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ETKİLİ HEMŞİRELİK DERGİSİ

ORIGINAL ARTICLE / ORİJİNAL MAKALE

# Compassion Levels and Care Burdens of Informal Caregivers to Cancer Patients: A Mixed Study

## Kanser Hastalarına İnformal Bakım Verenlerin Merhamet Düzeyleri ve Bakım Yükleri: Karma Bir Çalışma

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## Abstract

**Background:** The shift of care services from hospital care to family members providing care has led to changes in the living standards of family members.

**Objective:** This study aimed to determine the levels of compassion and care burdens among individuals providing informal care to cancer patients at an oncology center.

**Method**: A mixed-method research approach was used in this study. Quantitative data were collected from 200 individuals providing informal care to cancer patients undergoing chemotherapy, while qualitative data were collected from 30 individuals. The research was conducted at the chemotherapy unit of a university hospital in a province in Turkey between August and November 2022. In the analysis of quantitative data, the arithmetic mean, standard deviation, median, minimum, and maximum scores were used, along with the Mann-Whitney U and Kruskal-Wallis H tests, in the SPSS 25.0 program. In the analysis of qualitative data, the content analysis approach was used.

**Results:** The mean score of the compassion scale was 3.91±0.65 among informal caregivers. The highest sub-dimension mean score was in the compassion sub-dimension (4.15 ± 0.87). There was a significant difference between the indifference, disconnection, and disengagement sub-dimensions of The Compassion Scale and certain socio-demographic characteristics ($p < .05$, $p < .005$). In the qualitative evaluation, three main themes were reached in total: “Psychological and social dimensions of care burden,” “Physical dimension of care burden”, and “Strategies for coping with care burden”. It was concluded that the participants experienced care burden, felt unhappy, uncertain, tired and inadequate, and preferred family support, religious beliefs, and social activities to cope with the current situation.

**Conclusion:** The compassion levels of those caring for cancer patients were high. However, it was determined that they felt tired and unhappy. In this respect, it is recommended that nurses should develop psychological and social support programmes for informal caregivers.

**Keywords:** Cancer, Care Burden, Caregiver, Compassion, Nurse.

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## Abstract

**Giriş:** Bakım hizmetlerinin hastane bakımından, bakım veren aile üyelerine doğru kayması, aile üyelerinin yaşam standartlarının değişmesine neden olmaktadır.

**Amaç:** Bu çalışmada, bir onkoloji merkezindeki kanser hastalarına informal bakım veren bireylerin merhamet düzeylerini ve bakım yüklerini belirlemek amaçlandı.

**Yöntem:** Bu çalışmada karma araştırma yöntemi kullanıldı. Kemoterapi almak için başvuran kanser hastalarına informal bakım veren yakınları ile yapılan çalışmanın nicel verileri 200 kişi, nitel verileri ise 30 kişi ile tamamlandı. Araştırma Türkiye'de bir ilde bulunan üniversite hastanesinin kemoterapi ünitesinde Ağustos – Kasım 2022 tarihleri arasında yapıldı. Nicel verilerin analizinde SPSS 25.0 programında aritmetik ortalama, standart sapma, medyan, minimum ve maksimum puanlar ile Mann Whitney U ve Kruskal Wallis H testleri kullanıldı. Nitel verilerin analizinde içerik analizi yaklaşımı kullanıldı.

**Bulgular:** İnformal bakım verenlerin merhamet düzeyleri ortalama puanı 3,91±0,65'tir. En yüksek alt boyut ortalama puanı şefkat alt boyutundadır (4,15±0,87). Merhamet ölçeğinin umursamazlık, bağlantısızlık ve ilişik kesme alt boyutları ile bazı sosyo-demografik özellikler arasında anlamlı farklılık vardı ($p<.05$, $p<.005$). Nitel değerlendirmede toplamda üç ana temaya ulaşıldı; "Bakım yükünün psikolojik ve sosyal boyutları", "Bakım yükünün fiziksel boyutu", " Bakım yüküyle başa çıkma stratejileri". Katılımcıların bakım yükü yaşadığı, kendilerini mutsuz, belirsiz, yorgun ve yetersiz hissettikleri ve mevcut durumla baş ederken aile desteğini, dini inançları ve sosyal etkinlikleri tercih ettikleri sonuçlarına ulaşıldı.

**Sonuç:** Kanser hastalarına bakım verenlerin merhamet düzeyleri yüsekti. Ancak kendilerini yorgun ve mutsuz hissettikleri belirlendi. Bu doğrultuda hemşireler tarafından informal bakım verenlere yönelik, psikolojik ve sosyal destek programları oluşturulması önerilir.

**Anahtar Kelimeler:** Kanser, Bakım Yükü, Bakım Veren, Merhamet, Hemşire.

## INTRODUCTION

Cancer is one of the most critical public health problems frequently seen globally. It is estimated that cancer, which is the second leading cause of death after cardiovascular diseases, will rise to the first rank in 2040, and there will be approximately 29.5 million new cancer cases (Ritchie & Rose, 2020; International Agency for Research on Cancer [IARC], 2022).

Today, advances in cancer treatment and outpatient treatment modalities allow patients to continue their treatment and care at home (Rha, Park, Song, CE. Lee & J. Lee, 2015). This situation causes family members to assume more responsibility for the care of cancer patients (Orak &Sezgin, 2015). The shift of care services from healthcare professionals to caring family members causes the living standards of family members to change and their lives to become more difficult (Kurt, Ünsar &Özgül, 2020).  Family is the smallest cornerstone of society, which has a balance within itself, where individuals who have the same past and share the future interact with each other and their environment. System theory is one of the crucial theories used to explain the family. System theory, which treats the family as a system, explains how the relationship between family members affects the dynamics of the family. When a disease is seen in one of the family members, this situation does not only affect the sick individual; the whole family is affected by this situation and experiences the disease process. Therefore, cancer is a family disease (Toptaş Kılıç & Öz, 2019).

The care model offered by family members, friends or volunteers to people who have difficulty fulfilling their daily activities due to illness, old age, or disability is called “informal care” (Roth, Fredman &Haley, 2015). Informal care is based on relational contexts involving emotional bonds. There are tasks and responsibilities rather than mutual relationships. It includes duties such as emotional support, direct service, communication with formal services, and assistance in financial management. These tasks change and are shaped according to the needs of the person being cared for. Caring has no economic visibility. It is always available. Care continues even when the caregiver is ill or needs a holiday, and the labour spent on care is not compensated (Rha et al., 2015; Roth et al., 2015; Orbay, Baydur & Uçan, 2022).

The concept of caregiving can lead to many difficulties as well as positive features such as increased love and intimacy, personal development and satisfaction, social support from other individuals, development of social relations and self-respect. Studies show that the physical, psychological and social health of caregivers is negatively affected. The transformation of caregiving into a one-way, dependent, intensive and long-lasting obligation causes the caregiver to experience harmony problems between family relationships, social life roles and care roles, and care is perceived as a burden (Rha et al., 2015; Toptaş Kılıç & Öz, 2019; Ozdemir &Ozkaraman, 2022; Posluszny, Bovbjerg, Syrjala, Agha & Dew, 2019).

One of the conditions experienced by caregivers, which is least encountered in the literature or avoided to be associated with caregivers, is the level of compassion. Compassion is the motivation that enables the individual to understand the situations that cause pain around him/her and to take action to reduce pain. It is a necessary component and experience for individual and social well-being (Nas &Sak, 2020). The decrease in the level of compassion over time also points to physical, emotional and spiritual burnout and compassion fatigue related to caring for patients in significant emotional pain and physical stress (Figley, 1995). It is caused by changes in the ability of the caregiver to empathise with the stress encountered during caregiving, and there are multiple factors that are effective in its occurrence. In cases where compassion fatigue is not recognised and intervened, it can cause many chronic diseases (Figley, 2022; Sirin &Yurttas, 2015).

There are a limited number of studies on the compassion of caregivers of adult cancer patients in the literature, and these studies were mainly conducted with nurses (Hunt, Denieffe & Gooney, 2019; Wells-English, Giese & Price, 2019). Studies examining the compassion levels or care burdens of informal caregivers are very limited (Liao et al., 2022; Johansen, S., Cvancarova, M. & Ruland, C; Rha et al., 2015), and no study examining compassion levels and care burdens together has been found. This study examines the burden of caregiving, and the compassion levels of informal caregivers of cancer patients.

### *Quantitative Research Questions*

What are the compassion levels of informal caregivers?

Is there a significant difference between some socio-demographic characteristics of informal caregivers and their compassion levels?

Is there a significant difference between some socio-demographic characteristics of informal caregivers and the sub-dimensions of the compassion scale?

## METHODS

### *Research Type*

This research is a mixed-method study type. Mixed method research involves the use of both qualitative and quantitative data. The quantitative part of the research was conducted using a descriptive approach, and the qualitative part was conducted using a phenomenological approach.

### Research Place

This research was conducted in the chemotherapy unit of a university hospital in a province in Turkey.

### Universe/Sample of the Research

The population of this study consisted of informal caregivers of cancer patients who applied to the oncology centre of a university hospital in a province in Turkey to receive chemotherapy between August and November 2022. It was reported that 899 cancer patients received chemotherapy treatment in this unit between April and July 2022. The sample size was calculated with the formula determined by Salant and Dillman (1994). Using the sampling formula, the required sample size was calculated as [n = 899 (1.96)2 (0.2) (0.8) / (0.5)2 (899-1) + (1.96)2 (0.2) (0.8)] = 193 with a 95% confidence interval and ± 5% sampling error for this non-homogeneous population. The study was carried out between August 1 and November 30, 2022, with a sample size of 200 and a 96% confidence interval. (Salant & Dillman, 1996).

The population of the phenomenological qualitative part of the study consisted of 200 participants who participated in the quantitative research. Among these participants, the study was completed with 30 people using the purposeful random sampling method. The sample size was fixed when both researchers were satisfied. This is because purposive random sampling, commonly used in qualitative research, helps minimize the potential biases of researchers in the sample selection process. Moreover, the fundamental principle in determining the sample size is to continue data collection until saturation is reached and the findings begin to repeat. (Baltacı, 2018).

### Data Collection Tools

Quantitative data were collected face-to-face by the researcher with “Socio-demographic Information Form” and “The Compassion Scale”, and qualitative data were collected face-to-face by the researcher with a semi-structured “Qualitative Questionnaire”. The average data collection time was 60 minutes.

### Socio-demographic Information Form

It consists of nine questions that determine the gender, age, marital status, educational status, place of residence, family type, employment status, degree of closeness with the patient and number of children of the caregivers and six questions that evaluate the duration of caregiving, diagnosis, age, gender of the patient, presence of dependents at home other than the patient and the status of undertaking all care of the patient.

### The Compassion Scale

The original scale was developed by Pommier and adapted into Turkish by Akdeniz and Deniz (Akdeniz &Deniz, 2016). It is a five-point Likert-type, 24-item scale that measures compassion for others with six sub-dimensions (compassion, indifference, awareness of sharing, disconnection, mindfulness, and disconnection). “The items on the scale are rated on a five-point Likert-type scale as follows: Never (1), Rarely (2), Occasionally (3), Frequently (4), and Always (5). “When the total score average is taken on the scale, a minimum of one and a maximum of five points can be obtained. The higher the score is, the higher the level of compassion is. The indifference, disconnection and disconnection sub-dimensions of the scale are calculated by reversing. Cronbach's alpha value on the scale was found to be 0.89. The Cronbach alpha value of the scale for this study is 0.87.

*Quantitative Independent Variables;* Gender, age, marital status, educational status, place of residence, family type, employment status, degree of closeness with the patient, number of children of the caregiver, duration of patient care, diagnosis of the patient being cared for, age of the patient being cared for, gender of the patient being cared for, presence of dependents at home other than the patient, the state of providing all of the patient's care.

*Quantitative Dependent Variables;* The compassion scale

*Qualitative Questionnaire*

The semi-structured questionnaire was created by the researchers in line with their own experiences to examine in depth the feelings and experiences of family members who provide informal care to cancer patients. The questionnaire consists of three open-ended questions aiming to reveal the positive or negative experiences of the caregiving family member about the caregiving process.

1. How would you evaluate the care process psychologically and socially?
2. How would you rate the physical effects of the care process on you?
3. How do you cope with this process?

The study was conducted with people who agreed to participate in the study, who provided informal care to cancer patients, who did not have any psychiatric disease that would require the use of medication, who were older than 18 years of age and who could communicate verbally.

### *Validity and Reliability in Qualitative Findings*

Appropriateness for the purpose was taken into consideration in data collection. In data analysis, the researchers exhibited consistent behavior and provided unbiased evaluation. Both researchers evaluated the semi-structured forms separately, and the standard main themes were included in the reporting process. While determining the main themes, the participants' remarkable statements related to the subject were selected, and irrelevant statements were removed. Then, common expressions were clustered. The main themes were reached by bringing the clusters together. The statements of the participants were directly reflected. The findings provided consistency within themselves. The results obtained are consistent with the research questions. The coded and reported data were filed and stored by the researchers.

### *Data Analysis*

Quantitative data were analysed through SPSS 25.0 statistical software and arithmetic mean, standard deviation, median, minimum, and maximum scores; Also, Mann Whitney U and Kruskal Wallis H tests were performed for statistical analysis of socio-demographic data and compassion fatigue scale.

The qualitative data obtained through a semi-structured written questionnaire were analysed using the content analysis method. During the analysis process, consistent behaviour was exhibited by the researchers and the data were evaluated impartially. In accordance with the literature, firstly, the data were named by the coding method. Then, main themes were reached by combining similar codes. In the reporting, the sentences of the caregivers were written under each main theme as sample data.

### *Ethical Considerations*

The participants who agreed to participate in the study were first asked to fill out the “Informed Consent Form”. The research was conducted following the guidelines outlined in the Declaration of Helsinki and the ethical principles specified by the University’s ethics committee between August and November 2022. The research was conducted with institutional permission obtained from the relevant University’s Social and Humanities Ethics Committee (July 19, 2022, No. 162) and the Provincial Health Directorate (May 17, 2022, No. 3733).

## RESULTS

When we looked at the socio-demographic characteristics of caregivers and cancer patients receiving care, the mean age of caregivers was 42.95±14.47, and the mean age of patients receiving the care was 59.02±14.48. Of the caregivers, 58% were female, 69.5% were married, 38% were literate/primary education graduates, 41% lived in the province, 73.5% had a nuclear family structure, and 64.5% were not working. 32% of the caregivers were children of cancer patients. Among the caregivers, 74.5% had 1-4 children, and 36.5% had been caring for cancer patients for 0-1 year. Of the patients caregivers care for, 25.5% had lung cancer, and 58% were women. 59% of the caregivers had not provided care to patients other than the patient they cared for, and 51.5% did not provide continuous care to their patients (Table 1).

The mean score of compassion scale was 3.91±0.65. The highest sub-dimension mean score was in the compassion sub-dimension (4.15±0.87) (Table 2).

According to Table 3, the mean score of the disengagement subscale (p=.004) was statistically significantly higher in men. However, there was a statistically significant, weak negative correlation between the age of the caregivers and the mean score of the disengagement subscale (p=.050). Indifference, (p=.037) disengagement (p=.046) and disassociation (p=.021) subscale mean scores were statistically significantly higher in single caregivers. Similarly, the mean scores of indifference (p=.025), disengagement (p=.023), and disassociation (p=.043) sub-dimensions and the mean total score of the compassion scale (p=.034) were statistically significantly higher in those who had no children compared to those who had 1-4 children.

The mean score of the disengagement sub-dimension (p=.039) was statistically significantly higher for those with a caregiving period of 6 years or more than those with a caregiving period of 2-3 years.

There was a statistically significant, weak negative correlation between the caregiver’s age and the mean score of the disassociation subscale (p=.037). In addition, the mean score of the disengagement (p=.030) subscale was statistically significantly higher in caregivers who had no other dependents. In addition, the mean score of the disassociation (p=.003) sub-dimension was statistically significantly higher in those who did not undertake the care of the patient continuously.

There was no statistically significant difference between the education level, place of residence, family type, employment status, degree of closeness with the patient, diagnosis of the patient and gender, and the compassion scale score and its sub-dimensions (p>.05).

**Table 1.** Socio-Demographic Characteristics of Participants

| Socio-Demographic Characteristics | Mean ± SD | n | % |
|---|---|---|---|
| **Gender** | | | |
| Woman | | 116 | 58.0 |
| Male | | 84 | 42.0 |
| **Age** | 42.95±14.47 | | |
| **Marital status** | | | |
| Married | | 139 | 69.5 |
| Single | | 61 | 30.5 |
| **Education status** | | | |
| Literate-primary education | | 76 | 38.0 |
| High school | | 65 | 32.5 |
| University | | 52 | 26.0 |
| Postgraduate | | 7 | 3.5 |
| **Place of residence** | | | |
| Province | | 82 | 41.0 |
| District | | 81 | 40.5 |
| Village | | 37 | 18.5 |
| **Family type** | | | |
| Nuclear family | | 147 | 73.5 |
| Extended family | | 53 | 26.5 |
| **Employment status** | | | |
| Yes | | 71 | 35.5 |
| No | | 129 | 64.5 |
| **Degree of closeness with the patient** | | | |
| Spouse | | 51 | 25.5 |
| Child | | 64 | 32.0 |
| Brother | | 24 | 12.0 |
| Daughter-in-law | | 13 | 6.5 |
| Grandson | | 10 | 5.0 |
| Other[1] | | 38 | 19.0 |
| **Number of children of the caregiver** | | | |
| 1-4 | | 149 | 74.5 |
| 5 and above | | 8 | 4.0 |
| No children | | 43 | 21.5 |
| **Duration of patient care** | | | |
| 0-1 year | | 73 | 36.5 |
| 2-3 years | | 70 | 35.0 |
| 4-5 years | | 31 | 15.5 |
| 6 years and over | | 26 | 13.0 |
| **Diagnosis of the patient being cared for** | | | |
| Lung cancer | | 51 | 25.5 |
| Hematological cancer | | 26 | 13.0 |
| Breast cancer | | 30 | 15.0 |
| Gastrointestinal system cancer | | 48 | 24.0 |
| Genitourinary system cancer | | 18 | 9.0 |
| Other[2] | | 27 | 13.5 |
| **Age of the patient being cared for** | 59.02±14.48 | | |
| **Gender of the patient being cared for** | | | |
| Woman | | 116 | 58.0 |
| Male | | 84 | 42.0 |
| **The presence of other dependents at home other than your patient** | | | |
| Yes | | 82 | 41.0 |
| No | | 118 | 59.0 |
| **Continuous care of the patient's entire care** | | | |
| Yes | | 97 | 48.5 |
| No | | 103 | 51.5 |

Other[1](Mother, Father);Other[2](Womb, Brain)

**Table 2.** Mean Scores of Compassion Scale Subscales

| Compassion Scale | Mean±SD | Med (Min-Max) |
|---|---|---|
| Compassion | 4.15±0.87 | 4.25 (1-5) |
| Indifference | 3.79±0.89 | 4 (1.25-5) |
| Awareness of Sharing | 4.00±0.92 | 4 (1-5) |
| Disengagement | 3.71±0.91 | 3.75 (1-5) |
| Mindful Awareness | 3.91±0.84 | 4 (1-5) |
| Relationship Break | 3.89±0.90 | 4 (1-5) |
| **Total Points** | 3.91±0.65 | 4.08 (1.58-5) |

### *Qualitative Research Findings*

In the context of informal caregiving, the main themes identified through the analysis of the three questions aimed at understanding the caregivers' perceived burden are presented below, along with illustrative excerpts from participant responses that informed each theme.

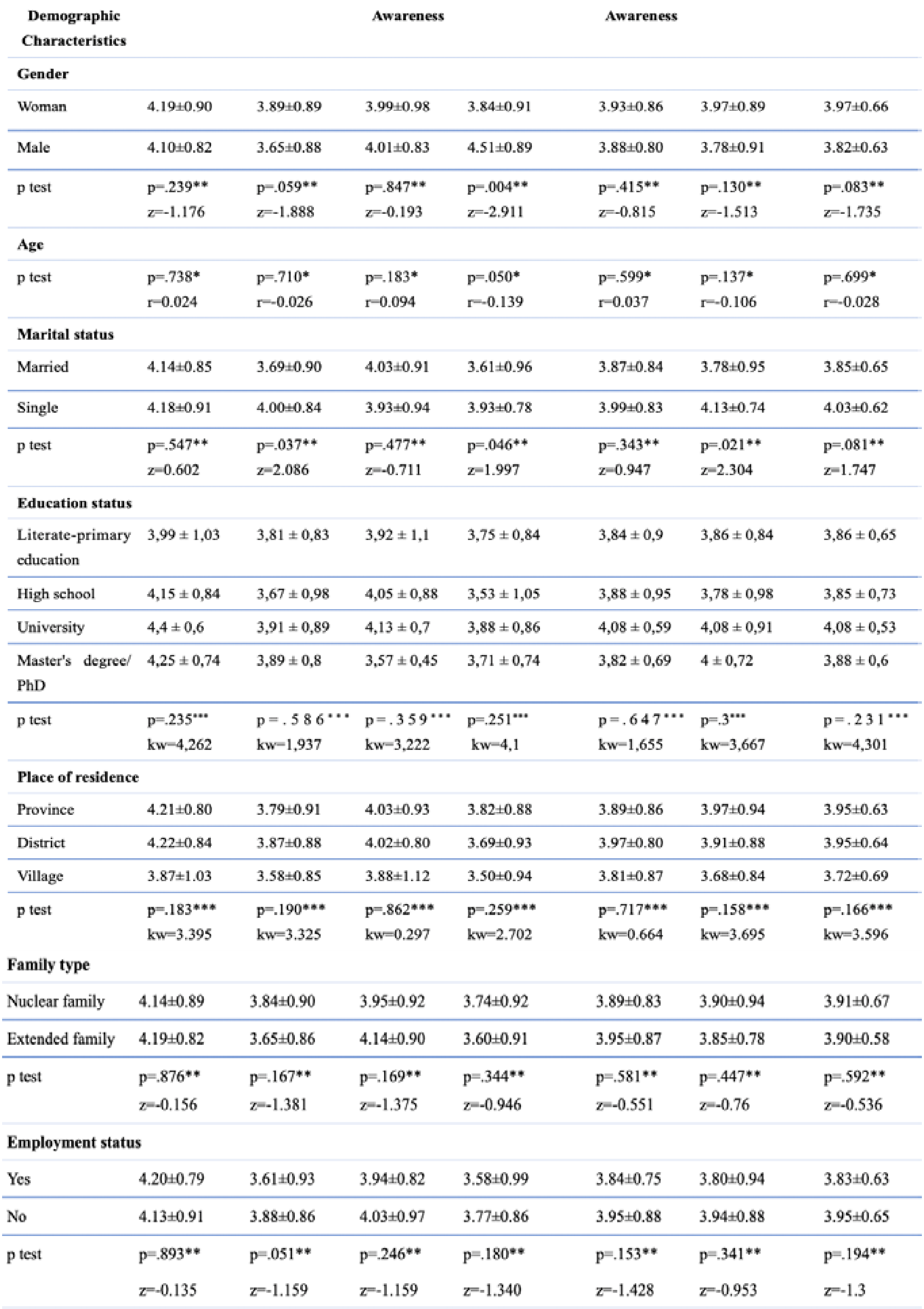
***Theme 1*** Psychological and social dimensions of care burden

In this theme, in which we evaluated the psychological and social effects of care burden, some participants expressed negative feelings such as *unhappy, sad, helpless, uncertainty, intolerant and dissatisfied*, while others expressed that they were *more patient and satisfied*. Participants stated that their focus was all on this disease, that they could not fully enjoy anything, and that they were experiencing stress. However, they said that they learned to be more patient and not worry about small things, and that this was a discovery process for them.

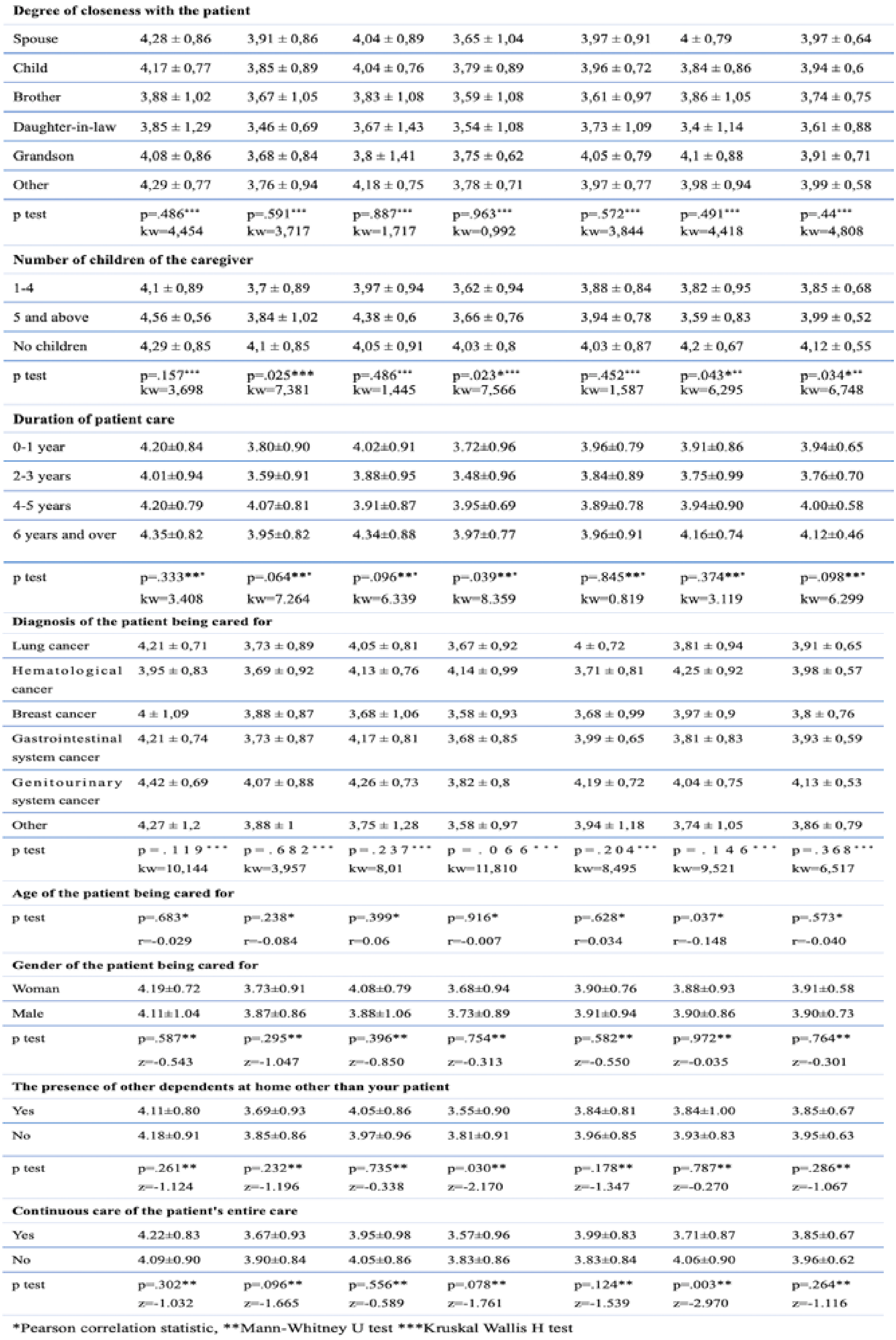
«It›s like having your smile left unfinished, like having your life frozen for three years.» *(Participant 1, F-36y)*

- "I feel sad." *(Participant 9, F-26y)*
- "Life becomes unbearable with an illness." *(Participant 21, F-28y)*
- "How possible it is for a person who is finished and fed up to be happy." *(Participant 30, M-25y)*
- «We were like a fish out of water; we didn›t know what to do.» *(Participant 8, F-46y)*
- "Sometimes repeating the same things over and over again makes you tired, and I feel helpless." *(Participant 16, M-40y).*
- "I cannot find a remedy for my mother." *(Participant 19, F-37y)*
- "It is difficult to determine whether my situation is good or bad at the moment." *(Participant 26, M-40y)*
- «Things that I was not angry about before seem too big to me.» *(Participant 7, F-35y)*
- "Sometimes my endurance level can go down. Sometimes I can react too much." *(Participant 13, F-28y)*
- "Sometimes I can overreact to things I don't realise." *(Participant 14, M-33y)*
- "I get angry faster." *(Participant 24, F-52y)*
- "Sometimes I feel like I can't keep up with everything." *(Participant 3, F-34y)*
- "I wish I could be more supportive." *(Participant 4, F-53y)*
- "I feel inadequate no matter what I do." *(Participant 6, F-28y)*

**Table 3.** Mean Scores of Compassion Scale According to Socio-Demographic Characteristics of Caregivers



| Socio-Demographic Characteristics | Compassion | Indifference | Your shares Awareness | Disengagement | Mindful Awareness | Disassociation | Total Points |
|---|---|---|---|---|---|---|---|
| **Gender** | | | | | | | |
| Woman | 4.19±0.90 | 3.89±0.89 | 3.99±0.98 | 3.84±0.91 | 3.93±0.86 | 3.97±0.89 | 3.97±0.66 |
| Male | 4.10±0.82 | 3.65±0.88 | 4.01±0.83 | 4.51±0.89 | 3.88±0.80 | 3.78±0.91 | 3.82±0.63 |
| p test | p=.239**<br>z=-1.176 | p=.059**<br>z=-1.888 | p=.847**<br>z=-0.193 | p=.004**<br>z=-2.911 | p=.415**<br>z=-0.815 | p=.130**<br>z=-1.513 | p=.083**<br>z=-1.735 |
| **Age** | | | | | | | |
| p test | p=.738*<br>r=0.024 | p=.710*<br>r=-0.026 | p=.183*<br>r=0.094 | p=.050*<br>r=-0.139 | p=.599*<br>r=0.037 | p=.137*<br>r=-0.106 | p=.699*<br>r=-0.028 |
| **Marital status** | | | | | | | |
| Married | 4.14±0.85 | 3.69±0.90 | 4.03±0.91 | 3.61±0.96 | 3.87±0.84 | 3.78±0.95 | 3.85±0.65 |
| Single | 4.18±0.91 | 4.00±0.84 | 3.93±0.94 | 3.93±0.78 | 3.99±0.83 | 4.13±0.74 | 4.03±0.62 |
| p test | p=.547**<br>z=0.602 | p=.037**<br>z=2.086 | p=.477**<br>z=-0.711 | p=.046**<br>z=1.997 | p=.343**<br>z=0.947 | p=.021**<br>z=2.304 | p=.081**<br>z=1.747 |
| **Education status** | | | | | | | |
| Literate-primary education | 3,99 ± 1,03 | 3,81 ± 0,83 | 3,92 ± 1,1 | 3,75 ± 0,84 | 3,84 ± 0,9 | 3,86 ± 0,84 | 3,86 ± 0,65 |
| High school | 4,15 ± 0,84 | 3,67 ± 0,98 | 4,05 ± 0,88 | 3,53 ± 1,05 | 3,88 ± 0,95 | 3,78 ± 0,98 | 3,85 ± 0,73 |
| University | 4,4 ± 0,6 | 3,91 ± 0,89 | 4,13 ± 0,7 | 3,88 ± 0,86 | 4,08 ± 0,59 | 4,08 ± 0,91 | 4,08 ± 0,53 |
| Master's degree/ PhD | 4,25 ± 0,74 | 3,89 ± 0,8 | 3,57 ± 0,45 | 3,71 ± 0,74 | 3,82 ± 0,69 | 4 ± 0,72 | 3,88 ± 0,6 |
| p test | p=.235***<br>kw=4,262 | p=.586***<br>kw=1,937 | p=.359***<br>kw=3,222 | p=.251***<br>kw=4,1 | p=.647***<br>kw=1,655 | p=.3***<br>kw=3,667 | p=.231***<br>kw=4,301 |
| **Place of residence** | | | | | | | |
| Province | 4.21±0.80 | 3.79±0.91 | 4.03±0.93 | 3.82±0.88 | 3.89±0.86 | 3.97±0.94 | 3.95±0.63 |
| District | 4.22±0.84 | 3.87±0.88 | 4.02±0.80 | 3.69±0.93 | 3.97±0.80 | 3.91±0.88 | 3.95±0.64 |
| Village | 3.87±1.03 | 3.58±0.85 | 3.88±1.12 | 3.50±0.94 | 3.81±0.87 | 3.68±0.84 | 3.72±0.69 |
| p test | p=.183***<br>kw=3.395 | p=.190***<br>kw=3.325 | p=.862***<br>kw=0.297 | p=.259***<br>kw=2.702 | p=.717***<br>kw=0.664 | p=.158***<br>kw=3.695 | p=.166***<br>kw=3.596 |
| **Family type** | | | | | | | |
| Nuclear family | 4.14±0.89 | 3.84±0.90 | 3.95±0.92 | 3.74±0.92 | 3.89±0.83 | 3.90±0.94 | 3.91±0.67 |
| Extended family | 4.19±0.82 | 3.65±0.86 | 4.14±0.90 | 3.60±0.91 | 3.95±0.87 | 3.85±0.78 | 3.90±0.58 |
| p test | p=.876**<br>z=-0.156 | p=.167**<br>z=-1.381 | p=.169**<br>z=-1.375 | p=.344**<br>z=-0.946 | p=.581**<br>z=-0.551 | p=.447**<br>z=-0.76 | p=.592**<br>z=-0.536 |
| **Employment status** | | | | | | | |
| Yes | 4.20±0.79 | 3.61±0.93 | 3.94±0.82 | 3.58±0.99 | 3.84±0.75 | 3.80±0.94 | 3.83±0.63 |
| No | 4.13±0.91 | 3.88±0.86 | 4.03±0.97 | 3.77±0.86 | 3.95±0.88 | 3.94±0.88 | 3.95±0.65 |
| p test | p=.893**<br>z=-0.135 | p=.051**<br>z=-1.159 | p=.246**<br>z=-1.159 | p=.180**<br>z=-1.340 | p=.153**<br>z=-1.428 | p=.341**<br>z=-0.953 | p=.194**<br>z=-1.3 |



| | | | | | | | |
|---|---|---|---|---|---|---|---|
| **Degree of closeness with the patient** | | | | | | | |
| Spouse | 4,28 ± 0,86 | 3,91 ± 0,86 | 4,04 ± 0,89 | 3,65 ± 1,04 | 3,97 ± 0,91 | 4 ± 0,79 | 3,97 ± 0,64 |
| Child | 4,17 ± 0,77 | 3,85 ± 0,89 | 4,04 ± 0,76 | 3,79 ± 0,89 | 3,96 ± 0,72 | 3,84 ± 0,86 | 3,94 ± 0,6 |
| Brother | 3,88 ± 1,02 | 3,67 ± 1,05 | 3,83 ± 1,08 | 3,59 ± 1,08 | 3,61 ± 0,97 | 3,86 ± 1,05 | 3,74 ± 0,75 |
| Daughter-in-law | 3,85 ± 1,29 | 3,46 ± 0,69 | 3,67 ± 1,43 | 3,54 ± 1,08 | 3,73 ± 1,09 | 3,4 ± 1,14 | 3,61 ± 0,88 |
| Grandson | 4,08 ± 0,86 | 3,68 ± 0,84 | 3,8 ± 1,41 | 3,75 ± 0,62 | 4,05 ± 0,79 | 4,1 ± 0,88 | 3,91 ± 0,71 |
| Other | 4,29 ± 0,77 | 3,76 ± 0,94 | 4,18 ± 0,75 | 3,78 ± 0,71 | 3,97 ± 0,77 | 3,98 ± 0,94 | 3,99 ± 0,58 |
| p test | p=.486***<br>kw=4,454 | p=.591***<br>kw=3,717 | p=.887***<br>kw=1,717 | p=.963***<br>kw=0,992 | p=.572***<br>kw=3,844 | p=.491***<br>kw=4,418 | p=.44***<br>kw=4,808 |
| **Number of children of the caregiver** | | | | | | | |
| 1-4 | 4,1 ± 0,89 | 3,7 ± 0,89 | 3,97 ± 0,94 | 3,62 ± 0,94 | 3,88 ± 0,84 | 3,82 ± 0,95 | 3,85 ± 0,68 |
| 5 and above | 4,56 ± 0,56 | 3,84 ± 1,02 | 4,38 ± 0,6 | 3,66 ± 0,76 | 3,94 ± 0,78 | 3,59 ± 0,83 | 3,99 ± 0,52 |
| No children | 4,29 ± 0,85 | 4,1 ± 0,85 | 4,05 ± 0,91 | 4,03 ± 0,8 | 4,03 ± 0,87 | 4,2 ± 0,67 | 4,12 ± 0,55 |
| p test | p=.157***<br>kw=3,698 | p=.025***<br>kw=7,381 | p=.486***<br>kw=1,445 | p=.023****<br>kw=7,566 | p=.452***<br>kw=1,587 | p=.043***<br>kw=6,295 | p=.034***<br>kw=6,748 |
| **Duration of patient care** | | | | | | | |
| 0-1 year | 4.20±0.84 | 3.80±0.90 | 4.02±0.91 | 3.72±0.96 | 3.96±0.79 | 3.91±0.86 | 3.94±0.65 |
| 2-3 years | 4.01±0.94 | 3.59±0.91 | 3.88±0.95 | 3.48±0.96 | 3.84±0.89 | 3.75±0.99 | 3.76±0.70 |
| 4-5 years | 4.20±0.79 | 4.07±0.81 | 3.91±0.87 | 3.95±0.69 | 3.89±0.78 | 3.94±0.90 | 4.00±0.58 |
| 6 years and over | 4.35±0.82 | 3.95±0.82 | 4.34±0.88 | 3.97±0.77 | 3.96±0.91 | 4.16±0.74 | 4.12±0.46 |
| p test | p=.333***<br>kw=3.408 | p=.064***<br>kw=7.264 | p=.096***<br>kw=6.339 | p=.039***<br>kw=8.359 | p=.845***<br>kw=0.819 | p=.374***<br>kw=3.119 | p=.098***<br>kw=6.299 |
| **Diagnosis of the patient being cared for** | | | | | | | |
| Lung cancer | 4,21 ± 0,71 | 3,73 ± 0,89 | 4,05 ± 0,81 | 3,67 ± 0,92 | 4 ± 0,72 | 3,81 ± 0,94 | 3,91 ± 0,65 |
| Hematological cancer | 3,95 ± 0,83 | 3,69 ± 0,92 | 4,13 ± 0,76 | 4,14 ± 0,99 | 3,71 ± 0,81 | 4,25 ± 0,92 | 3,98 ± 0,57 |
| Breast cancer | 4 ± 1,09 | 3,88 ± 0,87 | 3,68 ± 1,06 | 3,58 ± 0,93 | 3,68 ± 0,99 | 3,97 ± 0,9 | 3,8 ± 0,76 |
| Gastrointestinal system cancer | 4,21 ± 0,74 | 3,73 ± 0,87 | 4,17 ± 0,81 | 3,68 ± 0,85 | 3,99 ± 0,65 | 3,81 ± 0,83 | 3,93 ± 0,59 |
| Genitourinary system cancer | 4,42 ± 0,69 | 4,07 ± 0,88 | 4,26 ± 0,73 | 3,82 ± 0,8 | 4,19 ± 0,72 | 4,04 ± 0,75 | 4,13 ± 0,53 |
| Other | 4,27 ± 1,2 | 3,88 ± 1 | 3,75 ± 1,28 | 3,58 ± 0,97 | 3,94 ± 1,18 | 3,74 ± 1,05 | 3,86 ± 0,79 |
| p test | p=.119***<br>kw=10,144 | p=.682***<br>kw=3,957 | p=.237***<br>kw=8,01 | p=.066***<br>kw=11,810 | p=.204***<br>kw=8,495 | p=.146***<br>kw=9,521 | p=.368***<br>kw=6,517 |
| **Age of the patient being cared for** | | | | | | | |
| p test | p=.683*<br>r=-0.029 | p=.238*<br>r=-0.084 | p=.399*<br>r=0.06 | p=.916*<br>r=-0.007 | p=.628*<br>r=0.034 | p=.037*<br>r=-0.148 | p=.573*<br>r=-0.040 |
| **Gender of the patient being cared for** | | | | | | | |
| Woman | 4.19±0.72 | 3.73±0.91 | 4.08±0.79 | 3.68±0.94 | 3.90±0.76 | 3.88±0.93 | 3.91±0.58 |
| Male | 4.11±1.04 | 3.87±0.86 | 3.88±1.06 | 3.73±0.89 | 3.91±0.94 | 3.90±0.86 | 3.90±0.73 |
| p test | p=.587**<br>z=-0.543 | p=.295**<br>z=-1.047 | p=.396**<br>z=-0.850 | p=.754**<br>z=-0.313 | p=.582**<br>z=-0.550 | p=.972**<br>z=-0.035 | p=.764**<br>z=-0.301 |
| **The presence of other dependents at home other than your patient** | | | | | | | |
| Yes | 4.11±0.80 | 3.69±0.93 | 4.05±0.86 | 3.55±0.90 | 3.84±0.81 | 3.84±1.00 | 3.85±0.67 |
| No | 4.18±0.91 | 3.85±0.86 | 3.97±0.96 | 3.81±0.91 | 3.96±0.85 | 3.93±0.83 | 3.95±0.63 |
| p test | p=.261**<br>z=-1.124 | p=.232**<br>z=-1.196 | p=.735**<br>z=-0.338 | p=.030**<br>z=-2.170 | p=.178**<br>z=-1.347 | p=.787**<br>z=-0.270 | p=.286**<br>z=-1.067 |
| **Continuous care of the patient's entire care** | | | | | | | |
| Yes | 4.22±0.83 | 3.67±0.93 | 3.95±0.98 | 3.57±0.96 | 3.99±0.83 | 3.71±0.87 | 3.85±0.67 |
| No | 4.09±0.90 | 3.90±0.84 | 4.05±0.86 | 3.83±0.86 | 3.83±0.84 | 4.06±0.90 | 3.96±0.62 |
| p test | p=.302**<br>z=-1.032 | p=.096**<br>z=-1.665 | p=.556**<br>z=-0.589 | p=.078**<br>z=-1.761 | p=.124**<br>z=-1.539 | p=.003**<br>z=-2.970 | p=.264**<br>z=-1.116 |

*Pearson correlation statistic, **Mann-Whitney U test ***Kruskal Wallis H test

- I think I have become a more understanding person." *(Participant 3, F-34y)*
- "My perspective on life has changed; I have learnt to look at life more moderately and more positively." *(Participant 8, F-46y)*
- "One learns to be more patient." *(Participant 20, M-51y*)
- "When you notice that we are faced with a reality like death, you realise that some things are not worth getting angry about." *(Participant 28, F-22y)*
- «I am satisfied.» *(Participant 11, F-23y)*
- "I am satisfied with everything now." *(Par-ti-cipant 15, F-52y)*
- "Thank God." *(Participant 17, F-30y)*
- "I am delighted." *(Participant 27, M-26y)*

***Theme II*** Physical dimension of care burden

When we evaluate the physical effects of care burden in informal caregivers, the symptom of *fatigue draws* attention. Participants reported feeling absent-minded at times, wanting to sleep, feeling the burden, and that the process was tiring and difficult, especially as it was long.

- «There is fatigue from time to time. But I have a sense of responsibility and love for my patient.» *(Participant 5, F-21y)*
- "Sometimes, of course, there is fatigue." *(Participant 10, F-47y)*
- "I feel physical fatigue and mental fatigue, but I strive to do more." *(Participant 22, M-27y)*
- "I get tired from time to time, but I still do not give up caring." *(Participant 27, M-26y)*

***Theme III*** Strategies for coping with care burden

It was observed that the participants used strategies such as their families, beliefs and social activities to cope with the care burden they experienced during this process. Participants' coping strategies included participating in social activities, taking care of the child or grandchild, attending to household chores, being patient with faith, praying, talking to relatives, and knowing that their family is there for them.

- "I devoted myself to my work, my children and my family." *(Participant 3, F-34y)*
- "I cope by taking care of my children and grandchildren." *(Participant 4, F-53y)*
- "Having a three-year-old granddaughter keeps me alive." *(Participant 18, M-65y)*
- "I get support from my family." *(Participant 23, F-46y)*
- «Believing that good and evil come from God and acting accordingly.» *(Participant 16, M-40y)*
- "One often remembers the role of fate in this process." *(Participant 20, M-51y)*
- "With faith." *(Participant 25, M-55y)*
- "I do the best I can and leave the rest to God and pray a lot." *(Participant 29, F-22y)*
- «I try to spend my days well; I try to beautify them with activities.» *(Participant 2, F-33y)*
- "I give myself to cleaning; cleaning gives my mind a rest." *(Participant 7, F-35y)*
- "By doing things that are good for my soul, such as travelling, swimming and reading books whenever I have the opportunity." *(Participant 12, F-48y)*
- "By taking care of housework, travelling." *(Participant 13, F-28y)*

## DISCUSSION

Cancer, called the epidemic disease of the age, affects the vital activities of the patients as well as their family members and close environment who are obliged to take care of them physically, psychologically and socially (Ozdemir &Ozkaraman, 2022). When the qualitative findings of this study are evaluated in general, we can say that informal caregivers experience a "burden of care". The caregiver's age, gender, education-employment status, economic status, ethnic origin, religious belief, relationship with the patient, living together with the patient continuously, having other responsibilities other than the patient, having caregiving responsibilities not only in one subject but in various subjects (economic, social, spiritual, physical, etc.) or the patient's cancer stage, prognosis, dependency status may increase the burden of care (Johansen,Cvancarova & Ruland, 2018). In many studies conducted with formal/informal caregivers of cancer patients, the care burden of caregivers was found to be medium/high (Johansen et al., 2018; Thana, Lehto, Sikorskii & Wyatt, 2021). Increased care burden reduces the quality of care provided to the patient.

As the burden of caregivers increases, people's physical and psychological health may be affected, and they may experience feelings such as helplessness, guilt, fear of losing their loved one, and sadness (Pace et al., 2019). Informal caregivers within the scope of the study described the burden of care they experienced while caring for the cancer patient and stated that they felt psychologically "unhappy", "sad", "helpless", and "intolerant". They expressed that they felt "uncertainty" about the treatment process of the cancer patient they cared for and physically felt "tired". Numerous studies involving family members who provide care for cancer patients have reported that caregivers often experience high levels of fatigue. As the burden of care increases, caregivers tend to exhibit more pronounced physical and psychological symptoms. Additionally, emotions such as pessimism, fear, reluctance, hopelessness, and helplessness regarding their future, particularly in relation to their professional and social lives, become more prevalent. These challenges are also accompanied by negative changes in family relationships (Ozdemir &.Ozkaraman, 2022; Johansen et al., 2018). Another psychological dimension in the study is the expressions of "dissatisfaction" and "inadequate". In the relevant literature, it has been stated that caregivers have many roles, such as problem-solving, providing emotional support, and coordinating the care process, and may experience feelings of inadequacy and failure from time to time while fulfilling their roles (Polat & Atamer, 2020). It is known that the uncertainty experienced in individuals can increase mental distress by arousing an adverse effect, and subsequently, feelings such as anger and intolerance arise. In the literature, this situation is referred to as "intolerance of uncertainty" (Y.Gu, S.Gu, Lei & Li, 2020).

While evaluating the psychological dimension of care burden, it was concluded that some participants were "satisfied" and behaved more patiently. In a systematic review study by Reigada (2015), it was reported that caregivers of palliative care patients, the majority of whom had cancer, considered the caring role as a natural act, possibly imposed by society and fulfilling a moral obligation (Reigada,Pais-Ribeiro, Novellas, Tavares &Gonc Alves, 2015).In Turkey, the family plays a vital role in patient care. This is a tradition; caring for a sick individual in the family is considered an obligation. Caregivers try their best because of their moral obligation, readiness and ability, and religious beliefs. They may also experience the satisfaction and happiness of having helped another person. In addition, the satisfaction of the individuals coincides with a high level of compassion. In a study conducted with parents caring for children diagnosed with cancer, it was determined that parents were individually more patient and mature during the treatment process (Cug, 2021). Marcela (2022), in her study with family members caring for individuals with chronic diseases, stated that families saw the process as an opportunity for personal development (Blinka, Li, Sheehan, Rhodes & Rot, 2022).

The coping strategies adopted by participants to manage the burden of care during this process were identified as reliance on family support, faith, and engagement in social activities. Existing literature suggests that early support interventions involving family members can reduce caregiver burden and have a positive impact on the caregiving experience. (McDonald et al., 2017). In another study, it was stated that caregivers received support and comfort from their beliefs and traditions during the process (Pickard, Witt & Aitch, 2018). The results of this study show that nurses should psychologically support caregivers of cancer patients.

In the study, we can say that the compassion level of our participants who provide informal care to cancer patients is high. In the relevant literature, there is not any study on the level of compassion of informal caregivers. However, contrary to the findings of the study, Okoli et al. (2019) found the compassion of healthcare professionals at a low level in their study (Okoli et al., 2020). In his study of healthcare professionals caring for cancer patients, Hunt (2019) observed that one-fourth of the participants had a high level of compassion (Hunt et al., 2019). Jarrad (2020) found that the compassion levels of nurses were low in his study on oncology nurses (Jarrad &Hammad, 2020). We can say that informal caregivers in the study are more understanding, caring and compassionate towards themselves and others, because the "compassion" sub-dimension, which positively affects the level of compassion of the participants, is high. Compassion is the individual's understanding and caring towards himself/herself and others (Akdeniz & Deniz, 2016).

Informal caregivers are mostly family members of individuals with cancer and are faced with tasks they have not done before. They take an active role in the patient's treatment process, physical care and psychological support (Orbay et al., 2022). Although the compassion levels of the participants in the study were high, the mean indifference, disconnection and disengagement scores of single people were higher than those of married people, and those without children were higher than those with 1-4 children. In other words, the mean scores of the sub-dimensions that have a negative effect on the level of compassion are higher. In the literature, one of the factors that may affect the compassion fatigue of healthcare workers who provide professional care is related to "being single" (Sacco, Ciurzynski, Harvey & Ingersoll, 2015).

In addition, the fact that these findings, which negatively affect the level of compassion, were higher in people without children compared to those with children may be explained by the fact that having children may reinforce the sense of responsibility and compassion.

The mean score of the disengagement/disconnection sub-dimension was found to be higher in men in the study. The literature states that women believe that they should be more compassionate both cognitively and instinctively (Nas & Sak, 2023). Although there was no significant difference in the study, the higher level of compassion in women supports this finding.

In the study, the mean scores of the disconnection sub-dimension of caregivers with six years or more were significantly higher. Caregivers witness the pain, suffering and hopelessness of the cancer patient. Therefore, caregivers who meet the physical needs of cancer patients for a long time may also need intensive psychological and physical care (Yu, Jiang & Shen, 2016). As a result, we can say that the use of the disconnection mechanism, considered an ineffective coping method, increases as the duration of care increases. In this case, it is important to teach more effective coping mechanisms to informal caregivers.

When we examined the status of the informal caregiver participants who were obliged to care for someone other than the cancer patient (having a chronic disease, having a child, etc.), the mean score of the disengagement sub-dimension of those who were not obliged to care for someone other than the patient, and the disassociation score of those who did not provide continuous care to the cancer patient were significantly higher. When the literature is examined, it is reported that nurses, while helping the suffering patient, sometimes unknowingly establish an intense emotional bond, identify with them, and develop the thought of “I am important, I am necessary for the suffering person”, and think that they cannot be separated from that person; and if they are separated, there will be no one to help the patient (Lombardo & Eyre, 2011). In parallel with the literature, the findings of the study suggest that the bond between the caregiver and the patient may be stronger when the length of time spent with the patient and the caregiver’s responsibility for physical and psychological treatment are considered. Caregivers who do not provide continuous care or caregivers who are not obliged to care for someone else may not have a strong bond with the patient.

In the study, a weak negative relationship was found between age and the sub-dimensions of disengagement and disassociation, which negatively affect the level of compassion. This result suggests that there is a positive relationship between age and compassion level and that the sense of compassion increases with increasing age. Similarly, the literature reported a positive relationship between the sense of compassion and age (Hacıkeleşoğlu & Kartopu, 2017).

### *Limitations*

This study has several limitations, including being conducted at a single institution, involving only participants who volunteered during a specific time frame, and relying on self-reported data, which collectively restrict the generalizability of the results.

## IMPLICATION FOR NURSING PRACTICE

The results of this study show that nurses should psychologically support caregivers of cancer patients. because, it was concluded that although caregivers had high levels of compassion and caring, they felt unhappy, uncertain, tired, inadequate, and intolerant from time to time and experienced psychological problems and care burden. It was observed that they tried to cope with these negative feelings through family support, religious beliefs and participation in social activities.

In line with these results, it is recommended that nurses should recognise the difficulties experienced by informal caregivers during caregiving, provide counselling for them to overcome these difficulties and make positive contributions to their lives with psychological and social support programmes.

Consideration of these psychological and physiological burdens in informal caregivers by nurses in the patient care process will support the holistic approach. The patient care process offered with the understanding that “the patient is a whole with his/her family” will positively affect health service delivery and reveal quality health service.

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