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Contents

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Home Health Care Patients and Their Caregivers' Requirements of Psychosocial and Spiritual Support for Better Health

Mehmet Akif SEZEROL[1]
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ABSTRACT

Home health care services must be integrative and aims to improve both the patients' and their relatives' health physically, socially and mentally. The aim of this study is to determine the psychological, sociological and spiritual support needs of the caregivers in home health care.

This is a cross-sectional study which was conducted in Istanbul between May and October 2016 among 139 caregivers with convenience sampling in 15 district. Caregivers were preferred instead of patients because of their health disadvantages. The survey was carried out face to face. Survey has two parts one of which is about patients and the other about caregivers. Survey was applied to 89 people who accepted the interview.

64.0% of patients receiving home health care are women. All patients except for one are covered by an insurance system. 61.8% of patients have their own income and assets. 93.3% of the patients do not receive disability salary. In addition, 80.7% of patients do not have a disability report. Neurological (31.9%) and cardiovascular system (24.9%) are the most common problems of home

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health care patients. 84.3% of the caregivers are female. 61.8% of caregivers graduate primary school, 75.0% of them are married and 85.2% of them are unemployed. 92.1% of caregivers are first or second degree relatives of the patient. The duration of care doesn't exceed three years in 64.7% of individuals. Only 6,8% of caregivers receive the care fee provided by the government.

94.4% of caregivers were not trained in caregiving and 66.3% don't feel sufficient to give someone medical care. In addition, 56.2% of caregivers need psychological support and 23.6% need spiritual support.

It is observed that patients who receive home health services can't benefit from the social rights adequately provided by the government. Most of the caregivers need education in home health care. Also they need psychological, social and spiritual supports. Integrative home health care service models should be developed providing psychosocial and spiritual supports considering both patients and caregivers needs. Consequently, social workers, psychologists and spiritual support personels should be including more in home health care teams considering the social determinants of health.

Keywords: Home health care, psychosocial support, spiritual support

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INTRODUCTION

Health, as stated in the definition of the World Health Organization "is not the absence of disease or disability, but a state of physical, mental and social well-being". Health care plays an important role in ensuring and maintaining well-being. There are various approaches to addressing health care professionals in different dimensions. Presentation of holistic health care that the individual's physical, mental, emotional, social, cultural and spiritual dimensions are considered as a whole and each of these dimensions are related to each other is the most accepted approach (Baldacchino, 2015).

Home care is to provide health and social services to the patient in his / her own home or living environment by means of professional people in order to ensure the health of the individual, to improve the health level and to cure (Aslan, 2018). It can also be expressed as a care model that includes medical, psychosocial support and social services given by health and social service professionals or family members to elderly, physically disabled, bed-ridden, patients have chronic or malignant disease and need to long-term care. It also provides rehabilitation of individuals in need of medical and social support in the environment they live helping them adapt to the community and live happily. Within the scope of home care services, preventive, treatment and rehabilitative health services should be provided effectively and continuously (Altuntaş, 2010).

The way in which the health care provider offers care services varies with home health services. Medical examination, treatment and rehabilitation services are offered by health professionals such as physicians, nurses, physiotherapists and psychologists. In this way, the need to stay in the health institution and the cost to the health institution is reduced and the healing process in the social life of the individual is accelerated (Öksüz, 2018). In a study conducted in Turkey, it was determined that 63.1% of the elderly prefer the health care at home. 86.5% of elderly people want to have health care while having families with them (Özer and Şantaş, 2012).

History of home care dates back to the ancient Roman period and began with the discussion of whether birth should be done at home or in the hospital. Home health services are perceived as social services, such as food and shelter, rather than medical, in order to prevent individuals from transmitting the disease to the society in the Middle Ages. As of the 19th century, home care services developed and spread in Western societies have reached the size of health assistance for those in need of care (Aksoy et al., 2015). Especially in the 20th century, the implementation of the concept of quality in health and the introduction of health services in the home have started. At the beginning of the century, home health services were limited to nursing services, it became quickly widespread with the introduction of American Medicare and Medicaid insurance systems in 1965 and including home care in their coverage (Ma et al., 2017). In Turkey, home health care services has started to be carried out in 2005 within the scope of "Regulation on Home Care Services Report". With this regulation, the responsibilities of private enterprises on this subject are determined. The Directive on the Implementation Procedures and Principles of Home Health Services presented by the Ministry of Health entered into force in 2010 and the system of home health care services was started systematically (Official Gazette, 2015).

Although the scope of home health services is mostly different from each other, home health service is offered as for a short term or long term. Short-term home care services are usually limited to 30 days after medical service. Long-term home care is the case where both medical and social support and care services are provided to elderly, disabled and chronic patients for more than 6 months. The medical services of long-term patients are met with health units at home and their social care is provided by their family members. In the literature, home care services provided by experts or semi-experts from different professions are called formalcare, while home care services provided by family members or neighbors are called informal care (Dahlberg et al., 2017). Home care is part of public health services. However, long-term home care services are not provided by health professionals but mostly by non-professional family members. Conditions requiring long-term care such as chronic diseases, cancer and disability increase the physical and emotional needs of individuals. In addition, the social and spiritual needs of individuals in need of care are increasing. As spiritual needs are abstract and complex compared to physical ones, they are relatively difficult to measure. Defining the spiritual needs of the individual and providing appropriate care to meet this need is important for the peace and happiness of the individual (Burke et al., 2018). Research has shown that spiritual and psychosocial support are useful in preventing diseases, reducing pain and anxiety, fighting problems and improving quality of life. In a study on breast cancer, 88% of women with breast cancer stated that spiritual power/belief is important in combating disease (Daştan and Buzlu, 2010).

During the presentation of these services, some physical and psychological disturbances occur. Muscle skeletal system disorders occur in long-term caregiver families, in addition to some psychological disorders such as reduced capacity to deal with problems, anxiety, restlessness, loss of motivation and dissatisfaction. For this reason, it is important to provide spiritual and psychological support to those who receive or need home care and to their relatives who serve them. Although it is emphasized that spiritual and psychosocial care are important in holistic health care approach, current home care services are carried out mostly within the framework of medical services and they lack of the spiritual support. By providing the necessary spiritual support, both the family members who provide home care services and the care and home health care services will be affected positively (Lawrence et al. 2016).

The aim of this study was to determine the need for social, psychological and spiritual support of caregivers of the patients who were given home health care services by Community Health Centers in Istanbul.

METHODOLOGY

The study was conducted between 01.06.2016 and 30.10.2016 in Istanbul. Our research is a cross-sectional study. In May 2016, Community Health Centers provided services to 7.075 patients who were actively registered in 39 districts of Istanbul. The population of the research is composed of 7.075 citizens who are offered home health services by the Community Health Center. Within the scope of the research, convenience sampling method was used. Psychologists and social workers in Istanbul Health Directorate's home health coordination team were included in home health teams and visited 139 households in 15 districts. The caregivers of the patients were asked to be interviewed and could be allowed from 89 people.

A questionnaire form was prepared by the home health coordination team for psychologists and social workers before applying to the relatives of the patients. A total of 23 questions are included in the questionnaire. The first part of the questionnaire consists eight questions for patients receiving home health care. In the second part of the questionnaire, there are 15 questions for caregivers. In the first eight questions, the patient's sociodemographic characteristics and questions about the disease were included. The questions about caregivers were asked about sociodemographic conditions and caregiving.

The data in the questionnaires were entered into the excel database and evaluated with SPSS 21.0 programme. Since the questionnaires were implemented within the routine scope of service through the home health coordination center, no ethics committee permission was obtained. Informed consent was obtained from the relatives of the patients and permission was obtained from Istanbul Provincial Health Directorate for the use of the survey results. In descriptive statistics, categorical variables are expressed in numbers and percentages. Chi-square test was used for categorical variable analysis and statistical significance level was determined as $p < 0{,}05$.

RESULTS

Caregivers of 139 patients who were visited within the scope of home health care services were interviewed. Permission was granted to conduct a questionnaire and 64% (n = 89) of the caregivers allowed face-to-face surveys. All questions about patients were answered by caregivers. The data of 89 people who agreed to participate in the study were examined.

Among the patients, 64.0% of them were female. When the social security coverage of the patients was examined, 93.2% of them have Social Security Institution (SGK), 5.6% have General Health Insurance (GSS) and 1.2% of them have not any social security. 61.8% of patients have their own income and assets. Persons with disabilities can benefit from the pensions provided under Law No. 2022 that "The Law on Monthly Salary to Need, Week and Ordeal Turkish Citizens above 65 years old". However, only 6.7% of patients benefit from this social support, called 2022 salary. The distribution of the sociodemographic characteristics of the patients and need of social support was given in Table 1.

Table 1. Distribution of patients according to some sociodemographic characteristics*

Gender	**N**	**%**
Female	57	64,0
Male	32	36,0
Social Security Status	**N**	**%**
Social Security Institution	83	93,2
General Health Insurance	5	5,6
Have no insurance	1	1,2
Own Income and Assets	**N**	**%**
Have	55	61,8
Have not	34	38,2
2022 Salary	**N**	**%**
Have	6	6,7
Have not	83	93,3
Total	**89**	**100,0**

* Questions were answered by caregivers.

The percentage of patients who do not have a disability report was 80.7% while the patients with disability reports was 19.3%. It couldn't be learned whether one patient had a disability report. 81.3% of those with disability reports have a disability rate of 70% and above. There are no patients with disability rate below 40%. The distribution of the patients according to their disability status and need of social support is shown in Table 2.

Table 2. Distribution of disability status of patients*

Disabled Report	**N**	**%**
Have	17	19,3
Have not	71	80,7
Disable Rate	**N**	**%**
40-69%	3	18,7
70% and above	13	81,3

* Questions were answered by caregivers.

Table 3 shows the distribution of people receiving home health care according to their diseases. Additional diseases associated with the main diseases (such as anemia, pressure wounds, visual and hearing problems) were included in the other category. Chronic illnesses were among the health problems of the service users. The most common causes of chronic diseases were neurological (31.9%) and cardiologic (24.9%) diseases.

Table 3. Disease distribution of people receiving care*

Disease	N	%
Alzheimer's disease	25	17,7
Hypertension	20	14,2
Heart Failure	15	10,7
Diabetes Mellitus	12	8,5
Complete or partial stroke	9	6,4
Cancer	9	6,4
Parkinson's disease	8	5,7
Chronic Obstructive Pulmonary Disease (COPD)	5	3,5
Dementia	3	2,1
Muscular diseases	2	1,4
Osteoporosis	2	1,4
Other	31	22,0
Total**	**141**	**100,0**

* Questions were answered by caregivers

** The respondents indicated more than one option.

The questions in the second part of the questionnaire were asked to caregivers. 84.3% of caregivers were female. 2.3% of caregivers aged 18-29, 18.3% between 30-41 years old, 28.8% between 42-53 years old, 36.8% between 54-65 years old, and 13.8% were over 65 years old. Age information of two people could not be obtained. 61.8% of caregivers were primary school graduates. The most common duration of care was between 0-3 years (64.8%). 74.2% of caregivers were married. In addition, 85.2% of the caregivers don't have any other job. 73.9% of the patients were the first degree relatives of the caregiver. The distribution of sociodemographic characteristics of caregivers is shown in Table 4.

Table 4. Distribution of sociodemographic characteristics of caregivers

Gender	**N**	**%**
Female	75	84,3
Male	14	15,7
Marital Status	**N**	**%**
Married	66	74,2
Single	23	25,8
Work Status	**N**	**%**
Worker	13	14,8
Not worker	75	85,2
Age	**N**	**%**
18-29 years	2	2,3
30-41 years	16	18,3
42-53 years	25	28,8
54-65 years	32	36,8
>65 years	12	13,8
Education status	**N**	**%**
Not have literacy	6	6,7
Have literacy	1	1,1
Primary education	55	61,8
High school	19	21,4
University	8	9,0
Proximity to Patient	**N**	**%**
Parent	3	3,4
Partner	19	21,6
Children	43	48,9
Relative	16	18,2
Other	7	7,9
Duration of Care Giving	**N**	**%**
0-3 years	57	64,8
4-7 years	11	12,5
>8 years	20	22,7

Social security status of caregivers, income per capita and home care fee that is received from Ministry of Family and Social Policies is shown in Table 5.

Table 5. Distribution of socio-economic characteristics of caregivers

Social Security Status	**N**	**%**
Social Security Institution	83	94,3
General Health Insurance	1	1,1
Have no insurance	4	4,6
Total	**88**	**100,0**
Income per capita	**N**	**%**
0-784 Turkish Lira	47	54,0
785-1.569 Turkish Lira	36	41,4
1570-2.354 Turkish Lira	3	3,5
>2.355 Turkish Lira	1	1,1
Total	**87**	**100,0**
Receiving a Home Care Fee	**N**	**%**
Yes	6	6,8
No	82	93,2
Total	**88**	**100,0**

66.3% of caregivers did not consider themselves self-sufficient in terms of providing medical care. 94.4% of the participants did not receive any education about home care. However, almost all of the caregivers (98.9%) were not in favor of giving their patient to any institution for care. The last two questions of the questionnaire includes questions about the need of psychological and spiritual support in binary Likert scale (yes, no). More than half of the participants (56.2%) stated that they needed psychological support and about one fourth (23.6%) needed spiritual support during the caregiving period. Table 6 shows the responses of caregivers.

Table 6. Distribution of needs of caregivers (n = 89)

	Yes n (%)	**No** n (%)
Feeling Sufficient in Medical Care	30 (%33,7)	59 (%66,3)
Training for Caregiving	5 (%5,6)	84 (%94,4)
Training to Give a Patient Center for Care	1 (%1,1)	88 (%98,9)
Needing Psychological Support	50 (%56,2)	39 (%43,8)
Needing Spiritual Support	21 (%23,6)	68 (%76,4)

The need for psychological support of caregivers was examined according to some sociodemographic aspects. In the analysis, a statistically significant difference was found between the duration of care and the need for psychological support. There was no statistically significant difference between other sociodemographic features and psychological support. The results of the analysis are shown in Table 7.

Table 7. Changing the status of requesting psychological support according to some sociodemographic characteristics

	Requests for Psychological Support					
	Yes		**No**		**x^2**	**p**
Work Status	**n(49)**	**%**	**n(39)**	**%**		
Worker	6	40,0	9	60,0	1,802	0,179
Not worker	43	58,9	30	41,1		
Duration of Caregiving	**n(49)**	**%**	**n(39)**	**%**		
0-3 years	26	45,6	31	54,4	6,661	0,035
4-7 years	8	72,7	3	27,3		
> 8 years	15	75,0	5	25,0		
Receiving a Home Care Fee	**n(49)**	**%**	**n(39)**	**%**		
Yes	2	33,3	4	66,7	1,303	0,253
No	47	57,3	35	42,7		
Feeling Sufficient in Medical Care	**n(49)**	**%**	**n(39)**	**%**		
Yes	14	46,7	16	53,3	1,499	0,220
No	35	60,3	23	39,7		

Training for Caregiving	**n(49)**	**%**	**n(39)**	**%**		
Yes	3	60,0	2	40,0	0,040	0,841
No	46	55,4	37	44,6		

The need for spiritual support of caregivers was examined in terms of some sociodemographic aspects. In the analysis, a statistically significant difference was found between the need for self-sufficiency in medical care and the need for spiritual support. There was no statistically significant difference between other features. The results of the analysis are shown in Table 8.

Table 8. Changing the status of requesting spiritual support according to some sociodemographic characteristics

	Requests for Spiritual Support					
	Yes		**No**		**x²**	**p**
Work Status	**n(21)**	**%**	**n(67)**	**%**		
Worker	4	26,7	11	73,3	0,078	0,779
Not worker	17	23,3	56	76,7		
Duration of Caregiving	**n(21)**	**%**	**n(67)**	**%**		
0-3 years	16	28,1	41	71,9	5,418	0,066
4-7 years	4	36,4	7	63,6		
> 8 years	1	5,0	19	95,0		
Receiving a Home Care Fee	**n(21)**	**%**	**n(67)**	**%**		
Yes	1	16,7	5	83,3	0,183	0,668
No	20	24,4	62	75,6		
Feeling Sufficient in Medical Care	**n(21)**	**%**	**n(67)**	**%**		
Yes	2	6,7	28	93,3	7,408	0,006
No	19	32,8	39	67,2		
Training for Caregiving	**n(21)**	**%**	**n(67)**	**%**		
Yes	2	40,0	3	60,0	5,418	0,066
No	19	22,9	64	77,1		

DISCUSSIONS AND CONCLUSIONS

In our study, 80% of the patients receiving home health care services do not have a disability report. In addition, only 6,7% of them receive 2022 disabled salaries. It is clear that social services experts have three functions as consulting, resource management and education as stated in the article reported by Hasgul and named "Functions and Roles of Social Workers in Home Care Services". The necessity of social workers who will accompany visits to health personnel at regular intervals should be evaluated. In the light of these data, it is necessary to re-evaluate the methods used in the social evaluation of patients receiving home health care and in the efficient functioning of the support mechanisms (Hasgül, 2016). In spite of the difficulties of meeting the costs of treatment for home healthcare patients without social security, it is thought that their quality of life will be negatively affected by the fact that the caregiver is probably a relative. It is stated that this may be related to the decrease in quality of life as a result of the increase in stress and decrease in self-care besides economic losses (Akdemir et. al., 2011).

When home health care services are evaluated together within their scope, it can be expected that these patients are highly bedridden. Nearly half of the patients do not have their own income, however, very few are benefiting from economic support; may indicate the necessity of evaluating the health service offered in this area within the framework of care. (Çatak et. al. 2012). It is noteworthy for the target group to whom the service is offered that the patients are bedridden who suffer from chronic diseases rather than those requiring acute or temporary service. The fact that most of the caregivers have been doing this work for less than 3 years seems to be contradictory. However, it shows the importance of home health services as a service offered to individuals with chronic diseases who have concomitant chronic diseases in their final social care (Taşdelen and Ateş, 2012). In spite of the feeling insufficient while giving care, the desire of relatives to look at their patients at home supports this argument.

When the answers to the income questions were evaluated, 54% of the patients had a per capita income of 0-784 Turkish Liras. In the event that the income of the caregivers is within the specified range, the right to receive the patient care fee arises. However, only 6.8% of caregivers received a patient care fee from the Ministry of Family, Labor and Social Policies. This situation shows that 87.4% of the people who are in need could not receive the aid. It is also known that it is important to support the caregivers financially. As stated in the systematic review of 26 articles in Sweden, steps are needed to increase the proportion of financial support given to relative of patients (Stoltz et. al., 2004).

Another result obtained in our study is that a large part of the caregivers (94.4%) did not receive any training from any institution for care delivery. In addition, even if the person is responsible for the care of the patient in the process, two-thirds of the caregivers cannot see themselves as self-sufficient in medical care. Considering the fact that most of the caregivers are relatives of the patients, their need for training is undeniable. In the literature, two basic methods have been followed in terms of educating caregivers. Group training is the first of these. The effectiveness of supporting caregivers by focusing on preparation, competence, meeting the needs of information and the operation of reward mechanisms has been demonstrated. The study also states that no significant difference was found in the results of group training in rural or urban areas (Ufer et. al., 2018).

One of the methods used for education is informing the patient at bedside. In this style, where more need-spesific training is provided; the proximity of the caregiver with the patient is more important, and the caregiver's sense of proficiency is also negatively associated with a job at work (Rowland and Kumagai 2018). Interventions on the basis of psychosocial support have been shown to decrease the anxiety of the relatives of the patients and increase their care satisfaction (Götze et al., 2018). Caregivers who stated that they need psychological support constitute more than half of the participants, one fourth which stated that they needed spiritual support. Since the study can't be generalized, saying something about rates isn't scientific; however, it is thought that caregivers in home health services need more psychosocial support and spiritual care than other members of society, as stated by Çatak and Öner and by Whitlatch and Jeras (Çatak and Öner, 2012; Whitlatch and Jeras, 2018).

Conclusion

In our study, it was observed that patients who received home health care services could not benefit from the facilities such as disability report or disability salary at the expected level, and they were deprived of the social rights provided. Social workers can be included in the home health care teams to improve the scope of social support. Almost all of the caregivers of home health care patients were found to be family relatives. Despite the fact that caregivers are receiving home health care, they are deprived of the state's financial support for caregivers. Establishing a communication mechanism between the relevant ministry and the ministry of health will facilitate the identification of these caregivers. It was determined that caregivers considered themselves insufficient, accepted training deficiencies related to the care given, and needed patient or group training at the beginning of the patient. For every home care patient, it is recommended that caregivers should be given a basic training at the bedside and then be included in a group training led by guidelines.

Since our sample does not represent the population, our results cannot be generalized. More accurate estimates can be performed with simple random sampling method. It is about self awareness of the need for psychosocial support asked in our questionnaire, psychological tests and scales can be used to measure more evidence-based psychological conditions. In our survey, the percentage of unresponsiveness was high with 36% and the additional features to be able to form a group cannot be obtained.

Considering their own declarations of caregivers, they needed psychological support and spiritual support. While providing a very important service such as home health care, the importance of supporting the health, psychological and spiritual aspects of caregivers in maintaining a complete well-being should be recognized. Health workers should be supported by experts in these areas like psychologists, social workers and religious staff, and psychosocial evaluation of patients and caregivers should be seen as part of the service offered. Psychosocial and spiritual evaluation of patients and caregivers should be considered as an important part of the service offered.

Psychosocial and spiritual support services should be integrated into home health services. Besides the addition of health workers to their job descriptions as an additional workload; it will contribute complementary services as an appropriate model to Turkey's conditions which should be improved.

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Preparing the Manuscript

General Considerations

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