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Availability of assisted peritoneal dialysis in Europe: call for increased and equal access

Edwina A. Brown ¹, Agneta Ekstrand², Maurizio Gallieni^{3,4}, Maite Rivera Gorrin⁵, Helga Gudmundsdottir⁶, Anabela Malho Guedes ⁷, Marco Heidempergher⁴, Benno Kitsche^{8,9}, Thierry Lobbedez ¹⁰, Ulrika Hahn Lundström ¹¹, Kate McCarthy¹², George J. Mellotte ¹³, Olivier Moranne ¹⁴, Dimitrios Petras¹⁵, Johan V. Povlsen¹⁶, Sally Punzalan¹ and Martin Wiesholzer¹⁷

¹Imperial College Renal and Transplant Centre, Imperial College Healthcare NHS Trust, London, UK, ²Abdomen Centre, Nephrology, Helsinki University Hospital, Helsinki, Finland, ³Department of Biomedical and Clinical Sciences, Università di Milano, Milan, Italy, ⁴Nephrology and Dialysis Unit, ASST Fatebenefratelli Sacco, Milano, Italy, ⁵Servicio de Nefrología, Hospital Ramón y Cajal, Madrid, Spain, ⁶Department of Nephrology, Oslo University Hospital, Ulleval, Oslo, Norway, ⁷Serviço de Nefrologia, Centro Hospitalar Universitário do Algarve, Faro, Portugal, ⁸Kuratorium für Dialyse und Nierentransplantation e.V., Cologne, Germany, ⁹NADia—Netzwerk assistierte Dialyse, Berlin, Germany, ¹⁰Néphrologie, CHU CAEN, Normandy, France, ¹¹Division of Renal Medicine, Department of Clinical Science, Intervention and Technology, Karolinska Institutet, Stockholm, Sweden, ¹²Baxter Healthcare Ltd, Wallingford, Compton, Newbury, UK, ¹³Trinity Health Kidney Centre, Tallaght University Hospital, Tallaght, Dublin, Ireland, ¹⁴Department of Nephrology-Dialysis-Apheresis, CHU Caremeau Nîmes, Nîmes, France, ¹⁵Department of Nephrology, General Hospital ‘Hippokraton’, Athens, Greece, ¹⁶Department of Renal Medicine, Aarhus University Hospital, Aarhus, Denmark and ¹⁷Clinical Department for Internal Medicine, University Hospital St Poelten, Karl Landsteiner University of Health Sciences, St Poelten, Austria

Correspondence to: Edwina A. Brown; E-mail: e.a.brown@imperial.ac.uk

ABSTRACT

Background. Availability of assisted PD (asPD) increases access to dialysis at home, particularly for the increasing numbers of older and frail people with advanced kidney disease. Although asPD has been widely used in some European countries for many years, it remains unavailable or poorly utilized in others. A group of leading European nephrologists have therefore formed a group to drive increased availability of asPD in Europe and in their own countries.

Methods. Members of the group filled in a proforma with the following headings: personal experience, country experience, who are the assistants, funding of asPD, barriers to growth, what is needed to grow and their top three priorities.

Results. Only 5 of the 13 countries surveyed provided publicly funded reimbursement for asPD. The use of asPD depends on overall attitudes to PD, with all respondents mentioning the need for nephrology team education and/or patient education and involvement in dialysis modality decision making.

Conclusions and call to action. Many people with advanced kidney disease would prefer to have their dialysis at home, yet if the frail patient chooses PD most healthcare systems cannot provide their choice. AsPD should be available in all countries in Europe and in all renal centres. The top priorities to make this happen are education of renal healthcare teams about the

advantages of PD, education of and discussion with patients and their families as they approach the need for dialysis, and engagement with policymakers and healthcare providers to develop and support assistance for PD.

Keywords: community care, equity, frailty, peritoneal dialysis, quality of life

INTRODUCTION

The advantages of peritoneal dialysis (PD) have been recognized for some time for older people developing advanced kidney disease and having dialysis [1]. In Europe, demographic predictions suggest further significant increases in older people due to the ageing of the ‘baby-boomer’ generation [2]. This has major implications for predicting dialysis needs. The 2019 ERA Registry Report shows that the incidence of dialysis per million age-related population (pmarp) is highest in the 75+ years age group (539 pmarp compared with 165 pmarp in the 45–64 years age group) [3]. The majority of older people on dialysis are multimorbid, will have age-related syndromes and associated frailty [4], and will therefore require considerable healthcare and social support.

There is increasing awareness that for many older frail people, the trajectory after starting dialysis is often one of

Table 1. Advantages of and obstacles to PD for frail, older people

| Advantages | Obstacles |
|--|--|
| Treatment is at home | Decreased physical function |
| Reduces risk of exposure to transmissible infections | Difficulty in lifting bags |
| Avoidance of transport needs for dialysis sessions | Poor manual dexterity |
| Flexibility of treatment round social activities | Cognitive dysfunction; unable to learn and/or maintain technique |
| Enables travel—visiting family members locally and overseas | Impaired vision |
| Preservation of residual kidney function | Impaired hearing |
| Avoids haemodynamic stress and feeling ‘washed out’ associated with HD | General frailty |
| Simple procedure—enables assistance by family member or paid assistant | |
| Avoidance of anticoagulation | |
| Avoidance of creation and maintenance of vascular access for HD | |
| Most cost-efficient dialysis modality in public economic terms | |
| Possibility of achieving dialysis access under local anaesthetic | |

declining physical and cognitive function, increasing frailty and poor prognosis [5]. Quality of life measures are considerably poorer in patients of all ages with impaired functional status on both haemodialysis (HD) and PD [6]. In relatively fit older patients who can manage PD themselves, the illness intrusiveness is lower on PD compared with matched patients on in-centre HD [7]. There are many advantages of dialysis at home using PD compared with in-centre HD for older patients as shown in Table 1. Staying at home for dialysis treatment has become particularly important during the coronavirus disease 2019 (COVID-19) pandemic [8] and is particularly true for older, frail people, who are at the highest risk from COVID-19 [9].

With increasing age and frailty, many aspects of dialysis provision are made more difficult and more costly to deliver. For HD, many patients can no longer drive and therefore require health service-funded transport to and from dialysis, often for long journeys and at a huge cost. For PD, many older, frail people cannot perform their own PD without assistance (Table 1). The term assisted PD (asPD) implies assistance provided by a family or paid non-family member; it is available

Table 3. Patient groups, independent of age, who would benefit from the asPD

| | |
|--------------------|---|
| Incident patients | Multimorbid and/or frail Cognitive impairment Disabled Poor vision Learning disabilities Mental health, e.g. severe anxiety Acute start PD—as bridge to being trained |
| Prevalent patients | Family-assisted—relieve caregiver burnout caregiver no longer available Functional decline Cognitive decline Temporary after acute event, e.g. fracture, surgery |

in many countries worldwide and is mostly reimbursed by the healthcare system (Table 2). Although asPD is mostly used by older and frail people, it has also proved invaluable in other situations to enable people to be supported in their own homes (Table 3).

Table 2. Global models of assisted PD delivery

| Country | Non-family assistance | Model of care | Comments |
|-------------------------------|---|---|---|
| France [10] | Community nurses | Mostly CAPD 3–4 visits; some APD 2 visits | 51% incident patients on assisted PD: 82% nurse (funded by healthcare system) and 18% family |
| Denmark [11, 12] | Community nurses or nursing home staff | Predominantly APD with 2 visits | Assisted programme also used to support urgent start PD—funded by healthcare system |
| Ontario, Canada [12, 13] | Community nurses | APD 1–2 visits/day | Funded by healthcare system; many also have access to integrated geriatric care |
| British Columbia, Canada [14] | Community non-healthcare professionals with PD training | APD 1 visit/day | Trial in one centre; funded by healthcare system |
| UK [15] | Non-healthcare professionals with PD training | Predominantly APD 1 visit/day; 2 visits/day APD or CAPD supported in some centres | Assistants predominantly from healthcare agency organized by commercial supplier of PD fluid; some units employ own assistants; funded by healthcare system |
| Brazil [16] | Nurse assistant | APD 1–2 visits/day | Single centre experience; asPD funded by renal centre as not reimbursed by public healthcare system |
| China [17, 18] | Home care assistant, younger PD patients | CAPD 3–4 exchanges | Funded by family/patient; some centres train younger PD patients to assist older ones |

In Europe, France has the longest and largest experience of asPD [10, 19] using private community nurses funded by the healthcare system to support patients predominantly on continuous ambulatory peritoneal dialysis (CAPD) 3–4 exchanges/day. Data from the French Peritoneal Dialysis Registry have shown that the median survival of patients older than 75 years for those requiring nurse assistance (80% of the cohort) is 24 months [19], which is very similar to that for all comers (90% of whom would be on HD) in the UK renal registry data for the same time period [20]. Canadian data from Ontario also show that hospitalization rates are similar for patients on asPD and in-centre HD [21]. In a multi-centre study comparing quality of life measures in patients on in-centre HD requiring transport matched to patients on asPD, frailty was shown to be the predominant association with quality of life outcomes, with no differences between the asPD and HD groups longitudinally, though the asPD group had better renal treatment satisfaction scores [15, 22]. Despite the cost of providing assistance, recent reviews suggest that the overall cost of asPD remains lower than for providing in-centre HD [23, 24].

Availability of assisted PD has been shown to increase access to and use of PD, and therefore the feasibility of having dialysis at home [25, 26]. Although asPD has been available and widely used in some European countries for many years, it remains unavailable or poorly utilized in many. Indeed, a recent survey of European nephrologists revealed that around 40% had no access to asPD [27]. With this background, a group of leading nephrologists from a number of western European countries have formed a group to drive increased availability of asPD in Europe and in their own countries. As part of this initiative, each member of the group provided information about the use of asPD in their own centre and country, barriers to further developments and priorities to enable expansion of access to asPD.

EUROPEAN ASSISTED PD SURVEY

The group of European nephrologists (one or two nephrologists/country) started meeting in 2021 as a response to the need to increase access to asPD across Europe as a means of enabling people with advanced kidney disease who were unable to perform dialysis themselves to still have their dialysis in their own home. Meetings were virtual and were timetabled and funded by Baxter Healthcare (Europe). Discussions focused on individual members' experiences of asPD and the barriers to growing asPD in their own centre and country. There are very few registry data about the use of asPD apart from the French language PD Registry (Le Registre de Dialyse Péritonéale de Langue Française). Therefore, the group decided that members should fill in a proforma with the following headings: personal experience, country experience, who are the assistants, funding of asPD, barriers to growth, what is needed to grow and their top three priorities.

Information was obtained about individual and national experience with asPD from all 13 countries represented. The availability of asPD, nature of assistance and funding are

summarized in Table 4. Factors related to growth of asPD and the top three priorities of the individual members of the group are summarized in Table 5. Apart from Greece, all members of the group were using asPD in their own centre, though this was often using only family members, family-paid caregivers or their own PD nurses because of the absence of any reimbursement for assistance through the national public health system (Austria, Finland, Ireland, Italy, Portugal and Spain). In Germany, reimbursement for assistance only occurs after individual patient discussion with, and depends on, the health insurer. As a result, an independent volunteer group [Network Assisted Dialysis (NADia)] has been formed to achieve regulated funding and to create a nationwide network of ambulatory care services [28]. In Greece, not only is there no funding for assistance, but also hospital-employed nurses from the public sector are not allowed to participate in the care of patients in the community. Although there was reimbursement for asPD from the national public health service in five countries (Denmark, France, Norway, Sweden and the UK), use of asPD varies between centres. The largest and longest existing asPD programme in Europe is in France, where asPD started in 1977, is fully reimbursed through the public healthcare system (up to 3–4 visits/day), utilizes private community nurses as assistants, and is used by around half of patients on PD. Denmark, Norway and Sweden use a mixture of community nurses and non-professional healthcare personnel depending on local availability. The UK has developed a different model using non-professional assistants and with reimbursement from the National Health Service for only 1 visit a day; some units will also fund a second visit. A few centres employ, train and organize the assistants directly, but the majority use and pay for a scheme organized by Baxter Healthcare (UK) whereby the assistants are supplied by a private national healthcare agency and are trained by Baxter.

The principal theme that emerges for barriers to and priorities for growth in asPD is that the use of asPD depends on overall attitudes to PD, with all respondents mentioning the need for nephrology team education and/or patient education and involvement in dialysis modality decision making (Table 5). The need for involvement with healthcare policymakers regarding recognition and financial support of community care is particularly important for countries where no reimbursement for assistance exists. The perceived lack of government support for any home dialysis appears to be particularly felt in Greece, Ireland and Portugal. The availability of assistants was a concern in France and the UK, both countries with well-developed asPD programmes. In France, assistants are less available in rural areas. The main concern in the UK is the shortage of assistants in many areas partly related to the overall shortage of social and healthcare workers nationally. In countries dependent on family caregivers for assistance, there was concern about the need for better social and financial support of caregivers (Italy, Portugal and Spain). Other themes that emerged were need for collaboration between PD units so that expertise with asPD can be shared, working with patient associations to increase awareness of asPD, realistic cost comparisons between asPD

Table 4. Experience of asPD across 13 European countries

| Country | Personal experience | Country experience | Who are the assistants | Funding of assisted PD |
|----------|---|--|--|--|
| Austria | asPD since 2007. 45 PD; 6 on asAPD—uses own PD nurses in homes or nursing homes | asPD in two other PD centres; not available nationwide. Recently submitted project plan for widespread aPD to federal government | Family members Since 2015, nurses without nephrology experience allowed, but no funding. Assistance provided by PD nurses | No funding for assistance |
| Denmark | Established a programme for asAPD in 1999 | asPD available in all centres, but great variability in numbers related to doctors' preferences. Total PD penetration 20%; 11% PD patients on asAPD and 4% on asCAPD | Professional nurses or health care assistants in patients' own homes or nursing homes staff | Fully funded by public healthcare system |
| Finland | asPD for 20 years. Currently, 2 patients, but plans to increase to 10–20 | Successful programmes in smaller hospitals and regions. More difficult to build networks in bigger cities | Family members, home care staffs and personal assistants | No funding for assistance. Patient pays separately for all visits up to €50/day |
| France | asPD always available even when training as nephrologist | Nurse-assisted PD is covered by the healthcare insurance since 1977, fully covered since 1993. Nurse-assisted PD in nursing homes covered since 2011 | Community nurses working in the private sector Family members | Funded by the healthcare insurance. Private nurses are paid for CAPD or APD; payment is based on the number of exchanges on CAPD |
| Germany | Low awareness of asPD among health insurance companies. Sometimes very difficult individual requests, as there is no regulation for reimbursement. Permits often only after objection. High staff turnover among care providers. Staff shortages both at care providers and in dialysis teams | Obstacles due to lack of funding in Germany asPD is not part of the standard reimbursement for care providers Complex individual requests make asPD unattractive Staff shortages at care providers lead to supply bottlenecks | Family members Professional outpatient and inpatient care providers | Reimbursement according to individual requests to the patient's health insurance by nursing services Different levels of reimbursement for service provision of depending on health insurance fund and region Family members do not receive benefit payments |
| Greece | No asPD as no public home-based healthcare services | None | Occasional family members. Nurses from the public sector are not allowed to visit houses | No funding for assistance |
| Ireland | Mostly family supported. Occasional use of private healthcare companies | No formal asPD programme | Family members. Occasional nursing home staff members | No funding for assistance |
| Italy | 32% asPD; 33% non-family caregivers | Italian PD census 2019: 3466 patients, 24% asPD; 22% in 2016 | Italian PD Census 2019 for asPD: 84.1% family caregiver, 6.6% institutional care, 4.7% retirement home personnel and 4.4% caregiver paid by the family | No funding for assistance. Pilot projects are funded by regional governments (Sicily, Piedmont) reimbursing family members |
| Norway | asPD grown from a few family assisted PD to 20%–30% prevalent PD programme over last 10 years | asPD available across country, both CAPD with 3–4 visits a day and APD | Healthcare personnel (nurse or non-professional) in community or nursing homes. Sometimes family members | Fully funded by public healthcare system |
| Portugal | 20% prevalent patients on asPD. Helper always family member—not paid | No asPD programme—regional or national. An asPD taskforce was created in 2021 | Family members. Nursing homes or rehabilitation centres—depends on good will | No funding for assistance |
| Spain | 10%–15% incident patients on asPD. Started programme to keep prevalent patients on PD | Published experience of asPD is scarce. Some regional experience: Canary Islands, Basque Country, Alicante and Castilla y León | 50% assistance provided by spouses; 10% by non-health care worker. Nursing home staff trained by PD team—philanthropic as no payment | No funding for assistance. In the past, in the Canary Islands, caregivers received a fixed salary of €20 /day (€7280/year) per patient, for both CAPD and APD. Stopped 10 years ago |
| Sweden | 10% of prevalent PD patients; want to grow | asPD prevalence slowly increasing, from 11% in 2010 to about 16% of prevalent PD patients in 2020 | Community healthcare personnel, family members, nursing home staff. Varies between regions, with different access to community nurses to perform asPD | Fully funded by public healthcare system |

Table 4. Continued.

| Country | Personal experience | Country experience | Who are the assistants | Funding of assisted PD |
|---------|--|--|--|---|
| UK | Started asPD with healthcare assistant in 2005; initial model was APD with one visit/day. Currently, 25% prevalence with 17asAPD and 25asCAPD. Shortage of assistants mean patients have missed visits | Widely available in England; less so in other countries. Mostly asAPD with one visit/day. CAPD available in some centres. 5%–20% PD patients on asPD depending on centre | ‘Technicians’ (no professional healthcare training) from national healthcare agency trained and funded by Baxter; employed and trained directly by some units. Family support if limited to 1 visit/day for APD or CAPD (usually 2 visits/day) | Funded by public healthcare system for 1 visit/day. Renal unit absorbs cost of second visit when used |

Abbreviations: APD, automated peritoneal dialysis; CAPD, continuous ambulatory peritoneal dialysis.

and in-centre HD that include cost of patient transport for HD and increasing consideration of needs of older patients with focus on quality of life.

CALL FOR ACTION

The first report of asPD in Europe was published as a letter in *Nephrology Dialysis Transplantation* in 2007 [29] following a meeting of nephrologists who had started delivering asPD in seven countries (Belgium, Denmark, France, Norway, the Netherlands, Sweden and the UK). Like in the current survey, the models of delivery were different in the various countries and depended on the centre and nephrologist expertise and enthusiasm. The letter concluded that with the growing numbers of frail older people requiring dialysis, there was enough evidence to recognize asPD as a dialysis modality and to encourage its use. It is disappointing, and detrimental to the well-being of people unable to carry out their own dialysis at home, that this has not happened.

The recently published survey of European nephrologists [26] has shown that asPD is predominantly available in Western European and Scandinavian countries and is mostly not available in Eastern Europe. A survey of German nephrologists concluded that inadequate funding and lack of staff as assistants were the predominant barriers to developing asPD alongside lack of expertise and lack of motivation to develop new care pathways [30]. The assistance available to children in Germany, where ~60% are treated with assisted PD, results from the fact that this is a ‘natural assistance’ (parents, grandparents and family members). Only a very small proportion of children are treated with the help of professional care services. The current survey of nephrologists from countries in Western Europe and Scandinavia demonstrates that even amongst this group of countries, asPD is only reimbursed and therefore readily available in 5 out of 13 countries. Even in the countries where funded asPD is available, uptake is patchy and is dependent on centre and nephrology bias and expertise, and reflects the use of PD in general.

Although there is an expanding literature on the outcomes of asPD, there is little discussion of what this actually entails: which patient groups would benefit, identifying skills needed by assistants, training of assistants, costs. A recent systematic review of models and outcomes of asPD [31] demonstrated huge variation in models of delivery, types of patients, methods

of funding and outcomes. To enable asPD to be more widely available across Europe a better understanding is needed about which patients need assistance to enable them to have dialysis where they live (own home, residential care or nursing home), how should this assistance be delivered, what are the outcomes of patients on asPD, what healthcare infrastructure is needed and what would the impact be on costs of dialysis delivery.

Who needs assistance for PD?

Clinical practice recommendations from the International Society for Peritoneal Dialysis (ISPD) state that the availability of asPD will enable older, frail individuals to have PD [32]. A detailed Canadian study of 121 patients over 50 years old and starting PD showed a third required assistance for some aspect of PD delivery from friends or family, and 28% received assistance from paid caregivers; the need for assistance was associated with a higher comorbidity burden and cognitive impairment and a significant centre effect [33]. Subsequent follow-up of these patients showed that the need for assistance with PD-related tasks persisted over time, at least for the first 6 months after starting PD [34]. Younger, non-frail individuals also often need assistance when starting on PD. In France, 12% of patients on PD >18 and <65 years old received nurse assistance, associated with age, comorbidities, underlying nephropathy and gender, and with significant variability between centres [35]. It is hard to extract from publication the full picture of people who would be enabled to start or continue on PD if assistance were available. Table 3 summarizes the clinical experience of the authors of this paper and shows that the availability of asPD can enable PD in their own homes for many groups of patients who would otherwise be disadvantaged by having a treatment modality they may not want, i.e. in-centre HD, often with the inconvenience of hospital-provided transport—and the associated extra cost of this transport to the healthcare system and to the environment. These groups include younger patients with physical disabilities, mental health problems or learning disabilities. Availability of asPD also enables people already on PD to stay on their chosen dialysis modality as their health declines, or if the support from a family caregiver is no longer available. AsPD need not be long-term. Many people benefit from some assistance when starting on PD, particularly those who ‘crash-land’ and are therefore enabled to start PD acutely

Table 5. Barriers and priorities needed to expand assisted PD

| Country | Barriers to growth | What is needed to grow | Top three priorities |
|---------|--|--|--|
| Austria | Low use of PD. In general, no reimbursement for assistance. No nationwide standardized predialysis education programmes | Good collaboration between PD centres; yet a few centres have expertise and resources for training, quality assurance and on-site supervision, which are crucial to establish a successful asPD programme | <ol style="list-style-type: none"> 1. In the predialysis period, structured predialysis education programmes for patients and their relatives 2. We need to recruit PD enthusiastic healthcare professionals 3. Collaboration between PD centres is essential to overcome problems while setting up an asPD programme |
| Denmark | Same barriers as to growth of PD in general. Mainly lack of experience, confidence and education among nephrologists. Unused capacity for in-centre HD | Better education of nephrologists. A change in attitude from 'high dose dialysis—high Kt/V dialysis' towards relief of symptoms—especially for the frail elderly patients | <ol style="list-style-type: none"> 1. Better education of nephrologists/decision makers 2. Implementation of ISPD practice recommendations: prescribing high-quality goal-directed PD 3. Provide more data on clinical outcome including quality of life |
| Finland | Costs. Need a new system with separate team doing home visits | A totally new system, who will assist the patient? Costs taken by the community sector of the social security system | <ol style="list-style-type: none"> 1. Increase the number of PD patients 2. Enable support for old fragile patient at home 3. Home first policy |
| France | 50% of French PD patients are treated by nurse-assisted PD. Barriers are mainly in rural areas where the number of private nurses is too low | We do not believe that nurse-assisted PD could grow significantly in terms of % of patients. The potential growth of nurse-assisted PD mainly depends on the growth of the utilization of PD in France asPD as standard reimbursement for care providers. | <ol style="list-style-type: none"> 1. Shared decision making 2. Healthcare professional education 3. Financial incentive at the centre level (payment for performance) |
| Germany | Patients are not informed about the asPD option. Lack of standard reimbursement for asPD. Staff resources low for care providers. Too little awareness with existing need for asPD. Lack of support from professional societies and providers so far. Very good infrastructure of dialysis centres (~1050 centres in Germany) | Information and education for patients and society. Training—curriculum and certification of nurses from caregivers. Overall, creating greater awareness of home dialysis procedures (training doctors, nursing). Information for politicians and health insurance companies | <ol style="list-style-type: none"> 1. Financing and inclusion of asPD in the catalogue of services 2. Training and certification of care providers 3. Clarification of all parties involved |
| Greece | PD delivered only by public sector in a small number of general hospitals in big cities. Large number of HD patients unaware of alternatives | Increase prevalence of PD. According to the latest data of the Coordination and Control Service, PD prevalence: 6.3% in 2017 down from 8.2% in 2009. Benefits of PD should be communicated in effective ways to candidate patients. Creation of a network of trained nurses in PD who will visit mainly elderly and non-self-sufficient patients | <ol style="list-style-type: none"> 1. Convince healthcare decision makers about need to increase use of PD 2. Develop public home-based healthcare system with trained nurses and doctors 3. Early information/education for patients and nephrologists, in predialysis period about benefits of PD |
| Ireland | Primarily lack of funding. Currently, in-centre HD is supported directly on a 'money follow the patient model', whereas home dialysis therapy is funded as an annual block funding with no incentives to increase uptake. More predialysis education—limited by lack of predialysis nurses Incentives for patients to commence home dialysis. Patients do not receive any funding for the costs of providing home dialysis, e.g. electricity and waste disposal | Formal support structure and funding stream for PD. Engagement with policymakers to incentivise patient uptake. Increase predialysis education and support structures | <ol style="list-style-type: none"> 1. Formal support structure and funding stream for PD 2. Engagement with policymakers to incentivise patient uptake 3. Increase predialysis education and support structures |
| Italy | Most families cannot afford to support caregiver. Absence of a more convenient tariff for asPD, considering the need for more money to cover the cost of caregivers. Nursing homes show a low propensity to take care of PD patients | Pilot projects increased incidence but not prevalence of asPD: increasing reimbursement may not be enough. Education of nephrologists and nurses about advantages of asPD and PD in general is key. Nursing homes also need to be included in asPD development projects | <ol style="list-style-type: none"> 1. asPD recognition and adequate reimbursement from public healthcare system 2. Social support for patient and family, e.g. housing availability 3. Nurses and nephrologists home visits should be part of PD programme |

Table 5. Continued.

| Country | Barriers to growth | What is needed to grow | Top three priorities |
|----------|---|--|---|
| Norway | Barriers to asPD same as to PD in general: getting the information and education out to the patients and to nephrology teams | Increasing the prevalence of PD patients. More frequent deliveries as patients complain of number of boxes. Well-functioning PD clinics with nurses with solid experience are a key factor for success as is good collaboration with the surgical team operating PD catheters | 1. Increasing prevalence of PD in general 2. More education, experience and confidence in the treatment 3. Well-functioning PD clinics and cooperation between clinics enabling exchange of experience and enhancing confidence |
| Portugal | Lack of funding for asPD. AsPD may seem economically less attractive (due to bundle payment without the cost of transport for in-centre HD patients). Most nephrologists prefer HD | Governmental strategy to increment home dialysis: • awareness of the unmet need: absence of asPD; • allocation of the cost of transportations and vascular accesses for HD to Dialysis Unit providing home dialysis; • determination of a minimum percentage of home dialysis patients (and regular audit); • creation of a reimbursed 'PD assistant' position/adjust the present reimbursement policy of informal assistant; • regulation of nursing homes/rehabilitation units' responsibilities towards home dialysis patients' needs. Nephrologists' awareness of end-of-life care, quality of life and asPD benefits | 1. Government regulation of home dialysis patients' allocation 2. Financial incentive at the centre level (payment for performance) with abolition of conflict of interest between HD and PD 3. Payment to the carers |
| Spain | Low use of PD by many nephrologists. No payment for caregivers, including family members. No legal coverage for carers—important if they are not relatives (travel insurance, legal defence against home care problems, etc.). Kidney patients associations not aware of specific needs of dependent dialysis patients | 1. Increasing use of PD 2. Spread awareness of PD including among nephrologists 3. Public health system should pay for caregivers, including family members 4. Legal coverage must be offered to carers, mainly if they are not relatives 5. Kidney patients associations should be aware of specific needs of dependent dialysis patients | 1. Broadening the definition of asPD (not only for older people) 2. Paying carers 3. Involving patients associations in the promotion of asPD |
| Sweden | Organisational differences between municipalities and regions | Inform and share positive patient experiences with asPD to patients, health care professionals and society overall. Collaboration with patient organisations, to endorse importance of equal care and overcome regional differences. Strengthen the importance of the predialysis team to give recurrent and updated predialysis information about modalities | 1. Predialysis information about self-dialysis, PD and asPD as modalities 2. Establishing strategic goals within each nephrology clinic to align all healthcare professionals 3. Well-functioning PD clinics with solid experienced nurses to educate and support asPD |
| UK | Variable use of PD in different countries in the UK and centres. Default use of in-centre HD for frail older patients in many centres. Use of 1 visit/day model only suitable for patients able to do own connection/disconnection on APD unless family support and excludes use of CAPD unless renal unit funds extra visits. National health and social care funding problems resulting in shortage of available assistants | Increase awareness of advantages of PD and disadvantages of in-centre HD for frail older people—to patients, families and renal teams. Increase reimbursement for asPD so that 2 visits/day become the norm for APD and more visits possible for CAPD. Realistic comparison of costs between asPD and in-centre HD by including transport costs in HD costs | 1. 'Levelling-up' of PD use in renal centres to minimize variability and therefore increase access to PD overall 2. Increase reimbursement from public healthcare system for asPD to minimum of 2 visits/day 3. Critical shortage of assistants in many areas needs addressing: pay structure, career growth, integration with other caregivers |

[12] or those who 'fail' training because of anxiety and/or some cognitive impairment; once trained and confident, assistance is no longer needed.

What PD-related tasks may need assistance?

Assessing an individual for PD includes identifying which PD-related tasks they may or may not be able to carry out

themselves. Without assistance being available, the inability to carry out some key specific tasks would be considered a barrier to PD and that person would be considered as ineligible for PD. A detailed analysis of almost 400 patients in Toronto considered eligible for PD showed that two-thirds had at least one physical or cognitive barrier to self-care PD [36]. Of these 245 patients with barriers, 34% received family-assisted PD, 47% received home care-assisted PD and 12% received both.

Table 6. PD-related tasks that may require assistance

| Task | Potential barrier |
|--|--|
| Lifting dialysate bags (5 L, i.e. 5 kg used on APD) Preparing cyclor machine (if on APD) | Impaired physical function Cognitive impairment; learning disability; mental health disorder; and visual impairment |
| Connection/disconnection to dialysate bag (CAPD) or cyclor (APD) | Poor manual dexterity; cognitive impairment; learning disability; mental health disorder; and visual impairment |
| Discarding used dialysate | Impaired physical function; cognitive impairment; learning disability; mental health disorder; and visual impairment |
| Exit site dressing and care | Poor manual dexterity; cognitive impairment; learning disability; mental health disorder; and visual impairment |
| General observations: weight, blood pressure | Cognitive impairment; learning disability; mental health disorder; and visual impairment |
| Assessment: selecting type of dialysate; recognizing cloudy fluid; troubleshooting; and contacting PD unit | Cognitive impairment; learning disability; mental health disorder; and visual impairment |
| Ordering supplies | Cognitive impairment; learning disability; mental health disorder; and visual impairment |

The level of assistance will depend on which tasks required assistance as shown in Table 6.

Assistants: family, healthcare-provided—and caregiver burden

Family assistance for PD is ubiquitous, and it is common for family members to be trained to perform PD at the same time as the patient. However, particularly in high-income Western countries, people do not live in multi-generation families, so the family helper may well be a spouse who is also old and has his/her own health problems. Helping with PD is a significant burden for family members timewise, emotionally and financially, so the healthcare team needs to be aware of caregiver burden with the risk of burn-out. If the family caregiver stops being able to support PD either temporarily or permanently, then some other type of assistance needs to be available, or the patient will have to change dialysis modality to in-centre HD with an associated impact on quality of life and healthcare costs. There are no good data about caregiver burden, specifically asPD. A recent systematic review concluded that the quality of life of caregivers for people on dialysis is poorer than the general population and similar to those caring for people with other long-term conditions, but acknowledged there was a lack of knowledge about caregivers for family members on home dialysis [37]. A study from China of 60 patient–caregiver dyads with a mean age of 70 years showed that the significant associations with increased caregiver burden were being female, low financial and social support for the caregiver, and the patient needing assistance with activities of daily living and/or being depressed [38].

In the absence of family caregivers, paid assistance is required to support people unable to perform their own PD. Non-family caregivers are sometimes already employed for personal assistance to patients, and in this case, they can also be trained for asPD at no additional cost for the patient. Many patients and families, however, cannot afford this approach, particularly in European countries with high wages. Although, in high-income countries, healthcare-provided assistants are predominantly nurses, as shown in Tables 2 and 4, it is possible to use non-healthcare-trained individuals at consid-

erably less cost. Patients and family members performing the tasks necessary for PD are not healthcare trained. In the UK, a successful asPD programme has evolved using non-healthcare trained ‘technicians’ with significantly lower costs than employing nurses. In any system, the assistants for PD need training and in general, nurses will need less training time than non-healthcare-trained assistants. Usually, it is the PD centre that provides the training, and this needs to be built into the general workload of the PD team. There certainly needs to be a rigorous system to ‘sign off’ assistants for each PD-identified task and then to ensure that these skills are maintained. Qualified PD nurses ‘at base’ are also needed for troubleshooting, answering concerns from assistants and providing community ‘clinic visits’ for patients unable to travel to the central renal unit. Early experience from France showed that peritonitis rates were significantly lower where community nurses doing PD were trained and supervised by the PD team and not just by other community nurses [39]. Artificial intelligence powered devices and telemedicine could also be part of asPD programmes, as suggested by the experience with video-dialysis, which helped to overcome physical, cognitive and psychological barriers to PD [40].

Funding asPD

AsPD is not available in many European countries because there is no funding for assistants in the community. The results of the survey show that this is often due to disjointed healthcare systems, with PD patients being managed in a hospital system and the assistants working in the community. There is also the perception that the cost of assistance added on to the cost of PD makes asPD an expensive luxury. The cost of the actual assistance depends on many factors, including whether nurses or non-healthcare-trained personnel are used, the number of visits, whether the family does some assistance, the management system for organizing visits, etc. [41]. Incremental PD prescribing allowing for the slow decline in residual kidney function common in older people with advanced kidney disease will enable days off PD, so PD, and therefore the assistance, is only required 5–6 days a week [42]. There are also non-dialysis-related benefits to asPD, which

Table 7. Key recommendations for equity of access to assisted PD in Europe

1. Educate renal healthcare teams about the advantages of PD
2. Establish funding/reimbursement of asPD in those countries where it is not available
3. Address the shortage of nurses by training non-HCP assistants who could assist patients and receive payment for the assistance
4. Design a standardized training curriculum for non-HCP assistants to ensure that knowledge is consistent, and protocols are aligned
5. Define a clear model and protocols for setting up asPD programmes in renal units
6. Ensure that patients receive adequate information on asPD during shared decision-making discussions and pre-dialysis programmes

Abbreviations: HCP, healthcare professional.

enables regular social interaction for those who live on their own. The alternative dialysis modality for people unable to do their own PD would be in-centre HD. Studies comparing the cost of asPD with in-centre HD would have to include the cost of transport to and from the HD centre, including the fact that many of these individuals would need assisted transport given their disabilities. A recent detailed review comparing costs in Canada and Western Europe concluded that the cost of asPD is significantly lower than in-centre HD [24].

Recommendations

Following on from the results of the survey and discussion about what asPD involves, we would propose six key recommendations to expand the use of asPD and provide equity of access to asPD across Europe (Table 7). Given the great disparities between European healthcare systems, 'national' solutions are needed for each of these recommendations.

CONCLUSION

Many people with advanced kidney disease would prefer to have their dialysis at home, yet if the frail patient chooses PD, most European healthcare systems cannot provide their choice. As healthcare providers, we should be supporting individuals to have the treatment that optimizes their quality of life. The percentage use of home dialysis should be a quality indicator for hospital and dialysis clinics benchmarking, applied to both public and private sectors, independent of the health system. Growing PD has economic advantages as well as improving quality of life for individuals. As discussed in two recent publications from Europe and the USA [43, 44] integrated kidney care from presentation with kidney disease to kidney replacement therapy is key to enabling patient education and therefore choice of PD.

AsPD enables individuals who, for various reasons, cannot manage PD on their own. Population ageing in Europe will result in an increasing population of people with advanced kidney disease and facing life on in-centre HD. Patient isolation and social barriers with a lack of family support are often quoted as contraindications to home dialysis. The new tools of telemedicine and health monitoring with the use of digital (audio and video) communication will help support patients and their families at home. Many, however, would prefer to have dialysis in their own home but cannot

because they do not have a family member to provide support and they live in a country that does not provide healthcare funded asPD.

As a group of leading European nephrologists, we feel that all individuals requiring dialysis and, after discussion and education, wanting PD, and therefore dialysis at home, should be able to do so as long as this is medically feasible. This should be true for all countries in Europe and for all renal centres. The top priorities to make this happen are education of renal healthcare teams about the advantages of PD, education of and discussion with patients and their families as they approach the need for dialysis, and engagement with policymakers and healthcare providers to develop and support assistance for PD. Policies to increase home dialysis, including asPD, need to bring financial attractiveness to all the stakeholders, particularly those who are directly involved in the process of dialysis offer: providers and clinicians [44]. Our final recommendation, in addition to those in Table 7, is that the ERA should take a stronger leadership role in supporting home therapies and exposing the lack of equity in Europe.

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DATA AVAILABILITY STATEMENT

Data sharing is not applicable to this article as no datasets were generated or analysed during the current study.

CONFLICT OF INTEREST STATEMENT

E.A.B.: Baxter Healthcare—advisory board and speaker fees; LiberDi, AWAK—advisory boards; Vifor—speaker fees. G.J.M.: Baxter Healthcare—speaker fees. M.W.: Baxter Healthcare—advisory board and speaker fees; Fresenius Medical Care—speaker fees. B.K.: speaker fees: BAXTER and Fresenius Medical Care. U.H.L.: speaker and consultancy engagements for Baxter Healthcare. A.E.: Advisory Board Boehringer Ingelheim, AstraZeneca. The results presented in this paper have not been published previously in whole or in part.

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