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EDITORIAL

INTENSIVE CARE UNIT: THE CONCEPT OF A SPECIAL CARE

RESEARCH ARTICLES

AN INVESTIGATION OF PARENTAL CONCERNS ABOUT THE EDUCATIONAL AND PSYCHOSOCIAL DEVELOPMENT OF THEIR CHILDREN AGED 2-6 YEARS DURING THE COVID-19 PANDEMIC

A NEGLECTED PROBLEM IN CAREGIVERS OF CANCER PATIENTS: SUPPORTIVE CARE

EXPERIENCES OF LOSS AND THEIR MANAGEMENT BY INFORMAL CAREGIVERS IN THE COMMUNITY. PERCEIVED QUALITY OF LIFE OF PEOPLE WITH CHRONIC DISEASES

THROMBOSIS IN SEVERELY ILL PATIENTS ADMITTED IN ICU DUE TO COVID-19 PNEUMONIA. DATA FROM A GREEK HOSPITAL

CASE REPORT

CUTANEOUS AMYLOIDOSIS IN A PATIENT WITH SYSTEMIC AMYLOIDOSIS DUE TO MULTIPLE MYELOMA

SPECIAL ARTICLE

HOW HAS PSYCHOLOGY IMPROVED UNDERSTANDING OF WHY PEOPLE LIE?

REVIEW

WOMEN AND FAMILIAL HYPERCHOLESTEROLEMIA

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RESEARCH ARTICLE

A NEGLECTED PROBLEM IN CAREGIVERS OF CANCER PATIENTS: SUPPORTIVE CARE NEEDS

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Abstract

Background: Supportive care approaches are critical in meeting the needs of cancer patients and their families when they are diagnosed, during cancer treatment, and after therapy. The aim of this study was to determine the supportive care needs of cancer caregivers.

Methods: The study was descriptive and quantitative. Data was collected online between December 2021 and February 2022. The study's sample included 170 people aged 18 years up who had been responsible for the care of cancer patients for at least three months. "Partners and Caregivers Descriptive Information Form" and "Supportive Care Needs Survey Partners and Caregivers of Patients Diagnosed with Cancer" were used to collect data.

Results: According to the study, 81.2% of caregivers were female, 52.9% had a bachelor's degree, 74.1% were married, and 61.2% had a job. Additionally, 26.5% of individuals provided care to lung cancer patients, 64.1% lived with the patient, and 26.5% dedicated 7-12 hours each day to the provision of care. The most common supportive care needs of caregivers were psychological and emotional support (87.0%). Educational level, perceived income status, relationship with the patient and daily caregiving duration were determined as caregiver characteristics that affect supportive care needs ($p<0.05$).

Conclusion As a result of the research, it was determined that the partners and caregivers who care for cancer patients have a high level of supportive care needs. Psychological and emotional support was the most frequently reported need for supportive care by cancer patients caregivers in Turkish society.

Keywords: Cancer, caregivers, supportive care needs, nursing.

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INTRODUCTION

Cancer is an important health problem that negatively affects human life and leads to physical and social limitations with the progression of the disease. Along with the positive developments in the diagnosis and treatment of cancer, the increase in survival rates has caused patients and their relatives to be more exposed to the long-term effects of the disease. Cancer patients may need care and support from the moment of diagnosis to the treatment process, survival, end-of-life period or mourning. This process includes the person diagnosed with cancer, as well as the spouses and the other caregivers responsible for the care of the patient.[1, 2]

Caregivers play an indispensable role in maintaining the well-being of cancer patients. The caregivers of cancer patients mostly consist of spouses and family members. Caregivers of cancer patients assist in many areas such as managing symptoms related to the disease and the treatment process, accessing medical appointments and treatment, providing emotional support, and performing activities of daily living. Caring for an individual with cancer, especially a loved one, imposes a significant physical and emotional burden on caregivers. While caregivers are trying to cope with their own emotional and existential anxieties, the ability to care may be beyond their means. Therefore, determining the needs of caregivers is of vital importance in supporting them and increasing their capacity to provide care to the patients.[2,5]

Supportive care is the actions that help cancer patients and their relatives meet the needs arising from cancer diagnosis, treatment process, and after treatment and strengthen their coping processes. Health practices, which include meeting the supportive care needs, aim to maximize the benefit from the treatment process while increasing the life satisfaction and well-being of patients and their relatives.[6-9]

The needs of individuals caring for cancer patients are reported as disease-related characteristics such as diagnosis, stage, and treatment of cancer, and individual characteristics such as age, gender, economic status, chronic disease status, and belief. Not all needs are equally important to all caregivers.[10] Age (being younger) and gender (being female) have both been linked to a higher incidence of unmet needs among caregivers.[3,9] Kim et al.[11] reported that young cancer caregivers are likely to have higher psychosocial and economic needs 2 years after diagnosis. In addition, it has been reported that caregivers of patients with hematological malignancies need more supportive care than caregivers of cancer patients with solid, and caregivers of individuals with lung cancer and non-Hodgkin lymphoma have higher healthcare services and information.[12] This could be due to the fact that, including with all cancers, caregivers need additional information and support to address concerns about relapse and survival. Moreover, personalized or disease-specific support may be needed to solve the problems faced by caregivers in these cancers, which often remain incurable and require long-term and debilitating treatments.

In the literature, it is emphasized that there is a need to evaluate and support the care needs of cancer patients and their relatives.[12-16] The identification of the unmet care needs of partners and family members responsible for the care of cancer patients is important for the effectiveness of the care provided. It is thought that determining the supportive care needs of the individuals responsible for the care of cancer patients is extremely important in the planning/execution of the nursing care since it can increase the quality of life the patients and their relatives. It is essential to know the characteristics of caregivers' needs to identify the risky groups in terms of experiencing difficulties, to plan supportive initiatives to meet the needs of these groups, to develop the service to be provided by health institutions and health professionals, and to create policies in this context. Although supportive care needs in caregivers are an important issue in the cancer care process, sufficient studies on the subject have not been found in the Turkish society. In this direction, it is thought that the study will contribute to the literature in determining the problems faced by cancer patient caregivers and the areas of support needed.

Research Questions

- What are the supportive care needs of partners and caregivers of cancer patients in Turkish society?
- Do descriptive and care-related characteristics of partners and caregivers of cancer patients affect their supportive care needs?

METHODOLOGY

Study design

The aim of this descriptive study was to investigate the supportive care needs of partners and caregivers who care for cancer patients. The data of the study were collected between December 2021 and February 2022 in Türkiye. The research population consisted of the relatives of cancer patients who were treated at the outpatient chemotherapy center of a training and research hospital in İzmir, and the caregivers who could be reached through the social media accounts of the communities formed by the cancer patient relatives. The sample of the study consisted of 170 cancer patients, partners and caregivers who were responsible for the care of cancer patients who met the inclusion criteria and completed the data collection forms.

The inclusion criteria were as follows: (a) 18 years of age or older, (b) volunteering to participate in the study, (c) responsible for the care of cancer patients and (d) caring for a cancer patient for at least three months.

The exclusion criteria were as follows: (a) having any psychological problem and (b) refusing to participate in the study**.**

Data collection

Data was collected online by using a personal information form and the Supportive Care Needs Survey-Partners and Caregivers (SCNS-P&C). The data collection tools were transferred into a Google form. The link to the Google form including the data collection tools was shared with cancer caregivers. The time for the individual to fill out the forms was approximately 15 minutes.

Partners and Caregivers Descriptive Information Form: It consists of 15 questions about the characteristics of the participants regarding the introductory (age, gender, education, income) and the experience of caring for the cancer patient (such as the duration of care during the day, and the status of receiving education for caregivers.[1-5]

Supportive Care Needs Survey Partners and Caregivers of Patients Diagnosed with Cancer (SCNS-P&C): The scale was developed by Girgis et al.[13] to multidimensionally evaluate the supportive care needs of caregivers and partners of cancer patients. The Turkish validity-reliability study of the scale was conducted by Atlı Özbaş et al.[1] The scale evaluates the supportive care needs of cancer patients' relatives in four dimensions as the need for health care services, the need for psychological and emotional support, the need for work and social needs, and the need for information. Cronbach's alpha coefficient value ranged from 0.86 to 0.96 for each dimension. In the Turkish validity-reliability study of the scale, the Cronbach alpha coefficient was determined as 0.96.[1,13]

Ethical considerations

The study was approved by the Non-Interventional Clinical Research Ethics Committee at a university in Türkiye (decision no: 2021/472) and performed in accordance with the Helsinki Declaration. Participants first have read the informed voluntary consent text that explains the purpose and rationale of the study in the link sent online. Volunteers who agreed to participate in the study completed the questionnaire. Participants were also informed that they could withdraw from the study at any time.

Data analysis

The analysis of the data obtained from the research was made using the Statistical Package for the Social Sciences (SPSS) 25.0 (SPSS Statistics for Windows, Version 25.0, IBM Corp. Armonk, NY) program. Descriptive statistics for continuous variables and frequency distributions for categorical variables were determined. The Kolmogorov–Smirnov normality test was applied to the scale score for further analyses. One-way ANOVA and independent sample t test were used to evaluate the difference between partners and caregivers' characteristics and scale scores. Statistical significance was accepted as $p<0.05$.

RESULTS

The study showed that the average age of the participants was 38.2±10.3, while 81.2% were female, 52.9% had an undergraduate, 74.1% were married and 61.2% were unemployed. Additionally, 69.4% of the caregivers had a middle income level and 61.8% of them did not have a diagnosis of chronic disease. Moreover, 32.9% of cancer patient caregivers consisted of parents, 64.1% lived with the individual they cared for, and 26.5% cared for a patient diagnosed with lung cancer. Besides, 51.8% of caregivers allocated at least 7 hours a day for care, and 72.1% received support for their caregiving work

(Tablo 1).

The care needs of cancer patients' caregivers were mostly in the field of psychological and emotional support (87.0%). The care needs of the participants in other areas were health care services needs (86.2%), work and social support needs (85.2%), and information needs (72.6%) (Table 2). The study also identified the top 10 care needs of cancer caregivers. These needs were in the fields of psychological and emotional needs (7 items), health care needs (2 items), and information needs (1 item). It was determined that caregivers had the highest needs for "Accessing local health services when needed" (91.7%) and "Producing solutions to problems in sexual life" (91.7%) (Table 3). Other data on the supportive care needs of partners and caregivers of cancer patients are summarized in Table 2 and Table 3.

Supportive Care Needs Survey Partners and Caregivers of Patients Diagnosed with Cancer score averages of the participants were examined according to their descriptive characteristics. Educational level, income status, relationship status with the patient and daily caregiving duration were determined as caregiver characteristics that affect supportive care needs. (p<0,05). Sex, marital status, chronic disease status, and cancer diagnosis of the patient being cared for had no effect on the supportive needs of caregivers. (p>0,05) (Table 4).

DISCUSSION

In the present study, it was observed that the supportive care needs of spouses and caregivers who care for cancer patients were in accordance with previous studies and were at a high level in all dimensions, including the health care services needs, psychological and emotional support needs, work and social needs, and information needs.[17-24] In Türkiye, which is among the economically developing countries, the care process regarding the traditional and cultural structure and current status of health services is primarily carried out by the family members of the patient. Family members of cancer patients often experience burnout and loss anxiety, assuming the burden of care for the individual with whom they have close bonds and feelings of gratitude. In the cancer care process, the needs of caregivers are often overlooked and individuals who are too busy with their caregiver role cannot receive professional support. This study results, in line with the literature, show that there is a need for health professionals to develop holistic care programs targeting caregivers of cancer patients and to address the care needs of these individuals.

The most prominent areas in the first 10 needs of cancer caregivers among the supportive care needs were in the areas of health care needs and psychological and emotional needs. The results are consistent with many studies in the literature evaluating the unmet needs of caregivers of cancer patients.[23,25-26] In this study, cancer caregivers mostly reported the need for care to reach local health services when needed and to find solutions to problems in sexual life. According to the literature, the sexual experiences of cancer patients' spouses and relatives following cancer are often overlooked, even awareness of unmet needs in this area is continuously growing[27]. Sexuality is an important component of quality of life. The quality of life of cancer caregivers are negatively affected by reasons such as young age, changes in daily life activities, lack of experience, financial strength, and problems in using health services[24]. The young age group of caregivers in our study may have increased their needs in this area. In a systematic review examining the unmet needs of cancer patients and caregivers, health care services and psychological needs were identified as the first two of the four need areas most frequently reported by caregivers of advanced cancer patients. In the same study, it was reported that the unmet needs of the caregivers of patients with hematological cancer were in the first place.[28] The results of the studies conducted from German, Chinese, Korean and Iranian societies, have shown that the needs for health care services and health workers are priority.[2,23,25,29] Despite social characteristics and cultural differences, cancer caregivers seem to have similar support needs. It can be clearly said that health professionals in the field of oncology should pay more attention to the needs of patients and their relatives in terms of health services and psychological aspects of cancer care and support these areas.

In our study, it was determined that education level is a factor that affects the information needs of cancer caregivers. It has been found that the needs of cancer caregivers differ depending on the education level variable. The study of Niu et al. [23] found that individuals with a higher than moderate level of education have more information needs. Lambert et al.[9], Ashrafian et al.[25] and Chen et al.[30] reported that cancer caregivers with low education levels had higher supportive care needs. It is thought that the caregivers with a relatively high education level in our study group need more information about cancer care and available suport resources to provide better care to their relatives and increase their quality of life. In this study, it was also found that individuals with a moderate income level had supportive care needs in all areas. It has been shown in the literature that low income has a negative impact on the needs of cancer caregivers.[31] The increase in the survival time of patients with the new cancer treatments has increased the direct and indirect financial costs in the cancer care process. Expenses incurred due to cancer treatments, acute care services in healthcare facilities, medical measures required for home care, and patient transport cause an economic burden for caregivers.[32, 33] In our study, the increasing economic burden of caregivers who reported that they had a moderate income may have caused an increase in the needs that need to be supported in all areas. In addition, it is thought that the difficulties experienced by cancer caregivers, such as losing their current job, and changing or reducing their working styles/hours depending on their caregiving role, may have increased their needs for support.

Spouses that care for individuals with life-threatening diseases such as cancer are at greater risk for adverse effects due to the patient's increased need for physical care and emotional concerns compared to other caregivers.[34] In addition, witnessing the deteriorating or suffering of one's partner and coping with impending loss place a more signigicant emotional burden on partners than other caregivers.[34,35.] In the present study, similar to the literature, the majority of caregivers were women and caregivers had a higher level of supportive care needs in all areas, including the health care services needs, psychological and emotional support, work and social needs, and information needs. Actions towards patient care are recognized as the role of women in many cultures of the world. Women are often seen as “care providers” because of gender-related norms, familial experiences/expectations, and societal approaches. Studies reporting gender-related effects in caregivers differ in the literature.[36-38] It has been reported that the spouses (husband/wife) are adversely affected by the changes related to the caregiver role, such as relationship and lifestyle changes, sleep disorders and economic problems, both due to adaptation to the new role and trying to maintain the old roles.[37,39]

In the present study, it was found that the time spent by caregivers during the care process during the day had an effect on the supportive care needs. It was observed that the health care, psychological and emotional support, and information needs of the caregivers who spent the whole day for care activities were higher than the other individuals. It has been determined that individuals who care for 7-12 hours a day have more needs in the work and social areas. Studies have reported that the time spent by cancer caregivers for care during the day increases the unmet needs of individuals in the work and social field, consistent with this study.[19,23,40] Spending long hours in cancer care negatively affects the physical and mental health of caregivers and causes psychosocial problems. Restriction of freedom due to the care process, loss of job or economic difficulties due to changes in working conditions, problems in relationships with spouse, family or social environment are known to have a negative impact on the quality of life of caregivers.[41] Due to the chronic cancer burden in Türkiye, the insufficient number of health professionals per patient, the inadequacy of the application areas in the education process to meet the number of students, and the inadequacies arising from the health system increase the burden of cancer patients' relatives. In the literature, the importance of physical, social, psychological, and spiritual support provided by a multidisciplinary team approach for caregivers of cancer patients has been stated.[42] It is reported that interventions such as psychoeducation, supportive therapy, home care, cognitive behavioral therapy, interpersonal therapy and complementary/alternative medicine methods, and telephone support programs for cancer caregivers are important in reducing the burden of care.[42,43] It is thought that there is a need to implement intervention programs in line with the needs determined for the caregivers of cancer patients in our country and it is important to increase the well-being of these individuals.

CONCLUSION

As a result of the research, it was determined that the partners and caregivers who care for cancer patients have a high level of supportive care needs in all dimensions. Psychological and emotional support was the most frequently reported need for supportive care by caregivers of cancer patients in our society. Multidimensional and variable supportive care needs affect the physical and psychosocial well-being of caregivers of patients diagnosed with cancer. Identifying the needs of caregivers by health professionals in the cancer care process will contribute to the improvement of cancer care. In line with the data obtained from the study, it is recommended to minimize the supportive care needs of individuals caring for cancer patients and to develop interventions aimed at increasing/maintaining their quality of life.

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Data availability The datasets generated during and/or analysed during the current study are available from the corresponding author on reasonable request.

Declarations

Ethics approval This study was performed in line with the principals of the declaration of Helsinki The study was approved by the Non-Interventional Clinical Research Ethics Committee at Izmir Bakırcay University in Türkiye (decision no: 2021/472).

Competing interests The authors have no relevant financial or non-financial interests to disclose

Conflicts of interest The authors declare that they have no confict of interest.

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ANNEX

TABLE 1. Descriptive characteristics of caregivers (N=170)

Variables for Participants **The average age:** 38.2±10.3 (22.00-65.00)		**n**	**%**
Sex	Female	138	81.2
	Male	32	18.8
Educational status	Primary school	17	10.0
	Secondary school	56	32.9
	Graduate	90	52.9
	Postgraduate	7	4.1
Marital status	Married	126	74.1
	Single	44	25.9
Employment	Employed	104	61.2
	Not employed	66	38.8
Perceived income status	Low	34	20.0
	Moderate	118	69.4
	High	18	10.6
Having a chronic illness	Yes	65	38.2
	No	105	61.8
Relationship to the patient	Spouse	37	21.8
	Parents	56	32.9
	Children	20	11.8
	Relative	33	19.4
	Other	24	14.1
Co-residence with the patient	Yes	109	64.1
	No	61	35.9
Cancer diagnosis of the patient being cared for	Breast Cancer	26	15.3
	Lung Cancer	45	26.5
	Gastrointestinal Cancer	44	25.9
	Urogenital cancer	19	11.2
	Hematological cancer	30	17.6
	Head and Neck Cancer	6	3.5
Caregiving time/day	3 hours a day	40	23.5
	4-6 hours a day	42	24.7
	7-12 hours a day	45	26.5
	All day (24 hours)	43	25.3
Getting support during caregiving	Yes	121	72.1
	No	49	28.8

TABLE 2. Percentage of participants' supportive care needs by sub-dimensions of the Supportive Care Needs Survey—Partners and Caregivers (N=170)

SCNS-P&C domains	**No need or satisfied (%)**	**Supportive care needs**			**Total (%)**
		Low need (%)	**Moderate need (%)**	**High need (%)**	
Psychological and emotional support needs	13.0	16.6	34.4	36.1	87.0
Health care service needs	13.8	12.8	31.6	41.8	86.2
Work and social needs	14.8	15.3	33.3	36.6	85.2
Information needs	25.7	10.33	26.9	35.2	72.6

TABLE 3. Percentage (%) of participants' supportive care needs (10 most common needs) (N=170)

Need item	**Domain**	**No need or satisfied (%)**	**Supportive care needs**			**Total (%)**
			Low need (%)	**Moderate need (%)**	**High need (%)**	
Accessing local healthcare services when needed	**HCSN**[a]	8.2	8.2	31.8	51.8	91.7
Finding solutions to problems in your sexual life	**PESN**[b]	8.2	15.3	29.4	47.1	91.7
The effect of cancer on your relationship with an individual with cancer	**PESN**	8.8	9.4	24.1	57.6	91.1
Worrying about the physical and mental deterioration of the individual diagnosed with cancer	**HCSN**	9.4	10.0	42.4	38.2	90.5
Discovering your spiritual beliefs	**PESN**	9.4	16.5	38.8	35.3	90.5
Continuing relationships with people who do not understand the impact of caring for a person diagnosed with cancer on your life	**PESN**	10.0	12.9	35.3	41.8	90.0
Making decisions about your own life in the context of uncertainty	**PESN**	10.6	8.8	29.4	51.2	89.4
Find out about government support and financial support for the individual diagnosed with cancer and for yourself	**IN**[c]	11.2	12.9	31.8	44.1	88.8
Reckoning with your feelings about dying and being dying	**PESN**	11.2	13.5	34.7	40.6	88.8
Understanding the experience of an individual diagnosed with cancer	**PESN**	11.8	22.4	41.2	24.7	88.2

[a] **HCSN**; Health Care Services Needs [b] **PESN** Psychological and Emotional Support Needs [c] **IN;** Information Needs

TABLE 4. Univariate analysis of the relationships between supportive care needs and caregiver characteristics (N=170)

Variables for Participants (N=170)		n	HCSN[a]	PESN[b]	WSN[c]	IN[d]
Sex	Female	138	44.1±9.7	54.3±10.4	27.0±5.6	25.2±5.6
	Male	32	43.2±7.9	55.4±9.1	28.0±5.3	24.1±4.8
test			0.475*	-0.546*	0.938*	1.007*
p			0.635	0.586	0.350	0.315
Educational status	Primary school	17	45.1±6.2	54.3±6.1	27.17±4.44	24.70±3.98
	Secondary school	56	46.2±8.7	56.4±8.4	28.0±5.2	26.8±4.9
	Graduate	90	42.1±10.0	53.1±11.4	26.6±5.85	24.0±5.8
	Postgraduate	7	45.2±9.5	58.4±12.0	28.5±6.9	25.1±5.6
test			2,393**	1.516**	0.867**	3.064**
p			0,070	0.212	.0.460	0.030
Marital status	Married	126	44.4±9.8	54.6±10.5	27.1±5.9	25.3±5.6
	Single	44	42.5±8.0	54.2±9.03	27.4±4.5	24.3±5.1
test			1.180	0.251	-0.248	0.957
p			0.240	0.802	0.805	0.340
Perceived income status	Low	34	41.1±10.7	49.7±12.4	24.9±6.8	23.0±5.3
	Moderate	118	45.5±8.5	56.3±8.4	28.1±4.8	25.9±5.3
	High	18	39.0±10.1	52.0±12.7	25.4±6.0	23.2±5.4
test			5.928	6.569	5.619	4.952
p			0.003	0.002	0.004	0.008
Having a chronic illness	Yes	105	43.2±9.5	54.1±10.3	26.9±5.6	24.6±5.5
	No	65	45.1±9.1	55.3±9.9	27.7±5.5	25.0±5.5
test			1.638	0.580	0.824	1.413
p			0.202	0.447	0.365	0.236
Relationship to the patient	Spouse	37	48.1±6.7	57.6±6.6	29.0±4.8	27.6±4.4
	Parents	56	46.2±9.0	55.3±8.7	28.1±4.7	26.5±5.1
	Children	20	42.6±9.6	56.2±11.0	26.4±5.9	24.0±5.5
	Relative	33	39.5±8.9	50.6±11.1	24.8±6.0	23.4±5.2
	Other	24	39.5±10.3	52.0±13.6	26.2±6.2	20.8±5.1
test			6.594	2.823	3.393	8.907
p			0.000	0.027	0.011	0.000
Cancer diagnosis of the patient being cared for	Breast Cancer	26	45.2±8.4	54.8±6.7	26.9±5.5	26.3±4.0
	Lung Cancer	45	44.6±9.2	56.0±10.7	27.9±5.3	25.7±5.5
	Gastrointestinal Cancer	44	42.8±9.3	52.7±11.9	26.5±5.9	24.6±5.3
	Urogenital cancer	19	46.4±9.1	55.6±8.33	29.0±4.8	26.1±6.0
	Hematological cancer	30	41.1±10.8	53.3±10.7	25.8±6.0	22.5±6.1
	Head and Neck Cancer	6	47.6±7.5	58.6±4.6	29.5±3.0	26.6±3.6
test			1.266	0.786	1.279	2.046
p			0.281	0.561	0.276	0.075
Caregiving time/day	3 hours a day	40	39.4±9.8	50.5±12.7	25.3±6.2	21.8±5.3
	4-6 hours a day	42	39.9±9.4	52.5±10.6	25.3±5.8	22.5±5.0
	7-12 hours a day	45	47.4±7.1	57.15±7.33	29.0±4.6	27.3±3.7
	All day (24 hours)	43	48.5±7.5	57.65±7.84	28.9±4.3	28.1±4.8
test			13.56	5.296	6.660	19.69
p			0.000	0.002	0.000	0.000

***independent sample t test, ** One-way ANOVA,** [a]**HCSN**; Health Care Services Needs [b]**PESN** Psychological and Emotional Support Needs, [c]**WSN;** Work and social needs, [d]**IN;** Information Needs