

‘Reality and desire’ in the care of advanced chronic kidney disease

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Abstract

There is a long distance between the actual worldwide reality in advanced chronic kidney disease care and the desire of how these patients should be managed to decrease cardiovascular and general morbidity and mortality. Implementation of adequate infrastructures may improve clinical outcomes and increase the use of home renal replacement therapies (RRT). Current pitfalls should be addressed to optimise care: inadequate medical training for nephrological referral and RRT selection, late referral to nephrologists, inadequate patient education for choice of RRT modality, lack of multidisciplinary advanced kidney disease clinics and lack of programmed RRT initiation. These deficiencies generate unintended consequences, such as inequality of care and limitations in patient education and selection-choice for RRT technique with limited use of peritoneal dialysis. Multidisciplinary advanced kidney disease clinics may have a direct impact on patient survival, morbidity and quality of life. There is a common need to reduce health care costs and scenarios increasing PD incidence show better efficiency. The following proposals may help to improve the current situation: defining the scope of the problem, disseminating guidelines with specific targets and quality indicators, optimising medical speciality training, providing adequate patient education, specially through the use of general decision making tools that will allow patients to choose the best possible RRT in accordance with their values, preferences and medical advice, increasing planned dialysis starts and involving all stakeholders in the process.

Keywords: advanced chronic kidney disease care units; multidisciplinary care; planned dialysis start; quality indicators

Current status and pitfalls in pre-dialysis care

The increasing prevalence of advanced chronic kidney disease [ACKD; estimated glomerular filtration rate (eGFR) <30 mL/min/1.73 m²] has led to increasing morbidity–mortality and socio-economic costs [1]. Implementation of adequate infrastructure to care for this population will decrease cardiovascular morbidity–mortality, delay the

need for renal replacement therapy (RRT) and help prepare for RRT [2]. However, there are several pitfalls that can be addressed to improve outcomes and optimize the use of current resources [3]:

- (i) **Inadequate medical training for nephrological referral and RRT selection.** Published guidelines on referral for nephrological consultation are poorly disseminated and implemented. Internal medicine residents have widely differing perceptions of indications for nephrology referral: 10% of residents do not refer patients with ACKD and 20% refer only with an eGFR <15 mL/min [4]. Limited medical training in peritoneal dialysis (PD) or transplantation may also contribute to individual or centre biases. In a Spanish survey, over half of nephrology residents and their mentors believed that their training in PD was insufficient and 60% had never seen a PD catheter being inserted [5].
- (ii) **Late referral to nephrologists.** Early referral to the nephrologist is usually understood as at least a 3-month contact with the nephrology unit prior to initiating RRT. However, at least 1 year is required to provide CKD education and to optimize preparation for RRT [6]. There are wide differences between different centres and countries in late referrals [7]. In Spain, Italy and France, recent data show that 20–25% of patients experienced late referrals, while higher figures were reported for America and other European and Asian countries [8–16].
- (iii) **Inadequate patient education for choice of RRT modality.** Early diagnosis of CKD and early referral to the nephrologist are both necessary but insufficient to guarantee an informed choice of RRT technique. Patient education and preparation for RRT requires adequate time (7–24 h per patient) and frequent sessions. Although more than 90% of nephrologists inform patients about different RRT options, most of these practitioners lack a standardized procedure. In most cases, time spent informing about RRT techniques lasted 5–60 min, but some patients were not informed and more time was devoted to haemodialysis

(HD) than to PD or pre-emptive transplantation [17,18]. In Spain, only one-third of the centres use an informed consent document before starting RRT (unpublished data).

- (iv) **Lack of multidisciplinary ACKD/low-clearance/pre-dialysis clinics.** Multidisciplinary ACKD clinics require at least one nephrologist and a nurse to guarantee patient education, information, training, care and psychosocial support, as well as research support [19–27]. Other specialists such as dietitians, social workers and psychologists provide very valuable input. Centres with specialized ACKD clinics offer more complete information and care, devote more time to overall patient/family educational training and achieve a higher percentage of programmed RRT initiation despite a shorter overall monitoring period than conventional single-specialist practices [19–23,28,29]. However, such infrastructures are scarce and are frequently insufficiently staffed [7–12,19,30,31]. Interviews with representatives from 60 Spanish hospitals have revealed that ~35% of hospitals have multidisciplinary monographic ACKD clinics, 40% have conventional monographic ACKD clinics and 25% lack these clinics. In the United Kingdom, very few units had a full complement of the recommended multidisciplinary renal team [32].
- (v) **Lack of programmed RRT initiation.** There is a wide variability between countries, regions and centres in non-planned dialysis start times despite prior nephrological follow-up [7,33]. Failure of nephrological follow-up to prevent non-planned RRT initiation may be partially ascribed to events that deteriorate renal function, loss to follow-up or other medical reasons [20,21,28,34–36]. However, one key modifiable factor has been the failure to achieve a timely permanent RRT access because of deficient nephrology–surgery inter-departmental coordination [21]. Up to 60% of Spanish RRT patients were not offered optimal ACKD care, which was defined as adequate education on CKD and RRT options, starting RRT in a programmed fashion and care provided by a nephrologist [21].

Consequences of the existing deficiencies

A review of the literature suggests that current conditions have created several unintended consequences.

Inequality of care and limitations in patient education and selection–choice for RRT technique

PD and HD are complementary and not competitive techniques. They offer similar survival rates, except for diabetic female patients over 65 years of age according to the US Registry [37–40]. Over 70% of patients are potential candidates for HD or PD because they lack medical contraindications [41–46]. Nephrologists believe that 30–40% of patients are able to receive home RRT [47,48]. In the absence of medical contraindications or pre-emptive transplantation, PD should be considered as the first RRT option

in the large majority of patients: it provides good outcomes, a better preservation of residual renal function and vascular capital, it may speed up delayed graft function, it improves graft–patient survival and is cheaper [49]. However, the incidence of PD is much lower than HD, suggesting an influence of non-medical factors in the selection of RRT modality. There is a large geographical variability in the incidence and prevalence of PD and pre-emptive transplantation that has not been justified by clinical criteria. This variability has also been observed within countries and within centres in the same city. In Spain, the incidence of PD ranges from 20 to 25% in Madrid, Galicia and the Basque Country to almost zero in Aragon [3]. Pre-emptive transplantation accounts for 1–3% of incident patients [3,14]. The early registration of patients on transplant waiting lists is also highly variable among centres and countries [50].

Late referral inevitably lowers the possibility of receiving education on RRT techniques, choosing RRT modality and receiving pre-emptive transplantation or transplantation within 1 year [21,28,51]. HD was found to be both the initial and chronic RRT technique in 95% of patients with non-programmed start of RRT; these patients were never educated in RRT techniques despite nephrological monitoring and late referrals. By contrast, the incidence of PD was maximal (30%) in patients with programmed RRT starts and who were educated about RRT modalities. A balanced education in RRT techniques increased PD choice to 50% [42,52]. Participation of nurses in the education process may increase the incidence of home RRT modalities [53]. In surveys carried out by the patient advocacy group ALCER among patients with non-planned dialysis starts, one-third was unaware that they could choose their dialysis technique, 60% never chose the technique and most were unaware of alternatives to HD [54]. In patients with non-programmed dialysis starts, only 6% of hospitals informed about RRT options. However, balanced information backed up by decision-making tools resulted in the choice of home techniques in 38% of non-planned dialysis start patients [55].

Impact on outcomes

There is increasing evidence that late referrals and lack of multidisciplinary ACKD clinics negatively impact outcomes [17,19,21–23,35,56–61]. Late referral is associated with increased mortality and morbidity and deprives the patient of treatment to prevent or delay CKD progression. Multidisciplinary ACKD clinics may have a direct impact on patient survival, morbidity and hospitalization, permanent RRT access rates at RRT start and health-related quality of life (QOL). The absence of free choice for RRT options or permanent vascular or peritoneal access at dialysis initiation impairs vital prognosis [21,28,34,62–65].

Efficiency of care

European universal healthcare systems are threatened by runaway costs. ACKD patient care consumes double the amount of resources than RRT because of the higher prevalence, higher rates, longer duration of comorbidity-driven

hospitalizations and high cost of treatments. Efficacy will probably translate into more efficient care, since hospitalizations, HD treatment through catheters and earlier or emergency RRT all increase costs. Studies suggest that early referral to nephrologists may be associated with better outcomes and lower costs, but further cost–efficacy research is required [66]. A recent evaluation in Spain analysing all types of RRT showed that there are more cost-effective scenarios than the current situation, such as modifying the percentage of planned dialysis start ups to 75%, increasing PD incidence to 30% or a combination of both [67].

Proposals for improvement

Current incomplete data suggest that deficiencies in ACKD care are widespread, but that there are important differences among centres, regions and countries that raise questions about unequal access to healthcare. The following proposals may help to improve the current situation:

Define the scope of the problem. Current information is piecemeal and has been obtained with very different methodologies and definitions. A Europe-wide map of ACKD care and a registry of CKD Stage 4 patients are required. Without this information, all efforts to claim cost-effectiveness of ACKD care and early referral will remain inaccurate and vague [7].

Identify and correct country-, region- or centre-specific local factors that contribute to the current situation. As an example, nephrology outreach services may improve referral patterns [68].

Define and implement clear standards to limit potential biases of individual nephrologists or centres [44]. Guidelines should require diffusion and implementation. In general, guidelines suggest therapeutic targets but not quality indicators. Quality indicators allow for monitoring and for establishing areas for improvement and assessing the impact of ACKD clinics. A set of ACKD care quality indicators is currently being validated [69,70] but should be universalized and implemented.

Optimize medical education. Educational efforts during residency training to raise awareness and benefits of early referral and to guarantee adequate, high-quality exposure to PD and transplantation may improve CKD management.

Provide adequate patient education. Standardization of the information–education process for the election, and not selection, of RRT technique may reduce inter-centre variability in the use of RRT techniques by allowing informed patients to choose the best possible RRT modality, according to medical criteria and individual preferences. There is no consensus on the best method to provide education to patients and families. Group interventions are more effective in bringing about changes in conduct. A ‘group’ is a set of people who have common aims, who interact and play different roles, aware of forming part of a group and who set up relationships of interdependence. In CKD, the aims of group therapy should

be psychosocial adaptation (attitude change) to the disease, prevention of risky behaviour (dietary education) and training (education in CKD and RRT techniques). A pilot experience was performed that involved groups of 10 ACKD patients, relatives/friends, healthcare staff (nurse, assistant and nephrologist) and volunteer RRT patients who met six times in 6 months. Group therapy improved total and health-related QOL, the understanding of kidney disease and anxiety. Furthermore, 52% of participants chose PD, compared to 28% of same-centre non-participant patients [71]. Information–education of elderly patients is particularly challenging due to cognitive impairment and mood swings and family participation is encouraged [72].

Involve the stakeholders. It is the ultimate responsibility of professional societies and healthcare administrations to promote and provide the infrastructures which allow adequate information and education on CKD and RRT options to thus facilitate free informed choice of RRT modality. The right to adequate information that allows free choice of RRT technique was established in the Spanish Law Basic Regulatory Act on Patient Autonomy 41/2002 and similar European Legislation. Healthcare staff select the medical and physical/psychological factors that best fit each RRT modality, but informed patients and families choose the modality [41]. Free choice will contribute to the sustainability of RRT care by promoting home RRT [73]. Current guidelines highlight aspects such as the need for early referral to a multidisciplinary team and for documentation of balanced information by an informed consent form encompassing information about RRT techniques, choice of RRT technique and vascular or peritoneal access [32,74]. Social support to guarantee choice of home RRT in patients with loss of functional autonomy should also be provided.

Conclusions

There is increasing evidence that early referral to nephrologists, especially in the context of multidisciplinary ACKD units, facilitates access to balanced and complete information, provides effective and efficient comprehensive care for patients and family members, slows the progression of CKD, decreases comorbidity and CKD complications, promotes informed choice of RRT and prepares for self-care home-based RRT if required. All healthcare workers should contribute to implement this standard of care.

Conflict of interest statement. All authors declare not to have any conflict of interest except B.M. who is a Baxter employee working in the Renal Medical Affairs Department.

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