

Original Article

Evaluation of Care Burden and Quality of Life of Caregivers of Patients with Stroke

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Abstract

Background: Stroke affects lives of both the patients and their caregivers considerably.

Aims: This study was conducted in order to determine care burden and quality of life of the caregivers of the patients with stroke.

Methodology: The current study which was descriptively done in order to assess care burden and quality of life of the caregivers of the patients with stroke was carried out at a Neurology Clinics of a state hospital. The sample of the study was consisted of 121 caregivers. The data were collected with personal information form, the Barthel Index, Caregiver Burden Scale and Quality of Life Scale (SF-36).

Results: The patients demonstrated poor health on the SF-36, with a mean score of 52.91 ± 14.25 . The average burden score of caregivers was 48.66 ± 10.61 . A significant negative correlation was found between QOL and Caregiver burden ($p < 0.001$).

Conclusions: It was determined that as the care burden of the caregivers increased their quality of life decreased. The nurse caregiving to the patients with stroke should provide their caregivers with information about the care to be offered at clinical and domestic settings will positively affect the quality of lives of both caregivers and care-receivers.

Key Words: Caregiver, care-giving burden, stroke, quality of life, nursing

Introduction

With the aging of the societies; the need for caregivers has increased all over the world (WHO, 2002; Atagun et al., 2011). Although family members play a key role in providing care for the sick member of the family; the change in cultural and economic conditions has complicated the role of the caregivers (Zarit, 2004; Atagun et al. 2011). Becoming a caregiver is neither a chosen situation nor a planned situation. Therefore; adaptation with this situation occurs after the situation has happened (Eicher & Batshaw, 1993; Atagun et al., 2011). The direction of this role is determined by the course of the diseases for which care is given

and may grow difficult (Atagun et al., 2011). Being one of the chronic diseases; stroke causes important problems both for individual, family and the society. Stroke is a traumatic disease that develops suddenly and catches the patients and their families/caregivers off guard in terms of coping with the disease. That is why both the patients who suffer from stroke and their families experience changes in their lives and family members face complex problems unpreparedly (Akdemir, 1996; Lutz & Young, 2010).

According to the data of the World Health Organization; approximately 15 million people worldwide have a stroke each year and of these, 5

million die and another 5 million are permanently disabled; becoming a burden for the economy of their country, society and families. In the developed countries; heart diseases and stroke are the primary mortality cause among adult male and female population. Stroke is among the important morbidity and mortality causes in Europe. In the recent years; stroke has become one of the main death causes in the developing countries, too. In our country; among the top 10 death causes encountered in all age groups nationwide, cerebrovascular diseases are ranked at the second place with a rate of 15.0% (Ministry of Health, 2010).

Stroke affects not only the patients but also lives of their caregivers considerably. Caregivers of the stroke patients should be supported with physical and psychosocial trainings because caregivers may undergo excessive burden depending on both their situations and patients' situation. That excessive burden may negatively affect health status, social lives and wellbeing of the caregivers. Nearly 80% of the stroke patients return home after hospital discharge and are obliged to permanently or temporally receive help and assistance from someone. The help is generally to be offered by one of those living together with the patient, spouse or a child. After a stroke; caregivers should provide personal care to the patients, help them continue the activities of daily life and offer them medical support and social service (Opara & Jaracz, 2010). As a conclusion; in the wake of a stroke, caregivers experience adaptational complications in care (King et al., 2010). Since caregivers/families are the most important members of home care; the fact that burden of the caregiver is results in insufficient homecare support (Kuçukguçlu, Esen, & Yener, 2009; Ozer, 2010). Due to inadequate care; both burden of the caregivers increases and their quality of life are negatively affected. The studies; most of which have been crosssectionally conducted, demonstrated that -after a stroke- 25% of the close family members experienced high level of burden in the first month, 28% in the second month, 28-39% in the third month, 31-40% between the fourth and sixth months and 51% in a year (Opara & Jaracz, 2010; Van Exel et al., 2004; Ilse, Feys, de Wit, Putman & de Weerd, 2008; Blake, Lincoln & Clarke, 2003; Bugge, Alexander & Hagen, 1999).

In a study conducted with those who given care to the patients with stroke; it was explored that care burden of the caregivers was at a moderate level (Mollaoglu, Tuncay & Fertelli, 2011). In another study done on the caregivers of the patients that needed home care; it was found out that as dependency level in the activities of daily living of the patients increased so did time dependency burden of the caregivers but their emotional burden decreased (Tasdelen & Ates, 2012).

As the burden of the caregivers of the stroke patients increase; changes are seen in their life styles and as a result their quality of life is negatively affected. In a study done, it was reported that life styles of the 95% of the patient relatives went through changes following a stroke (Periard & Ames, 1993). Many studies conducted with those who provided care for a patient with a chronic disease pointed out that quality of life of the caregivers decreased as their burden increased (Morimoto, Schreiner & Asano, 2003; Kalav, 2011; Tel, Demirkol, Kara & Aydin, 2012).

Care is one of the most basic functions of nursing. When a long term care is needed, this function undertakes to family members of the patients. Most of the family members do not have all the necessary qualifications, knowledge and skills so as to provide long term care. Nurses who are members of the professional health team are supposed to prepare caregivers from the moment when diagnosis is made to the hospital discharge for home care. Nurses should observe caregivers' communication with the patient and their knowledge, attitudes and behaviors and help caregivers develop a positive attitude by focusing on their abilities. Nurses should offer the necessary support and should activate the appropriate support groups so that the caregivers do not endanger own physical and psychological health and experience less care burden while maintaining the required care for the patients. We are of the opinion that if nurses teach caregivers about manual skills which are necessary for the care and about facilitative methods that enable patients to do daily activities and give hospital discharge training about basic nursing practices; then burden of the caregivers may be lessened and their quality of life may be increased (Asiret & Kapucu, 2012). Caregivers should absolutely be provided with physical and emotional supports (Eyigor, 2007). In light of these

explanations; the current study was conducted in order to determine care burden and quality of life of the caregivers of the patients with stroke.

Methods

The current study which was descriptively done at a Neurology Clinics of a state hospital. The population of the study was composed of the caregivers of the patients who were diagnosed with and were treated for stroke at Neurology Clinics. The sample of the study was consisted of 121 caregivers who volunteered to participate and were mentally competent and able to communicate. The data were collected face-to-face interviews conducted by researchers. The researchers introduced the questionnaire to the participants and explained the material covered. The average time for completing the questionnaires was 25-30 minutes. All of the participants completed the questionnaires.

Data collection tools

The data were collected with a Personal Information Form, the Barthel Index, Caregiver Burden Scale and Quality of Life Scale SF-36.

Personal Information Form: The form was composed of a total of 15 questions about caregivers' socio-demographic characteristics and caregiver role.

Barthel Index (BI): The Barthel Index, whose validity and reliability have been proved in various patient groups and various countries, is a scale that basically assesses mobility and self-care activities. It includes 10 items that measure physical independence in activities of daily living (motion: transferring from wheelchair, walking on a level surface and going up and down stairs; personal cleanness and dressing; bathing, meeting toilet needs and eating; excretion: urinary control and fecal control). BI was modified by Shah (1989) introducing a five-step scoring system to increase the sensitivity of the index. BI was also adapted for the Turkish people and the index was shown to be valid and reliable for patient groups with stroke and spinal cord injury (Kucukdevesi, 2005).

The score of the index ranges between 0 and 100 and a score of 0-20 indicates total dependence, a score of 21-61 indicates severe dependence, a score of 62-90 indicates moderate dependence and

a score of 91-99 indicates slight dependence while a score of 100 indicates total independence. In the studies where Barthel Index has been used; a score of 60 is baseline and scores over 60 account for the ability to function independently (Langhammer & Stanghelle, 2000; Tuncay & Mollaoglu, 2006; Mollaoglu, Tuncay & Fertelli, 2011).

Zarit Caregiver Burden Scale: Scale was adapted to Turkish by Inci. This instrument, which is used to evaluate the difficulties experienced by the caregivers of individuals in need of care, is comprised of 22 items.

The scale includes a 4-point Likert scale ranging from 0 to 4, indicating 'never', 'rarely,' 'sometimes,' 'frequently' and 'almost always', respectively. The scale yields a minimum score of 0 and a maximum score of 88. The items in the scale are mostly related to social and emotional domains.

A high score from the scale indicates that the level of difficulties experienced by the caregiver is high. A factor analysis of the Caregiver Burden Scale showed that this instrument could be used to indicate a single dimension (İnci, 2008).

In this study, the Cronbach's alpha index for Caregiver Burden Scale was 0.88.

SF-36 Quality of Life: In all the patients, quality of life was assessed using the SF-36 questionnaire (Ware & Sherbourne, 1992). The SF-36 is a validated and commonly used instrument for the self-evaluation of physical and mental health. Quality of Life Scale Short Form 36 was designed by Ware in 1987 in order to be used in clinical practice and studies, assessment of health policies and the general population studies (Ware & Sherbourne, 1992).

The feasibility and validity and reliability studies of this scale were confirmed by Pınar (1995). It is a Likert scale that is composed of subscales and assesses four major health domains (functional status, wellbeing, perceptions of health and global quality of life) and nine health domains through 36 items. The items are summed per scale and transformed into scores between 0 (poor health) and 100 (optimal health) (Pınar, 1995). In the study by Pınar, the internal consistency range was .92 for all the items. Cronbach's alpha was .92 in this study.

Data Assessment

SPSS (Statistical Package for Social Sciences) for Windows 11 software package was used for statistical analysis of study data. During analysis of data, descriptive statistical data (Mean, Standard deviation), Kruskal-Wallis, Mann Whitney-U and independent samples t-test were used for between-group comparisons. Pearson's Correlation analysis was used for the analysis of associations between scales and sub-scales. The results were interpreted using a confidence interval of 95% and significance level set at $p < 0.05$.

Ethical Considerations

Ethical requirements were met during the conduct of the study. Written permission was obtained from the manager of the hospital to conduct this study. Patients were informed about the purpose of the research and each participant gave informed consent. The participants were assured of their right to refuse to participate or to withdraw from the study at any time. Anonymity and confidentiality of patient data were guaranteed.

Results

It was found out that 45.5% of the caregivers were aged between 35 and 49; 71.7% were female, 47.9% had primary school degree, 83.5% were married, 62.8% were housewives and 68.6% had moderate economic status. When the caregivers were investigated in terms of role load; it was noted that 43.8% had a health problem of any kind, 56.2% provided care for those who were their sons or daughters, 34.7% provided care for the patient for ≥ 6 months, the role of the 43.2% of the participants was only to give care for the patient, 47.1% received assistance from other members of the family while providing care, patients of the 56.2% were bedridden and 59.5% lived together with the patient at the same household.

The subjects demonstrated poor health on the SF-36, with a mean score of 52.91 ± 14.25 for this sample. Table 1 illustrates that the average burden score of caregivers was 48.66 ± 10.61 .

A significant negative correlation was found between QOL and Caregiver burden, indicating lower QOL with higher burden intensity ($p < 0.001$) (Table 2).

It was found out that there were significant differences between caregivers' burden and their health problems, assessment of the patients' health ($p < 0.001$), role load, having someone as assistant ($p < 0.05$). Also; there were significant differences between caregivers' functional status and having health problems ($p < 0.001$), role load, financial vulnerability and living with the patient at the same household ($p < 0.01$). Also; there were significant differences between caregivers' wellbeing and age, having health problems ($p < 0.001$), degree of kinship, role load, assessment of patients' health ($p < 0.05$). Also; there were significant differences between caregivers' perceptions of health and having health problems ($p < 0.001$), age, role load, financial vulnerability ($p < 0.01$), economical status, degree of kinship, having someone as assistant ($p < 0.05$). Also; there were significant differences between caregivers' global quality of life and age, having health problems, role load ($p < 0.001$), financial vulnerability ($p < 0.01$), educational status, economical status, degree of kinship, living with the patient at the same household (Table 3 and 4).

Discussion

Stroke happens suddenly and unexpectedly in human lives. The patients are hospitalized in comatose and discharged in semi-comatose. These results indicate that caregivers are affected by the disease as much as the patients. In this study, the average caregiver burden score was 48.66 ± 10.61 . In a study conducted by Schreiner et al. (2006), the intersecting value of Zarit's Scale was 24–26. In a study conducted by Maldonado and Urizar (2007), scale scores between 0 and 26 were regarded as 'no burden', scale scores between 27 and 33 were regarded as 'moderate burden' and those between 34 and 88 were regarded as 'severe burden'. In accordance with these values, burden of the caregivers in the research group was quite high. The subjects demonstrated poor health on the SF-36, with a mean score of 52.91 ± 14.25 for this sample. In a study conducted; it was noted that quality of life was rather low among all of the individuals in the family (Karabuga-Yakar & Pınar, 2013). In a study conducted by Jonsson et al. (2005), too, it was found out that emotional and mental domains of quality of life among the caregivers were low and the most important determinants of the quality of life were age of the caregivers and patients' functional status.

Table 1. The Mean Scores of Quality of Life Scale (SF-36) and Zarit Caregiver Burden Scale of Caregivers (n=121)

| Scales | Range | | X± SD |
|--------------------------------|-------------------------|-------------------------|--------------|
| | Possible (Min.-Max.) | Obtained (Min.-Max.) | |
| Quality of Life Scale | | | |
| Functional status | 0-100 | 12-100 | 58.54±18.63 |
| Wellbeing | 0-100 | 11-95 | 47.96±1.62 |
| Perceptions of health | 0-100 | 8-85 | 52.33±14.17 |
| Global quality of life | 0-100 | 22-88 | 52.91±14.25 |
| Caregiver Burden Scales | 0-88 | 13-66 | 48.66 ±10.61 |

Table 2. The correlation between caregivers' care burden and quality of life (n=121)

| Quality of Life Scale | Zarit Caregiver Burden Scale | |
|------------------------|------------------------------|------|
| | r | p |
| Functional status | -.291 | .001 |
| Wellbeing | -.487 | .000 |
| Perceptions of health | -.257 | .004 |
| Global quality of life | -.396 | .000 |

Recent studies have shown that being a caregiver of a patient is a stressful responsibility (İnci, 2006). A significant negative correlation was found between QOL and Caregiver burden, indicating lower QOL with higher burden intensity in present study. In other studies conducted, there were important relations between a low life quality and a perception of higher burden (Foldemo, Gullberg, Ek & Bogren, 2005; McCullagh, Brigstocke, Donaldson & Karla, 2005; Tel, Demirkol, Kara & Aydın, 2012). In another study conducted with stroke patients; it was determined that quality of life of the caregivers decreased as their burden increased (Kalav, 2011). The role of decreases the life quality of caregivers to a great extent.

When quality of life of the caregivers were examined in relation with socio-economic and characteristics that would affect their quality of life and burden; it was demonstrated in this study that as age of the caregiver increased so did burden but

their quality of life decreased. It was determined that there was no significant difference between age and burden; yet, an important difference existed between global quality of life and wellbeing and perceptions of health. In a study done with the family members who provided care to the patients diagnosed with stroke; it was indicated that those caregivers aged ≥ 52 years had high burden but low quality of life (Kalav, 2011).

In a study conducted by Yildirim, Engin and Baskaya (2013) with the caregivers of stroke patients; it was understood that those caregivers aged ≥ 55 years underwent higher level of burden in time dependency. Many studies carried out with caregivers, too, showed that burden of the older caregivers was higher; which concurred with the findings of the current study (Mollaoglu, Tuncay & Fertelli, 2011; Urizar & Maldonado, 2006; Chien, Chan, Morrissey & Thompson, 2005).

When the mean scores of the caregiver burden scale and SF-36 scale were analyzed in terms of gender, there was no significant difference between the groups. In the study of Kalav (2011), too, it was seen that no significant difference was found between sex of the caregivers and their burden and quality of life. In many studies conducted with those who gave care for the patients with stroke; it was determined that sex did not affect caregivers' burden significantly (Han & Haley, 1999; van den Heuvel, de Witte, Schure, Sanderman & Meyboom-de Jong, 2001; McCullagh, Brigstocke, Donaldson & Karla, 2005; Yildirim, Engin & Baskaya, 2013; Tel, Demirkol, Kara & Aydın, 2012).

When the educational status of the caregivers was examined; it was detected that those illiterate had higher burden as compared to other groups. When quality of life was analyzed, it was seen that those with university degrees had higher global quality of life. There was no significant difference between educational status and burden while the only difference existed between global quality of life and educational status. Results of many studies conducted with caregivers demonstrated similar results to ours; too (Maldonado & Urizar, 2007; Yildirim, Engin & Baskaya, 2013; Mollaoglu, Tuncay & Fertelli, 2011; Kalav, 2011; Tel, Demirkol, Kara & Aydın, 2012).

In the study, burden of the married caregivers was higher than the single and widowed/divorced. As for quality of life; it was higher in the single group and it was found out that there was no statistically significant difference between marital status and burden and quality of life. In a study conducted by Kalav (2011); it was pointed out that burden of the widowed/divorced was lower and their quality of life was higher. Another study indicated that burden of the married was higher and quality of life of the single was higher as compared to other groups; which concurred with our results (Tel, Demirkol, Kara & Aydın, 2012).

It was found out that burden of those whose economic status was unsatisfactory was higher and there was no significant difference between economic status and burden. However; it was seen that quality of life of those whose economic status was satisfactory was higher as compared with others and there was statistically significant

difference between economic status and perceptions of health and global quality of life. The study that Kalav (2011) conducted reported that burden of those whose income was less than expense was higher than those whose income was equal to expense but there was no statistically significant difference between the two groups. Quality of life of those whose income was less than expense was lower than those whose income was equal to expense and the difference between the groups was statistically significant. In the study conducted by Yildirim, Engin and Baskaya (2013), too, it was determined that there was no significant difference between burden and perceived income level of the caregivers.

It was noted that those with any kind of health problem had higher burden but lower quality of life and there was statistically significant difference between having a health problem and burden and quality of life. In the study of Mollaoglu, Tuncay and Fertelli (2011); it was emphasized that burden of the caregivers with a health problem was higher.

In the current study; it was seen that burden of the caregivers who were the spouses of the patients was higher than other groups but their quality of life was lower; on the other hand there was no significant difference between degree of kinship and burden and functional status of quality of life whereas statistically significant difference occurred between degree of kinship and wellbeing, perceptions of health and global quality of life. The findings of the study of Kalav (2011) were in line with ours.

In terms of role load of the caregivers; burden of those who provided only patient-care had lower care burden but higher quality of life and it was seen that there was statistically significant difference between role load and care burden and quality of life.

It was found out that caregivers who did not receive any assistance while providing care for the patients had higher level of burden and had lower quality of life than other groups. In a study done, it was noted that caregivers without any help in caring the stroke patients had higher burden while lower quality of life (Kalav, 2011). It is essential that those providing care to patients with chronic diseases accept the assistance given by family, friends and social resources. It is important to

encourage caregivers not to behave the patients as if they were kids and to maintain their functions as well as to offer the family members counseling to lead a productive life style (Ozer, 2010).

It is necessary that family members who provide care for a patient with a chronic disease employ social resources in a useful manner and to develop the necessary skills in order to facilitate independent living (Ozer, 2010).

When financial vulnerability caused by of the caregivers was examined; those who suffered financial vulnerability had higher care burden whereas quality of life was higher among those who did not suffer financial vulnerability. In the study of Kalav (2011), it was pointed out that caregivers who received help in caring had higher care burden while lower quality of life. In a study, too, it was stated that in terms of financial burden, caregivers worried about present condition of the patients' diseases and their financial conditions in the future. Meanwhile, financial stress was identified in most of the caregivers (Das et al., 2010).

Nearly 20% of the patients with stroke recover in the early period while nearly 20% die before hospital discharge in the early period (Rundek & Sacco, 2004; Utku, 2007). Other patients comprising 60% require rehabilitation in the following period of their lives and their disability degree is closely and directly correlated with the rehabilitation they receive; which determines their return to the society. In this sense; rehabilitation of the stroke patients has social importance (Utku, 2007). It was noted that whereas a statistically important difference existed between the condition of the patients and care burden of their caregivers; no statistically important difference existed between the condition of the patients and the quality of life of their caregivers. In the study of Kalav (2011) conducted with the stroke patients' relatives; it was found out that care burden of those family members who provided care for the patients totally dependent was higher than those family members who provided care for the patients semi-dependent.

It was explored that there was no significant difference between care burden and wellbeing and perception of health for those caregivers who lived together with the patients at the same house while

a statistically significant difference was seen between care burden and functional status and global quality of life. The study of Kalav, too, demonstrated that those living together with the patients diagnosed with stroke had higher care burden but lower quality of life (Kalav, 2011).

In terms of dependence level of the patients determined by Barthel Index score, it was noted that there were not significant differences between dependence level and caregivers' care burden and mean quality of life scores. However; it was noted that caregivers of the patients whose Barthel Index score was between 62-90 had higher care burden but lower global quality of life. In a study conducted; it was seen that caregivers' care burden reduced as patients' Barthel Index score increased (Mollaoglu, Tuncay & Fertelli, 2011). Providing care for a bedridden patient may both alleviate care burden and affect quality of life of the caregivers.

Conclusions

In the current study which was undertaken in order to assess care burden and quality of life of the caregivers of the patients with stroke; it was determined that caregivers' quality of life decreased as their care burden increased. It was seen that caregivers' having a health problem, assessment of the patients' health, role load and presence of someone as assistant affected care burden. Besides; it was noted that caregivers' age, health problems, role load, financial vulnerability, educational status, economical status, degree of kinship, living with the patient at the same household affected their quality of life. In sum; it is very crucial that nurses should organize educational activities and home-care services should be intensified so that caregivers' care burden do not affect their quality of life negatively. We are of the opinion that advancements and progresses made in relation with this problem will have positive effects both on patients and their relatives. In addition; studies with larger sample group should be done in order to uncover the issues that lead to care burden and affect the quality of life negatively. It is vital for nurses to understand these caregiving perceptions and their related factors to provide a holistic care plan.

Acknowledgements The present study was performed without any external funding.

Conflict of interest Authors declared no conflict of interest.

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Table 3. Comparison of scores of Caregiver Burden Scale and Quality of Life Scale according to socio-demographic characteristics of the caregivers (n=121)

| Descriptive characteristics | Caregiver Burden Scale | KW/t p | QUALITY OF LIFE SCALE | | | | | | | |
|-----------------------------|------------------------|--------|-----------------------|--------|-------------|-------------|-----------------------|-------------|------------------------|-------------|
| | | | Functional status | KW/t p | Wellbeing | KW/t p | Perceptions of health | KW/t p | Global quality of life | KW/t p |
| Age | | | | | | | | | | |
| 20-34 years | 44.91±13.16 | 2.757 | 66.66±15.49 | 2.941 | 60.41±13.89 | 10.728. | 59.91±12.67 | 5.166 | 62.41±11.56 | 7.619 |
| 35-49 years | 48.40±10.65 | .068 | 56.34±20.46 | .057 | 46.25±14.30 | .000 | 51.76±13.54 | .007 | 51.40±13.87 | .001 |
| 50 ≥ years | 51.16±8.28 | | 56.78±16.79 | | 43.09±16.62 | | 48.73±14.45 | | 49.47±14.08 | |
| Sex | | | | | | | | | | |
| Female | 48.30±10.63 | -.595 | 57.70±18.80 | -.772 | 47.66±16.34 | -.321 | 51.60±14.75 | -.882 | 52.31±14.65 | -.728 |
| Male | 49.57±10.67 | .553 | 60.60±18.33 | .441 | 48.71±16.23 | .748 | 54.11±12.64 | .379 | 54.40±13.30 | .468 |
| Educational Status | | | | | | | | | | |
| Illiterate | 53.73±6.87 | 1.660 | 52.80±16.04 | 1.939 | 39.93±16.52 | 2.263 | 45.00±19.14 | 2.168 | 45.80±16.02 | 2.481 |
| Literate | 52.12±5.74 | .150 | 45.62±23.26 | .093 | 42.75±11.65 | .053 | 44.37±10.79 | .062 | 44.37±13.40 | .036 |
| Primary school | 47.98±11.39 | | 59.25±17.71 | | 46.56±16.27 | | 52.56±14.18 | | 52.74±14.11 | |
| Secondary school | 43.84±12.97 | | 61.76±15.88 | | 54.92±16.92 | | 53.84±11.97 | | 56.84±12.58 | |

| | | | | | | | | | | |
|------------------------------------|-------------|-------|-------------|-------|-------------|-------|-------------|-------------|-------------|-------------|
| High school | 49.43±9.25 | | 60.17±21.07 | | 53.08±14.96 | | 57.34±10.70 | | 56.86±12.70 | |
| University | 44.00±11.74 | | 44.00±11.74 | | 56.75±14.45 | | 58.50±11.26 | | 63.75±10.71 | |
| Marital Status | | | | | | | | | | |
| Married | 49.12±10.17 | .889 | 58.23±18.66 | .202 | 47.12±17.02 | .880 | 51.76±14.67 | .547 | 52.32±14.71 | .663 |
| Single | 47.31±11.19 | .410 | 61.12±20.69 | .818 | 52.87±12.04 | .418 | 55.75±11.39 | .580 | 56.75±12.82 | .517 |
| Divorced/Widowed | 42.50±19.01 | | 56.00±9.41 | | 49.50±4.79 | | 53.00±11.48 | | 52.50±1.91 | |
| Profession | | | | | | | | | | |
| Housewives | 48.93±10.31 | 1.684 | 56.51±18.23 | 2.213 | 47.07±16.90 | .997 | 50.80±14.99 | .595 | 51.43±14.65 | 1.283 |
| Retired | 54.66±5.12 | .144 | 60.16±8.25 | .058 | 40.50±12.12 | .423 | 50.83±8.68 | .704 | 50.50±9.13 | .276 |
| Worker | 48.14±11.31 | | 53.42±22.05 | | 45.85±17.09 | | 54.78±15.51 | | 51.42±16.00 | |
| Civil servant | 38.00±16.41 | | 73.16±17.34 | | 55.83±19.17 | | 56.50±11.36 | | 61.83±14.13 | |
| Unemployed | 51.00±00.00 | | 93.00±00.00 | | 57.00±00.00 | | 55.00±00.00 | | 68.00±00.00 | |
| Other (farmer, self-employed etc.) | 49.38±9.35 | | 63.77±16.99 | | 52.72±12.33 | | 55.83±12.10 | | 57.33±11.47 | |
| Economic Status | | | | | | | | | | |
| Unsatisfactory | 52.37±10.87 | 1.865 | 52.91±20.87 | 2.076 | 41.41±17.28 | 3.002 | 46.95±17.88 | 3.250 | 47.08±16.34 | 3.544 |
| Moderate | 47.67±10.76 | .159 | 59.03±18.03 | .130 | 48.92±14.72 | .054 | 52.83±11.61 | .042 | 53.56±12.50 | .032 |

| | | | | | |
|--------------|------------|-------------|-------------|-------------|-------------|
| Satisfactory | 48.21±8.29 | 65.28±16.57 | 53.50±20.58 | 58.57±18.46 | 59.07±17.62 |
|--------------|------------|-------------|-------------|-------------|-------------|

Table 4. Comparison of scores of Zarit Caregiver Burden Scale and Quality of Life Scale according to caregiving characteristics of the caregivers (n=121)

| Descriptive Characteristics | N/% | Caregiver | | QUALITY OF LIFE | | | | | | | |
|--------------------------------|---------|--------------|-------------|-------------------|-------------|-------------|-------------|-----------------------|-------------|------------------------|-------------|
| | | Burden Scale | KW/t p | Functional status | KW/t p | Wellbeing | KW/t p | Perceptions of health | KW/t p | Global quality of life | KW/t p |
| Having a health problem | | | | | | | | | | | |
| Yes | 53/43.8 | 52.13±6.76 | 3.294 | 51.52±19.34 | -3.863 | 41.50±14.82 | -4.105 | 47.16±14.80 | -3.720 | 46.66±13.96 | -4.607 |
| No | 68/56.2 | 45.97±12.22 | .001 | 64.01±16.19 | .001 | 53.00±15.61 | .000 | 56.35±12.33 | .000 | 57.79±12.55 | .000 |
| Degree of Kinship | | | | | | | | | | | |
| Spouse | 32/26.4 | 50.12±8.61 | 1.048 | 54.81±18.21 | 2.040 | 41.59±15.68 | 3.657 | 46.93±14.28 | 3.269 | 47.65±14.49 | 3.435 |
| Son / Daughter | 68/56.2 | 48.85±10.87 | .354 | 58.23±20.14 | .135 | 49.72±16.44 | .029 | 54.23±14.45 | .042 | 54.11±14.63 | .035 |
| Relatives | 21/17.4 | 45.85±12.39 | | 65.23±11.85 | | 52.00±14.34 | | 54.38±11.24 | | 57.04±10.42 | |
| Duration of care | | | | | | | | | | | |

| | | | | | | | | | | | |
|---------------------------------------|---------|-------------|-------------|-------------|-------------|-------------|-------------|-------------|-------------|-------------|-------------|
| < 6 months | 79/65.3 | 49.59±8.96 | 1.319 | 59.83±17.70 | 1.045 | 48.63±14.16 | .616 | 53.35±14.62 | 1.091 | 53.86±13.56 | .998 |
| ≥ 6 months | 42/34.7 | 46.92±13.13 | .190 | 56.11±20.27 | .298 | 46.71±19.73 | .539 | 50.40±13.24 | .278 | 51.14±15.49 | .320 |
| Role load | | | | | | | | | | | |
| Only patient | 52/43.0 | 46.00±11.80 | 2.877 | 64.38±17.00 | 5.198 | 52.13±13.31 | 3.860 | 56.55±11.88 | 4.376 | 57.71±11.82 | 6.137 |
| Patient+children | 13/10.7 | 46.69±12.45 | .039 | 59.69±13.70 | .002 | 51.30±23.54 | .011 | 50.92±13.65 | .006 | 54.00±15.20 | .001 |
| Patient+other family members | 12/9.9 | 50.33±12.16 | | 62.08±13.15 | | 49.58±15.35 | | 55.75±12.58 | | 55.75±12.44 | |
| Patient+ their (caregivers') diseases | 44/36.4 | 51.95±6.81 | | 50.34±20.32 | | 41.61±15.66 | | 46.81±15.62 | | 46.15±14.83 | |
| Assistants | | | | | | | | | | | |
| No | 56/46.3 | 49.89±10.69 | 2.855 | 55.08±20.09 | 1.465 | 45.89±18.05 | 1.073 | 48.80±14.42 | 2.710 | 49.89±15.54 | 1.988 |
| Other family members | 57/47.1 | 48.36±9.43 | .040 | 61.33±17.29 | .228 | 49.98±14.61 | .364 | 54.73±13.27 | .048 | 55.26±12.74 | .120 |
| Official institutions/ NGOs | 2/1.7 | 28.50±3.53 | | 72.50±3.53 | | 60.00±7.07 | | 65.50±0.70 | | 66.00±1.41 | |
| Friends/Loved ones/ Relatives | 6/5.0 | 46.83±16.20 | | 59.66±15.57 | | 44.16±13.61 | | 58.00±15.76 | | 54.50±12.80 | |
| Financial vulnerability | | | | | | | | | | | |
| Yes | 83/68.6 | 49.83±9.61 | 1.795 | 55.60±20.34 | -2.630 | 46.45±16.64 | -1.517 | 49.90±14.57 | -2.866 | 50.63±14.88 | -2.664 |
| No | 38/31.4 | 46.13±12.29 | .075 | 64.97±12.14 | .010 | 51.26±15.04 | .132 | 57.63±11.76 | .005 | 57.89±11.46 | .009 |
| Status of the patient | | | | | | | | | | | |

| | | | | | | | | | | | |
|---|---------|-------------|-------------|-------------|-------------|--------------|--------|-------------|--------|-------------|-------------|
| Bedridden | 68/56.2 | 49.01±10.48 | 6.557 | 59.01±16.62 | .228 | 47.69±16.47 | .976 | 51.26±14.73 | .337 | 52.64±13.77 | .249 |
| Able to walk with a stick | 42/34.7 | 51.28±7.56 | .000 | 56.97±21.95 | .877 | 46.78±15.67 | .407 | 53.88±13.45 | .799 | 52.52±15.21 | .862 |
| | 6/5.0 | 38.16±11.54 | | 62.83±14.28 | | 58.83±13.83 | | 51.66±12.24 | | 57.66±11.12 | |
| Able to use wheelchair | 5/4.1 | 34.60±17.35 | | 60.20±23.12 | | 48.60±20.68 | | 54.60±17.27 | | 54.20±18.78 | |
| Others | | | | | | | | | | | |
| Living together with the patient at the same household | | | | | | | | | | | |
| Yes | 72/59.5 | 48.44±10.87 | -.281 | 54.77±20.23 | -2.770 | 46.58±17.955 | -1.136 | 50.69±14.57 | -1.548 | 50.69±15.56 | -2.109 |
| No | 49/40.5 | 49.00±10.33 | .779 | 64.08±14.49 | .007 | 0.00±13.28 | .258 | 54.73±13.35 | .124 | 56.18±11.47 | .037 |
| Dependence level in terms of Barthel Index Score of the patients cared | | | | | | | | | | | |
| 0-20 | 30/24.8 | 49.27±10.38 | 1.881 | 58.33±16.43 | 2.143 | 46.23±15.89 | 2.463 | 51.97±15.14 | 4.739 | 52.27±13.73 | 3.058 |
| 21-61 | 44/36.4 | 47.36±11.30 | .597 | 60.00±16.53 | .543 | 50.20±16.86 | .482 | 50.84±14.16 | .192 | 53.59±13.62 | .383 |
| 62-90 | 33/27.3 | 50.73±8.24 | | 54.52±23.42 | | 45.21±16.10 | | 51.93±13.26 | | 50.48±15.53 | |
| 91-100 | 14/11.5 | 46.64±13.74 | | 63.93±16.45 | | 51.14±15.61 | | 58.71±13.96 | | 57.93±14.29 | |