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## RESEARCH ARTICLE

### ON CARE GIVERS BURDEN OF ORTHOPEDIC PATIENT

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#### ABSTRACT

**Introduction:** The caregiver is the person who takes primary responsibility for someone who cannot carefully for himself or herself. The caregiver may be a family member, a trained professional or another individual. Depending on culture there may be various members of the family engaged in care. **Methodology:** In this survey, the data was analyzed from the previous conducted researches regarding the caregivers burden and the quality of life of caregivers who are providing the care to the chronically ill patients or orthopedic client. **Result:** The result shows that the common problems faced by the caregivers while providing care to the chronically ill patients or orthopedic client are insufficient time, emotional and physical stress, lack of privacy, financial burden, lack of sleep, being afraid to ask for help, depression and isolation. **Discussion:** The result shows that the common problems faced by the caregivers while providing care to the chronically ill patients or orthopedic client can be solved with proper guidance, support of family and cooperation.

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#### INTRODUCTION

*I feel the capacity to care is the thing which gives life its deepest significance. -Pablo Casals*

The terms care and caring is used to describe the innate work and value of nursing. Care is defined as to have feelings like concern, responsibility or love for the one who need assistance of someone in doing their daily routine activities as well as who need support in making decision while they are not so capable for doing so. The caregiver is the person who takes primary responsibility for someone who cannot carefully for himself or herself. The caregiver may be a family member, a trained professional or another individual. Depending on culture there may be various members of the family engaged in care. And the care giving is most commonly used to address impairments related to old age, disability, a disease, or a mental disorder. The duties of a caregiver includes taking care of someone who has a chronic illness or disease; managing medications or talking to doctors and nurses on someone's behalf; helping to bathe or dress someone who is frail or disabled; or taking care of household chores, meals, or bills for someone who cannot do these things alone.

The care giver could be paid or unpaid member of society; paid like healthcare professionals who will charge for the services which is provided by them or unpaid like family members, friends, relatives, etc. of the patient. Orthopedic client are the ones who are having any musculoskeletal disease condition like arthritis, soft tissue injuries, low back pain, fracture etc. Among all these conditions the soft tissue injury and fracture (upper limb, lower limb and hip fracture) requires a care giver more than other and also put more stress to the person who is going to provide care to such patients. Caregivers burden is the stress which is perceived by caregivers of the orthopedic patient or by the caregiver of other chronic illnesses. This subjective burden is one of the most important predictors for negative outcomes of the care situation for the orthopedic client as well for the caregivers themselves. The caregiver's burden is defined as the physical, psychological, emotional, social, and financial problems that can be experienced by individuals providing care for orthopedic client or disabled person. There is considerable literature describing orthopedic trauma outcome studies regarding functional disability, depression levels, and quality of life measures. However, these analyses do not measure the residual effects on family members that take the role of caregiver to the orthopedic patient. Understanding the impact of a potentially debilitating fracture and subsequent treatment on the patient's caregiver and the consequences to his/her psychological and socioeconomic well-being can lead to better posttraumatic counseling by primary care physicians,

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multidisciplinary approaches to treatment and rehabilitation, and careful consideration of the needs of family members or primary caregiver or both. Occurring against the backdrop of possible preexisting medical conditions, the financial and emotional cost to the individuals and their families may be extremely high. There are various studies which shows the caregivers burden while caring a chronically ill person / orthopedic client; such as Ariza-Vega P, et al. 2019 conducted a study to determine the profile of the main informal caregivers, the evolution of the caregiver burden, and the influencing factors of caregiver burden at 1-year after hip fracture surgery. In this study, the researcher found that the main caregiver is predominantly female and is most often the daughter of the patient. New treatment strategies such as the support and training of the caregivers in patient handling during hospital stay could be carried out to reduce caregiver burden. Implications for rehabilitation The main caregiver of a hip fracture patient is usually a woman who is the daughter of the patient, and reducing her burden of care should be included as one of the objectives of rehabilitation treatment. The caregivers of hip fracture patients must be considered as part of the treatment during the patient's recovery period, and patient handling training should be provided to the caregivers of hip fracture patients during the hospital stay to prepare the process of going back home. The caregivers of older patients, those with a low pre-fracture functional level, and of those who suffered post-operative complications, should receive more attention prior to hospital discharge and receive more assistance at home to reduce caregiver burden.

Genç et al. 2019 conducted a study to assess the caregiver burden (CB) in early and late stages of disease and to search if there was a relationship between quality of life and CB. The result shows that 74 patients (male, 58.1%) were included in the study. The mean age of patients was  $66.18 \pm 8.5$  and the mean duration of disease was  $67.23 \pm 41.8$  months. According to the H&Y scale, the patients were divided into two groups; stage I-II as early stage and stage III-V as late stage. Group 1 (H&Y I-II) consisted of 40 patients, and group 2 (H&Y III-V) comprised 34 patients. The mean duration of disease and UPDRS scores were significantly higher in group 2 ( $p=0.003$ ,  $p=0.001$ , respectively). Significant differences were found in group 2 according to BDI. There were significant differences between group 1 and 2 according to SF-36 sub domains such as general health, emotional role, social functioning, pain, and mental health ( $p=0.019$ ,  $p=0.038$ ,  $p=0.005$ ,  $p=0.004$ ,  $p=0.014$ , respectively). However, there were no significant differences between these two groups concerning CB. Although CB was found in 35 (47.3%) caregivers in our study, we found no significant differences between the caregivers of patients with early and late-stage IPD patients. We thought that this might be due to strong family relationships and cultural dynamics in Turkey. Burden was found to be higher in depressive patients' CGs and CGs who had depressive symptoms. It is important to recognize depressive symptoms earlier to protect the relationship between the CG and the patient because the main providers of care are family members. Xie Z, et al. 2015 conducted a study to evaluate the costs of outpatient medical care and family burden associated with osteoporosis-related fracture rehabilitation following hospital discharge in China. The researcher found that hip fracture was the most frequent fracture site (62.6%), followed by vertebral fracture (34.2%). The mean direct medical care costs per patient totaled 3,910¥, while mean indirect medical costs totaled 743¥. Lost work time for unpaid family caregivers was 16.4 days, resulting in

an average lost income of 3,233¥. The average post hospital direct medical cost, indirect medical cost, and caregiver lost income associated with a fracture patient totaled 7,886¥. Patients' ambulatory status was negatively impacted following fracture. And the significant time and cost of care are placed on patients and caregivers during rehabilitation after discharge for osteoporotic fracture. It is important to evaluate the role and responsibility for creating the growing and inequitable burden placed on patients and caregivers following osteoporotic fracture. As per above literature it is found that the primary care givers of chronically ill / orthopedic client are having caregivers burden in any form (economic, health, etc.). so, for dealing with the burden there should be some interventions or implementations which could help the primary caregivers to reduce the burden. Caregiver burden is highest among the care provider who is providing care to their spouse. Family care giving involves the multiple like bathing, dressing and eating, etc. The family care giving is an genuinely rewarding experience, the caregivers often face common challenges in their daily day to day life while providing care and that may results in anxiety, stress, frustration and burden, etc. Some of the problems faced by the primary caregivers are such as:

- **Knowledge deficits:** Knowledge deficits are observed correlated with physical care, diet, medication, the disease, exercise, function of the system. Additionally, caregivers suffer from fatigue and sleep disorders.

**Solution:** The knowledge of caregivers can be increased by providing the health education, i.e. how the caregivers can understand the needs of the orthopedic client as well as by teaching them the method of providing basic care o the patient like, maintaining personal hygiene, active passive exercises for the patient according to the patient, drug regimen, diet management, prognosis / recovery as well as about rehabilitation of the patient.

- **Insufficient time. Caregivers of chronically ill patient / orthopedic clients** have less time for themselves and for their family members. They spend so abundant time on caregiving duties for their patient then they have to compromise with other things and they have to manage their time schedule as per the need of the patient because they should be available all the time when the patient assistance so their leisure activities would be affected, like daily routine activities / vacations. Or they will also have trouble in balancing work schedule around caregiving.

**Solution:** For managing the insufficient time to the caregivers we can make the time schedule according to the patient's needs and the activities of the patients. According to the timetable the caregiver can perform their self care activities like daily routine activities, exercise, etc. As well as for balancing their work schedule they can ask for the assistance for the time while the primary caregiver is doing his / her work.

- **Emotional and physical stress. Some statistical data shows that** 22% of caregivers reported that when they are providing care to their patient then their physical as well as mental health will also affect. Caring for chronic conditions like chronically ill patient / orthopedic patient or psychiatric illnesses puts more emotional stress. While

lifting and helping with mobility to patient also put physical stress.

**Solution:** While dealing with the orthopedic patient the primary caregiver may suffer from emotional and physical stress. To cope up with the emotional stress the caregiver will have counseling sessions individually as well as family counseling so that the other family members can support or help the primary caregiver. The primary caregiver can indulge their selves in recreational activities like listening music, watching television, doing exercise, yoga, meditation or communicating with their family members, friends or relatives. While the primary caregiver facing the physical stress then we can help them by teaching appropriate techniques of mobility, lifting of the orthopedic patient, etc. to the primary caregiver, as well as the primary caregiver can ask for the help and assistance to the other person to relieve the physical stress and ease out their burden.

- **Financial burden. In developing countries the primary caregivers are mostly** unemployed or unpaid, then they would have financial burden, especially when the dependent patient is the earning source. As the longer disease will the financial burden will be more.

**Solution:** For dealing with the financial burden the primary caregiver and his / her family can seek the help of insurance companies or other schemes that can help out them with financial matters. As well as the primary givers who are under below the poverty line and doesn't have the any resource of income and they don't have any policy can seek the help of NGOs, social workers for the health care expenditure. To generate the source of income the primary caregiver can do some vocational jobs (part time / full time) according to their skills and support the family and health care expenditure for the patient.

- **Lack of sleep.** Lack of sleep can be a big issue for a family caregiver, as often the loved one's sleep-wake cycle can be mixed up. Sleep deprivation can take a huge toll on a caregiver who is already feeling the strain of being burned from both ends.

**Solution:** As the primary caregiver will analyze the schedule of caring the orthopedic patient as well as after analyzing their roles and responsibilities towards the patient the primary caregiver can plan the time plan for their selves to fulfill their biological need of sleep and rest. As well as while the primary caregiver are having the strain due to sleep deprivation, then they can ask their trustworthy family member, relative or friend to do the job of primary caregiver for the alternate period of time so that their biological needs can be fulfilled.

- **Being afraid to ask for help.** Many caregivers feel ashamed or burdened to ask for help from others. They feel they must assume the full caregiver burden as that asking for some assistance may be a sign of weakness. The caregiver in turn starts to feel guilty that they aren't providing the best care for their loved ones that they could.

**Solution:** The primary caregiver can ask for the help / assistance from the person to whom they can trust among their family member, relatives or friends. And assign the duties to perform in a day. And before passing the responsibilities of patient to someone else, the primary caregiver can teach them about the roles and responsibilities regarding care (like how to do cleaning, how to turn the sides of the patient, how to lift the patient, etc.) of the patient to ensure the quality of care provided by the other person.

- **Depression and isolation.** A family caregiver is often at high risk for depression. Often times, Caregiving duties take up so much of their time that they no longer maintain social connections outside of the home.

**Solution:** While the primary caregiver feeling depressed and isolated, they can indulge their selves in recreational activities like listening music, watching television, doing exercise, yoga, meditation, reading books or communicating with their family members, friends or relatives through phone calls (audio / video), chatting, social media, etc.

The above mentioned problems can also result in the poor quality of life of caregivers during the period of care. So, we can reduce the burden of caregivers by doing counseling and providing education related to the care of the patient as per their need as well as by providing the assistance and cooperation to primary caregivers which will lead to increase and excellent quality of life of a primary caregiver as well as increase the quality of care that is provided to the patient.

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