



Original Article

Investigating the Needs of Caregivers of Patients Suffering from Chronic Diseases: A Mixed-Method Study

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ABSTRACT

Objectives: The objective of this study was to investigate the needs of carers of patients suffering from chronic diseases.

Material and Methods: The present study is a mixed approach, quantitative and qualitative. The study population consisted of 560 caregivers of patients with chronic diseases. The data collection was done with an improvised needs survey questionnaire, which included 57 questions. The questionnaire surveyed carers' financial needs, social needs, psychological needs, and patients' education needs. The Cronbach- α index of the Patient Needs Survey was 0.956 and that of caregivers was 0.965. Carers' burden of care was assessed with The Zarit Burden Interview scale. The statistical analysis of the data was done with the statistical program IBM SPSS for Windows version 26.0.

Results: The main diseases of the patients were chronic renal failure (22.6%), multiple sclerosis (19%), cancer (19%), diabetes mellitus (7.1%), dementia (6%), and chronic obstructive pulmonary disease (6%). The majority of patients (82.1%) had health problems for more than 24 months. Caregivers provided 12.5 ± 8.3 h of daycare and cared for patients for more than 24 months (73.2%). Caregivers seek information from health professionals (4.41 ± 1.2), need more information (4.11 ± 1.4), feel stressed about the role of caregiver (3.91 ± 1.3), time available for vacation is limited (3.89 ± 1.4), time available for entertainment is limited (3.80 ± 1.3) and they feel intimidated with the role of carer (3.76 ± 1.3). The caregivers' charge was 42.4 ± 19.6 . Most caregivers reported moderate to severe burdens.

Conclusion: Caregivers experience a lack of clear and comprehensible information about the treatment that caring patients receive, as well as a lack of ongoing care from health professionals.

Keywords: Carers, Chronic diseases, Needs, Long-term care networks

INTRODUCTION

Through the description of the Chronic Care Model theory, it is recognised that a significant part of chronic care takes place outside of formal health-care facilities. The model states that six elements are central to initiatives to improve chronic care: community resources, health-care system, patient self-management, decision support, service delivery system redesign, and clinical information systems. The chronic care model is a multidimensional solution to the complex problem of providing care to patients with chronic health problems.^[1] Successful implementation of the chronic care model can lead to better processes and outcomes of care, including clinical outcomes, satisfaction, and costs.^[2] These trends appear to apply to adults and children^[3] with chronic

diseases, such as asthma,^[4] diabetes mellitus,^[5] heart failure^[6] and depression.^[7]

Interventions that include at least one component of the chronic care model are associated with improved outcomes and processes of care for people with asthma, diabetes mellitus, heart failure, and depression. Only subjects with heart failure and depression had improved quality of life.^[8]

In Greece, there are no specific studies on the implementation and/or evaluation of chronic care models and there is no organised network of state structures providing long-term care. The purpose of this work was to investigate the needs of caregivers of patients suffering from chronic diseases.

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MATERIAL AND METHODS

Study design

This study was a mixed approach, quantitative and qualitative.

Study population

The study population consisted of 560 caregivers of patients with chronic diseases (>6 months).

Instruments

First, the demographic, social, and work data of the caregivers were recorded. A questionnaire consisting of 57 questions was created by the researchers, with the answers given on a five-point Likert scale (Strongly disagree, disagree, neither agree nor disagree, agree and strongly agree). The questionnaire included eight questions investigating the financial needs of caregivers, five questions investigating the social needs of caregivers, 23 questions investigating the psychological needs of caregivers, 11 questions investigating the educational needs of caregivers, and ten questions investigating other needs of caregivers. The Cronbach-a index of the caregiver needs questionnaire which was found to be 0.965.

Caregiver burden from caregiving was assessed with the Zarit Burden Scale, which consists of 22 questions that reflect the feelings of people caring for elderly people with dementia. The burden measurement scale has been translated into the Greek language and validated in the Greek population.^[9] The Cronbach-a index of the Zarit burden scale was found to be 0.934.

Caregivers were interviewed semi-structured and guided by nine questions. Out of the total number of questions, five questions were about the type of services that they would prefer to receive and four questions were about the educational needs of caregivers.

Ethical issues

The participants were voluntarily included in the study and there was no participation cost. In particular, the information and consent forms of the Research Ethics and Ethics Committee of the University of West Attica were given to the participants, to ensure the signed consent of the participants. The distribution, completion, and collection of the questionnaires were done in an anonymous manner. All procedures followed were in accordance with the Helsinki Declaration of 1975, as revised in 2000.

Statistical analysis

The prevalence and mean for the investigated issues were calculated, while Chi-square tests and t-tests were used to assess differences between caregivers who provided care to patients <2 years versus >2 years. Pearson correlation was used to correlate caregiver burden with caregivers' needs. Statistical analyses were performed using IBM SPSS Statistics

for Windows, Version 25.0. (Armonk, NY, USA: IBM Corp.), statistical significance being considered at $P < 0.05$.

RESULTS

This study included 560 caregivers, of which 73.2% were women, 28.6% were private employees and 17.9% were retired. The main health problem experienced by patients cared for by caregivers was multiple sclerosis (19.6%) and cancer (28.6%). Caregivers provided 12.5 ± 8.3 h of daily care and 87.8 ± 57.5 h of weekly care. In total, 410 (73.2%) caregivers cared for patients for more than 24 months. [Table 1] presents the demographic, economic, and occupational data of the caregivers.

Caregivers seek information from health professionals (4.41 ± 1.2), they need more information (4.11 ± 1.4), they feel stressed with the role of caregiver ($3.91 \pm 1, 3$), they have limited time for vacation (3.89 ± 1.4) and for fun (3.80 ± 1.3) and they feel fear with the role of the caregiver (3.76 ± 1.3).

Table 1: Demographic and occupational data of caregivers.

Variable	n	%
Gender		
Males	150	26.8
Females	410	73.2
Age, years		
20–50	280	50
51–70	260	46.4
Over 70	20	3.6
Education level		
Primary/High school	350	62.5
University/College	210	37.5
Type of job		
Unemployed	70	12.5
Employed	390	69.8
Pensioners	100	17.9
Income, euro		
Up to 600	140	25
601–1300	360	64.3
Over 1300	60	10.7
Relation with patient		
Husband	110	19.6
Parents	100	17.9
Children	110	19.6
Other relative	180	32.1
No relative	60	10.7
Main health problem of patient		
Multiple sclerosis	130	23.2
Cancer	180	32.1
Stroke	80	14.2
Dementia	100	17.8
Chronic kidney failure	70	12.5
Time of care provided to patients		
Up to 24 months	150	26.8
Over 24 months	410	73.2

[Table 2] presents the mean and standard deviation of the caregivers' responses to the questions.

Caregivers who had provided care for <2 years needed more days off work to provide care (3.20 ± 1.5 vs. 2.56 ± 1.7 , $P < 0.05$), their social life has been limited due to caregiving (3.80 ± 1.3 vs. 3.39 ± 1.6 , $P < 0.05$), the time they have for relaxation (4.07 ± 1.1 vs. 3.44 ± 1.4 , $P < 0.05$), for entertainment (4.13 ± 1.1 vs. 3.68 ± 1.4 , $P < 0.05$) and for vacations is limited (4.20 ± 1.2 vs. 3.78 ± 1.5 , $P < 0.05$), they feel 'imprisoned' (3.40 ± 1.5 vs. 3.02 ± 1.5 , $P < 0.05$), they feel significantly more stressed (4.27 ± 1.1 vs. 3.78 ± 1.4 , $P < 0.05$) and fear with the caregiver role (4.00 ± 1.2 vs. 3.68 ± 1.4 , $P < 0.05$), they seek information from the internet (3.47 ± 1.5 vs. 3.17 ± 1.4 , $P < 0.05$) and they feel uncertain about what to do for their relative (2.93 ± 1.2 vs. 2.41 ± 1.2 , $P < 0.05$). The results of the correlations are presented in [Table 3].

The caregiver burden was 42.4 ± 19.6 . Totally, 35.7% of caregivers were found to have moderate to severe burden, 32.1% of caregivers had mild to moderate, 16.1% of caregivers had severe and 16.1% of caregivers had little or no burden.

Caregiver burden was found to be positively associated with age ($r = 0.136$), hours of daily patient care ($r = 0.408$), duration of patient care ($r = 0.126$), financial needs ($r = 0.461$), social needs ($r = 0.609$), information needs ($r = 0.278$), support needs about their work ($r = 0.417$) and training needs ($r = 0.614$) [Table 4].

From the analysis of the interviews, the need for more information emerged.

Information about the patient's progress, psychological support, specialist visits

qualified maintenance and treatment teams

Access to doctors, social benefits, information

Several caregivers focused on and emphasised the need for home care

Due to the mobility problems he has, it is difficult to do the examinations he needs anywhere other than at home

Nursing home care, help with physical therapy

Immediate service without waiting by the health service units was also emphasised.

Direct service to the health-care organisations

Direct and efficient

One issue that was mentioned was the financial support of patients and the financial burden from the provision of health services.

Prompt, free, efficient services

Mainly psychological support, as well as universal financial coverage

Totally, 80% of caregivers supported they would benefit from providing services through mobile phones or digital media. Only, 20% of caregivers supported direct contact.

Two-thirds of caregivers would prefer a caregiver to come to the home considering the patients' better mental health.

Definitely home, for the mental health patient

and the rest argued that the patient should be in some structure to provide holistic care.

In a structure that approaches my person in a holistic manner

Furthermore, 80% of caregivers reported that they had no training in caring for patients with chronic diseases

I had no relevant training

In addition, all caregivers reported that people with chronic conditions 'Suffer' from the health system.

Yes, because it is difficult for them to go to a public hospital for assistance (examinations, X-rays, etc.)

Most of the time, there is no easy access

Participants' suggestions for improving the quality of health services

provision of free health services

All health services have to be free and immediately accessible

better organisation

Better organisation and more sensitivity

Yes, the health system can follow the gym system. Same programming, different service

guarantee by the state of the transport of the patient to the hospital

There should be a way to transport him once a year to a hospital for a medical check-up

provision of education and information

More training, various seminars via video conference

More information is needed for the patient, carer and physiotherapists, and nurses

provision of more personnel – health-care professionals

More staff for home nursing and hospitals

Needs more health-care professionals.

DISCUSSION

The purpose of this study was to investigate the needs of caregivers of patients suffering from chronic diseases. A total of 560 caregivers of patients with chronic diseases were included, the majority of whom had been caring for the patient for more than 24 months. Caregivers seek information mainly from health-care professionals, they need more information, they feel stressed with the role of caregiver, the time available to them for holidays and entertainment is limited and they feel afraid of the role of caregiver. Furthermore, most caregivers reported moderate to severe burdens.

In the present study, caregivers were found to have moderate to high burdens. In cases where care is provided solely by caregivers, the lack of support programs from the state, society, and family members could increase the burden of caregiving responsibility and fatigue for primary caregivers. In another study, the emotional, intellectual, and informational support of caregivers was emphasised. In addition, it was considered important to empower caregivers to deal with the problems associated with caring for patients with chronic diseases as well as managing family

Table 2: Caregivers' responses to questions (1: Strongly disagree and 5: Strongly agree).

Questions	Mean±SD
The insurance fund covers all the costs of medical visits	2.93±1.5
The insurance fund covers all the costs of the medicines	3.23±1.6
The insurance fund covers all the costs of the supporting materials needed for the treatment (diapers, pads, etc.)	2.12±1.2
The government meets the financial requirements of the patients you care for	2.14±1.1
You have retired – quit your job due to the caregiving	1.82±1.4
You have reduced your working hours due to your duty to provide care	2.21±1.5
You need more days off work to provide care	2.73±1.6
Your social life has been limited due to caregiving	3.50±1.5
Visits from relatives at home have decreased	3.27±1.2
Visits from friends at home have decreased	3.32±1.3
Your visits to relatives' homes have decreased	3.34±1.3
Your visits to friends' homes have decreased	3.33±1.4
The time available to you for relaxation is limited	3.61±1.3
The time available to you for fun is limited	3.80±1.3
The time you have available for vacations is limited	3.89±1.4
Feeling 'imprisoned'	3.12±1.5
You have more aggressive behaviour than before	2.25±1.3
You are more impulsive than before	2.11±1.2
Your memory has faded compared to before	2.31±1.3
You perform your tasks at a slower rhythm than before	2.41±1.3
You feel apathetic or are more apathetic than before	2.18±1.2
You feel upset due to your health problem	2.89±1.4
You feel sad due to your health problem	2.73±1.4
You feel disappointed due to your health problem	2.39±1.2
You feel despair due to your health problem	2.36±1.3
You feel worried about the future due to your health problem	3.11±1.4
You feel that you have not the control of the situation	3.37±1.3
You feel overwhelmed with the role of caregiver	2.34±1.3
You feel tired with the role of caregiver	3.54±1.5
You feel angry with the role of caregiver	2.04±1.2
You feel guilty with the role of caregiver	1.89±1.2
You feel stressed with the role of caregiver	3.91±1.3
You feel fear with the role of caregiver	3.76±1.3
You feel embarrassed with the role of caregiver	2.02±0.9
You feel a lack of acceptance of the role of the caregiver	1.82±0.9
You have all the information you need about the condition of the patient you are caring for	3.29±1.2
You have all the information you need about the patient support services available	3.05±1.1
You have all the information you need about support services for carers	2.93±1.1
You have all the information you need about available resources – material supplies	2.80±1.2
You have all the information you need about financial benefits	2.66±1.2
You have all the information you need about the disease progression of the patient you are caring for	3.07±1.3
You are looking for information from libraries	1.95±1.3
You are looking for information on the internet	3.25±1.4
You are looking for information from medical papers	1.88±1.4
You are looking for information from brochures	1.86±1.4
You are seeking information from health-care professionals	4.41±1.2
Your relatives do not understand what you are going through	2.80±1.2
Your friends don't understand what you're going through	2.84±1.2
You need home care services	3.55±1.6
You need respite services (a service where professionals come to your home for a few hours so you have time to focus on your career, relationships and other leisure activities)	3.57±1.6
You need financial support	3.23±1.6
You need access to support services	3.57±1.5

(Contd...)

Table 2: (Continued).

Questions	Mean±SD
You need more information	4.11±1.4
You need community support	3.36±1.5
You need support from support networks	3.02±1.4
You need support from social support groups	3.62±1.4
You need to share your feelings with the rest of your family	3.63±1.3

SD: Standard deviation

Table 3: Differences between the duration of caregiving.

Question	<2 years	≥2 years	P-value
The insurance fund covers all the costs of the supporting materials needed for the treatment (diapers, pads, etc.)	1.93±1.1	2.20±1.3	0.022
You have retired–quit your job due to the caregiving	1.33±0.9	2.00±1.5	0.001
You need more days off work to provide care	3.20±1.5	2.56±1.7	0.001
Your social life has been limited due to caregiving	3.80±1.3	3.39±1.6	0.005
The time available to you for relaxation is limited	4.07±1.1	3.44±1.4	0.001
The time available to you for fun is limited	4.13±1.1	3.68±1.4	0.001
The time you have available for vacations is limited	4.20±1.2	3.78±1.5	0.002
Feeling ‘imprisoned’	3.40±1.5	3.02±1.5	0.009
You have more aggressive behaviour than before	2.07±1.3	2.32±1.3	0.041
You are more impulsive than before	1.87±1.2	2.20±1.1	0.004
Your memory has faded compared to before	1.93±1.2	2.44±1.3	0.001
You perform your tasks at a slower rhythm than before	2.13±1.2	2.51±1.3	0.001
You feel apathetic or are more apathetic than before	1.93±1.2	2.27±1.2	0.003
You feel upset due to your health problem	2.53±1.3	3.02±1.5	0.001
You feel disappointed due to your health problem	2.20±1.1	2.46±1.3	0.025
You feel despair due to your health problem	2.13±1.1	2.45±1.3	0.009
You feel angry with the role of caregiver	1.80±1.2	2.12±1.2	0.005
You feel stressed with the role of caregiver	4.27±1.1	3.78±1.4	0.001
You feel fear with the role of caregiver	4.00±1.2	3.68±1.4	0.011
You feel embarrassed with the role of caregiver	1.80±1.1	2.10±0.9	0.001
You have all the information you need about the condition of the patient you are caring for	2.53±0.8	3.24±1.2	0.001
You have all the information you need about available resources–material supplies	2.43±0.9	2.93±1.3	0.001
You have all the information you need about financial benefits	2.47±1.3	2.73±1.2	0.022
You are looking for information on the internet	3.47±1.5	3.17±0.4	0.032
You are looking for information from medical papers	1.67±1.4	1.95±1.4	0.030
You are seeking information from health-care professionals	4.00±1.6	4.56±0.9	0.001
You need financial support	2.87±1.7	3.37±1.6	0.001
You need community support	3.93±1.6	4.17±1.3	0.007
Burden (Zarit scale)	38.3±16.4	43.9±20.5	0.003

caregiving.^[10] Despite the need for social support, there are no support programs in Greece, including financial, mental, and social support programs, from government agencies, peers, families, and society for patients with chronic diseases. Information is the main need expressed by families,^[11–15] which is in line with the results of the present study. Family members require clear information about the symptoms of the disease, its management, and its expected progression because they have difficulty understanding the initial diagnosis, treatment options, and the course of the disease.^[16] Family members also describe uncertainty and insecurity due

to the worsening patient's condition and due to their inability to manage an emergency health situation at home. All of this causes family members great distress.^[12,13] Thus, caregivers should receive clear and understandable information about patients' chronic diseases so that they can understand their nature and how to manage it. On the other hand, informing caregivers also involve a risk. Caregivers think that health-care professionals provide them with a lot of information so that treatment is 'transferred' exclusively to caregivers.^[16] It is important for caregivers to have a good relationship with the health-care professionals who provide care to their family

Table 4: Correlations with dependent variable: Caregivers' burden.

Variable	Pearson	P-value
Age	0.136	0.001
Education level	-0.118	0.005
Hours of patient care, daily	0.408	0.001
Patient care time long (2 years)	0.126	0.003
Financial needs	0.461	0.001
Social needs	0.609	0.001
Information needs	0.278	0.001
Support needs about their work	0.417	0.023
Training needs	0.614	0.005

members. To achieve this, the same team of health-care professionals should provide care to the patient.^[12,13] In many cases, caregivers feel abandoned and have to take care of themselves.^[14] Other caregivers express concerns that home visits are not available to all patients, emphasising the need and the importance of expanding home health-care delivery networks.^[16] In the present study, it was found that caregivers feel anxiety and fear with the role of caregiver.

Psychological needs refer to the feelings and experiences of family members while caring for a patient.^[11-15] Oestreich *et al.* (2021) reported that the experience of 'having to care indefinitely', which reflects family members' concerns about their ability to manage the patient's health condition for a long time, causes them frustration and panic. In general, this occurs after family caregivers were wary of the expected course of the disease and treatment outcomes due to patients' small improvements in health status.^[14] Providing care for a long time, as required in chronic illnesses, can lead to changes in family roles, making it difficult for a couple to maintain a relationship after taking on the care of a person from the family environment.^[16]

Another feeling constantly expressed by the caregivers of patients with chronic diseases is the uncertainty and worry about the deterioration of health and death of the patients, the insufficient preparation for this, and the difficulty in discussing these topics with the patient, because they believe that such discussions can increase the patient's pain.^[12,13,16]

This is in line with our study. Caregivers believe that such discussions should be held by health-care professionals. Furthermore, caregivers believe that these discussions should take place as early as possible, at the beginning of the disease diagnosis.^[15]

We found that the fear the caregivers feel and the financial difficulties they face reflect their social needs for support. Social needs include family members' perceived need for support from social institutions and other people in their family environment.^[12,15] Many carers report difficulties in getting help at home from social services. Even in cases where they receive such help, they consider that these services do not meet their needs.^[16]

Not a few caregivers claim financial difficulties that prevent patients from having regular access to health services and achieving better control of their symptoms.^[16] Furthermore, caregivers report feeling a lack of support for patients, which has negative consequences such as hopelessness and frustration with health service delivery.^[15]

In the present study, caregivers provided 12.5 ± 8.3 h of daily care. A study conducted in the Philippines found that caregivers provided moderate care to patients, spending an average of 10.65 h/day and 5.08 days/week. The most difficult barriers they reported when providing care were increased costs, being forced to give up work, and experiencing negative emotions such as stress and physical difficulties. They also had low levels of confidence in deciding when to contact health-care organisations to find patient care services.^[17]

CONCLUSION

The results of the present study showed that caregivers experience a lack of clear and understandable information about the treatment received by the patients they care for, as well as a lack of continuity of care from health professionals. Caregivers experience psychological burdens due to feelings of care over time and constant uncertainty and worry about deteriorating health and death. They, also, have not the necessary support from their family and social institutions. It is essential not to treat caregivers as a simple patient care resource, but to integrate them into the health-care process. Supportive strategies are needed to address the challenges faced by caregivers of chronically ill patients.

Declaration of patient consent

The Institutional Review Board (IRB) permission obtained for the study.

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Conflicts of interest

There are no conflicts of interest.

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