

Renata Klak, Krzysztof Letachowicz, Dorota Ziełńska

Department of Nephrology and Transplantation Medicine, Wrocław Medical University

Caregiver burnout syndrome in assisted peritoneal dialysis

ABSTRACT

The article describes the history of a 90-year-old patient participating in a program of assisted peritoneal dialysis for 11 years. Assistance during the procedures was provided by the patient's daughter. Care provided by relatives is the most common form of long-term care; however, the long duration of the disease, nature of care provided, require-

ment of constant availability and having to cope with the progressing disability of the ward may lead to physical and psychological exhaustion as well as loss of social ties on the side of the caregiver.

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Key words: assisted peritoneal dialysis, elderly patient, caregiver burnout syndrome

INTRODUCTION

Elderly patients are now a large group of patients receiving renal replacement therapy. Problems related to the treatment affect the quality of life of the patient and their family. By definition, the model of assisted peritoneal dialysis requires that the exchange of dialysis fluids be carried out at the patient's home by a third party. In Poland, the care of elderly dialysis patients is most frequently provided by family members, which constitutes a heavy physical, mental, and material burden and may result in numerous problems and dysfunctions within the family.

CASE REPORT

The reported patient had been diagnosed with chronic kidney disease secondary to ischemic nephropathy at the age of 79 years. Due to disease progression, preparations for a chronic dialysis program were started after a few months. As per the preference of the patient and her family, a Tenckhoff catheter was implanted into the peritoneal cavity. Following the healing of the postoperative wound, the patient was hospitalized and subjected to dialyses with 1.5% glucose at 4×2000 mL. As a result of dialysis therapy, improvement in the patient's condition and laboratory pa-

rameters was achieved along with normalization of blood pressure. Due to the patient's reluctance, amblyopia and slowly progressing decrease in cognitive abilities, the patient's daughter was trained to perform continuous ambulatory peritoneal dialysis (CAPD) exchange procedures. The patient's daughter willingly participated in the training. For the following 3 years, the patient and her daughter used to systematically report for follow-up visits at the Peritoneal Dialysis Center once a month. During the scheduled follow-ups, we observed that the daughter became gradually withdrawn and reluctant to make contact. Conversations revealed difficulties in the relationship between the patient and the caregiver. The daughter was the only family member willing to provide assistance to the patient at her home. The daughter was dependent on and treated badly by her mother. Due to the need to provide respite to the daughter as a result of her life situation, the patient was hospitalized for a brief period.

Four years after the start of therapy, the first episode of dialysis-related peritonitis developed; the treatment and the course of the episode were typical of the condition. Over the following 4 years, both women systematically reported for follow-up visits; since the treatment was efficient and the patient did not wish to change the modality, peritoneal dialy-

Address for correspondence:

Renata Klak,
Department of Nephrology
and Transplantation Medicine,
Wrocław Medical University,
e-mail: renataklak@wp.pl

sis was continued. During one of the visits, the patient's daughter reported that she had to undergo hospital treatment and asked for help in providing care for her mother. In the absence of other options, a decision was made to hospitalize the patient as before. Despite the earlier agreement, the patient's daughter or any other member of her family could not be contacted for 2 weeks. Finally, the patient was discharged home after 3 weeks of hospitalization. Over the following 3 years, the patient's condition gradually deteriorated, with progressing cognitive decline and de novo malnutrition. The patient was no longer self-sufficient and required constant assistance. Eleven years after the initiation of CAPD, the patient was admitted to the hospital with a diagnosis of dialysis-related peritonitis. Given the general clinical presentation, including the presence of fluid within the pleural cavities, a decision was made to switch the management modality from peritoneal dialysis to hemodialysis.

DISCUSSION

Chronic renal insufficiency in elderly patients is a great challenge to nephrologists [1]. Until very recently, access to dialysis therapy was significantly limited for this group of patients in Poland and worldwide [2]. At present, no clear guidelines exist on renal replacement therapy in elderly patients. Options to be taken into account in this age group include peritoneal dialysis, hemodialysis, kidney transplant, and conservative treatment. When choosing the optimum dialysis method, it is necessary to take into account not only the preferences of the patient or the family caregiver but also the expected lifespan and quality of life with consideration of the underlying disease, comorbidities, prognosis, and impact of the chosen method [3–6].

The presented case illustrates the implementation of assisted peritoneal dialysis in an elderly patient with a family member providing the required assistance (dialysis fluid replacements). In addition to the effectiveness of the method, attention should be paid to the effect of renal replacement therapy on the life of the patient's caregiver. Peritoneal dialysis has many advantages, particularly for older patients with physical and mental disabilities. One of these is the ability to deliver the treatment at home, in a patient-friendly setting, which was of particular importance in the era of the COVID-19 pandemic. In addition,

peritoneal dialysis facilitates conservation of residual kidney function while providing hemodynamic stability and ensuring simple access to dialysis, without the need for the establishment of vascular access. Moreover, the number of complications and the quality of life are comparable to those observed in younger patients on peritoneal dialysis [6, 7].

Chronic kidney failure is a long-term disease. It is a great threat to the quality of life of the family as the main burden of care for the sick person has to be carried by their relatives. Family-provided care is the most common form of long-term care in Poland as well as worldwide [8–10]. It should be emphasized that family is the primary source of support and care for elderly individuals. However, the disease of an aging spouse or parent results in significant changes for their family (due to material and social limitations), particularly functioning of the closest caregiver. Living with a chronically ill person not only alters the tasks and roles of individual family members but also switches the entire focus of the family on patient care and support [10–12]. In Poland, 80% of elderly patients are supported by their family members who provide for their care- and therapy-related as well as emotional and social needs, take up household chores and transportation-related tasks, and provide mental or even financial support [10]. The EUROFAMCARE (Services for Supporting Family Carers of Elderly People in Europe: Characteristics, Coverage, and Usage) study conducted between 2003 and 2006 in 6 European countries (Greece, Germany, Sweden, Great Britain, Italy, and Poland) concluded that the demand for the aforementioned types of support in elderly individuals is very high and support is provided mainly by family members — from 82% to 96% of cases, depending on the kind of needs [10, 13]. According to estimates, family caregivers in Poland are a group of more than two million individuals not listed in any register, ignored by the Polish legislation, and left without any formal support systems. A Polish report revealed a large disproportion between the support received by elderly patients and the support provided to caregivers [14–16]. On the one hand, the provision of care to a family member is a source of satisfaction for the caregiver. However, the long duration of the disease, nature of care provided, requirement of constant availability, and coping with the progressive limitations on the side of the ward may lead to physical and psychological

exhaustion as well as loss of social ties on the side of the caregiver [8, 17, 18].

In the 1980s, the new concept of “caregiver burden” has been introduced in psychogeriatrics. The term is used to describe the physical, emotional, material, and social costs incurred as a result of caring for a chronically ill family member [17–19]. Care burden is a multidimensional phenomenon encompassing two main components: the objective burden associated with real adverse consequences for the caregiver’s health, social and professional functioning, financial problems, and changes in family life; and the subjective sense of burden associated with the caregiver’s reactions and experiences in specific situations related to the nuisance of care, psychological tension and other emotional reactions [18–20]. The burden of caring for a family member may lead to the development of depression, anxiety and sleep disorders, drug abuse, negative perception of own health, and deterioration of the quality of life of the caregiver [8, 21, 22]. In the study by Schulz and Beach [18], caregivers of chronically ill patients were found to present with higher mortality rates as compared to controls (i.e. the general population) [21].

In the English-language literature, caregivers are referred to as “hidden patients” as they require outside help and support to maintain their health and to be able to continue to function properly [8, 18, 23, 24]. As seen in numerous studies, caregivers are more prone to present with hypertension, ischemic heart disease, vascular incidents, and reduced immunity [25, 26]. As shown by Schulz [18], providing care to an elderly, disabled person in old age is burdensome and stressful for family members. A combination of prolonged stress, physical requirements of care, and physiological weaknesses of older caregivers was suggested to compromise their own functioning and cause an increased risk of health problems, resulting in an increased mortality rate. In a 4.5-year follow-up of a group of 427 caregivers — spouses of elderly patients — subjects reporting fatigue with providing care were found to be at 63% higher risk of death, particularly for cardiovascular reasons than age-matched controls who did not provide care to chronically ill family members [21].

The level of care burden varies individually. The coping style and perception of one’s situation as more or less burdensome depend on both caregiver- and patient-related factors [19]. Sezer et al. [23] carried out a study involv-

ing 33 caregivers (17 women, 16 men) for hemodialysis patients, 27 caregivers (11 women, 16 men) for patients receiving peritoneal dialysis, and a control group of 49 individuals (23 women, 26 men) not providing care to chronically ill family members. The analysis revealed higher rates of depression and a greater tendency toward experiencing mental discomfort and somatization of mental problems in the group of caregivers for HD patients as compared to caregivers for PD patients and controls. In addition, somatization was correlated with caregivers’ age and educational background [27]. In another study, Avsar et al. [24] analyzed groups of caregivers for patients receiving peritoneal dialysis and patients after kidney transplant to find that the caregivers within the former group presented with higher levels of anxiety and depression as well as higher markers of care-related burden as compared to the caregivers within the latter group [28].

The psychophysical condition of the caregiver is of great importance in renal replacement therapy of elderly patients. Prolonged care may lead to dissatisfaction and conflicts within the family. Therefore, the quality of the caregiver’s support network is of great importance. In contrast to informal support, formal support as provided by professionals, is much less important [29]. Some studies have demonstrated a strong correlation between informal support and the level of burden. Thanks to the support, the caregiver can cope better with their stress, thus reducing the risk of depression [30, 31]. It must be stressed that the support must be both expected and welcome. Adamiak and Juczyński [27] examined the relationship between stress and social support levels. A significant difference was observed between caregivers’ reception of support provided by their spouses vs. their children. The support provided by the spouses was well below the expectations of caregivers. This may be because more is expected from one’s spouse than from one’s child [32].

In their article titled “Burden of Care and Quality of Life Among Caregivers for Adults Receiving Maintenance Dialysis: A Systematic Review” [28], Gilbertson et al. reviewed the literature on the quality of life and care burden on the caregivers of dialysis patients. A total of 61 studies from 21 countries were identified, with a total of 70 different measurement scales used. Most of the studies were cross-sectional in design (85%). The largest group of caregivers consisted of female spouses providing

care to HD patients (72.3%) and PD patients (20.6%). The quality of life of caregivers was below that of the general population, but mostly comparable to that of caregivers of patients with other chronic conditions. The authors of the article stated that it was impossible to carry out a quantitative meta-analysis of the studies due to the use of different methodologies and missing or incomplete data required for standardization of the results. The conclusions state that the effects of long-term care have not been well studied and that further research is needed in this area; the research objectives should also include the development of an optimum information program regarding proper education and support being provided to family caregivers [33].

Due to the changes in populational demographics, care provided to elderly family members with end-stage renal disease and the role as well as the quality of life of family caregivers are becoming important issues. At present, no adequate systemic solutions are available in Poland, and the existing support systems show a gap with regard to the support to caregivers of chronically ill elderly patients. Thus, the problems and needs of caregivers as well as their wards require more detailed analysis so that appropriate strategies for integrated care can be developed [9, 18, 34, 35].

CONFLICT OF INTEREST

None to declared.

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