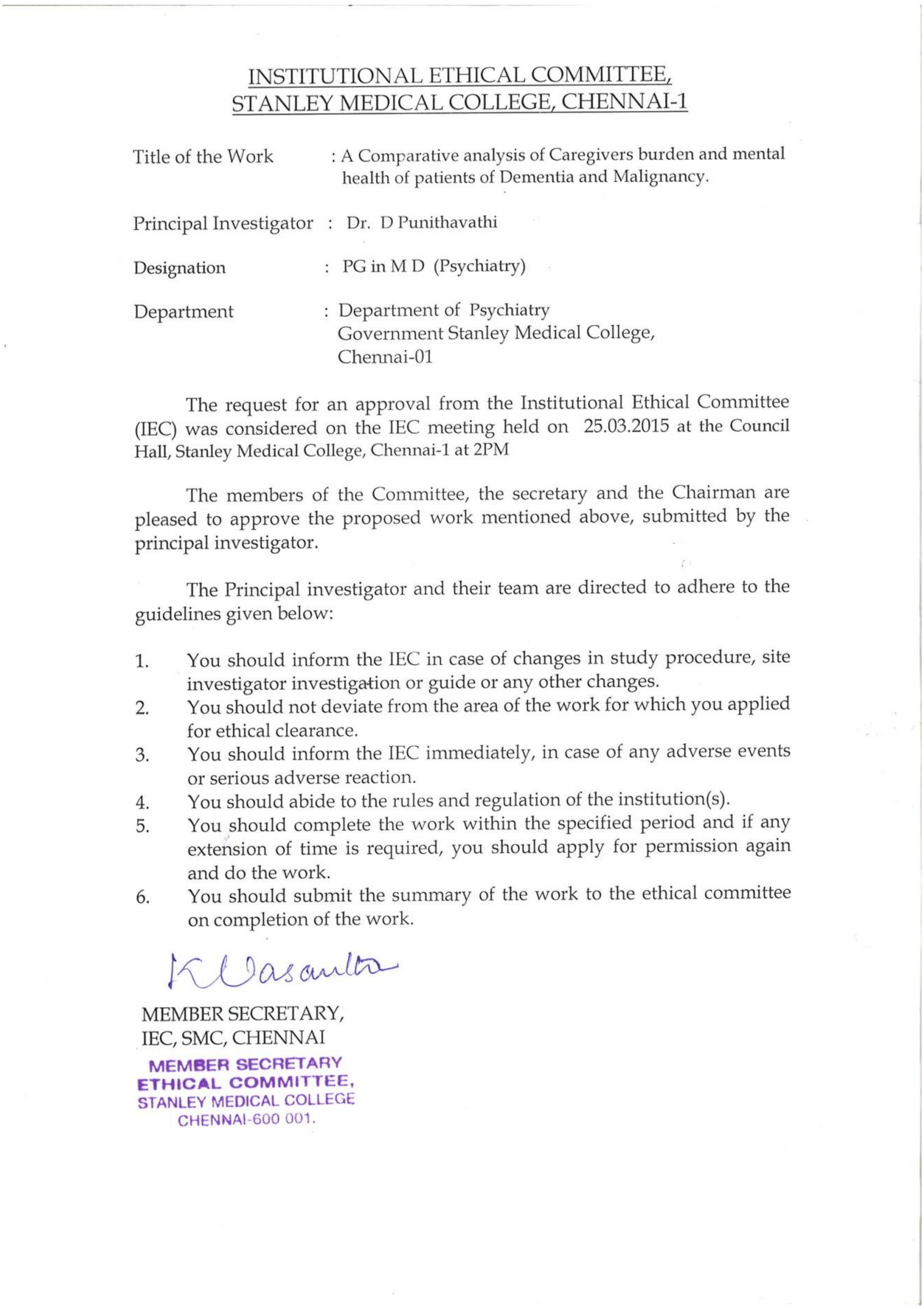
வயது .... ஆண்டுகள் அல்லது பிறந்த தேதி ....

நோயாளி / பராமரிப்போர் தொடர்பு கொள்ளும் முகவரி

....

4	இந்த ஆய்வின் மூலம் கிடைக்கப்பெறும் குறிப்புகளையும் தகவல்களையும் மற்றும் பரிசோதனை முடிவுகளையும், உபயோகப்படுத்த தடை செய்ய மாட்டேன் என சம்மதிக்கிறேன். அதனால் அவைகள் விஞ்ஞானம், ஆராய்ச்சிக் கட்டுரைகள் போன்ற சம்மந்தப்பட்டவைகளுக்கு பயன் உள்ளதாக இருக்க வேண்டும். இக்குறிப்புகள், அதன் விளக்கங்கள், ஆய்வுக் கட்டுரைகள் ஆகியவற்றை பிரசுரிக்கவும் / பதிப்பிக்கவும் என் முழு மனதுடன் சம்மதிக்கிறேன்.	
5	மேற்கூறிய ஆய்வில் என் சுய விருப்பத்தின்படி பங்கு கொள்ள நான் சம்மதிக்கிறேன்.	

ஆய்வில் பங்கேற்பவர் /
சட்டபூர்வமாக
ஏற்கப்பட்ட நபர் கையொப்பம்
அல்லது பெரு விரல் பதிவு



INSTITUTIONAL ETHICAL COMMITTEE, STANLEY MEDICAL COLLEGE, CHENNAI-1

Title of the Work : A Comparative analysis of Caregivers burden and mental health of patients of Dementia and Malignancy.

Principal Investigator : Dr. D Punithavathi

Designation : PG in M D (Psychiatry)

Department : Department of Psychiatry
Government Stanley Medical College,
Chennai-01

The request for an approval from the Institutional Ethical Committee (IEC) was considered on the IEC meeting held on 25.03.2015 at the Council Hall, Stanley Medical College, Chennai-1 at 2PM

The members of the Committee, the secretary and the Chairman are pleased to approve the proposed work mentioned above, submitted by the principal investigator.

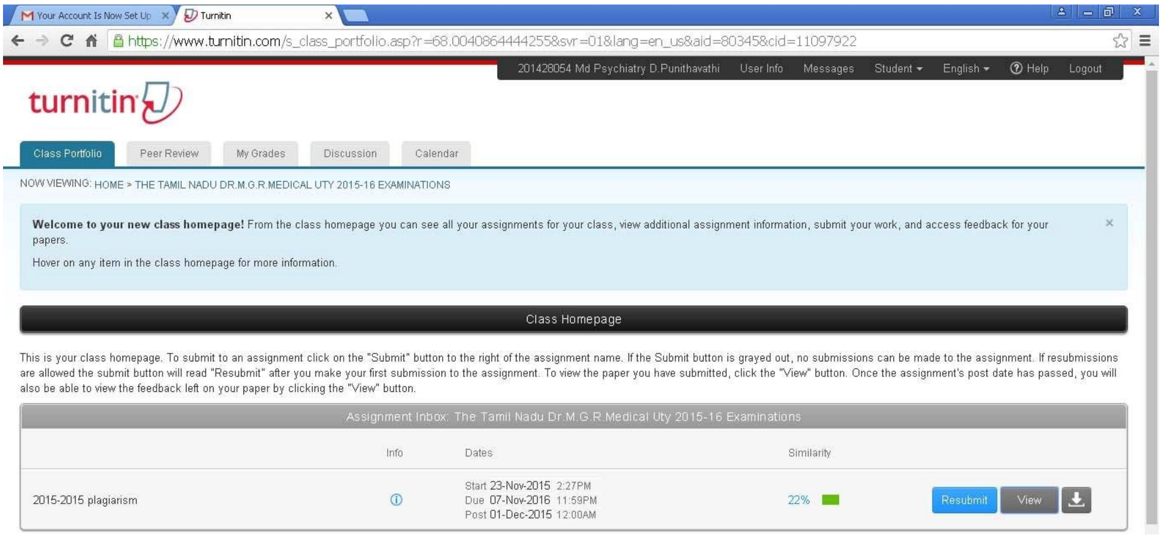
The Principal investigator and their team are directed to adhere to the guidelines given below:

1. You should inform the IEC in case of changes in study procedure, site investigator investigation or guide or any other changes.
2. You should not deviate from the area of the work for which you applied for ethical clearance.
3. You should inform the IEC immediately, in case of any adverse events or serious adverse reaction.
4. You should abide to the rules and regulation of the institution(s).
5. You should complete the work within the specified period and if any extension of time is required, you should apply for permission again and do the work.
6. You should submit the summary of the work to the ethical committee on completion of the work.

K Vasantha

MEMBER SECRETARY,
IEC, SMC, CHENNAI

MEMBER SECRETARY
ETHICAL COMMITTEE,
STANLEY MEDICAL COLLEGE
CHENNAI-600 001.



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BY 201428054 MD PSYCHIATRY D.PUNITHAVATHI

A COMPARATIVE ANALYSIS OF CAREGIVERS' BURDEN AND MENTAL HEALTH OF PATIENTS WITH DEMENTIA AND MALIGNANCY

INTRODUCTION

Population ageing is an upcoming public health challenge,

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Unique key	Patient age	Patient sex	Caregiver age	Caregiver sex	Religion	Education status	Employment status	Marital status	No. Of children	Net monthly income	Relationship to patient	Family type	Locality	Duration of caregiving	Participation of other family members in caregiving	Any chronic illness	ZBI SCORE	Degree of burden	ICD-10 Diagnosis	MADRS score	Caregiver burden present	Depression present	Severity of depression	Patient's diagnosis	Katz ADL score	IADL score	Katz independence	IADL independence
1	68	1	26	1	3	3	0	0	2	4	3	0	2	4	0	0	26	1	0	4	1	0	0	1	6	2	1	0
2	74	0	65	1	1	0	0	0	1	1	1	0	1	4	0	1	18	0	0	2	0	0	0	1	6	4	1	0
3	62	0	53	1	1	1	0	0	2	3	1	1	2	3	1	0	8	0	0	4	0	0	0	1	6	5	1	1
4	54	0	48	1	2	1	1	0	2	1	1	0	2	3	1	0	43	2	1	11	1	1	1	1	2	3	0	0
5	59	0	51	1	1	0	0	0	1	2	1	0	1	3	0	1	8	0	1	9	0	1	1	1	6	3	1	0
6	74	0	65	1	1	0	0	0	1	1	1	0	1	4	0	0	13	0	0	4	0	0	0	1	6	4	0	1
7	63	1	70	0	1	1	0	0	2	1	1	1	1	4	1	1	19	0	0	2	0	0	0	1	5	5	0	0
8	52	0	42	1	3	2	1	0	2	3	1	0	2	3	0	0	65	3	1	18	1	1	1	1	5	0	1	1
9	82	0	53	0	1	3	1	0	2	3	2	0	2	4	0	0	8	0	0	0	0	0	0	1	6	4	1	0
10	62	0	55	1	1	0	0	0	1	1	1	0	1	4	0	0	14	0	0	4	0	0	0	1	6	5	0	0
11	67	0	63	1	1	1	1	0	1	0	1	0	2	3	0	1	24	1	0	1	1	0	0	1	6	5	1	1
12	66	1	40	1	1	2	0	0	2	2	3	0	2	4	0	0	9	0	0	2	0	0	0	1	3	4	0	0
13	79	0	65	1	1	0	0	0	1	0	1	0	1	4	0	0	16	0	0	0	0	0	0	1	5	3	1	0
14	76	0	60	1	1	1	0	0	1	3	1	1	2	3	0	1	61	3	2	31	1	1	2	1	2	1	0	0
15	69	0	42	1	1	1	0	0	1	2	3	0	2	3	1	0	6	0	0	2	0	0	0	1	5	3	2	0
16	77	1	36	1	1	1	0	0	2	2	2	0	1	3	1	0	13	0	0	4	0	0	0	1	6	5	1	0
17	80	1	57	1	1	1	0	0	1	2	2	0	2	4	0	0	8	0	0	2	0	0	0	1	6	6	1	0
18	67	1	75	0	1	0	1	0	1	1	1	2	1	4	1	0	14	0	0	4	0	0	0	1	6	6	1	0
19	72	0	36	1	1	2	0	0	2	1	3	0	2	4	0	0	17	0	0	2	0	0	0	1	4	4	1	0
20	58	0	45	1	3	1	0	0	1	1	0	1	2	4	0	0	6	0	1	15	0	1	1	1	4	1	1	**0**
21	88	1	56	1	1	2	1	3	4	2	2	0	2	3	0	1	20	0	0	3	0	0	0	1	6	4	1	0
22	72	0	62	1	1	0	0	0	1	1	1	0	1	4	0	0	12	0	0	4	0	0	0	1	6	4	1	0
23	69	1	40	1	1	2	1	0	2	2	3	0	1	3	0	0	9	0	0	2	0	0	0	1	6	5	1	0
24	72	0	37	1	1	1	0	0	2	2	3	0	2	4	0	0	6	0	0	6	0	0	0	1	6	3	1	0
25	67	0	53	1	2	0	0	0	1	1	1	1	2	3	1	0	18	0	0	2	0	0	0	1	3	4	1	0
26	50	0	41	1	1	1	1	0	2	1	1	0	2	2	0	0	67	3	1	36	1	1	3	1	1	0	0	0
27	82	1	56	1	1	1	0	0	2	3	2	0	2	3	0	1	36	1	0	4	1	0	0	1	5	3	2	0
28	62	1	22	1	1	1	1	0	2	1	3	1	1	4	1	0	9	0	0	2	0	0	0	1	6	4	1	0
29	70	0	61	1	1	0	0	0	2	2	1	0	2	3	0	1	24	1	0	4	1	0	1	1	4	4	0	0
30	67	1	72	0	1	1	1	0	3	2	1	0	2	4	0	0	17	0	0	0	0	0	0	1	5	3	2	0
31	59	1	72	1	1	0	1	3	3	1	4	0	1	3	0	1	56	2	1	4	1	0	0	1	3	2	0	0
32	82	0	67	1	1	0	1	0	2	0	1	0	1	2	0	1	62	3	0	2	1	0	0	1	2	2	0	0
33	67	0	45	1	1	2	1	2	1	2	2	0	2	3	1	0	24	1	0	7	1	1	1	1	3	2	0	0
34	62	1	70	0	1	2	1	0	3	3	1	0	2	2	1	1	68	3	0	4	3	0	0	1	2	4	0	0
35	65	1	40	1	3	1	0	0	2	4	3	1	2	4	0	0	11	0	0	2	0	0	0	1	5	3	0	0
36	64	0	56	1	3	1	0	0	2	3	1	0	2	4	0	1	5	0	0	0	0	0	0	1	6	5	2	1
37	85	0	72	1	3	0	0	0	1	2	1	1	1	4	1	1	6	0	0	0	0	0	0	1	4	3	1	0
38	78	1	45	1	2	2	0	0	1	4	2	0	2	4	0	1	18	0	0	4	0	0	0	1	6	5	1	0
39	75	1	71	1	1	0	0	2	4	0	0	0	1	3	1	0	4	0	0	0	0	0	0	1	5	5	2	0
40	74	1	45	1	2	2	0	0	1	3	2	0	2	4	1	0	12	0	0	4	0	0	0	1	6	4	1	0

Unique key	Patient age	patient sex	Caregiver age	Caregiver sex	Religion	Educational status	Employment status of caregiver	Marital status	No. Of children	Relationship to patient	Family type	Locality	Duration of caregivig years	Participation of other family members in caregiving	Any chronic illness	ZBI Score	Degree of burden	ICD-10 Diagnosis checklist for depression	MADRS	Caregiver burden present	Depression present	Severity of depression	Net annual family income	Patient's diagnosis	Katz ADL score	IADL score	Katz independence levl	IADL independence level	
1	52	0	45	1	1	1	1	0	2	1	1	2	3	0	1	67	3	1	46	1	1	3	3	2	5	0	0	0	
2	59	1	23	1	1	3	0	1	0	2	0	2	3	0	0	38	1	1	8	1	1	1	2	2	4	6	1	0	
3	68	0	55	1	1	1	1	0	1	1	0	2	3	0	0	10	0	0	5	0	0	0	1	2	6	5	0	0	
4	55	0	45	1	1	0	1	0	1	1	1	1	3	0	0	64	3	1	19	1	1	1	1	2	2	4	0	0	
5	38	0	29	1	1	1	0	0	2	1	0	1	4	0	0	53	2	1	32	1	1	2	2	2	2	3	0	0	
6	28	1	50	1	1	0	0	0	3	4	0	2	4	0	1	53	2	1	36	1	1	3	3	2	0	2	0	0	
7	76	0	65	1	1	0	0	0	1	1	1	2	2	0	1	35	3	0	8	1	1	1	2	2	6	4	1	0	
8	65	0	58	1	1	0	1	0	2	1	0	2	3	0	1	13	0	0	0	0	0	0	3	2	4	4	1	0	
9	40	1	65	1	1	0	1	3	3	4	0	1	4	0	0	26	1	1	8	1	1	1	1	2	4	5	1	0	
10	58	0	57	1	3	0	0	0	3	1	0	1	4	0	0	21	1	0	2	0	0	0	2	2	5	5	2	1	
11	66	0	60	1	1	0	0	0	3	1	0	2	4	0	0	54	2	1	18	1	1	1	4	2	2	2	0	0	
12	48	0	35	1	1	0	1	0	3	1	1	1	4	1	0	68	3	1	26	1	1	2	1	2	1	1	0	0	
13	49	1	24	1	3	2	1	1	4	2	0	2	4	0	0	9	0	0	4	0	0	0	2	2	6	5	1	0	
14	58	0	53	1	1	1	1	0	2	1	1	2	4	1	1	46	2	1	12	1	1	1	1	2	6	0	1	0	
15	57	1	32	1	1	1	1	1	4	2	0	1	4	0	0	47	2	0	6	1	0	0	3	2	2	2	0	0	
16	59	0	45	1	1	1	1	0	3	1	0	1	4	0	0	67	3	1	37	1	1	3	4	2	2	2	0	0	
17	40	0	35	1	1	0	0	0	1	1	0	1	4	0	0	34	1	1	20	1	1	2	1	2	0	2	0	0	
18	56	0	48	1	1	0	1	0	2	1	1	2	4	0	1	58	2	1	32	1	1	2	3	2	5	1	2	0	
19	32	0	47	1	1	1	0	0	2	4	1	2	4	0	0	19	0	1	40	0	1	3	3	2	5	2	2	0	
20	38	1	40	0	1	1	1	0	2	1	0	1	3	0	0	12	0	0	0	0	0	0	2	2	6	8	1	1	
21	56	0	54	1	2	1	0	0	2	1	1	2	4	1	1	33	1	0	6	1	0	0	4	2	5	3	2	0	
22	55	0	45	1	1	0	1	0	1	1	1	2	3	0	1	60	2	1	18	1	1	1	2	2	3	3	1	0	
23	35	0	29	1	1	2	1	0	2	1	0	2	4	0	0	13	0	1	37	0	1	3	1	2	2	4	0	0	
24	45	0	65	1	3	0	0	3	0	4	0	1	3	0	0	55	2	1	42	1	1	3	0	2	3	5	1	1	
25	57	1	36	1	1	2	0	0	2	3	0	2	3	0	0	10	0	1	9	0	1	1	0	2	6	3	2	0	
26	62	0	52	1	2	0	0	0	2	1	1	2	3	1	1	45	2	1	37	1	1	3	0	2	4	6	1	0	
27	52	0	40	1	1	1	1	0	0	2	0	1	4	0	0	23	1	1	58	1	1	3	2	2	1	4	0	0	
28	39	0	35	1	3	3	1	0	2	1	0	2	4	0	0	61	3	1	45	1	1	3	2	2	1	3	0	0	
29	68	1	40	1	1	1	1	0	1	2	0	1	3	0	0	13	0	1	16	0	1	1	3	2	4	5	1	1	
30	48	1	22	1	2	2	1	1	0	2	0	1	4	0	0	20	0	0	3	0	0	0	2	2	3	5	1	0	
31	54	0	45	1	1	0	1	0	2	1	0	1	3	0	0	45	2	1	35	1	1	3	3	2	4	7	1	0	
32	32	0	22	1	1	2	1	0	2	1	0	2	4	0	0	44	2	1	41	1	1	3	3	2	2	3	0	0	
33	75	0	69	1	1	0	0	0	2	1	0	1	2	0	1	15	0	1	5	0	0	0	0	2	3	4	1	0	
34	55	0	50	1	1	0	1	0	2	1	0	1	4	0	0	25	1	1	8	1	1	1	1	2	6	5	2	1	
35	57	1	55	1	1	0	1	3	1	0	0	2	3	0	1	12	0	0	2	0	0	0	2	2	0	6	0	0	
36	51	1	60	0	1	0	0	0	2	1	0	2	4	0	0	9	0	0	0	0	0	0	0	2	2	4	0	0	
37	59	0	53	1	1	1	1	0	3	1	1	2	4	0	1	65	3	1	19	1	1	1	2	2	4	4	1	0	
38	58	0	55	1	1	1	1	0	3	1	0	2	3	0	1	22	1	1	8	1	1	1	1	2	6	3	2	0	
39	52	0	47	1	1	1	1	0	2	1	1	2	4	0	0	18	0	1	36	0	1	3	1	2	1	3	0	0	
40	60	0	51	1	2	1	0	0	3	1	0	2	4	0	0	62	3	1	31	1	1	2	2	2	4	4	1	0	