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Caregiver Burden and Responsibilities for Nurses to Reduce Burnout

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Additional information is available at the end of the chapter

<http://dx.doi.org/10.5772/intechopen.68761>

Abstract

The world has been aging, and technology has been advancing. Increasing population and chronic diseases indicate that importance of home care will continue. Many important chronic diseases in the world-such as chronic obstructive pulmonary disease (COPD), hemodialysis and heart failure-affect the daily life and quality of life of the individual negatively. The patient needs help and support from the caregiver in many ways, such as using medicines, maintaining health checks, and maintaining daily living activities. In particular, in the home care process of the disease, there are difficulties in the physical, social, emotional and economical areas for both individuals and caregivers. Through the role of educator, the nurse can help to share the burden of care with family members, to give equal responsibility for each individual in the family and to plan the care period.

Keywords: burnout, caregiver, common diseases, home care, nurse

1. Introduction

Home care services are included in general health and social services in many countries as well as in developed countries. These services refer to care activities that are provided to those in need by conventional caregivers such as family, friend or neighbors, by formal home caregivers and by volunteers. Depending on the structure of general health and social service systems of countries, these services may be given by governmental, private or voluntary institutions, and primary, secondary and tertiary health institutions can design organizations in order to provide home care services [1]. Home care services are more economic than institutional health care in the short term or are more acceptable care model on behalf of those

in need of care and their significant others. However, in the case of prolonged care, home care may not produce the same benefits due to different difficulties on behalf of those who provide these services at home. It is necessary to construct legal and financial background to provide home care services as well as education programs to be given by health professionals to those who will receive the care and will give the care and material background so that home care services can be offered.

1.1. Some definitions for home care

Scope of home care system: Similar to general health system, home care system also targets home preventive care, home diagnostic care, home therapeutic care, home rehabilitative care, long-term home care and home hospice care.

Home health care (HHC): HHC, broadly defined, refers to all the services and products provided to clients in their homes to maintain, restore, or promote their physical, mental and emotional health.

Purpose of home health care: The aim is to maximize clients' level of independence and minimize the outcomes of existing disabilities via non-institutionalization services. Its primary objective is to use these supportive services to reduce hospitalization and prevent or delay institutionalization.

Home health nursing (HHN): HHN is an expert area of nursing practice roots of which have firmly been placed in community health nursing [2].

Types of home care personnel: Home care providers are generally characterized as either informal or formal caregiver. Informal caregivers are family members and friends who give care in the home and are unpaid. Formal caregivers are professionals and para-professionals who are compensated for the homecare they provide.

Caregiver burden: Caregiver burden has been explained as a multidimensional response to the negative appraisal and perceived stress resulting from caring sick individuals. Caregiver burden threatens the physical, psychological, emotional and functional health of caregivers [3–6].

Difficulties about health care for family caregivers: Family caregivers encounter numerous problems and at present families are mostly alone with their own coping strategies. Psychosocial problems are widespread among the caregivers. Knowledge deficits are observed correlated with physical care, diet, medications, the disease, exercise, function of the system. Additionally, caregivers suffer from fatigue and sleep disorders. They experience problems in affording medications and in taking the patients to check up. Some caregivers have financial problems so they prefer to hospitalize their patients in a government facility.

Perceived social support in caregivers: All interpersonal relations—which influence individuals' lives and provide emotional, physical and cognitive assistance to them whenever needed—are defined as “Social Support Systems” that support the state of health [7]. It has been stated that social support, which is conceptualized as the support given to any person in a troublesome or burdensome situation by family members, relatives as well as resources exerted by social connections, helps promote physical health and feeling oneself good [8].

There are some studies reporting that caregivers who get social support feel less care burden and that there exists a negative relation between the increase in social support and intensity of care burden [9, 10]. It has also been reported that social support level perceived by caregivers is among the primary factors affecting the health state of caregivers. For health professionals, it is highly important to protect the health state of caregivers providing service to long-term patients in particular and to save them from the negative effects of the treatment process.

1.2. Positive and negative aspects of home care

Home care has spread widely in the world, but it is known that there are negative and positive aspects of this care.

1.2.1. Positive aspects of home care

- The patient still continues to be a part of family life, and thus, family integrity is maintained.
- The patient keeps his/her comfort in a place to which he/she is accustomed.
- The patient can maintain previous activities and relations.
- Social isolation is prevented.
- Disease control can be enhanced because the patient feels independent.
- Quality of life of patients increases; recovery accelerates.
- The patient is protected against hospital infections.
- Cost of home care is relatively lower than the cost of hospital care and other institutions.
- Stress experienced by caregivers is reduced and their satisfaction increases because they are able to arrange and to plan health services.

1.2.2. Negative aspects of home care

- The patient may feel that his/her private life is intervened.
- The patient may be disturbed by too many family members, visiting relatives at home and interventions of medical devices depending on his/her condition.
- The patient in need of care may feel that his/her condition is more serious than he/she thought.
- Increasing economic, emotional and physical pressure may be exerted on family during caregiving procedure.
- Knowledge and skill deficit of home care providers in terms of medical tools and devices may lead to problems.
- Lack of professionals who can instantly intervene in an emergent case may be considered as a disadvantage of home care [11–13].

1.3. Home care team

Because home care is a team work, it necessitates interdisciplinary collaboration. This collaboration starts when the patient is at the hospital. Patient who is considered to need home care, physician who plans hospital discharge, physician who carries out observation of home care and caregiver who carries out home care should act together. The patient is discharged from home care in line with instructions (i.e. home care settings may be institutions or patients' own houses in some countries.). The physician in charge of home care team takes all responsibilities legally. Responsible caregiver must always be in contact with home care physician even if the patient receives these services through family members. Realization of home care depends on the willingness of the patient to receive these services and consent of his/her significant others to answer patient's needs. Basically, tasks expected to be realized by care providers are as follows:

1. To provide emotional support to patient
2. Make observation of patient
3. To provide physical support to patient
4. To help patient maintain housework
5. To participate in treatment plan
6. To seek assistance

To realize these functions, it is necessary for caregivers to receive education and training about these issues, which will enhance patient satisfaction and reduces care burden of caregivers.

Importance of home care givers: A basic component of home care is caregivers. In cases where care is necessary and if there are not any caregivers at home, it is impossible to continue home care. In economically underdeveloped or backward countries, the only care source for those who are functionally dependent on others is composed of care providers arranged with patients' significant others (husbands, wives, children, relatives or friends). Additionally, it is known that those who undertake caregiving responsibilities do not have enough education and training. These people receive education and training from the doctors or nurses about what to do at home for patient and emergency aid institutions in case of emergent situations. Besides, caregivers undergo personal, economic and social problems due to deficiency of healthcare system. The studies done identified that most of the care providers are female in the developed countries such as the USA, the UK, Canada and other countries [14].

The world has been aging, and technology has been advancing. Increasing population and chronic diseases indicate that importance of home care will continue. It should be considered as a necessity that from each family, those who are voluntary, are trained and are able to improve skills should be trained about caregiving. From each family, those who are voluntary and can improve knowledge and skills should be selected for caregiving. It should be considered as a necessity to provide these caregivers with education and training about caregiving. Besides, through programs designed for caregivers, care burden of those who want the

responsibility of care will be lightened. When these interventions are developed with social actions and government supports, economic burden will go down and satisfaction of care providers will go up.

2. Home care of patients with COPD and caregivers

2.1. Introduction

Chronic obstructive pulmonary disease (COPD), a widespread preventable and treatable disease, is characterized by persistent airflow limitation that is usually progressive and associated with an enhanced chronic inflammatory answer in the airways and the lung to noxious particles or gases. Exacerbations and comorbidities contribute to the overall severity in individual patients [15].

According to World Health Organization (WHO) estimations, COPD, ranking fifth among the most common death causes today, will be in the third place in 2030, whereas according to DALY (Disability Adjusted Life Year) incidence/prevalence, it is estimated that COPD will rank seventh in 2030 [16, 17].

The characteristic symptoms of COPD are chronic and progressive dyspnea, cough, and sputum production that can be variable from day to day.

Dyspnea: Progressive, persistent and characteristically worse with exercise.

Chronic cough: May be intermittent and may be unproductive.

Chronic sputum production: COPD patients commonly cough up sputum [15].

Patients suffer from a cough, sputum/mucus, dyspnea as well as hemoptysis, chest pain, anorexia, lack of appetite and weight loss [18–20].

COPD patients undergo serious limitation/incompetence in physical and social functions, dependence, loss of productivity, social isolation and—therefore—need assistance and support of caregivers in many areas such as leading daily life, using medications, and attending medical checks. The disease socially isolates families from the society and deteriorates friendships and neighborhood relations. Those who provide care in the post-disease period experience physical, emotional, economic and professional difficulties. These difficulties turn the social life of families/care provider's upside-down. It is highly critical to give professional support by identifying these difficulties so that anxiety of caregivers can be decreased.

2.2. The importance of caregivers in COPD patients

Patients with COPD undergo limitedness/incompetencies, dependency, loss of productivity and social isolation and therefore are in need of help and support from a caregiver in many aspects such as continuing daily life, using medications, and maintaining health checks [21, 22]. Caregivers involved in answering these requirements are responsible for many aspects such as determining the needs of the patient, monitoring disease symptoms and maintaining

treatment, preventing unexpected medical problems, repetitive hospital admissions and maintaining contact with healthcare providers [23–25].

2.2.1. Difficulties of home care providers in COPD patients

Since ambulatory treatment and home care have been accepted for today's health system, care burden of primary care providers who give care to patients with chronic diseases has been intensified. Family-based long-term care is an expensive process for caregivers, changing responsibilities and roles [26, 27]. Since many of the caregivers have to maintain their professional and social roles, the responsibilities of the patient along with care are expanding [28, 29]. Changes occur in intrafamilial roles and lifestyles and quality of life of caregivers worsens due to fear to lose patient, economical difficulties, poor sources and inadequate services, inability to answer basic needs satisfactorily and modified recreational and professional activities, all of which leads to burnout [23, 25, 29–31].

Quality of life of caregivers is physically, psychologically, socially and economically affected negatively and caregivers have difficulties in these areas. *Physical difficulties* may produce such negative outcomes as nutrition and digestion disorders, headache, muscle pain, increase or decrease in body weight, sleep disorders, concentration difficulty, wearing careless clothes and caregivers start to spare less time for self-care [32–34]. *Emotional difficulties* are uneasiness, sleeplessness, a decrease in self-esteem, social isolation, depression, sarcastic behaviors, increase in alcohol consumption and medication use and difficulty with problem-solving [35]. Time for ease and relaxation, leisure and free time activities of primary caregivers are restricted due to social difficulties, and they sacrifice from friendships or social activities, which—in turn—reduces social support, causes loneliness feeling in caregiving role and increases the risk for social isolation [33]. *Economic and profession-related difficulties* cause individuals to arrange their jobs in line with caregiving roles, and therefore, they generally have more difficulties and may give up advantages and benefits of work life and retirement, personal satisfaction and financial profits [33, 34].

In literature; it was identified that care providers of COPD patients begin caregiving without preparing for caregiving role, and—as a result—taking care responsibility affects the life of half of the caregivers negatively. Besides, observing new symptoms or taking new responsibilities and patients' loss of ability to care himself/herself create the biggest stress for caregivers [24, 36, 37].

It is very important to detect difficulties of caregivers in reducing pressure and anxiety related to their caregiving role [33, 38, 39]. In order to reduce difficulties of care providers of COPD patients, giving the necessary professional support, sharing caregiving burden with family members, assigning equal responsibility to each family member and detecting social support mechanisms will help them realize caregiving roles and enhance their quality of life [40–42].

2.3. Nursing care in COPD patients and training of caregiver

Disease course limits patient's activities and leads to incapacity. It is necessary to meet physiological needs of individuals so that they can continue their lives. As long as these needs are

not met, it is difficult for them to live in a healthy way. The basic objective of home care is to help a patient maximize independent functions and to increase his/her quality of life.

Nurses play a critical role in controlling symptoms—dyspnea in the first place—and in implementing both pharmacological and non-pharmacological treatment modalities during treatment process [43]. As a part of the nursing care at hospital and home of COPD patients, such general and patient-specific nursing interventions as—quitting smoking, disease course, nutritional habits, maintaining activities, infection signs and symptoms, preventing environmental and professional problems, teaching medication principals and effective inhalation methods, preventing and detecting exacerbations early, oxygen treatment, strategies to decrease dyspnea feeling, opening respiratory way and increasing gas change, learning daily respiratory exercises and bronchial hygiene techniques, reducing activity intolerance and anxiety, preventing feeding which is less than the amount body needs, providing sleep routine, realizing routine medical checks, realizing hygienic home environment and clear air circulation, keeping body weight at a proper level, assessing free time and travel-related, psychological, social and behavioral interventions and causes of attending health institutions—are planned and implemented [44–48].

COPD affects not only patient but also his/her family and friends, too. Therefore, that patient can take responsibility in his/her life, his/her personal care ability can be increased and they can possess a more productive, satisfactory, happier and more quality life is possible only with an effective home care program that will provide patient and his/her care provider with specific knowledge and skills. Caregiving is a multi-dimensionally perceived experience on behalf of caregiving individuals. As a part of the trainer role, the nurse can increase the success of treatment by determining learning potential of care provider and improving the quality of care of patient through the training and education she will give. During the education and training planned for caregiver—particularly when disease and symptom management begins—such topics as quitting smoking, oxygen use, treatment, energy preventive techniques, sexuality, sleep, feeding, respiration exercises, coping with anxiety/depression and end-of-life care should be emphasized [15, 48, 49].

Respiration exercises: Care provider should encourage patient to cough through pursed-lip and diaphragmatic respiration exercises. Thus, secretion clearance becomes easy, and respiration difficulty of the patient may be lessened.

Exercises: Aerobic and strength exercise done by COPD patient reduce the energy needed for many activities by elevating exercise tolerance. Caregiver and the patient should determine duration, frequency, mode and intense of exercises considering data of the initial tests and severity of the disease.

Feeding: Headache manifested in the mornings and abnormally elevated carbon dioxide in the blood (hypercapnia) may affect COPD patients negatively in terms of preparing foods and feeding (malnutrition). However, such conditions as increased energy need for respiration, CO₂ retention and respiration inflammation augment energy need of patient [50]. Therefore, it is necessary to raise awareness of caregiver about preparing a proper diet for COPD patient and to maintain the diet. A dietary program designed with the help of a dietician and by taking patient expectations into consideration should be employed and feeding support should be provided.

Sleep: COPD patients are more hypoxemic than daytime relaxation and under risk for sleep apnea-hypoapnea syndrome. Therefore, patients should be watched by caregivers during sleep periods, and caregivers should be trained about ventilator devices.

Psychological, social and behavioral interventions: Anxiety and depression often accompany with COPD. Caregivers should motivate patients about psycho-social and behavioral therapies, training and stress management, progressive muscle relaxation techniques and panic control [51].

Sexuality: Sexuality is an issue that should be discussed because it leads to anxiety, embarrassment and fear feelings. Since caregivers are generally spouses, this issue should be discussed with spouses. Those special topics such as taking bronchodilators before sexual activity and using energy saving positions should be explained to individuals [49].

End-of-life care: Family and patients should receive support so that they can cope with this process positively. In decision-making process of end-of-life period, everything should clearly and explicitly be determined by paying the due respect to decisions of patients and family [49]. Caregivers should be informed of end-of-life care of the patient. Resources of palliative and hospice care centers should be explained and individuals should be directed taking decisions of family into consideration.

3. Home care of hemodialysis patients and caregivers

3.1. Introduction

With the technological advancements today, lifespan has increased, which results in an increase in the incidence of chronic diseases [52, 53]. Chronic diseases require long-term treatment and care, cause permanent changes that limit activities of daily life, and produce socio-economic problems for patients, families, and economy of the countries [54, 55]. Chronic renal failure (CRF), one of the significant chronic diseases in the world, may create deficits in the daily life of individuals and affect the quality of life of individuals negatively, aggravate impairment in renal functions and progress into end-stage renal disease [55, 56]. According to the statistics of 2004, it was reported that there were 1,783,000 CRF patients over the world, and CRF and end-stage renal failure (ESRF) prevalence were 1505 per 1,000,000 in North America, 2045 in Japan, 585 in Europa, 70 in Asia (Japan not included), 70 in Africa, 380 in Latin America and 180 in the Middle East [57]. According to findings of Turkish Society of Nephrology (TND) 2011, it is reported that end-stage renal failure (ESRF) prevalence is 809 per 1,000,000 and 60,443 patients that receive renal replacement therapy are ESRF patients [58]. In chronic renal failure, patients are treated with peritoneum dialysis or hemodialysis methods until they receive renal transplantation [59]. Both in Turkiye and Europe, hemodialysis is known to be the widest renal replacement therapy [60]. Besides, according to 2011 data, 49,404 patients received hemodialysis treatment in Turkiye, and the number of these patients was higher as compared to those receiving peritoneum dialysis [58].

3.2. What is hemodialysis?

Hemodialysis—one of the life-saving treatment methods in renal failure—is defined as the process in which a suitable vascular route of entry named fistula, graft or catheter is used, patient's blood is cleared from waste products through a semi-permeable membrane that is called dialyzer that functions like an artificial kidney and returns blood again to patient by providing suitable fluid-electrolyte replacement [59, 61, 62].

According to Turkish Language Association (TLA), hemodialysis refers to “clearance of circulating blood from waste agents through pumping it into a machine named dialyzer when kidneys do not function” and “a treatment method used to clear blood and to remove toxic agents by filtrating them in a permeable membrane” [63]. Hemodialysis treatment is the process in which metabolic waste products are removed from the body with the help of dialyzer by using diffusion, osmosis and ultrafiltration methods of dialysis solution and regulating fluid-electrolyte balance [60, 64]. Hemodialysis patients are taken to dialysis therapy given at hemodialysis unit by healthcare team on certain days, at certain hours of the week organized by doctors in a certain manner depending on their general conditions [65, 66]. Hemodialysis therapy—determined according to patients' existing renal function and protein amount in their diets—is generally given 2–3 times a week in 4–6 h [55, 67]. The basic objective of hemodialysis therapy is to relieve patients' uremic symptoms, to establish body homeostasis and therefore to protect their quality of life and to decrease mortality and morbidity [53, 67].

3.3. The importance of caregivers in hemodialysis patients

Chronic renal failure patients come to a turning point in their lives with hemodialysis therapy. In the beginning, patients and their families have difficulty accepting and thus adapting into the disease and this treatment modality, and therefore, they react [68]. Reactions demonstrated by patients against the disease, and hemodialysis therapy and their adaptation process vary depending on so many factors such as age, sex, educational level, residential place, religious life, family structure [69]. Patients in adolescence period resist against dialysis and dietary dependence more, while adult patients do not experience so many difficulties in terms of adaptation thanks to family support [70]. Patients, who are challenged by the inability to do activities of daily living, become more dependent on others and have more difficulties [71]. Toward last phases of adaptation into the disease and treatment process, patients perceive that they are saved from death by hemodialysis, and hemodialysis has changed their lifestyles and are now in need of various alternatives that will enhance their quality of life [64]. Besides, since they alleviate disease symptoms, add meaning and energy into life, doctors, nurses and other healthcare personnel and significant others of patients should show an optimistic attitude toward patients and give hope them [72]. Not only healthcare professionals but also care providers should demonstrate a sincere, reliable, supportive attitude toward patients in the struggle against the disease and adaptation into new lifestyles created by hemodialysis therapy.

Home care providers are defined as formal caregivers (professionals who are compensated for the homecare they provide) or informal caregivers in charge of supporting patients physically,

socially, economically, emotionally by functioning as a bridge between medical treatment and psycho-social curing process [66, 73, 74]. People who provide assistance to the unable individuals who cannot self-care due to a disease, disability or elderliness or who regulate this assistance are called care-providers [75]. Those who stay with patients during all processes—from diagnosis process, treatment process to home care process—owing to limitedness caused by CRF therapy, support and help them and are mainly composed of family members are called “Primary caregivers” [53].

During hemodialysis therapy, one family member who acts like patient’s dialysis partner is accepted as a primary caregiver [76]. When a family member suffers from a serious disease such as renal failure and dialysis therapy, the homeostatic balance of the family is broken, emotional energy reduces, and changes in intrafamilial roles and tasks occur [77]. Therefore, the disease may seriously impair quality of life of both sick individuals and their caregivers [78, 79].

Due to numerous physical and psycho-social problems caused by hemodialysis therapy among patients such as fluid-dietary restriction, medication intake, loss of work, functional disorders, change in body image, their healthy life cycle is broken [66, 80]. Individuals whose normal life cycle is broken owing to hemodialysis therapy, renal failure disease and the other factors affecting the disease (other chronic diseases) undergo various physical, psychological and social problems and become partially or fully dependent [81]. To these people, who become dependent, care services are provided by professional nurses at hemodialysis unit, while care responsibility out of dialysis units is taken by those being in the social environment and domestic places of the patients [55]. Caregivers who are in charge of the primary care of hemodialysis patients should mutually be in contact with healthcare team when they provide these services.

3.3.1. Difficulties of home care residents in hemodialysis patients

Caregiving, caregiving difficulty and care burden are significant problems for the families with chronic and progressive patients. Care burden is considered as emotional and financial difficulties encountered during care process [9, 33, 82]. While giving care to those with a chronic disease or disability, a family member or a significant other may experience difficulties, get nervous and undertake too heavy care burden to tolerate; which creates care burden and difficulties [83, 84].

On the one hand, the transition to hemodialysis during a chronic disease affects patients’ quality of life and depression level negatively, and on the other hand, primary caregivers that take home care burden are negatively affected and undergo some problems [80, 85]. Primary caregivers may face various problems and experience difficulties at a different level [86, 87]. According to the studies in literature, it is identified that care providers who care patients during treatment process undergo such problems as anxiety, depression, fatigue, social isolation, deteriorated family relations and financial problems [86, 88, 89]. Caregivers have difficulty coping with helping patients do activities of daily living depending on patients’ dependency level, routine transfer of patients to the dialysis unit, symptoms, medications, diet, body image changes, depression, social and economical problems [80, 90]. It is emphasized that in

addition to these difficulties, caregivers undergo troubles in fulfilling their tasks and responsibilities owing to excessive medication use caused by depression, fatigue and other health problems, negative perception of physical health, gradual deterioration in their health status and quality of life [91]. Continually being engaged with their patient's care, changed life routines, fatigue, weariness, burnout, unhappiness, development of their own health problems, negligence of their own care and social relations contribute to impairment of their quality of life [55, 92].

Health professionals who are aware of these difficulties patients and their care providers may have help caregivers to adapt into changed domestic, family and social roles and lifestyles, to improve coping skills and thus contribute to quality of care given by those in charge of home care, which will result in a holistic care [74, 93].

3.4. Nursing care in hemodialysis patients and training of caregiver

Individuals can cope with diseases and changes in their life, keep up with changes caused by the diseases and live happily with hemodialysis as long as they are able to adapt themselves into these outcomes. It is healthcare professionals that will first help individuals who receive hemodialysis therapy as a result of chronic renal failure to adapt into modified lifestyles caused by the disease, to cope with existing or possible problems. Since it is nurses that spend the most time and interact with hemodialysis patients in the healthcare team, with the training and education, they support patients so that they can adapt into their new life [62]. During this process, patient and his/her family undergo, nursing care to be provided as training, implementation and research in relation to nursing model and theories are very important [94]. Nurses—developing a close communication with patients, answering their needs instantly and intervening them—take significant tasks and responsibilities [95, 96].

The objective of the nurses, who provide treatment and care services to hemodialysis patients in an interpersonal manner, is to provide individual, family, and society with health promoting, disease preventing experiences and help sick people and their caregivers to increase their own potentials [97]. To this end, nurses are supposed to provide patients' significant others who are together with the patient during hemodialysis process with training programs about hemodialysis and troubles created by it. Through patient-family group meetings, self-support groups and training programs, details about the disease should be explained to patients and their caregivers and considering life conditions in which patients and their caregivers are, a positive rehabilitation program should be initiated; thus, patients and their caregivers are prevented from having depression, their quality of life can be enhanced, and they can see future more positively and hopefully [53, 92]. Rehabilitation plays a crucial role in enabling hemodialysis patients and their families to overcome concurrent problems and other problems. This rehabilitation should include such issues as protection and promotion of general health, self-care education, physical therapy, feeding education, medication training, transport, domestic arrangements, job rehabilitation, sexual rehabilitation, talk-rehabilitation [98].

That hemodialysis patients and their caregivers are able to manage home treatment and care activities during their education and training is an important component in terms of continuity

of care. If medications are delivered to patients' home or are given to patients by hand, it should be assured that caregivers in charge of home care should keep these medications properly and administer the correct medications to patients at the correct time and doses. In the training of patients and their caregivers, implementation phases of such care practices as feeding, excretion, hygiene, fistula or catheter care should be explained with visual materials and they should practice under the supervision of a health professional [99].

4. Home care of patients with heart failure and caregivers

4.1. Introduction

Heart failure is a clinical and life-threatening syndrome in which sufficient amount of blood that meets metabolic needs of the body is not pumped due to a structural or functional disorder of the heart and basic complaints of which are shortness of breath and fatigue [100, 101]. Because heart failure requires a long care process and treatment since its diagnosis phase, it affects patients as well as their families physically, psychologically, socially, economically and morally [102]. Public care is substituted with home care in developed countries. In home care; all aspects such as physical, emotional, social, economic and environmental factors are discussed. Home care burden is taken on by those who provide patients with care and answer their needs; therefore, they are named as a caregiver/care provider. The role of caregiver is to meet patients' physical, emotional, cultural and social needs and to maintain the health service relation with healthcare organization and healthcare professionals [103–105].

4.2. What is heart failure (HF)?

4.2.1. Definition of heart failure

HF is a clinical syndrome characterized by typical symptoms (shortness of breath, ankle swelling, and fatigue) accompanied by such signs as elevated jugular venous pressure, pulmonary and peripheral edema by causing structural and/or functional cardiac anomaly [101].

4.2.2. Prevalence of heart failure

Heart failure is a major public health problem that has now reached epidemic proportions in the United States and many other countries [106]. Recent estimates indicate that heart failure affects nearly 5 million Americans or approximately 1.9% of the general population and that more than 400,000 new cases are diagnosed each year [107, 108]. Heart failure (HF) afflicts nearly 6 million Americans and more than 1 million annual hospital discharges [109]. By 2030, an estimated 25% increase in HF prevalence will result in an additional 3 million affected individuals [109, 110]. Heart failure accounts for nearly 1 million hospitalizations annually, and it is the leading cause of hospital admission in individuals older than 65 years of age [107, 111]. Heart failure is also a leading cause of death in the United States, listed as the primary cause in 43,000 deaths each year and as a contributory cause in another 220,000 cases [107, 108].

4.2.3. Symptoms of heart failure

Clinically, HF results from structural or functional disorders in heart and patients typically experience such physical and emotional disturbances as dyspnea (shortness of breath–air hunger), fatigue, edema, sleep disorders, depression and chest pain. Among other physical symptoms, night coughing, wheezing, feeling of swelling, loss of appetite, confusion (particularly among elders), tachycardia, dizziness, and syncope are important [101].

4.2.4. Symptoms that patients manifest because of heart failure and descriptive characteristics of these symptoms

Dyspnea: Dyspnea is a syndrome with choking sensation leading to fear of death among patients. The presences of such accompanying diseases as edema in lungs, lung infections, pleural effusion, pulmonary embolism, neoplasm and chronic obstructive pulmonary disease may lead to dyspnea [112].

Fatigue: Failure and low exercise tolerance in heart failure are generally caused by reduced cardiac output. Anemia, use of diuretics and depression, may also lead to or elevate fatigue [113].

Edema: Accumulation of fluid spreads in HF and periphericedema is evident in feet, legs, and abdomen (hepatomegalia, pulmonary crepitation, pleural effusion, and acid). In particular, in patients who sit for a long time, bilateral edema develops in feet [101].

Sleep disorders: Patients with symptomatic HF may largely suffer from sleep-related respiratory disorders (central or obstructive sleep apnea) [101].

Depression: Patients with heart failure often suffer from depression and depression influences heart failure morbidity and mortality seriously [112]. Depression reduces patients' adaptation and may lead to social loneliness, and therefore, it should be included in HF management as a part of self-care and of care provided by family/caregivers [101].

Pain: Pain affects 80% of end-stage heart failure patients. In last days, patients complain about as much pain as cancer patients. Pain in heart failure may be associated with ischemia, diabetic neuropathy or osteoarthritis [114].

4.2.5. Treatment process of heart failure

Heart failure requires life-long treatment, leads to frequent hospitalization by causing high cost in economies of countries due to complicated and expensive treatments with technologically advanced medical devices. In chronic heart failure, the basic objective of the treatment includes interventions that decrease mortality and re-hospitalization, correct symptoms and signs, increase functional capacity and improve the quality of life [111, 115]. For most of the patients—especially for the elders—leading an independent life, not experiencing disturbing symptoms and not having hospitalization may mean the wish to maximize lifespan. Preventing heart failure and repressing its progress constitute the main two objectives [116]. In the ESC guidelines of heart failure diagnosis and treatment, three concepts are discussed in classifying heart failure: these are new onset heart failure (heart failure developing for the first time, acute or slow onset),

transitory heart failure (heart failure with recurrent course or course with attacks), chronic heart failure (heart failure persistent, stabile, severe or decompensated heart failure) [116]. In acute periods, patients' clinical status and symptoms are assessed and hemodynamic status is balanced. In subacute period; cardiac function is evaluated, a suitable chronic pharmacologic treatment is commenced, and patients' treatment strategy is optimized. In the chronic period, patients' symptoms, their adaptation into treatment and prognosis are evaluated, and pharmacological treatment and use of medical devices are optimized. In the end-stage period, patients' worries and symptoms are found. It is recommended that patients' symptomatic treatment and long-term care should be planned, and their families should be supported [116].

4.3. Lifestyle changes recommended for home care given to those with heart failure

A successful management of HF often necessitates adaptation into lifestyle changes on behalf of both patients and their families. Main lifestyle changes projected for home care of those with heart failure are symptom control, daily weight monitoring, activity program, quitting smoking and alcohol, low salt diet and adaptation into treatment [117].

Symptom control: It is highly critical that the most commonly seen symptoms of heart failure patients should be controlled, patients and their care providers should recognize the symptoms of which they should see physicians and should know what to do for the symptoms. For pain, dyspnea, and fatigue, recommendations to be considered in symptom control are as follows [101].

Pain: In heart failure, pain may be associated with ischemia, diabetic neuropathy or osteoarthritis. In pain management, methods used in other chronic pains are used. Analgesics, sedatives, nitrates and opioids are some of the drugs used [114].

Dyspnea: In the respiratory management of the patients, the objective is to reduce dyspnea through oxygen treatments, pharmacological treatments, and non-pharmacological interventions. The position in which the patients feel comfortable for respiration is taken. Controlled respiration and relaxation techniques are among the helpful techniques to decrease dyspnea [113, 114].

Fatigue: Planning diuretics hours and sleep history are important factors in fatigue management. For example, making patients sleep by lifting their feet slightly so that they can sleep better, giving oxygen treatment as a support to periodic respiration, administering opiates of small doses before bedtime, nocturnal non-invasive ventilation if there is sleep apnea are among useful techniques [112].

Daily weight monitoring: Since sudden weight gain may be correlated with edema, it is crucial to watch patients' weight at home. Daily fluid intake restriction of 1.5–2 lt. may be considered in HF patients in order to reduce excessive fluid intake, signs and congestion. The hypotonic fluid restriction may correct hyponatremia. Fluid restriction proportional to weight (30 ml/kg; if > 85 kg 35 ml/kg) may produce less thirst [101].

Activity program: It is necessary to get rid of worries about physical activity, to relax and to understand benefits of exercises [101]. Regular exercise that consists of a 30-minute exercise program 5 days a week by increasing duration gradually is recommended. Patients with heart

failure can be advised moderate continuous aerobic exercises (brisk walking, cycling slight running). Exercises that are adjusted to 3–5 grades of Borg scale, raise heart rate by 65–85% and produce an oxygen consumption of 50–75% can be considered [118].

Smoking and drugs: An expert opinion should be asked for to quit smoking and illegal drugs. For those patients who are unable to stop these dangerous habits, a coordination with relevant healthcare disciplines (seeking for mental, behavioral, psychological assistance and supports) should be sought for [101].

Use of low-salt diets: If recommended by a physician, sodium restriction includes a daily salt consumption of 5–6 g (a teaspoon of 2300 mg sodium). For those with severe HF symptoms, the salt restriction should be lower than 2 g sodium [118]. To the patients and caregivers, it is explained that salt causes accumulation of fluid in the body and if saltless foods are consumed edema in lungs and body will decrease and extra salt should not be added to food while cooking or eating. Also, it may be recommended to take salt away from dining tables and to use spices to flavor foods. Fresh fish, chicken, fatless beef, legumes should be consumed. Instead of canned and take-home foods, home-made foods should be preferred and directions on take-home foods should always be observed [117].

Adaptation into treatment: It should be clarified how to take medicines, what side effects medicines produce and which signs require medical help [101]. In particular, it is highly important to understand indications, doses and prescriptions of medicines, to notice common side effects of each prescribed medicine, to watch blood pressure in hypertension, to follow a strict glucose control in diabetes, to learn treatment options if suitable, to understand importance to observe treatment recommendations and to continue determination to implement treatment plan [118].

Sexuality: It is explained that a normal sexual life can be continued with a proposed diet, medicine treatment, and regular check-ups. After consuming heavy meals, when patients suffer from any bodily fatigue, are nervous, stay in extreme hot or cold weather conditions, and are drunk, it is advisable not to have a sexual relation. During sexual intercourse, if patients feel pain in the chest, back, arm, feel bad, shortness of breath, dizziness, excessive tachycardia, the sexual relation should be stopped and patients should rest. If these complaints go on, seek medical assistance [119].

Conditions for which patients/care providers should consult the doctor are:

- Sudden weight gain (2 kga day or 5 kg a week)
- Increasing dyspnea
- Elevated swelling in foot, legs and abdomen
- Need for more pillows while sleeping
- Waking up due to difficulty breathing
- Newly occurring or worsening dizziness
- Increasing heart beat or irregular heart beat
- Any problem with heart failure medicines (Interview)

Conditions for which patients/care providers should call Emergency Aid Center and seek help are:

- Increase in the severity of difficulty breathing
- Pink foamy mucus/sputum when coughing
- The pressure in the chest and/or feeling of pressure, pain not relieved by sublingual pills [119]

4.4. Nursing care in heart failure and role of home caregivers

Nursing care to be used in heart failure should be planned in a way to cover the patients and their families and is realized through patients' direct participation in their care. In order to enhance the quality of life of the patients, education and training programs including patients and their families should be designed, and they should regularly be watched. Nurses in charge of heart failure care management should improve and assess self-care skills by providing a detailed and comprehensive patient and family education in order to maintain physical stability, to avoid of acts that will aggravate the condition and to detect symptoms that indicate aggravation of the condition at an early period [118]. In particular, the target should be to correct lifestyles of HF patients and their families, diet and activity-related changes, to achieve regular drug intake and to realize symptom control, to quit smoking and alcohol consumption and to monitor weight on daily basis [116].

Self-care contribution of patients and contribution of caregivers are really of high importance. As a health care and disease management process, basic components of self-care—defined as the ability to promote health—are care, monitoring, and management. Care includes those behaviors demonstrated to improve health through reducing risk factors and adapting into advice (e.g., follow dietary restrictions, take medicines prescribed, and do exercises regularly). Monitoring refers to the observance of heart failure symptoms routinely/being careful (e.g., daily pains, edema control) and recognition of changes when they occur. Management includes assessment of changes in symptoms and determining necessary interventions (e.g., call a healthcare personnel) and assessment of the efficacy of actions [120].

Self-care in heart failure generally refers to necessary behaviors that will protect health, maintain or improve lifestyle changes and manage symptoms and outcomes created by living with heart failure. Care providers mostly make significant contributions to activities of self-care of patients and generally are in the same position in all care processes as are patients.

4.5. Difficulties experienced by home care providers to patients with heart failure

Symptoms of heart failure are generally insidious and worsen in time. The course of the disease is generally unpredictable, and signs may change from day to day. Therefore, patients with HF should change lifestyle habits by adapting themselves to life, prioritizing and redirecting life. In this case, these may lead to negative changes in physical and emotional roles of patients [111].

Because heart failure requires a long care process since its diagnosis, caregivers are affected physically, psychologically, socially, economically and spiritually as much as patients themselves

and undergo a heavy economic burden in addition to intense stress [111]. It is stated that those who provide home care suffer from higher mental burden than other members of the family and therefore are more inclined to depression [121]. Care providers experience stress, helplessness, worry, loneliness, inability to spare time for themselves and disappointment with life. It is reported that female caregivers are under bigger risk than male caregivers [122]. Besides, it is emphasized that caregivers who are not experienced with HF acute affective disorders are considered as psycho-social care burden [123].

HF causes evident changes and difficulties in the daily life of patients' care providers. To increase knowledge level of health experts about risk factors of caregivers and to know factors that facilitate care will reduce risks in patients' and caregivers' health [124].

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References

- [1] Yurtsever S, Özge A, Kara A, et al. The relationship between care burden and social support in Turkish Alzheimer patients family caregivers. *Journal of Nursing Education and Practice*. 2017;**3**(9):1-6. DOI: <http://dx.doi.org/10.5430/jnep>
- [2] ANA. American Nursing Association (internet) (available access: 01.11.2016), 1998
- [3] Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: Correlates of feelings of burden. *The Gerontologist*. 1980;**20**(6):649-655. DOI: <https://doi.org/10.1093/geront/20.6.649>
- [4] Parks SM, Novielli KD. A practical guide to caring for caregivers. *American Family Physician*. 2000;**62**(12):2613-2622. PMID: 11142468
- [5] Eters L, Goodall D, Harrison BE. Caregiver burden among dementia patient caregivers: A review of the literature. *Journal of the American Academy of Nurse Practitioners*. 2008;**20**(8):423-428
- [6] Carretero S, Garces J, Rodenas F, Sanjose V. The informal caregiver's burden of dependent people: theory and empirical review. *Archives of Gerontology and Geriatrics*. 2009;**49**(1):74-79

- [7] Kahriman F, and Zaybak A. Caregiver burden and perceived social support among caregivers of patients with cancer. *Asian Pacific journal of cancer prevention*. 2015;**16**(8):3313-3317. PMID:25921137
- [8] Ardahan M. Social support and the nursing. *J Ataturk University School of Nursing*. 2006;**9**:68-75 (in Turkish)
- [9] Edwards NE, Scheetz PS. Predictors of burden for caregivers of patients with parkinson's disease. *The Journal of Neuroscience Nursing*. 2002;**34**:184-190
- [10] Chiou CJ, Chang HY, Chen P, Wang HH. Social support and caregiving circumstances as predictors of caregiver burden in Taiwan. *Archives of Gerontology and Geriatrics*. 2009;**48**:419-424. ISSN: 0167-4943. DOI: <http://dx.doi.org/10.1016/j.archger.2008.04.001>
- [11] Gamez B, Calanzani N, Higginson IJ. Benefits and costs of home palliative care compared with usual care for patients with advanced illness and their family caregivers. *JAMA*. 2014;**311**(10):1060-1061. DOI: 10.1001/jama.2014.553
- [12] Sayan A. Home care in today. *Journal of Anatolia Nursing*, 2004;**7**(3):91-96
- [13] Drummond MF, Sculpher MJ, Claxton K, et al. *Methods for the economic evaluation of home health care programs*. 4th Ed, United Kingdom: Oxford Press; 2015. ISBN:978-0-19-966587
- [14] Keefe J, Guberman N, Fancey P, et al. (2014) "Policy Brief No. 19–Caregiver assessment: An Essential Component of Continuing Care Policy," *Population Change and Lifecourse Strategic Knowledge Cluster Research/Policy Brief*: 2014;**1**(5):7. DOI: http://ir.lib.uwo.ca/pclc_rpb/vol1/iss5/7
- [15] GOLD. *Global Strategy for the Diagnosis, Management and Prevention of COPD 2017* [updated 11.02.; cited 2017 11.01]. DOI: <http://goldcopd.org/gold-2017-global-strategy-diagnosis-management-prevention-copd/>
- [16] Association TT. Agreement report of COPD diagnosis and treatment. *Turkish Thoracic Association*. 2010;**11**
- [17] WHO. *Chronic respiratory diseases Burden of COPD 2017* [updated 11.02.2017; cited 2017 11.02.2017]. DOI: <http://www.who.int/respiratory/copd/burden/en/>
- [18] ME COPD: Clinical and Diagnostic Approaches. In: Özlü T MM, Karadağ M, Kaya A (editors), editor. *Respiratory System and Diseases*. İstanbul: Medical Bookstore; 2010. pp. 693-700
- [19] M. T. Frequency of Anemia and the correlated factors in COPD. İstanbul: Ministry of Health, Dr.Lütfi Kırdar Kartal Education and Research Hospital; 2009
- [20] Pauwels RA, Rabe KF. Burden and clinical features of chronic obstructive pulmonary disease (COPD). *The Lancet*. **364**(9434):613-620. PMID: 15313363
- [21] Currow DC, Ward A, Clark K, Burns CM, Abernethy AP. Caregivers for people with end-stage lung disease: characteristics and unmet needs in the whole population.

International Journal of Chronic Obstructive Pulmonary Disease. 2008;3(4):753-62. PMID: 19281090. PMCID: PMC26505958

- [22] Van Manen JG, Bindels PJE, Dekker FW, IJzermans CJ, van der Zee JS, Schadé E. Risk of depression in patients with chronic obstructive pulmonary disease and its determinants. *Thorax*. 2002;57(5). PMID: 11978917
- [23] Bergs D. 'The Hidden Client'—women caring for husbands with COPD: their experience of quality of life. *Journal of Clinical Nursing*. 2002;11(5):613-621. PMID: 12201888. DOI: 10.1046/j.1365-2702.2002.00651.x
- [24] Leff B, Burton L, Mader S, Naughton B, Burl J, Clark R, et al. Satisfaction with hospital at home care. *Journal of the American Geriatrics Society*. 2006;54(9). PMID: 16970642 DOI: 10.1111/j.1532-5415.2006.00855.x
- [25] Pinto RA, Holanda MA, Medeiros MM, Mota RM, Pereira ED. Assessment of the burden of caregiving for patients with chronic obstructive pulmonary disease. *Respiratory Medicine*. 2007;101(11):2402-2408. DOI: 2402-2408.10.1016/j.rmed.2007.06.001
- [26] Blumenthal JA, Keefe FJ, Babyak MA, Fenwick CV, Johnson JM, Stott K, et al. Caregiver-assisted coping skills training for patients with COPD: Background, design, and methodological issues for the INSPIRE-II study. *Clinical Trials*. 2009;6(2):172-184. PMID: 19342470. DOI: 10.1177/1740774509102565
- [27] Kim JH, Kim EK, Park SH, Lee KA, Hwang YI, Kim EJ, et al. Burden of COPD among Family Caregivers. *Tuberc Respir Dis*. 2010;69(6):434-441. DOI: <https://doi.org/10.4046/trd.2010.69.6.434>
- [28] Langa KM, Fendrick AM, Flaherty KR, Martinez FJ, Kabeto MU, Saint S. Informal caregiving for chronic lung disease among older americans. *Chest*. 2002;122(6):2197-2203. PMID: 12475863. DOI: 10.1378/chest.122.6.2197
- [29] Cain CJ, Wicks MN. Caregiver attributes as correlates of burden in family caregivers coping with chronic obstructive pulmonary disease. *Journal of Family Nursing*. 2000;6(1):46-68. DOI: 10.1177/10748407000600104
- [30] Hasson F, Spence A, Waldron M, Kernohan G, McLaughlin D, Watson B, et al. Experiences and needs of bereaved carers during palliative and end-of-life care for people with chronic obstructive pulmonary disease. *Indian Journal of Palliative Care*. 2009;25(3):157-163. PMID: 19824276
- [31] Montgomery R, Kwak J. TCARE: Tailored caregiver assessment and referral. *Journal of Social Work Education*. 2008;44(sup3):59-64. PMID: 18797229
- [32] Beaudreau SA, Spira AP, Gray HL, Depp CA, Long J, Rothkopf M, et al. The relationship between objectively measured sleep disturbance and dementia family caregiver distress and burden. *Journal of Geriatric Psychiatry and Neurology*. 2008;21(3):159-165. PMID: 18503035
- [33] İnci FH, Erdem M. Validity and reliability of the burden interview and its adaptation to Turkish. *Journal of Anatolia Nursing and Health Sciences*. 2008;11(4):85-95. ISSN: 1309-5471

- [34] Saunders MM. Factors associated with caregiver burden in heart failure family caregivers. *Western Journal of Nursing Research*. 2008;**30**(8):943-959. PMID: 18612092. DOI: 10.1177/0193945908319990
- [35] Kasuya RT, Polgar-Bailey MP, MPH Robbyn, Takeuchi M. Caregiver burden and burn-out a guide for primary care physicians. *Postgraduate Medicine*. 2000;**108**(7):119. PMID: 11126138. DOI: 10.3810/pgm.2000.12.1324
- [36] Kanervisto M, Paavilainen E, Heikkilä J. Family dynamics in families of severe COPD patients. *Journal of Clinical Nursing*. 2007;**16**(8):1498-1505. PMID: 17655538. DOI: 10.1111/j.1365-2702.2006.01804.x
- [37] Spence A, Hasson F, Waldron M, Kernohan G, McLaughlin D, Cochrane B, et al. Active carers: Living with chronic obstructive pulmonary disease. *International Journal of Palliative Nursing*. 2008;**14**(8):368-372. PMID: 19023952. DOI: 10.12968/ijpn.2008.14.8.30771
- [38] Schulz R, Sherwood PR. Physical and Mental Health Effects of Family Caregiving. *Journal of Social Work Education*. 2008;**44**(sup3):105-113. DOI:10.5175/JSWE.2008.773247702
- [39] Sherwood PR, Given CW, Given BA, Eye Av. Caregiver burden and depressive symptoms: analysis of common outcomes in caregivers of elderly patients. *Journal of Aging and Health*. 2005;**17**(2):125-147. PMID: 15750048. DOI: 10.1177/0898264304274179
- [40] AkgünŞahin Z. Determine burden care and depression for caregivers of chronic obstructive pulmonary patients. *Medicine Reserches Journal*. 2014;**12**(3):113-119
- [41] Selçuk KT, Avcı D. The care burden of caregivers caring for elderly with chronic diseases and affecting factors. *Süleyman Demirel University Health Sciences Journal*. 2016;**7**(1): 1-9
- [42] Tel H, Demirkol D, Kara S, Aydın D. Care burden and quality of life Among the caregivers of patients with COPD. *Turkish Thoracic Journal*. 2012;**13**(3):87-92. DOI: 10.5152/ttd.2012.21
- [43] Upton J, Madoc-Sutton H, Sheikh A, Frank TL, Walker S, Fletcher M. National survey on the roles and training of primary care respiratory nurses in the UK in 2006: Are we making progress? *Primary Care Respiratory Journal*. 2007;**16**:284. PMID: 17906825. DOI: 10.3132/pcrj.2007.00068
- [44] Coultas D, Frederick J, Barnett B, Singh G, and Wludyka P. A randomized trial of two types of nurse-assisted home care for patients with copd. *Chest*. 2005;**128**(4):2017-2024. PMID: 16236850. DOI: 10.1378/chest.128.4.2017
- [45] Kara M, Aşti T. A home care of the chronic obstructive pulmonary disease. *Eurasian Journal of Medicine*. 2002;**34**:75-81
- [46] Karadakovan A. Chronic obstructive pulmonary disease. In: Akbayrak NSEİ, Ançel G, Albayrak A, editors. *Nursing Care Plans*. Ankara: Alter; 2007; pp. 201-205
- [47] Ovayolu N, Ovayolu Ö, Ateş Ç. COPD and nursing care. *Fırat Health Services Journal*. 2008;**3**(9):3-16

- [48] Özkaptan BB, Kapucu S. The importance of home care to improve self-efficacy of people with chronic obstructive pulmonary disease. *Cumhuriyet Nursing Journal*. 2015;4(2): 74-80
- [49] Fadiloğlu Ç. Home care in respiratory system diseases. In: ÇiçekFadiloğlu FD, GülErtem, editor. *Home care*. İzmir: Meta Basım; 2006
- [50] Çiftçi H, Akbulut G, Mercanlıgil SM. Respiratory system diseases and nutrition treatment. Ankara: Ministry of Health Publications. 2008. Available from: http://beslenme.gov.tr/content/files/yeterlibeslenme/hastaliklarda_beslenme/c9.pdf
- [51] Paz-Díaz H, Montes de Oca M, López JM, Celli BR. Pulmonary rehabilitation improves depression, anxiety, dyspnea and health status in patients with COPD. *American Journal of Physical Medicine & Rehabilitation*. 2007;86(1):30. PMID: 17304686. DOI: 6.10.1097/PHM.0b013e31802b8eca
- [52] Aydemir Ç, Kasım İ, Cebeci S, Göka E, Tüzer V. Quality of life and psychiatric symptoms in the caregivers of chronic renal insufficiency patients. *Journal of Crisis*. 2002;10(2):29-39
- [53] Kaya Akı M, Demir Y. A review on caregiver burden and quality of life of primary family caregivers for hemodialysis patients. *Journal of Duzce University Institute of Health Sciences*; 2012;2(3):24-28. ISSN: 2146-443X
- [54] Deeken JF, Taylor KV, Mangan P, Yabroff KR, Ingham JM. Care for the Caregivers: A review of self-report instruments developed to measure the burden, needs, and quality of life of informal caregivers. *Journal of Pain and Symptom Management*. 2003;26(4): 922-953
- [55] Hacimusalar DG. The identification of the problems of caregivers responsible for the nursing of hemodialysis patients. 2005; Master Thesis, Kayseri: Erciyes University Institute of Health Sciences
- [56] KaradakovanA, Aslan FE. Care in the medical and surgical diseases. 2nd Ed. Adana: Nobel Medical Bookstore. 2011; ISBN:978-605-397-055-2
- [57] Grassmann A, Gioberge S, Moeller S, Brown G. ESRD Patients in 2004: Global overview of patient numbers, treatment modalities and associated trends. *Nephrology Dialysis Transplantation*. 2005;20(12):2587-2593
- [58] Süleymanlar G, Altıparmak MR, Seyahi N, Trabulus S. Türkiye’de Nefroloji-DiyalizveTransplantasyon Registry Raporu 2011. İstanbul: Türk Nefroloji DerneğiYayınları; 2012
- [59] SezenA, Arslan H. Renal Failure. In A. Sezen (Ed.) *Dialysis Nursing*. İstanbul: Nobel Medical Bookstore. 2014; pp. 113-142
- [60] Ören B. Investigation of factors affecting the quality of life and self care agency of patients receiving hemodialysis and peritoneal dialysis. (PhD Thesis), 2010; İstanbul: İstanbul University Institute of Health Sciences

- [61] Daugirdas JT, Blake PG, Ing TS. Handbook of Dialysis. (Vol. Fourth Edition). Philadelphia: Lippincott Williams & Wilkins. 2010
- [62] Vicdan AK, Karabacak BG. The use of patient education Roy adaptation model hemodialysis. *Journal of Human Sciences*, 2014;**11**(2):209-220. ISSN:1303-5134. DOI: <http://dx.doi.org/10.14687/ijhs.v11i2.2729>
- [63] TDK (Turkish Language Association), Great Turkish Dictionary. Access Date: 06.02.2017 http://tdk.gov.tr/index.php?option=com_bts&arama=kelime&guid=TDK.GTS.589860a3652b79.04938173
- [64] Asan, T. The evaluation of people whose family members have chronic kidney disease. 2007; Master Thesis, Istanbul: Haliç University Institute of Health Sciences
- [65] Demirbilek H, Ciğerli Ö, Yakupoğlu Ü, Turhan F, Erman AM, Köse A, et al. Sign of burnout and depression in relatives or caregivers of dialysis patient. *Göztepe Medical Journal*. 2011;**26**(3):103-107. ISSN 1300-526X. DOI: 10.5222/J.GOZTEPETRH.2011.103
- [66] Kekeç, M. Determination of burden of caregivers to patients under hemodialysis therapy and affecting factors. (Master Thesis), Kayseri: 2011;Erciyes University Institute of Health Sciences
- [67] Akpolat T, Utaş C. Common Problems in Hemodialysis Patients. *Hemodialysis Nurse Handbook*. 2000; Istanbul: GüzelSanatlar Printing House
- [68] Güler Ö, Yüksel Ş, Acartürk G, Emül HM, Özbulut Ö, Çölbay M, et al. Psychosocial assessment in patients with end-stage renal disease treated with hemodialysis. *Anatolian Journal of Psychiatry*. 2007;**8**(3):173-178
- [69] Günler OE. Social role change, expectations and challenges in hemodialysis patients due to the disease: A study of health sociology. 2011; Master Thesis, Konya: Selçuk University Institute of Social Sciences
- [70] Yeğenağabakioğlu I. Fundamentals of hemodialysis. 1995; Istanbul: Nobel Medical Bookstore
- [71] Levendoğlu F, Altıntepe L, Uğurlu H. Disability, depression and quality of life among older hemodialysis patients. *Turkish Journal of Geriatrics*; 2004;**7**(4):195-198. ISSN: 1307-9948
- [72] Gordon T, Edwards WS. Doctor-Patient Cooperation. Aksay, E. (translator) Istanbul: Sistem Publishing. 1997
- [73] Karahan A, Güven S. Homecare for elderly. *Turkish Journal of Geriatric*; 2002;**5**(4):155-159. ISSN: 1307-9948
- [74] Suri RS, Larive B, Garg AX, Hall YN, Pierratos A, Chertow GM, et al. and FHN Study Group. Burden on caregivers as perceived by hemodialysis patients in the Frequent Hemodialysis Network (FHN) trials. *Nephrology Dialysis Transplantation*, 2011;**26**(7):2316-2322. PMID: 21421590. DOI: <https://doi.org/10.1093/ndt/gfr007>

- [75] Küçükgülçü Ö. The reliability and validity of the caregiver burden inventory in Turkey. (PhD Thesis), 2004; İzmir: Ege University Institute of Health Sciences
- [76] Ferrario SR, Zotti AM, Baroni A, Cavagnino A, Fornara R. Emotional reactions and practical problems of the caregivers of hemodialysed patients. *Journal of Nephrology*. 2002;**15**(1):54-60. PMID: 11936427
- [77] Könezoglu B. The family and family protection. (Master Thesis), 2006; Ankara: Ankara University Institute of Social Sciences
- [78] Tüzer V. Systemic family approach to chronic illness and disability. *Turkish Journal of Clinical Psychiatry*; 2001;**4**:193-201. ISSN 1302-0099 https://www.journalagent.com/kpd/pdfs/KPD_4_3_193_201.pdf
- [79] İlaslanArıkan E. The problems and burn out level experienced by caregivers responsible for the care of hemodialysis patients. 2009; Master Thesis, Istanbul: Istanbul University Institute of Health Sciences
- [80] Aydemir Ç, Kasım İ, Cebeci S, Göka E, Tüzer, V. Ouality of life and psychiatric symptoms in the caregivers of chronic renal insufficiency patients. *Crisis Journal*. 2002;**10**(2):29-39
- [81] Ünsar S, Dindar İ, Zafer R, Kumasoglu Ç. The self-care agency and affecting factors in hemodialysis patients. *Journal of the Firat Health Services*; 2006;**1**(3):70-80
- [82] Lee JE, Shin DW, Cho J, Yong HK, Kim SY, Yoo SH. Caregiver burden, patients' self-perceived burden, and preference for palliative care among cancer patients and caregivers. *Psycho-Oncology*; 2015;**24**(11), pp. 1545-1551. Published online in Wiley Online Library. PMID: 25920720. DOI: 10.1002/pon.3827 <http://onlinelibrary.wiley.com/doi/10.1002/pon.3827/full>
- [83] Ilse IB, Feys H, De Wit L, Putman K, Weerdt WD. Stroke caregivers' strain: prevalence and determinants in the first six months after stroke. *Disability and Rehabilitation*. 2008;**30**(7):523-530. PMID: 18365864
- [84] Urizar AC, Maldonado JG, Garcia MF, Molina PD. Burden of care in Aymara caregivers of patients with schizophrenia. *Revista de Psiquiatría y Salud Mental*; 2012;**5**(3):191-196. ISSN: 2173-5050. DOI: 10.1016/j.rpsmen.2011.07.004
- [85] Shanks-McElroy HA, and Strobino J. Male caregivers of spouses with Alzheimer's disease: Risk factors and health status. *American Journal of Alzheimer's Disease and Other Dementias*. 2001;**16**(3):167-175. PMID: 11398566
- [86] Gülpak M, Kocaöz S. The care burden and the affecting factors of individuals receiving hemodialysis treatment. *TAF Preventive Medicine Bulletin*. 2014;**13**(2):99-108. ISSN:1303-734X. DOI: 10.5455/pmb 1-1359391140
- [87] Atagün Mİ, Balaban ÖD, Atagün Z, Elagöz M, Özpolat AY. Caregiver burden in chronic diseases. *Current Approaches in Psychiatry*. 2011;**3**(3):513-552. DOI: <http://dx.doi.org/10.5455/cap.20110323>

- [88] Schneider RA. Fatigue among caregivers of chronic renal failure in patients: a principal components analysis. *Nephrology Nursing Journal*. 2003;**30**(6):629-633. PMID: 14730783
- [89] Cukor D, Cohen SD, Peterson RA, Kimmel PL. Psychosocial aspects of chronic disease: ESRD as a paradigmatic illness. *Journal of the American Society of Nephrology*. 2007;**18**(2):3042-3055. DOI: 10.1681/ASN.2007030345
- [90] Bülbül E. Quality of life of hemodialysis patients according to patients, family members and healthcare personnel. 2010; Master Thesis, Istanbul: Haliç University Institute of Health Sciences
- [91] Belasco A, Barbosa D, Bettencourt AR, Diccini S, Sesso R. Quality of life family caregivers of elderly patients on hemodialysis and peritoneal dialysis. *American Journal of Kidney Diseases*. 2006;**48**(6):955-963. ISSN: 0272-6386. DOI: <http://dx.doi.org/10.1053/j.ajkd.2006.08.017>
- [92] Gayomali C, Sutherland S, Finkelstein FO. The challenge for the caregiver of the patient with chronic kidney disease. *Nephrology Dialysis Transplantation*. 2008;**23**:3749-3751. PMID: 19028759
- [93] Tuncay FÖ, Mollaoğlu M, Fertelli TK. Care burden and social support of caregivers caring for patients with chronic diseases. *LiteratürSempozyum Journal of Psychiatry Neurology Behavioral Sciences*, October/November/December 2015, 2015;issue 8. http://www.literatursempozyum.com/pdf/m_1453712649.pdf
- [94] Birol L. *Nursing Process*. 9th Ed, Izmir: Etki Publications, 2009: pp. 78-81
- [95] GökÖzer F, TaşçıBeydağ KD, Cengiz Ş, Kiper S. Hopelessness levels of patients undergoing hemodialysis. *Journal of the Fırat Health Services*. 2009;**4**(10):123-136
- [96] Karabulutlu Yılmaz E, Okanlı A. The evaluation of illness perceptions in hemodialysis patients. *Journal of Anatolia Nursing and Health Sciences*. 2011;**14**(4):25-30. ISSN: 1309-5471
- [97] Özaltın G. Patients and patients' family in psychiatric nursing. *Journal of Cumhuriyet University Nursing School*, 1999;**3**(1):1-8
- [98] Polat M. Home Care Rehabilitation. In: Konak, Ş. (Ed.) *Social, Psychological and Medical Aspects of Home Care*. First Edition, Kongre Bookstore. 2016; pp. 335-340. ISBN: 978-605-66925-1-2
- [99] Zaybak A. Home Care for Patients with Invasive Procedures. Konak, Ş. (Ed.) *Social, Psychological and Medical Aspects of Home Care*. First Edition, Kongre Bookstore, 2016; pp. 269-293. ISBN: 978-605-66925-1-2
- [100] Kılıçkesmez K, Ökçün B, Küçükoğlu S. Definition and Pathophysiology of Heart Failure. In Ö. Kozan and M. Zoghi (Eds.), *A to Z Chronic Heart Failure 2010*; (pp. 25-38). Ankara: Güneş Medicine Bookstores
- [101] Ponikowski P, Voors AA, Anker SD, Bueno H, Cleland JG, Coats AJ, et al. 2016 ESC Guidelines For The Diagnosis And Treatment Of Acute And Chronic Heart Failure. *European heart journal*. 2015. ehw128. DOI: <https://doi.org/10.1093/eurheartj/ehw128>

- [102] Molloy G, Johnston DW, Witham MD. Family caregiving and congestive heart failure. Review and analysis. *European Journal of Heart Failure*, 2005;**7**(4):592-603. DOI: 10.1016/j.ejheart.2004.07.008
- [103] Friedman MM, Bowden VR, Jones E. Family Nursing: Research, Theory & Practice. In: Friedman MM, Bowden VR, Jones E. (Eds.). Introduction to the family. Upper Saddle River: Prentice Hall. 2003: pp. 3-33
- [104] Goldstein G, Kenet G. The impact of chronic disease on the family. *haemophilia*. 2002;**8**(3):461-465. DOI: 10.1046/j.1365-2516.2002.00642.x
- [105] Williams LA. Theory of caregiving dynamics. In: Smith M, Liehr P (Eds.), Middle range theory for nursing 2008; pp. 261-276). New York: Springer Publishing Company
- [106] Lloyd-Jones D, Adams RJ, Brown TM, Carnethon M, Dai S, De Simone G, et al. Heart disease and stroke statistics—2010 update. *Circulation*, 2010;**121**(7):e46–e215. DOI: 10.1161/CIRCULATIONAHA.109.19266
- [107] Levy D, Kenchaiah S, Larson MG, Benjamin EJ, Kupka MJ, Ho KK, et al. Long-term trends in the incidence of and survival with heart failure. *New England Journal of Medicine*, 2002;**347**(18):1397-1402. DOI: 10.1056/NEJMoa020265
- [108] McMurray J, Petrie M, Murdoch D, Davie A. Clinical epidemiology of heart failure: Public and private health burden. *European Heart Journal*. 1998;**19**:9-16. DOI: PMID:9886707
- [109] Roger VL, Go AS, Lloyd-Jones DM, Adams RJ, Berry JD, Brown TM, et al. Heart disease and stroke statistics—2011 Update. A Report From the American Heart Association. *Circulation*, 2011;**123**(4):e18–e209. DOI: 10.1161/CIR.0b013e3182009701
- [110] Heidenreich PA, Trogdon JG, Khavjou OA, Butler J, Dracup K, Ezekowitz MD, et al. Forecasting The future of cardiovascular disease in the united states. *Circulation*. 2011;**123**(8):933-944. DOI: 10.1161/CIR.0b013e31820a55f5
- [111] McMurray JJ, Adamopoulos S, Anker SD, Auricchio A, Böhm M, Dickstein K, et al. ESC guidelines for the diagnosis and treatment of acute and chronic heart failure 2012. *European Journal of Heart Failure*. 2012;**14**(8):803-869. DOI: 10.1093/eurjhf/hfs105
- [112] Johnson MJ. Management of end stage cardiac failure. *Postgraduate Medical Journal*. 2007;**83**(980):395-401. DOI: 10.1136/pgmj.2006.055723
- [113] Stuart B. Palliative Care and hospice in advanced heart failure. *Journal of Palliative Medicine*. 2007;**10**(1):210-228. DOI: 10.1089/jpm.2006.9988
- [114] Wingate S, Wiegand DLM. End-Of-Life care in the critical care unit for patients with heart failure. *Critical Care Nurse*, 2008;**28**(2):84-94
- [115] Yancy CW, Jessup M, Bozkurt B, Butler J, Casey DE Jr, Drazner MH, et al. 2013 ACCF/AHA guideline for the management of heart failure: a report of the American College of Cardiology Foundation/American Heart Association Task Force on Practice Guidelines. *Journal of the American College of Cardiology* 2013;**62**:147-239

- [116] Dickstein K, Cohen-Solal A, Filippatos G, McMurray JJ, Ponikowski P, Poole-Wilson PA, et al. ESC guidelines for the diagnosis and treatment of acute and chronic heart failure 2008. *European Journal of Heart Failure*. 2008;**10**(10):933-989. DOI: 10.1016/j.ejheart.2008.08.005
- [117] Demir M, Ünsar S. Heart failure and home care. *Firat Health Services Journal*. 2008;**3**(8): 119-130
- [118] Özer S, Sezgin ÖGD. Self-care in heart failure. *Heart Failure Electronic Newsletter*, 2015;**7**(4):1-3
- [119] Özdemir Ü. Heart failure patient and family education. *Heart Failure Electronic Newsletter*. 2009;**1**:1-6. <http://www.tdk.org.tr/KYBulteni/makale=66>
- [120] Riegel B, Jaarsma T, Strömberg A. A Middle-range theory of self-care of chronic illness. *Advances in Nursing Science*. 2012;**35**(3):194-204. DOI: 10.1097/ANS.0b013e318261b1ba
- [121] Pinquart M, Sörensen S. Correlates of physical health of informal caregivers: A meta-analysis. *Journals of Gerontology. Series B: Psychological Sciences and Social Sciences*. 2007;**62**(2):126-137. DOI: 10.1093/geronb/62.2.P126
- [122] Humphrey L, Kulich K, Deschaseaux C, Blackburn S, Maguire L, Strömberg A. The caregiver burden questionnaire for heart failure (CBQ-HF): Face and content validity. Health and quality of life outcomes. 2013;**11**(1):84. DOI: 10.1186/1477-7525-11-84
- [123] Scott LD. Caregiving and care receiving among a technologically dependent heart failure population. *Advances in Nursing Science*. 2000;**23**(2):82-97. PMID: 11104326
- [124] Strömberg A. The situation of caregivers in heart failure and their role in improving patient outcomes. *Current Heart Failure Reports*. 2013;**10**(3):270-275. DOI: 10.1007/s11897-013-0146-8