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Caregivers of Patients on Haemodialysis

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Abstract

Background: Caregivers of patients on haemodialysis play a vital role in their lives. They have to look after them, their medical treatment and diet, to accompany them to dialysis unit, to help them in everyday activities, and to provide psychological support.

Methods: Literature review was based on studies and reviews derived from international (MEDLINE, PubMed, CINAHL) databases concerning caregivers of patients undergoing haemodialysis.

Results: Caregivers have physical and psychological distress, increased workload, limitations to personal and social activities, and financial problems. They may feel tired, anger, depression, helplessness, guilt, isolation, loss of freedom, fear, vulnerable, and neglect their own health. They face difficulties with dating and marriage and problems with their job.

Conclusions: Caregivers have a variety of psychosocial concerns due to long care of patients undergoing haemodialysis. The provision of support and information is essential in order to provide effective care to their patients.

Keywords: caregivers, family caregivers, end-stage renal disease, haemodialysis, kidney failure

1. Introduction

Haemodialysis has been proved to be the most common treatment method worldwide for chronic renal failure (CRF) [1]. However, patients on dialysis have a variety of psychological disorders due to complications and restrictions of the treatment [2]. Patients face depression and anxiety, low self-esteem, dependency on others, fatigue, infertility, sexual dysfunction, problems with bones, anaemia, cardiovascular and gastrointestinal disorders, and frequent hospitalizations. Additionally, long-term haemodialysis causes a number of psychological, social, and cultural problems to their families [3].

Dialysis population is becoming older and older [4] and has an increased risk of physical, cognitive, and emotional deterioration [5], due to diabetes, hypertension, cardiovascular risk factors, pulmonary and skeletal problems [4], and multiple metabolic disturbances [5], with their mobility and ability to self-care being negatively affected. Thus, elderly dialysis patients need care not only from health professionals but also from caregivers, including spouses, parents, brothers and sisters, friends, as well as emotionally involved volunteers [4].

A large number of dialysis patients rely on their family members for their daily activities and medical care [6, 7], since family is the best source for providing care to these patients. Family caregivers play a vital role in caring for older adults. It is estimated that 36 million people provide unpaid care to a family member who is age 65 or older, while about 80% of these are spouses or adult children. Family caregivers usually provide more than 20 h of care per week to older adults [8].

Family caregivers are persons being responsible for the care of their patient, without receiving any money [9]. Studies have shown that a good family support has a positive effect on successful patients' adaptation to dialysis treatment and compliance with dietary regimen. However, sometimes patients discontinue dialysis treatment due to their perception that they have become a 'burden' to their family. Thus, family caregivers play an important role in the provision of effective communication to dialysis patients when it is appropriate [10]. However, caregiving is regarded as a chronic stressor due to the demanding activities and the emotional burden of caring [11].

2. Caregivers' role in haemodialysis patients

Caregivers play a significant role in the support of patients undergoing haemodialysis [12], since a large number of them have a poor physical function and cognitive impairment and are unable to look after themselves [13]. Caregivers are involved in patients' care and assistance during haemodialysis in order to help them adapt and effectively manage their treatment [14]. They help patients with their daily activities, household tasks, and personal care, such as bathing and dressing, while they undertake responsibility for technical health procedures in dialysis [15]. They also manage their money or communicate with professional caregivers when appropriate [16].

Additionally, their role involves management of medical treatment and symptoms caused by haemodialysis, transportation to dialysis unit and other medical appointments, management of diet, and helping in personal hygiene [17]. A large proportion of family members take full responsibility for making decisions about the dialysis method the patients will follow, taking into consideration the opportunity to maintain their lifestyle and the possible risk of the therapy. They also take into account their priorities and their capability to manage home haemodialysis [1]. However, sometimes family caregivers have to take difficult decisions, such as interruption of dialysis therapy or referring their patients to hospice services [18].

3. The effect of caring process on caregivers

3.1. Positive effects of caregiving

Since the 1970s, there has been an increased recognition of the importance of family care, as it includes a variety of positive impacts on the caregiver, such as improvement of caring relationships. Caregivers frequently experience positive aspects of care such as satisfaction, rewards, and enjoyment [16]. Brouwer et al. [19] found that half of the caregivers would become less happy, if somebody were to take over their caregiving tasks. A positive attitude toward caregiving may positively influence the perception of care delivery and improve health status of both patients and caregivers [16]. Bertrand et al. [20] found that caregiving for at least 1 year has a strong association with enhanced cognitive functioning among elderly women.

Older caregivers usually have a better physical, emotional, and cognitive health status and reduced mortality compared to noncaregivers, since the positive aspects of caregiving may create a sense of meaning, emotional closeness, and a purpose for their life [21]. Caregivers may feel useful and satisfied, and they may view caring as a way to pay back for the help they received from their patients in the past [8].

3.2. Negative effects of chronic disease on caregivers

Haemodialysis may have a negative impact on caregivers' social life since patients need more physical support due to their functional independence [10]. Thus, the long duration of haemodialysis, the large number of complications of the treatment, and changes in patients' life cause high rates of stress and anxiety to their caregivers [22].

Families of patients on haemodialysis have to accept a large number of limitations derived from the disease, which have a negative impact on their psychological well-being. Difficulties with family members are mainly attributed to dietary and fluid restrictions, difficulty in going on holiday, time spent on haemodialysis, feeling of fatigue, inadequate sexual activity, frequent hospitalizations, financial problems, uncertainty about the future, reduced social life, changes in family roles, and limitation in physical activities [23, 24]. Patients and caregivers have to spend at least three days a week on haemodialysis treatment. This results in limitations in social life and daily activities, while it creates a feeling of dependence on dialysis unit and health professionals.

Caregivers of patients on haemodialysis have lower quality of life compared to the entire population. More specifically, unemployed women caregivers, particularly mothers and wives, with physical and mental diseases and low educational level have more distress. The provision of care in hospitalized patients and the increase of caregivers' age cause decrease in the quality of their life [23]. It was found that caregivers with chronic illnesses had physical health limitations, body pains, emotional distress, and less activity [18]. On the other hand, caregivers with lower burden of care, better social support, good marital relationships, better understanding of patients' disease, and using effective coping strategies have higher quality of life [25].

At the beginning of dialysis therapy, patients and caregivers have similar mental health, with an improvement in their social interaction. However, with the progression of the illness, caregivers present a worse mental health, with depression being identified as the most common problem [26]. Caregivers face financial problems and feel depression, anxiety, fatigue, social isolation, tension in relationships [27], and disappointment due to the demands of haemodialysis treatment [28]. The demanding nature of caregiving usually leads family members to neglect their own health needs [29].

Moreover, family caregivers who live with their patients provide care for long periods of time, spend a lot of hours in the provision of care and have a feeling of a great responsibility for them [30]. Thus, taking care of patients for a long time is a stressful process for the caregiver and leads to low psychological status, decreased physical health, reduced social interaction, and physical and emotional burden [6]. More specifically, they feel physical and psychological distress, limitations to their personal and social activities, while wife caregivers feel anger, helplessness, guilt, isolation, and loss of freedom [5].

Additionally, caregivers often feel fear for their patients, tired, vulnerable, and unable to have their own activities. They often face difficulties with dating, marriage, and work, since they decrease or rearrange their working hours, take days off without pay, stop their job, or retire early in order to provide care to their patient [6]. They have to spend at least 3 days a week to accompany their patients on haemodialysis [23]. Alnazly [6] found that 30% of the participants were unemployed since they used to spend 50 h a week for providing care to their patients, while they delayed their education, which affected their career and their financial situation.

The treatment method may also have an effect on family members, since it has been found that spouses of transplant patients are more positive, self-sufficient, and have the ability to face all the aspects of the treatment better than spouses of patients on dialysis [10].

However, caregivers feel less responsible if patients are independent in their everyday activities and have fewer complaints about dialysis treatment and comorbid diseases. This was found in patients receiving home haemodialysis or waiting for a kidney transplant, where caregivers were not experiencing depression or anxiety, felt less responsibility, and had better quality of life [10].

It has also been found that caregivers are more possible to have negative feelings toward patients if they live in a rural environment, have no prior experience of the dialysis process, and have a high level of responsibility in the caring of patients on dialysis. Caregivers have difficulties with the transportation to and from renal unit and the possible necessity for changing residence to the nearest dialysis unit [10].

Additionally, it was found that mother caregivers of children on peritoneal dialysis were overloaded due to the activities of the dialysis procedure. They had to clean the dialysis room, the walls up to the ceiling, the floor, and the utensils at least once a week [31]. Similarly, a higher treatment-related overload to family caregivers of children on peritoneal dialysis was found compared with patients on haemodialysis and renal transplantation [32].

3.3. Caregivers' burden

The provision of long care to patients undergoing haemodialysis on a daily basis and their step-by-step frustration and exhaustion leads to physical and psychological burden [4]. Family burden is a psychological condition caused by the combination of physical work, emotional pressure, social restrictions, and economic demands during the provision of care to their patients. Burden has been found to be associated with a significant reduction in caregivers' quality of life and their health status [9].

Caregivers' burden is a widely used term to describe the physical, financial, and emotional cost of care. It reflects the permanent difficulty, stress, and negative experiences derived from the provision of care to the patient. Burden includes all the changes and difficulties in caregivers' life caused by patients' treatment [14].

Mashayekhi et al. [14] found that 72.5% of the caregivers had average to severe burden. Caregivers who had low quality of life had high rates of burden and high scores of depression [11]. Similarly, Grapsa et al. [12] found that 97% of caregivers were extremely or very worried about their patients' problem. It was found that caregivers' burden was influenced by the relation between the caregiver and the patient, the length of the treatment, and the changes in life [6]. Gill et al. [33] found that caregivers of patients on dialysis expressed higher burden than those of nondialysis patients with end-stage renal disease.

Metzelthin et al. [16] found that caregivers' subjective burden increased with more patients' comorbidities and higher levels of disability, caregiving hours, and more variation in caregiving tasks. With regard to the caregiver characteristics, being female, being the partner, and living together with the patient were significantly associated with more subjective burden. Similarly, caregivers of both genders, and particularly women, who live with patients, have higher ratings of subjective burden, more depressive symptoms, and poorer self-rated health than caregivers who do not live with their patients [30].

Caregivers' burden may be affected by their level of education and their age, since those of a middle age are usually most worried about missed workdays, interruptions at work, and reduced productivity due to caregiving [5].

3.4. Spousal adaptation to caregiving process

Spouses of patients on dialysis feel isolated due to the loss of social activity, their increased workload, and their negative economic situation. These couples have high rates of depression, sexual problems, and difficulty in communication [2]. It was found that marital relationships were significantly confounded in patients undergoing long-term haemodialysis, since spouses with high psychological stress and impaired adjustment had a negative impact on family functioning [29].

Spouses are usually old and may suffer from more health problems, which leads to greater perceived stress during the provision of long-term care [34]. Male spouses experience high rates of stress when women are ill due to decreased nurturer role of women during their illness [2].

Both male and female spousal caregivers usually receive fewer caregiving rewards and have greater caregiver burden and poorer physical and mental health than other types of caregivers [30]. However, a supportive family is significant for patients undergoing haemodialysis, since they have better perception of their illness and their medical treatment, better adherence to restrictions of the disease, and less symptoms of depression and anxiety [29].

Although caregiving is stressful for both genders, it has been found that women are particularly vulnerable to this process [30]. Women who provide care to their husbands may be particularly stressed by this process, since they do not usually have any help during the provision of care and they usually live with their patients and provide care for more hours than other types of caregivers [30]. Additionally, women providing care to their husbands may have the additional burden of providing care to children and their families.

Patients' ability to work is usually reduced after the beginning of haemodialysis, forcing the spouse to increase their work for a longer time. Additionally, negative emotions of patients in combination with sexual dysfunction can cause emotional and psychological distress to their spouses [35].

4. Support information of caregivers

Caregivers have health and social care necessities that need to be managed [29]. Families of patients on haemodialysis need guidance, training, and continuous support by the healthcare team [36]. Support interventions can improve the quality of caregivers' life, their satisfaction, and ability to effectively cope with their patients, improving medical and psychological outcomes [27]. Social support includes economic support (material and economic help to caregivers), information about the disease, and emotional support [12]. Tavallai et al. [29] found that spouses with high levels of social support reported the least marital stress.

Additionally, caregivers require the appropriate knowledge, specific skills, education, and guidance from healthcare team in order to provide effective care to their patients. They need to have exact knowledge about the disease and the dialysis treatment [6]. However, they do not usually receive the available information needed [18]. Thus, pre-dialysis programmes need to be designed for caregivers in order to help them make informed decisions about the dialysis method their patient will follow [1].

Moreover, Internet-based information, support groups, psychological therapy, and practical support are very useful for family caregivers [27]. Trisolini et al. [37] found that family members of predialysis patients wanted to have access to more information about kidney disease and its treatment methods in order to effectively support patients and were particularly worried about their lack of knowledge. Additionally, they pointed out the importance of early learning about kidney disease, since the first 6 months of kidney failure is usually the most difficult for the patient, who needs the most support from family in order to effectively cope with the disease.

For this purpose, it has been suggested the development of a special web page providing information to family caregivers, highlighting their significant role in caregiving. It can

include model questions, so that caregivers can ask doctors and other renal professionals in order to help patients [37].

Furthermore, a number of external website links can provide further educational alternatives for caregivers. They can include newsletters, lessons from kidney disease and other chronic illnesses, as well as support groups. Caregivers can benefit from these websites by learning useful information and techniques for an effective management of care at home [37].

Information and guidance are very useful for caregivers undertaking an advanced technical health procedure at home. Caregivers' willingness to manage a technical procedure at home haemodialysis depends on the cognitive understanding of the purpose and the benefits of the procedure. Caregivers can resist to a procedure if they do not understand its benefits for the patient [15].

Finally, health professionals can play a vital role in guidance, education, and support of family caregivers for better adherence to changes in lifestyle and effective coping with the burden of care. They also need to require the appropriate skills for active participation in the caring process of haemodialysis and effective communication with the patients [38].

5. Conclusion

Caregivers of patients on haemodialysis are at high risk for the development of emotional and psychological distress, low quality of life, and increased burden. They have a variety of psychosocial concerns due to the long duration of the treatment.

They usually have increased workload, limitations to personal and social activities, and financial problems and feel tired, anger, depression, helplessness, guilt, isolation, loss of freedom, fear, vulnerable, and neglect their own health.

Support interventions and information are essential for caregivers, since they can help them improve their quality of life and their capability to cope effectively with their patients' treatment. Caregivers require the appropriate knowledge, specific skills, education, and guidance in order to help patients achieve better adherence to haemodialysis treatment.

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