Daily haemodialysis and caregiver burden

Bolesław Rutkowski¹ and Ivan Rychlik²

¹Department of Nephrology, Transplantology, and Internal Disease, University Medical of Gdansk, Gdansk, Poland and ²nd Department of Medicine, 3rd Faculty of Medicine, Charles University, Prague, Czech Republic

Correspondence and offprint requests to: Bolesław Rutkowski; E-mail: bolo@amg.gda.pl

A few years ago, a group of Canadian and American nephrologists established the Frequent Hemodialysis Network (FHN) aiming at establishing potential advantages of daily and/or nocturnal haemodialysis (HD) both for patients and the health care system [1]. This initiative is supported by the National Institute of Health in conjunction with Centers for Medicare and Medicaid Services. Preliminary results of the FHN group have shown that this intensive HD system has an impact on important end points, such as blood pressure control, metabolic equilibrium, quality of life and patient survival [1]. A recent study of this group of researchers (Suri et al. [2]), published in this issue of Nephrology Dialysis Transplantation, is dedicated to the problematic relationship between the patients’ perceived burden on their unpaid caregivers, depression and quality of life. The studies were carried out in 496 patients enrolled in the two FHN trials (378 daily trial and 118 nocturnal trial) and the final results obtained from 412 participants were presented in this paper. Fifty-seven percent of the patients had unpaid caregivers. The majority of them perceived a substantial burden on their unpaid caregivers and this fact was associated with a worse depression and quality of life (SF—36PHC score, Beck Depression score and Cousineau score). Suri et al. suggested that the evaluation of the impact of frequent HD on the perceived burden of care put on caregivers should be one of the elements in the objective evaluation of the real value of the feasibility and usefulness of the frequent HD system.

Nevertheless, other important questions arise concerning the feasibility of such a frequent home HD system for patients. We have to remember that together with ageing of the general population, also the subpopulation of end-stage renal disease (ESRD) patients is becoming older and older [3]. This fact is clearly visible in the annual reports of the National or International Renal Registries [4–7]. In this respect, in the Polish Renal Registry, as many as 54% of incident and 49% of prevalent dialysis patients are >65 years old [6]. In this group of older patients, the subpopulation 75+ is still growing, e.g. in the Czech Registry of dialysis patients, it represents 22.5% of the patients on HD and 7.5% on peritoneal dialysis (PD) treatment [7]. These patients are often type 2 diabetics or may have arterial hypertension and other comorbidities mainly involving cardiovascular and pulmonary systems. Also diseases of the muscular and skeletal system or dementive syndromes may be present in a substantial proportion of these patients, affecting their mobility and ability to self-care and independence. This is the reason why elderly dialysis patients may need additional care not only from professional caregivers, like physicians, nurses or other medical staff, but also from so-called unpaid caregivers, who help them with their everyday activities. Among them, one may quite often find spouses, parents, siblings, friends or even unrelated but emotionally involved volunteers. The problem of unpaid caregivers is as old as medicine and there have always been two subpopulations which needed their special attention: children and the elderly.
This has been widely experienced in PD patients [8,9]. It is obvious that PD patients who are treated at home and rely on their self-care and own involvement in the therapy may often need additional help and care. It thus happens quite frequently that family members are educated simultaneously with PD patients on how to perform and maintain the treatment. On the other hand, the definition of ‘unpaid caregiver’ is not precise and it therefore causes some confusion when it concerns the extent of care delivered to the patient. In several countries, for the special care patients who were unable to perform PD therapy and had no help from a family member, an assisted mode of this treatment was developed where care is delivered by an institutional caregiver [13,14]. One can understand that unpaid caregivers may also play a special role in the daily home HD system which could surely have an impact on the quality of the treatment delivered to the patient. However, providing long-term help to a severely ill and disabled person on an everyday basis may be a serious physical and psychological burden for the caregiver. This situation may also create additional stress within the family which is already struggling with the difficult situation caused by the chronic illness of its member. Loss of independence and perceiving oneself as a burden for family members may put additional stress on the patient reducing his or her quality of life and inducing a feeling of guilt. Although unpaid caregivers are usually very enthusiastic when starting their mission, step-by-step frustration and exhaustion may develop causing serious social and psychological problems. The question then arises if it is worthwhile to bother the nephrological community with data on these problems of the patient and his family environment. The answer to this question has to be positive because all these problems have a profound and direct influence on the final results of the treatment from different points of view. Each physician, and in this case each nephrologist, should have a basic knowledge about psychology and psychological problems of his or her chronically ill patients. Furthermore, we urge to remember that during long-term relations, HD patients very often consider their medical staff as additional members of their family [15]. Taking into account all arguments mentioned above, the study performed by Suri et al. [2] in caregivers of HD patients in the FHN introduces interesting and valuable data in this matter. These data also help to better understand the relationship between the professional caregiver patients and non-paid (family) caregiver patients despite some worries about the inclusion criteria of patients to the study (more ill or less motivated simply refused to participate) and thus, the results can even be underestimating the real burden on caregivers. It is necessary to take into account that fortunately, in the present civilization, we are taught about the practical value of sympathy and charity for chronically ill people. Also three great religions, Judaism, Islam and Christianity, are giving us the imperative of compassion and pity for such persons. These religions and the psychological obligations are the basis for the presence of voluntary unpaid caregivers who are also more widely present in palliative medicine. This branch of medical sciences is transferring more and more to supportive medicine not only embracing oncological patients but chronically ill people in general [16]. On the other hand, it is worth underlining that frequent HD is not only present in North America.

The idea of frequent HD performed at home is not new and one can find roots of such initiative in Europe. First home HD programmes started quite early in the 1960s and were initiated by Stanley Shaldon in the UK [17]. This form of dialysis therapy was being developed in the 1970s and early 1980s in that country and in few other economically developed European countries as well as in the USA and Canada [18,19]. However, during the next three decades, the home HD concept was abandoned and in-centre HD expanded and became the leading model of HD therapy throughout the world. Nowadays, despite development of PD as another concept for home dialysis, HD is the main dialysis method. Among >2 million of the patients with ESRD treated by dialysis, this procedure is used in 89% of them [20]. In the expectation to achieve better outcomes for dialysis patients, nephrologists tried to increase the frequency of HD sessions and the total amount of time spent by the patient on therapy during the week. This idea laid the basis of developing the concept and development of frequent, short daily or nocturnal HD programmes. These forms of therapy are now established and maintained mainly in Australia, New Zealand, Canada and the USA [18,19,21,22]. But even in these rich countries, the number of patients treated by daily or nocturnal home HD programmes is very limited. However, this problem should not appear marginal from the perspective of the ‘Old Continent’. One has to remember that the idea of short daily HD was simultaneously developed, established and further evolved in Italy, The Netherlands and France [23–25]. The Italian nephrologists were among the precursors of this mode of dialysis [26]. On the other hand, both the clinical outcomes and economical results of such therapy seem to be better than those of classical intermittent, in-centre HD [27–29]. It was shown that survival of patients maintained on a frequent HD programme may be comparable to that of kidney transplant recipients [19,28]. In addition, using a special dialysis machine or, more specifically, a compact HD system developed for this programme by Twardowski et al. [30,31], showed that the total costs of such a procedure are comparable or even lower than of standard HD. This fact was also confirmed by other investigators involved in a similar programme [32]. Taking into account the still rising number of ESRD patients needing dialysis therapy, which is globally causing economical problems for health care systems, it is worth discussing such alternative.

On the other hand, one has to remember that the long-term burden on caregivers, especially the volunteers and unpaid ones, participating in this procedure may lead to the development of a burnout syndrome. This phenomenon may develop both in patients and their caregivers.

Conflict of interest statement. None declared.

(See related article by Suri et al. Burden on caregivers as perceived by hemodialysis patients in the Frequent Hemodialysis Network (FHN) trials. The CORES Study. Nephrol Dial Transplant 2011; 26: 2316–2322.)
Kidney transplantation is the treatment of choice for patients with end-stage renal disease and since many years transplantation from living donors is considered to be the optimal choice with the best outcome for the recipients [1,2]. Due to this fact and the lack of cadaveric donors, it is not astonishing that a certain pressure arose to recruit living donors [3]. Reports that living donation is safe are therefore important and would justify this treatment of choice for our recipients. But is kidney donation really safe therefore important and would justify this treatment of choice for our recipients. But is kidney donation really safe?