

RESEARCH ARTICLE

## Caregiving Burdens among Family Caregivers of Cancer Patients Undergoing Chemotherapy at Hiwa Cancer Hospital in Sulaimani - Iraq

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### ABSTRACT

**Background:** Caring for a patient informally during chemotherapy can cause a variety of burdens upon the caregiver, who may be a family member, a relative, or a friend of the patient.

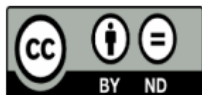
**Aim:** The aim of the study was to assess caregivers' burdens of cancer patients undergoing chemotherapy.

**Methodology:** One hundred ninety-eight dyads of informal caregivers and cancer patients undergoing chemotherapy were recruited for the current descriptive study at Hiwa Cancer Hospital. Non-probability convenience sample technique was used to select the sample. The data were collected through a direct interview by a questionnaire that included caregivers' and patients' characteristics and the caregiving burden was assessed by Caregiver Burdens Inventory, Caregiver Distress Index, and Caregiver Strain Index. Statistic Package of Social Science 25 software was used for statistical analysis.

**Results:** The score of the Zarit Burden Interview was  $49.1 \pm 14.9$ , and the caregivers' burden was moderate for 45.5% and severe for almost 29%. The score of strain index for nearly 30% was  $\geq 7$  which indicate high caregiving strain and overall caregiver distress was moderate Median (Interquartile range) 32(11). There was strong positive correlation among study dependent variables  $p < 0.01$ .

**Conclusions & Recommendation:** Overall caregivers' burden was moderate and the domain of caregiving burdens correlated to each other. It seems reasonable that the nurse takes more effort to relieve caregivers' burden and adopt early interventions to deal with their emotional problems.

**Keywords:** Caregiver, Burden, Chemotherapy.



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## INTRODUCTION

Cancer is a complex disease defined by the uncontrolled growth of abnormal cells due to genetic changes. Despite intensive investigations by both clinicians and scientists in trying to determine its underlying causes and eliminate them, cancer is still one of the most common and deadly chronic conditions affecting the world's population (Lee et al., 2021). According to Global Cancer (GLOBOCON 2020), an estimated 19.3 million new cancer cases and almost 10.0 million cancer deaths in 2020 worldwide, and the cancer burden will increase by 64.7% from 2020 to 2040 (Sung et al 2021). Evidence predicts that the incidence of cancer will increase to 22.2 million by 2030 (Li et al, 2020).

It is well recognized that cancer disrupts not only patients' but also family members' everyday life routines. When a person is diagnosed with cancer, a family member usually becomes a primary caregiver involving many aspects of care, including dealing with the diagnosis of cancer and treatment decisions, assisting in daily living activities, managing treatment-related adverse effects, and coping with negative emotional feelings (Liu et al 2020).

Moreover, Changes in the health care system have decreased hospital stays, increasing reliance on individuals to cope with cancer at home with the support of family. Nowadays, most cancer treatment is given in outpatient treatment centers. This means someone is needed to be part of the day-to-day care of the person with cancer and most patients are being cared for at home. As a result, caregivers have many roles, which roles change as the patient's needs change during and after cancer treatment (La et al 2021). Caregiver burden is a combination of the subjective negative feelings and the objective adverse effects that are incurred by the care delivery during the care process, which in turn may have a potential impact on the patient's quality of life, treatment outcomes, and rehabilitation. Chemotherapy is the primary treatment for most malignancies but it is associated with painful side effects, which often require lengthy treatments and repeated hospitalizations, leading to an increased burden on the patients and their informal caregivers (Zuo et al 2020).

Chemotherapy has been widely applied as one of the most effective antineoplastic therapies to improve cancer patient prognosis. As has been previously reported in the literature, chemotherapy treatments are quite vital for patients, since these drugs not only kill tumor cells but also destroy normal healthy cells.

However, chemotherapy can also contribute to various unpleasant symptoms that significantly deteriorate patients' functional status and increase their physical, psychological, and financial burden (Tan et al, 2020). Therefore, understanding the difficulties experienced by cancer patients and their relatives and investigating their needs and expectations during chemotherapy are important and essential to fully discover the impact of cancer (Ferrell & Wittenberg, 2017).

Family caregivers are valuable sources of support, and they play an important role in supporting cancer survivors. However, caring for cancer it is straining experience, especially in countries where family caregiving is often the only option for cancer care (Ghorbani et al., 2020). In Iraq, cultural expectations (e.g., family members have to take care of cancer survivors otherwise the family members are not welcomed by the society) make families consider it their main responsibility to care for cancer survivors. Hence, Iraqi people tend to take up the responsibility of caring for a family member with cancer to meet cultural expectations.

Despite the increasing attention given to caregivers and families in the cancer literature, some health professionals still remain unaware of the fact that patients and caregivers have an interdependent relationship therefore fail to address the needs of caregivers as a part of the therapeutic strategy (Borges et al, 2017). Therefore, the purpose of this study was to determine cancer caregiver burdens during chemotherapy and find out correlation among caregiving burden domains.

## METHOD

This research is a cross-sectional study that was conducted in chemotherapy units at Hiwa cancer hospital in Sulaimani city/Iraq. The study population consisted of the caregivers of patients being treated in the chemotherapy outpatients between February 2020 and February 2021. A non-probability, convenience sample technique was used to recruit (198) dyad of cancer patients and their family caregivers to the study.

### Data collection

Before interviewing the caregivers, informed consent has been achieved, latter a brief introduction was given and the purpose of the research was explained by the researcher to the caregivers. Patients' records and caregivers themselves were used as primary data collection sources. The data were collected through the

utilization of the questionnaire by structured interview technique with caregivers. Researcher-administered forms were used. The interview was conducted in a separate comfortable room (Nurses room) at both male and female outpatients' clinics in the morning time (9 - 11:30 am).

### Study instruments

The questionnaire consists of 2 parts; 1st part is related to; patient caregivers and patients' sociodemographic characteristics, caregiving-related factors, and patients' clinical characteristics. The second part includes 3 standardized scales to measure caregivers' burdens.

#### Zarit Burden Interview (ZBI)

The ZBI was developed by Zarit et al. in (1980). This scale is used to rate the difficulty experienced by individuals who provide care to those who are in need of care. This 22-item scale can be filled out either by the responder or by the investigator, and it measures the impact of caregiving on a caregiver's life. Each item in this Likert-type scale includes five choices. The total score would range from 0 to 88; the higher the score, the heavier the burden. Levels of burden are categorized as no burden (0-20), mild burden (21-40), moderate burden (41-60) and severe burden (61-88). The ZBI is widely used, and data obtained from various studies demonstrate good internal consistency, with Cronbach's alphas above 0.80. The ZBI has been validated test-retest reliability and face validity established previously (Yu et al, 2020).

#### Caregiver Distress Scale (CDS)

This scale was developed by Cousins et al. in 2002 to assess caregivers' distress. CDS is based on four validated scales: Burden, Impact of Caregiving Scale, Caregiving Burden Scale, and Frustration Scale. All four measures were internally consistent with Cronbach's alpha values over 0.70. The scale includes 17 items divided into five sub-constructs: relationship distress (items 5, 8, 11, 13), emotional burden (items 4, 9, 12, 15), social impact (items 1, 2, 3), care-receiver demands (items 6, 14, 16), and personal cost (items 7, 10, 17). According to a five-point Likert scale, the responses were graded as: strongly disagree, disagree, neutral, agree, and strongly agree. The score of relationship sub-constructs ranged between 0 and 16 points, emotional burden score ranged between 0 and 16 points, social impact score ranged between 0 and 12 points, care-receiver demands score ranged between 0 and 12 points,

and personal cost score ranged between 0 and 12 points. Overall CDS scores is ranged 0-68.

#### Caregiver Strain Index (CSI)

The Caregiver Strain Index (CSI) is a screening instrument that can be used to identify the strain of caregivers, assess their ability to go on caring, and identify areas where support may be needed. The CSI consists of 13 questions, with answers being Yes or No. The instrument can be either answered by the caregiver or with staff asking questions in an interview situation. The time frame for administration is approximately 5 minutes. The score is determined by adding up the "Yes" answers (giving one point to each yes answer). A score of 7 or greater indicates a high level of stress (Terry 2003).

#### Statistical analysis

The data were analyzed with Statistical Package for the Social Sciences (SPSS) version (24.0). Different statistical tests have been used in order to achieve the objectives of the study. Descriptive statistics were used, to identify participants' socio-demographic, clinical characteristics, caregiving-related factors, levels of burdens, and strain. The caregivers' distress was shown in the Median and interquartile range (IQR). The inferential statistical method was used to establish the correlation among the score of variables of interest such as caregivers' burdens, distress, and strain for this reason Pearson's Correlation Coefficient was applied. In the present study ( $p \leq 0.05$ ) is considered significant.

### RESULTS

One hundred twenty-nine dyads of cancer patients and family-caregiver were recruited for the present study to determine the levels of caregiving burdens faced by caregivers during chemotherapy. The caregivers' mean age was ( $38.1 \pm 10.3$ ). Most 68.2% were female, 72.2% married. Almost one-third 33.3% were paid employed, and 34.8% were secondary school graduates. More than one-third 39.4% were poor and 41.9% were caring for their parents, as shown in Table 1.

The majority 74.2% of caregivers were living with patients and had no chronic disease 90.9%, and the duration of caregiving for 36.4% was more than 12 months, one-third were giving care for more than 12 hours a day, and 37.9% of them were giving care whole day (Day & night) as illustrated in Table 2.

The patients' mean age was  $51.1 \pm 13.9$  years, most were male 57.6%, married 72.7%, 31.8%

were retired or jobless, 38.9% had no formal education, and the incomes for half of the patients were less than expenditures, and the majority 76.8% were from urban, Table 3.

The proportion of slight and moderate dependency on activity in daily living was 30.8% and 31.3% respectively, 34.3% had the comorbid disease, 45.5% were admitted to the hospital due to chemotherapy adverse effect, medical diagnoses for 25.7% were gastrointestinal cancer, the cancer stage for 50.5% was third, almost half 48.5% had 7 to 9 cycles of chemotherapy, 52.0% underwent cancer-related surgery, and 48% received radiotherapy, as showed in Table 4.

The levels of caregiving burden which was the main objective of the current study according to Zarit's Burdens Interview is illustrated in Figure 1; the burden was moderate for (45.5%) of caregivers and the proportion of caregivers who had a severe caregiving burden was almost 29%. Furthermore, nearly one-fifth 21.2% of caregivers had a mild caregiving burden, while the percentage of caregivers who has no burden was 4.5% only. Furthermore, the mean score and

standard deviation for Zarit's Burden Interview was  $49.1 \pm 14.9$ .

Caregivers' distress was another variable assessed in the present study, according to Caregiver Distress Scale; the median and interquartile (IQR) for the total distress scale was 32 (26 - 37) on a scale (0 - 68) respectively. Emotional burden, care-receiver demand, and personal cost were more affected subscales with median (IQR) of 8 (6-9), 6 (5-7), and 6 (5-7) respectively. Social impact and relationship were less affected subscale with median (IQR) of 5 (4-7) and 7 (5-8) respectively, as presented in Table 5.

The results of the present study revealed a correlation between all dependent variables to various degrees, ( $p > 0.01$ ). The strongest positive correlation was found between caregivers' burdens and each caregiver's strain ( $r: 0.805$ ;  $p: 0.000$ ) and caregiving distress ( $r: 0.728$ ;  $p: 0.000$ ). A moderate positive correlation was found between caregivers' strain and caregiving distress ( $r: 0.619$ ;  $p: 0.000$ ), as illustrated in Table 6.

Table 1: Distribution of caregivers' socio-demographic characteristics

| Caregivers' Socio-demographic Characteristics |                      | Frequency       | Percentage |
|-----------------------------------------------|----------------------|-----------------|------------|
| Age Groups                                    | 20 - 39 years        | 111             | 56.1       |
|                                               | 40 - 59 years        | 81              | 40.9       |
|                                               | $\geq 60$ years      | 6               | 3.0        |
|                                               | Mean $\pm$ SD        | 38.1 $\pm$ 10.3 |            |
| Gender                                        | Female               | 135             | 68.2       |
|                                               | Male                 | 63              | 31.8       |
| Occupation                                    | Paid Employed        | 66              | 33.3       |
|                                               | Self Employed        | 37              | 18.7       |
|                                               | Housewife            | 59              | 29.8       |
|                                               | Student              | 23              | 11.6       |
|                                               | Retired/ Jobless     | 13              | 6.6        |
| Marital Status                                | Married              | 143             | 72.2       |
|                                               | Widow                | 16              | 8.1        |
|                                               | Single               | 39              | 19.7       |
| Education                                     | No Formal Education  | 33              | 16.7       |
|                                               | Primary              | 51              | 25.8       |
|                                               | Secondary            | 69              | 34.8       |
|                                               | Institute/University | 45              | 22.7       |
| Financial Status                              | Income >Expenditure  | 27              | 13.6       |
|                                               | Income = Expenditure | 93              | 47.0       |
|                                               | Income <Expenditure  | 78              | 39.4       |
| Relation                                      | Children             | 83              | 41.9       |
|                                               | Parent               | 53              | 26.8       |
|                                               | Spouse               | 42              | 21.2       |
|                                               | Sibling              | 20              | 10.1       |
| Total                                         |                      | 198             | 100        |

Table 2: Distribution of some caregiving-related characteristics

| Caregiving-related factors |               | F   | %    |
|----------------------------|---------------|-----|------|
| Co-residency               | Yes           | 147 | 74.2 |
|                            | No            | 51  | 25.8 |
| Duration of Caregiving     | < 3 months    | 51  | 25.8 |
|                            | 3-6 months    | 36  | 18.2 |
|                            | 7-12 months   | 72  | 36.4 |
|                            | > 12 months   | 39  | 19.7 |
| Caregiving Hours / Day     | 3 - 5 Hours   | 27  | 13.6 |
|                            | 6 - 9 Hours   | 30  | 15.2 |
|                            | 10 - 12 Hours | 66  | 33.3 |
|                            | > 12 Hours    | 75  | 37.9 |
| Time of Caregiving         | Day           | 82  | 41.4 |
|                            | Night         | 41  | 20.7 |
|                            | Both          | 75  | 37.9 |
| Caregiver Chronic Disease  | Yes           | 18  | 9.1  |
|                            | No            | 180 | 90.9 |
| Total                      |               | 198 | 100  |

Table 3: Distribution of patients' socio-demographic characteristics

| Patients' Socio-demographic Characteristics |                     | Frequency   | %    |
|---------------------------------------------|---------------------|-------------|------|
| Age Groups                                  | 20 - 39 years       | 42          | 21.2 |
|                                             | 40 - 59 years       | 96          | 48.5 |
|                                             | ≥ 60 years          | 60          | 30.3 |
|                                             | Mean ± SD           | 51.1 ± 13.9 |      |
| Gender                                      | Female              | 84          | 42.4 |
|                                             | Male                | 114         | 57.6 |
| Occupation                                  | Paid Employed       | 54          | 27.3 |
|                                             | Self Employed       | 29          | 14.6 |
|                                             | Housewife           | 42          | 21.2 |
|                                             | Student             | 10          | 5.1  |
|                                             | Retired/Jobless     | 63          | 31.8 |
| Marital Status                              | Married             | 144         | 72.7 |
|                                             | Widow               | 17          | 8.6  |
|                                             | Single              | 37          | 18.7 |
|                                             | No Formal Education | 77          | 38.9 |
|                                             | Primary             | 63          | 31.8 |

|                  |                      |     |      |
|------------------|----------------------|-----|------|
| Education        | Secondary            | 32  | 16.2 |
|                  | Institute/University | 26  | 13.1 |
| Financial Status | Income >Expenditure  | 18  | 9.1  |
|                  | Income = Expenditure | 81  | 40.9 |
|                  | Income <Expenditure  | 99  | 50.0 |
| Residency        | Urban / City         | 156 | 78.8 |
|                  | Rural / Village      | 42  | 21.2 |
| Total            |                      | 198 | 100  |

Table 4: Distribution of patients' clinical characteristics

| Patients' Clinical Characteristics                      |                            | F   | %    |
|---------------------------------------------------------|----------------------------|-----|------|
| Activities of Daily Living (according to Barthel Index) | Total Independent          | 18  | 9.1  |
|                                                         | Slight Dependency          | 61  | 30.8 |
|                                                         | Moderate Dependency        | 62  | 31.3 |
|                                                         | Severe Dependency          | 40  | 20.2 |
|                                                         | Total Dependent            | 17  | 8.6  |
| Comorbidity                                             | Yes                        | 68  | 34.3 |
|                                                         | No                         | 130 | 65.7 |
| Hospitalization due to Chemotherapy Adverse effect      | Yes                        | 90  | 45.5 |
|                                                         | No                         | 108 | 55.5 |
| Medical Diagnosis                                       | Blood-related Cancer       | 34  | 17.2 |
|                                                         | Breast Cancer              | 42  | 21.2 |
|                                                         | GIT-related Cancer         | 51  | 25.7 |
|                                                         | Head & Neck Cancer         | 17  | 8.6  |
|                                                         | Lung Cancer                | 36  | 18.2 |
|                                                         | Gynecologic-related Cancer | 18  | 9.1  |
| Stage of Cancer                                         | 2nd Stage                  | 45  | 22.7 |
|                                                         | 3rd Stage                  | 100 | 50.5 |
|                                                         | 4th Stage                  | 53  | 26.8 |
| Chemotherapy's Cycle                                    | 4 - 6 Cycles               | 21  | 10.6 |
|                                                         | 7 - 9 Cycles               | 96  | 48.5 |
|                                                         | 10 - 20 Cycles             | 66  | 33.3 |
|                                                         | > 20 Cycles                | 15  | 7.6  |
| Cancer-related Surgery                                  | Yes                        | 103 | 52.0 |
|                                                         | No                         | 95  | 48.0 |
| Radiotherapy                                            | Yes                        | 96  | 48.5 |
|                                                         | No                         | 102 | 51.5 |
| Total                                                   |                            | 198 | 100  |

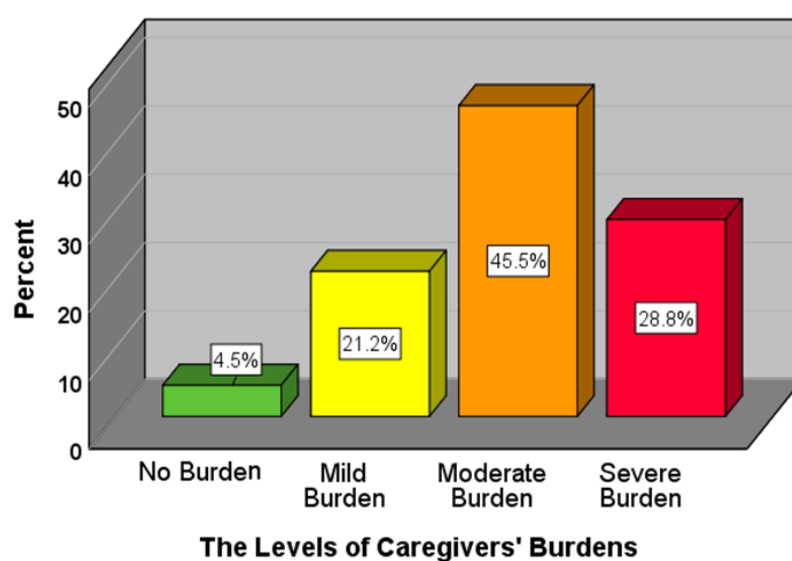


Figure 1 the level of caregivers' burdens

### Caregiver Strain Index

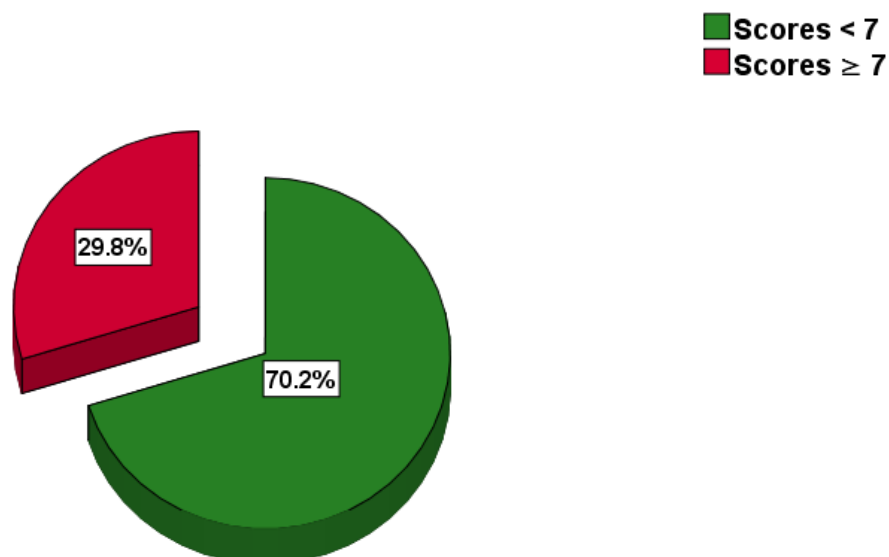


Figure 2 The levels of Caregivers' Strain

Table 5 distribution of Caregivers' Distress Scores

| CDS Subscales                | Median | IQR          | Mode | Min-Max |
|------------------------------|--------|--------------|------|---------|
| Relationship Distress (0-16) | 7      | 5 - 8 (3)    | 9    | 0 - 12  |
| Emotional Burden (0-16)      | 8      | 6 - 9 (3)    | 9    | 0 - 13  |
| Social Impact (0-12)         | 5      | 4 - 7 (3)    | 4    | 0 - 10  |
| Care-receiver Demand (0-12)  | 6      | 5 - 7 (2)    | 6    | 0 - 10  |
| Personal Cost (0-12)         | 6      | 5 - 7 (2)    | 7    | 0 - 10  |
| Total CDS (0-68)             | 32     | 26 - 37 (11) | 34   | 2 - 54  |

CDS: Caregiving Distress Scale, IQR: Interquartile Range

Table 6: Correlation among Zarit Burdens Interview, Caregivers Strain Index and Caregiving Distress Scale Scores

|                          |   | Caregivers Strain Index | Caregiving Distress Scale |
|--------------------------|---|-------------------------|---------------------------|
| Caregivers Burdens Index | r | 0.805**                 | 0.728**                   |
|                          | p | 0.000                   | 0.000                     |
| Caregivers Strain Index  | r | 1                       | 0.619**                   |
|                          | p | 1                       | 0.000                     |

\*\*. Correlation is significant at the 0.01 level (2-tailed).

## DISCUSSION

The present study assessed the caregiving burdens faced by caregivers during the active stage of treatment which was chemotherapy in a sample of Kurdish family caregivers of cancer patients.

Caregivers' and Care-receivers' characteristics

The caregiver mean age was  $38.1 \pm 10.3$  years, most of them were young adults (20 to 39) years old, more than two-thirds were female, almost one-third paid employed and secondary school graduates, the majority were married, the income of 2 out of 5 was less than their expenditures and they were caring for their parents. The Majority of caregivers were coresident with patients, the duration of caregiving for most of caregivers was 3 to 6 months, most of them had provided either 10 to 12 or more than 12 hours on a daily basis, the caregiving time for 2 out of 5 was during the day, and more one-third had provided care during both day and night. Nearly two-thirds of caregiver was getting help from other during caregiving for patients.

Moreover, the patients' mean age was  $51.1 \pm 13.9$ , the age of almost half was middle adulthood (40 to 49) years, and about one-third were late (old) adulthood ( $\leq 60$ ) years (Cole et al., 2018), more than half were male, nearly one-third were housewives, the majority were married, from the urban districts, and low educated, and half were had lower incomes than expenditure (poor). Majority of patients were married and they have children. Furthermore, most of the care-receivers have no comorbidity, almost one-third was either slightly or moderately dependent on performing the basic activity of daily living, about half was admitted to the hospital due to chemotherapy side effect, the medical diagnosis for 3 out of 10 patients was gastrointestinal related cancer, the stage of cancer was 3rd stage for more than half of patients, nearly half of them received 7 to 10 cycles of chemotherapy, nearly half of patients treated with surgical intervention and radiotherapy.

Similarly, the mean age of caregivers was  $41.6 \pm 14.7$  in the Jite et al (2021) study, which showed that the majority of the family caregivers are in the prime of life. The

implication of this is the loss of productive man-hours as caregiving takes away time that may otherwise be spent in paid employment. National Cancer Institute (2022), reported through a survey of the respondents which identified a representative sample of adult caregivers who provided unpaid care to an adult relative or friend that the most (58%) of participants were female, (88%) cared for a relative, 50% were employed while caregiving, working 35 hours per week, caregiving for patients with cancer was episodic and lasted for approximately 2 years on average, and 39% lived with the person being cared for.

The caregiver's mean age in Mishra et al (2021) study was  $30.7 \pm 8.96$ , the majority were married 88.2%, and most were employed 41.6%. The mean age of  $41.6 \pm 14.7$  in this study showed that the majority of the family caregivers are in the prime of life, and these caregivers are likely to be the spouses of these women, especially because there are a higher proportion of young females with breast cancer in our environment than in developed countries. The implication of this is the loss of productive man-hours as caregiving takes away time that may otherwise be spent in paid employment (Jite et al 2021). Caregivers' burdens, distress, and strain

Family caregivers of cancer patients have extensive burdens due to the morbidity associated with the disease and the side effects of chemotherapeutic drugs. The burden also adds to the need for multiple hospital visits, inpatient admissions, and need for assistance at home when caring for symptomatic patients. There is an adverse effect on the physical, psychosocial, and emotional well-being of the caregiver. This also has a bearing on their mental health, QOL, occupation, and financial condition. In this study, a multi-evaluation strategy was applied in order to measure caregiver burden by using Zarit burden inventory, caregiver strain index, and caregiver distress scale.

The results of current study reveal caregivers' burdens scores according to ZBI was ( $49.1 \pm 14.9$ ), about half of caregivers complained of moderate caregiving burdens, nearly one-quarter perceived severe caregiving burdens, and one-quarter of either no or mild burden according to the same scale, as illustrated in Figure 1.

Zuo et al (2020) reported similar caregivers burden score  $53.2 \pm 10.97$  in the sample of gynecological oncology patients undergoing chemotherapy and overall burdens was moderate for most of the participants. While, Mishra et al (2021) in the sample of caregivers caring for the cancer patients during chemotherapy reported slightly lower ZBI scores ( $39.0 \pm 10.5$ ) and a similar proportion of caregiving burdens level, minimal or no burden was 8.5%, moderate burden 70.2%, and 20.3% of caregiver had severe caregiving burdens. In addition, most (81.2%) of the caregivers of children with cancer receiving chemotherapy in Rattanakamonkarn et al (2021)

had the mean score of caregiving burden at a moderate level (Mean; 58.5, S.D.;10.6).

We believe that the differences in the results are due to several reasons, for example, the present study results were lower than the results obtained in the Mishra et al (2021) study, which may be due to the differences in the communities in which the study was conducted. Social values may have a significant impact on the way individuals think and feel about burdens. Kurdish society has its own burdens that may not exist in other societies, especially financial burdens that have a negative impact on the Kurdish individual. The proportion of the female gender in the present study was higher than in the Mishra et al, study, this may be another factor for increasing caregivers' burden, the female in Kurdish society is performing most of the household responsibility, by adding caregiving for the sick member will increase the load to her and causing further burden.

Furthermore, the finding of Rattanakamonkarn et al, was higher than our finding, because they conducted their study in the pediatric samples which may be the main factor of difference. Mothers are usually caring for their children, and being female may increase the caregiving burdens because of householding responsibility in addition females are more emotional than males.

The present study results are lower than the study conducted on Iranian caregivers where a significant proportion (48.1%) of caregivers reported a high burden. Mirsoleymani et al. (2017) conducted the study on cancer patients referred to the outpatient chemotherapy wards, using the caregiver burden inventory. While it was higher than Lukhmana et al (2015) finding, they used ZBI in outpatient cancer patient caregivers which suggested that 56.5% of family caregivers had no or minimal burden due to caregiving and 43.5% had burden varying from mild to moderate the proportion of severe burden was 5.0% only, while caring for cancer patients. In addition, was higher than the Nigeria cancer patients, the total mean ZBI score was  $29.8 \pm 13.9$ . Most caregivers (52.2%) experienced mild burden, whilst moderate and severe burden were experienced by (17%) and (2.5%) of the respondents, respectively. Less than a third (28%) of the respondents did not experience a burden. (Jite et al, 2021).

Cancer is a chronic disease with associated physical, emotional, social, financial and spiritual problems. The primary caregiver takes care of all these cancer-related issues for the patient. Almost one-third caregivers complained of highly caregiver strain which was assessed via the caregiver strain index. Meanwhile, caregiving distress among the sample of the current study was moderate (32 out of 68) according to the caregivers' distress scale. Emotional burden and personal cost dimensions were more affected, followed by relationship distress and care-receiver demand, and social impact was less

affected dimension as a result of caregiving. It explains that the data on caregivers' worries shed light on some specific aspects that could play a role in the caregiving distress of caregivers and affect their psychosocial needs.

Limonero et al (2020) found similar distress, they reported that the main caregivers of patients with advanced or end-stage cancer tend to experience a large emotional burden, which can lead to emotional distress. In their study, the caregivers recorded an average emotional distress score of  $11.21 \pm 4.24$ , and it was observed that about half of the caregivers registered scores  $\geq 11$  points which was considered significant. Furthermore, the highest areas of burden identified by most caregivers in Towle et al (2020) study was: personal strain (ie, juggling between caregiving and time for own self); trying to meet other responsibilities, and uncertainty about what to do in caring for their loved one.

These consequences may all result in caregivers perceiving lower psychosocial connectedness with others. Interestingly, caregivers providing care to someone in active treatment were more likely to report higher psychosocial connectedness, compared to those whose care recipient was not receiving treatment. This finding is consistent with a recent study of the relationship between cancer caregivers' burdens and psychological outcomes by Yuen and Carlene Wilson, (2021), that reported increased psychological impairment in respondents who were caregivers compared to those who were not.

A recent study found that most family caregivers for patients with cancer suffer from negative consequences of physical and psychological distress related to the presence and intensity of the symptoms due to treatment adverse effects (Valero-Cantero et al, 2022). Furthermore, Kong and Guan (2019) reported the caregiver burden rate among cancer caregivers as 55.6%. Psychological factors remained significant after adjusted in multivariate analysis. The caregiver depression was significantly associated with the caregiver burden (OR 4.26, CI 1.87 - 9.72,  $p = 0.001$ ).

About 30% of all cancer survivors and their caregivers have reported psychological distress, which encompasses diagnoses of depression, anxiety, and overwhelming stress (Badger 2022). Haun et al (2014) found that the 33% of the caregivers and 25% of the patients exhibited significant distress, with a tendency towards a higher frequency in the caregivers ( $p = 0.010$ ). Our explanation for this difference they assessed distress among caregivers for advanced or end-stage cancer which may cause more psychological distress for a family member.

Correlation among caregiving burden domains

Informal caregivers might experience a burden as a consequence of cancer diagnosis and management in a close relative (Johansen et al, 2018). There is little information, however,

about the relations and the predictive utility of the different burdens' domains. The results of the current study revealed a strong positive correlation between caregivers' burdens and each caregiving strain ( $r: 0.805$ ;  $p < 0.0001$ ) and caregiving distress ( $r: 0.724$ ;  $p < 0.0001$ ), in another word any increase in caregiving burden causes more caregiving strain and distress and vice-versa. Furthermore, a moderate positive correlation was found between caregiving strain and distress. Our data show that caregivers suffering from caregiving distress and strain are more likely to exhibit caregiving burdens.

Our findings finding was in line with the study of Tan and colleagues (2018), the caregiver burden was shown to be significantly associated with caregiver emotional distress, the reported a significant impact of cancer care on the global health status of the caregivers, although the causality between caregiver burden and their emotional problems. Given the close interrelationships among caregiver burden, emotional status. Similar results were also reported in caregivers of patients with chronic diseases (Fujinami et al, 2015).

Previous researches have shown a correlation among burden domains experienced by caregivers of cancer patients, Garcia-Torres et al (2020) reported moderate to strong correlation among caregiving burdens and emotional stress. Furthermore, Otsuki et al (2022) found moderate levels of correlation among caregiving burden domains.

## CONCLUSIONS & RECOMMENDATIONS

Overall caregiver burden was moderate, almost half experienced moderate caregiving burdens. Overall caregiver distress was moderate, emotional burdens were the most dimension affected. Caregiver burden increased with increasing caregiver distress and caregiver strain, and vice-versa. Nursing outreach services such as home visits and phone call follow-up should be considered for chemotherapy clinics. Participatory health education involving the informal caregivers may be explored for better humanitarian nursing support during chemotherapy to ease their lasting tension and fatigue, lower their burden and eventually improve the quality of lives of both patients and their informal caregivers.

## ETHICAL CONSIDERATIONS COMPLIANCE WITH ETHICAL GUIDELINES

The proposal of the present study was approved by the Scientific Committee at the College of Nursing and the Ethical Committee at the College of the Medicine / University of Sulaimani, the participants were informed they have the right to withdraw from the study whenever they want.

## REFERENCES

- Badger T., 2022. Psychological Distress Is Interdependent in Patients with Cancer and Their Caregivers | ONS. [online] Available at: <<https://www.ons.org/articles/psychological-distress-interdependent-patients-cancer-and-their-caregivers>> [Accessed 18 May 2022].
- Borges, E. L., Franceschini, J., Costa, L. H., Fernandes, A. L., Jamnik, S., & Santoro, I. L. (2017). Family caregiver burden: the burden of caring for lung cancer patients according to the cancer stage and patient quality of life. *Jornal brasileiro de pneumologia : publicacao oficial da Sociedade Brasileira de Pneumologia e Tisilogia*, 43(1), 18-23. <https://doi.org/10.1590/S1806-37562016000000177>.
- Cole, R., Driscoll C., and Greal L., 2018 Classifying adulthood A history of governing minority in media classification The University of Sydney - Academia.edu. [online] Sydney.academia.edu. Available at: <<https://sydney.academia.edu/LiamGreal>> [Accessed 25 April 2022].
- Cousins, R., Davies, A., Turnbull, C. and Playfer, J., 2002. Assessing caregiving distress: A conceptual analysis and a brief scale. *British Journal of Clinical Psychology*, 41(4), pp.387-403. <https://doi.org/10.1348/014466502760387506>.
- Ferrell B, & Wittenberg E. (2017) A review of family caregiving intervention trials in oncology. *CA Cancer J Clin.*, 67(4):318-325.
- Fujinami, R., Sun, V., Zachariah, F., Uman, G., Grant, M., & Ferrell, B. (2015). Family caregivers' distress levels related to quality of life, burden, and preparedness. *Psycho-Oncology*, 24(1), 54-62.
- García-Torres, F., Jabłoński, M., Gómez Solís, Á., Jaén-Moreno, M., Gálvez-Lara, M., Moriana, J., Moreno-Díaz, M. and Aranda, E., 2020. Caregiver Burden Domains and Their Relationship with Anxiety and Depression in the First Six Months of Cancer Diagnosis. *International Journal of Environmental Research and Public Health*, 17(11), p.4101.
- Ghorbani, F., Zare, M., Heshmati Nabavi, F., Behnam Vashani, H., Bari, A. (2020). 'Effect of Education and Telephone Counseling on Caregiver Strain and Unmet Needs in Family Caregivers and Self-care Behaviors in Patients with Cancer: A Randomized Clinical Trial', *Evidence Based Care*, 10(1), pp. 51-60. doi: 10.22038/ebcj.2020.45647.2244.
- Haun MW, Sklenarova H, Brechtel A, Herzog W, Hartmann M. Distress in cancer patients and their caregivers and association with the caregivers' perception of dyadic communication. *Oncol Res Treat.* 2014;37(7-8):384-8. doi: 10.1159/000364885. Epub 2014 Jun 17. PMID: 25138298.
- Jite IE, Adetunji AA, Folasire AM, Akinyemi JO, Bello S. Caregiver burden and associated factors amongst carers of women with advanced breast cancer attending a radiation oncology clinic in Nigeria. *Afr J Prm Health Care Fam Med.* 2021;13(1), a2812. <https://doi.org/10.4102/phcfm.v13i1.2812>.
- Johansen, S.; Cvancarova, M.; Ruland, C. The effect of cancer patients and their family caregivers physical and emotional symptoms on caregiver burden. *Cancer Nurs.* 2018;41, 91-99 doi: 10.1097/NCC.0000000000000493.
- Kong, S. and Guan, N., 2019. Burden in Family Caregivers of Cancer Patients: The Association with Depression, Religiosity and Religious Coping. *Asian Pacific Journal of Cancer Care*, 4(4), pp.171-182.
- Lee, L., Wehrlen, L., Wallen, G., Ding, Y. and Ross, A., 2021. Symptom Clusters and Influencing Factors in Family Caregivers of Individuals with Cancer. *Cancer Nursing*, (44(6); p E547-E555. doi: 10.1097/NCC.0000000000000877.
- Li, J., Luo, X., Cao, Q., Lin, Y., Xu, Y. and Li, Q., 2020. Communication Needs of Cancer Patients and/or Caregivers: A Critical Literature Review. *Journal of Oncology*, 2020, pp.1-12.
- Limonero, J., Maté-Méndez, J., Gómez-Romero, M., Mateo-Ortega, D., González-Barboteo, J., Bernaus, M., López-Postigo, M., Sirgo, A., Viel, S., Sánchez-Julve, C., Bayés, R., Gómez-Batiste, X. and Tomás-Sábado, J., 2020. Family caregiver emotional distress in advanced cancer: the DME-C scale psychometric properties. *BMJ Supportive & Palliative Care*, pp.bmjspcare-2020-002608.
- Liu, Z., Heffernan, C. and Tan, J., 2020. Caregiver burden: A concept analysis. *International Journal of Nursing Sciences*, 7(4), pp.438-445.
- Lukhmana, S., Bhasin, S., Chhabra, P. and Bhatia, M., 2015. Family caregivers' burden: A hospital based study in 2010 among cancer patients from Delhi. *Indian Journal of Cancer*, 52(1), p.146.
- Mirsoleymani, S. R., Rohani, C., Matbouei, M., Nasiri, M., & Vasli, P. (2017). Predictors of caregiver burden in Iranian family caregivers of cancer patients. *Journal of education and health promotion*, 6, 91. [https://doi.org/10.4103/jehp.jehp\\_137\\_16](https://doi.org/10.4103/jehp.jehp_137_16).
- Mishra, S., Gulia, A., Satapathy, S., Gogia, A., Sharma, A., & Bhatnagar, S. (2021). Caregiver Burden and Quality of Life among Family Caregivers of Cancer Patients on Chemotherapy: A Prospective Observational Study. *Indian journal of palliative care*, 27(1), 109-112. [https://doi.org/10.4103/IJPC.IJPC\\_180\\_20](https://doi.org/10.4103/IJPC.IJPC_180_20).
- National Cancer Institute. 2022. Informal Caregivers in Cancer: Roles, Burden, and Support (PDQ®)-Health Professional Version. [online] Available at: <<https://www.cancer.gov/about-cancer/coping/family-friends/family-caregivers-hp-pdq>> [Accessed 15 May 2022].

- Otsuki, N., Yamamoto, R., Sakaguchi, Y. et al. Care needs level in long-term care insurance system and family caregivers' self-perceived time-dependent burden in patients with home palliative care for cancer: a cross-sectional study. *Support Care Cancer* 30, 1587-1596 (2022). <https://doi.org/10.1007/s00520-021-06579-x>.
- Rattanakamonkarn Ch, Niyomkar S, and Jintrawet U., 2021) Self-efficacy, Social Support, and Caregiving Burden Among Caregivers of Children with Cancer Receiving Chemotherapy, *Nursing Journal* 48(2).
- Sung, H., Ferlay, J., Siegel, R., Laversanne, M., Soerjomataram, I., Jemal, A. and Bray, F., 2021. Global Cancer Statistics 2020: GLOBOCAN Estimates of Incidence and Mortality Worldwide for 36 Cancers in 185 Countries. *CA: A Cancer Journal for Clinicians*, 71(3), pp.209-249.
- Tan JY, Suen LKP, and Wang T. (2020) Auricular therapy for chemotherapy-induced nausea and vomiting in cancer patients: Perspectives from the traditional zang-fu organs and meridians theory. *TMR Integr Nurs.*, 4(5):149-155. doi:10.12032/TMRIN20201002.
- Tan, J. Y., Molassiotis, A., Lloyd-Williams, M., & Yorke, J. (2018). Burden, emotional distress and quality of life among informal caregivers of lung cancer patients: An exploratory study. *European Journal of Cancer Care*, 27(1). <https://doi.org/10.1111/ecc.12691>.
- Terry S. 2003. Caregiver Strain Index (CSI), *Home Healthcare Nurse: The Journal for the Home Care and Hospice Professional*, 21(3). Pp. 197-198.
- Towle, R., Low, L., Tan, S. and Hendrix, C., 2020. Quality improvement study on early recognition and intervention of caregiver burden in a tertiary hospital. *BMJ Open Quality*, 9(3), p.e000873.
- Valero-Cantero, I., Casals, C., Carrión-Velasco, Y., Barón-López, F., Martínez-Valero, F. and Vázquez-Sánchez, M., 2022. The influence of symptom severity of palliative care patients on their family caregivers. *BMC Palliative Care*, 21(1).
- Yu, Y., Liu, Z., Li, T., Zhou, W., Xi, S., Xiao, S. and Tebes, J., 2020. A comparison of psychometric properties of two common measures of caregiving burden: the family burden interview schedule (FBIS-24) and the Zarit caregiver burden interview (ZBI-22). *Health and Quality of Life Outcomes*, 18(1). <https://doi.org/10.1186/s12955-020-01335-x>
- Zarit SH, Reever KE, and Back-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. *Gerontologist* 1980; 20(6):649-55.
- Zuo, Y., Luo, B. R., Peng, W. T., Liu, X. R., He, Y. L., & Zhang, J. J. (2020). Informal caregiver burden and influencing factors in gynaecological oncology patients hospitalized for chemotherapy: a cross-sectional study. *The Journal of international medical research*, 48(11), 300060520974927. <https://doi.org/10.1177/0300060520974927>.