

Coping with stress of family caregivers of cancer patients in Turkey

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ABSTRACT

Objective: Cancer is a disease that not only affects the individual's mental and physical integrity but also affects the functionality of the family system. Caregivers experience stress when patients cannot cope with the symptoms they are experiencing. The stress experienced by caregivers gives rise to psychological and physical symptoms. The purpose of this study is to determine the attitude of coping with stress of family caregivers of cancer patients. **Methods:** This study was conducted as a descriptive research at the Medical Oncology Clinic. The study sample group comprised of 127 family caregivers. In the collection of the data, the Personal Information Form and Attitude of Coping with Stress Inventory were used. **Results:** The coping attitude used

most frequently by family caregivers was active planning, and the least used coping attitude was avoidance isolation (biochemical). There was no significant statistical difference between the coping attitude depending on the descriptive characteristics of the family caregivers ($P > 0.05$). **Conclusion:** Results show that family caregivers of cancer patients tend to choose effective coping methods. However, there were still caregivers that displayed ineffective coping attitudes. Therefore, it is important to support the effective coping attitudes of caregivers and intervene in order to change the ineffective coping attitudes.

Key words: cancer, caregiver, stress, epidemiology

Introduction

Cancer is a disease that not only affects the individual's mental and physical integrity but also affects the functionality of the family system. The way the patients cope with their disease, the way they adapt to their treatment and whether or not they develop psychopathology interact with the coping methods of the family, family dynamics and support systems.^[1]

Family members are the most important physical and emotional care providers.^[2] Caregiving family members

help the patient perform activities such as self-care, movement, transport, communication, household chores, shopping, cooking, financing, organization of appointments and social activities. In addition, they need to perform various other activities such as helping the patient cope with symptoms and coordination of medical care.^[3,4] As well as physical care, they also take on emotional care such as enabling social support, helping them make decisions and searching for/obtaining information. As a result, those who provide care suffer from numerous difficulties such as physical issues, social issues and financial difficulties.^[4]

Cancer patients experience various problems regarding both their disease and their treatment methods. Caregivers are directly affected by the change in the physical capability, body functions, appearance, job status, sexual functions and roles within the family and society of patients. Caregivers experience stress when patients cannot cope with the symptoms they are experiencing. The stress experienced by caregivers gives rise to psychological symptoms such as

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stress, depression, anxiety, fear, loneliness, psychosomatic symptoms and marital problems, and physical symptoms such as tiredness, anorexia, indigestion, constipation, serious sleeping disorders and pain.^[5-8]

Family member caregivers have no idea how to carry out their carer role, how much care the patient needs and how to use current resources as they usually feel unprepared, have inadequate information regarding the disease and the care required and have limited support from health care givers. As a result, they neglect their own health and portray inadequate coping reactions.^[7] Coping is the process of managing requirements and difficulties caused by the individual's inner and outer world, expending cognitive and behavioral efforts to solve personal and interpersonal problems and seeking to control and reduce stress.^[9] The literature proves that caregivers of cancer patients use different coping strategies to cope with the difficulties they experience.^[10-17]

Caregivers' health usually deteriorates during the diagnosis period of the disease. Their health improves and they adapt much better once they develop their role of caregivers and use effective coping methods.^[4,18] For this reason, stress factors should be reduced, sources of the families should be increased and negative attitudes must be eliminated in order to help families to cope with the issues. In addition, family members should be trained on patient care and meeting the needs of patients, recognizing and avoiding the resulting crisis, how to cope with the limitations and how to apply the treatment regimen.^[1]

The purpose of this study was to determine the attitude of coping with stress of family caregivers of cancer patients.

Materials and methods

Study design

This study was designed as a descriptive research. The study was carried out in the Medical Oncology Clinic of Atatürk University Research Hospital. The study population comprised of 175 family caregivers of cancer patients admitted to the clinic as inpatients between the dates stated above. The study sample group comprised of 127 family caregivers who accepted to participate in the study and were aged 18 and over, were literate and with whom communicating was easy.

Instruments

Demographic and clinical characteristics

A personal information form was used to gather information about the descriptive characteristics of caregivers and their

thoughts on the disease and care. This form contains patients' basic information such as age, sex, marital status, education and employment. This questionnaire includes questions related to the degree of family relationship to the caregiven person, time allocated for caregiving, degree of adequate information on the care needs, level of training on care needs, frequency of caregiving and presence of any chronic disease.

Attitude of coping with stress inventory (ACSI)

Özbay and Şahin^[19] adapted the ACSI, developed by Özbay, into Turkish. The purpose of this scale is to determine how individuals cope in different stressful situations. The scale is composed of 43 questions. The scale is designed as a five-point Likert scale. There are six component identified as a result of factor analysis; active planning (10 item), seeking external aid (9 item), religious asylum (6 item), avoidance isolation (emotional-actual) (7 item), avoidance isolation (biochemical) (4 item) and acceptance cognitive restructuring (7 item). Active planning consists of behaviors such as doing something actively, starting to work on something immediately, increasing the active efforts and creating action plans in order to deal with various problematic situations. Seeking external help consists of the tendency to request for foreign (instrumental) assistance and looking for emotional external help toward concrete solutions. Religious asylum mostly emphasizes refuge in divine power, pray and the power of faith. Avoidance isolation (emotional-functional) deals with isolation of people passively as an attitude toward coping with the stress. Avoidance isolation (biochemical) is about the physiological changes in metabolism as a passive coping strategy. Smoking, alcohol consumption, drug use and drug abuse are among the ways of coping within the scope of this dimension. Acceptance cognitive restructuring reflects the acceptance of the problem and looking for new solutions cognitively on his/her own. This factor emphasizes the perspective of the individual in coping rather than efforts to change the situation. Active planning, seeking external aid, religious asylum and acceptance cognitive restructuring were accepted as effective coping attitudes, while avoidance attitude was accepted as an ineffective coping attitude. The general Cronbach Alfa coefficient of the scale was 0.81.^[19] In this study, the general Cronbach Alfa coefficient of the ACSI was 0.75.

The data were collected by means of face-to-face interviews held by researchers. The interviews held with those who volunteered lasted about 15-20 min.

Statistical analysis

The data were analyzed using the Statistical Program for Social Sciences (SPSS) 16.0. With regard to data

assessment, the one-sample t test was used to identify percentages to assess the descriptive characteristics of family caregivers and their thoughts about the illness and care and mean scores of caregivers. The Cronbach Alfa test was applied to determine the reliability of the scale.

Ethical considerations

The family caregivers were informed about the objective of the study and were assured that they could withdraw from the study at any time. The study was approved by the Atatürk University Faculty of Health Sciences ethics committee.

Results

Descriptive data of family caregivers are presented in Table 1. With regard to the descriptive characteristics of the family caregivers, 52.8% were female, 37% were aged between 18 and 30 years, 62.2% were married and 70.9% were unemployed, 29.9% were taking care of their parents and 70.1% had been carers for 3-12 months. And 54.3% were informed of the patient's care requirements and 94.5% had not received training about the care requirements of the patient, 77.2% provided patients with constant care and 17.3% of caregivers had a chronic disease [Table 1].

The coping attitude used most frequently by family caregivers was active planning (28.14±5.98), and the least commonly used coping attitude was avoidance isolation (biochemical) (3.31±3.20). With regard to the attitude of coping with stress for family caregivers, results show that they tend to choose effective coping methods [active planning (28.14±5.98), acceptance cognitive restructuring (17.51±4.25), seeking external aid (23.05±5.83) and religious asylum (17.52±4.18)] [Table 2].

There was no significant statistical difference between the coping attitude depending on the descriptive characteristics of family caregivers ($P>0.05$) (data not shown in table).

Discussion

This study analyzed the coping attitude of cancer patient family caregivers in coping with stress they experience while caring for the patients. The study concluded that family caregivers mainly preferred the effective coping attitude (active planning, acceptance cognitive restructuring, seeking external aid and religious asylum), although some did choose the ineffective coping attitude [avoidance isolation (emotional actual) and avoidance isolation (biochemical)]. Caring is an experience that is perceived by caring

Table 1: Characteristics of family caregivers

Characteristics	n	%
Gender		
Female	67	52.8
Male	60	47.2
Age, yrs		
18-30	47	37.0
31-40	28	22.0
41-50	24	18.9
51-60	18	14.2
≥61	10	7.9
Marital status		
Married	79	62.2
Single-widowed	48	37.8
Education status		
Literate	26	20.5
Primary school	66	52.0
High school and above	35	27.5
Employed		
Yes	37	29.1
No	90	70.9
Degree of affinity to the patient		
Spouse	31	24.4
Mother-father	38	29.9
Daughter	15	11.8
Son	15	11.8
Sibling	13	10.2
Other	15	11.8
Duration of care		
3-12 months	89	70.1
13-24 months	9	7.1
24 months and above	29	22.8
Are they adequately informed of the care required for the patient		
Yes	32	54.3
No	26	20.5
Partially	69	25.2
Have they received training to meet the care requirements of the patient		
Yes	7	5.5
No	120	94.5
Do they help the patient?		
Always	94	77.2
Mostly	29	22.8
Does the caregiver have a chronic disease?		
Yes	22	17.3
No	105	82.7
Total	127	100

Table 2: The mean ACSI scores for the family caregivers

ACSI	Mean±SD	Min-max scores
Active planning	28.14±5.98	0-40
Seeking external aid	23.05±5.83	0-36
Religious asylum	17.52±4.18	0-24
Avoidance isolation (emotional actual)	13.98±5.24	0-28
Avoidance isolation (biochemical)		
Acceptance cognitive restructuring	3.31±3.20	0-16

individuals as multi-dimensional. Caregiving may lead to positive matters such as increased intimacy and affection, personal development, improved close relationships, satisfaction, social support by other individuals, self-respect as well as physical, psychological, emotional, social and economic problems.^[20,21] Therefore, the fact that caregivers prefer the effective coping attitude when overcoming difficulties during caring is a welcome result.

The mean active planning and acceptance cognitive restructuring (effective coping attitude) scores were high for family caregivers. These attitude types enable carers to be more active, establish action plans, use a problem-solving systematic and cognitively accept the problem to find new solutions when solving problems they are faced with.^[19] Studies conducted prove that caregivers displaying constructive problem-solving skills experienced less stress^[12] and that there was a decrease in the negative stress response.^[22] Lazarus and Folkman^[23] recommended that individuals should be provided adequate information, strengthen coping behavior and improve coping skills, especially for problem-focused stress, in order to adapt to the developing status.

The religious asylum score mean was high for this study. The religious asylum emphasizes seeking refuge in a divine power, praying and gaining strength from beliefs. Religious belief is an important factor in coping with stress. The religious asylum helps individuals to effectively cope with the psychological effects of cancer. The religious asylum increases the ability to cope with cancer and its treatment as it decreases anxiety, depression and stress levels, increases mental peace, adds a positive point of view, increases hope, decreases the sense of loneliness and isolation, increases the sense of loyalty and belonging, strengthens the will to live and controls the fear of death.^[13,24,25] Studies conducted proved that caregivers using a religious coping strategy had a higher level of life satisfaction,^[15] experienced lower psychosocial distress and had a higher cancer adaptation.^[26,27] A study conducted with cancer patients in Turkey reported that patients feel that they are closer to God and started to pray after a disease. It is known that adherence to treatment and coping strategies of patients with cancer are affected by cultural beliefs and norms. The faith in the religion of Islam and the belief that diseases are a godsend ease coping with the disease.^[28] These beliefs are among the very important characteristics of Turkish culture. Considering the cultural and religious features of the region of the study, patients' tendency to be more religious may be associated with this condition in situations difficult to cope, such as cancer.

Seeking external aid scores for caregivers were high for this study. It is thought that caregivers cope with the intense stress by seeking emotional help and patient care-related help. Seeking external help incorporates requesting external help directed at material solutions and tendency to seek emotional external help.^[19] Studies conducted prove that caregivers seeking social support show less psychiatric disorders and display better psychosocial adaptation.^[29] Social support was an important determinant of caregivers' well-being and health.^[30] Family members are required to provide support and care for the patient as well as coping with their own complications.^[1] Support provided by health care systems has a positive effect on the coping skills of caregivers.^[2] Therefore, increasing the sources of social support is of great importance for caregivers to overcome the physical and psychological distress that may arise.

Study results conclude that avoidance isolation (emotional actual) and avoidance isolation (biochemical) attitudes are used less by family caregivers. These attitude types are assessed as the individual's tendency to change their metabolism physiologically and their abstraction type passively (smoking, drinking, medication and using drugs).^[19] According to Lazarus and Folkman, avoidance is an ineffective coping method that alienates the individual from the stress-related situation.^[23] Avoidance strategies enable caregivers to emotionally alienate themselves from the sense of distress; however, they experience worse caregiving experiences.^[10] Studies conducted prove that the psychosocial issues^[31] and care burden^[16] increase for caregivers who choose avoidance strategies, as well as resulting in them experiencing bad adaptation periods^[17] and decreasing their quality of life.^[11]

The previous studies proved that caregivers receiving coping training had better well-being, improved effective coping methods, used present resources more effectively and maintained their social support systems.^[8,32,33] Therefore, it is important that the coping attitude of caregivers is assessed, and such interventions are planned.

The information of the cancer caregivers (such as age, sex, marital status, education and employment degree of affinity to the patient, duration of care and the situation of any accompanying chronic disease) are all very important factors in determining the issues like attitude of coping with stress during that time. But, in this study, the descriptive characteristics of family caregivers did not affect their coping attitude ($P > 0.05$). For this reason, it is recommended that similar studies should be conducted with larger study populations.

Limitations of the study

Only family caregivers of cancer patients at the Medical Oncology Clinic were included in this study; different variables that may affect coping attitudes were not analyzed. Therefore, it is suggested that future studies should be conducted using larger populations, and different variables that may affect the coping attitude of caregivers should be investigated.

Conclusion

In Turkey, family caregivers have an important place in the health care system. They take on the majority of the care responsibility both at the hospital and at home. Therefore, it is important to develop effective coping attitude types in order for the caring period to be perceived positively by both the patient and the carer. In this study, the majority of the caregivers displayed effective coping attitude types; however, there were still caregivers who displayed ineffective coping attitudes. Therefore, it is important to support the effective coping attitudes of caregivers and intervene in order to change the ineffective coping attitudes. Caregiving may lead to positive matters such as increased intimacy and affection, personal development, improved close relationships, satisfaction, social support by other individuals, self-respect, as well as physical, psychological, emotional, social and economic problems.

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