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# Proactively boosting home dialysis adoption in Europe

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## **INTRODUCTION**

This publication builds upon a previous editorial outlining the advantages of home dialysis [1], and suggests strategies to boost the adoption of home dialysis across Europe. By the end of 2021, the ERA Registry [2, 3] reported a dismal 8.6% and 1.3% of dialysis patients across Europe on peritoneal dialysis (PD) and home hemodialysis, respectively, with marked variations between countries (Table 1). Failure to take proactive stimulating measures risks jeopardizing the long-term continuity of quality kidney care in Europe.

#### **EDUCATION AND INFORMATION**

The EDITH (Effect of Differing Kidney Disease Treatment Modalities and Organ Donation and Transplantation Practices on Health Expenditure and Patient Outcomes) project investigated disparities in adoption of kidney replacement strategies across European nations. One of the studies conducted an evaluation of patient satisfaction regarding the information they received concerning kidney replacement therapies. Forty-two percent of patients received no information at all regarding home hemodialysis, and 23% were not informed regarding PD. Among those provided with information, only 55% rated the delivery of information very good to good for home hemodialysis, and 65% did so for PD. These satisfaction levels were notably lower compared with in-center hemodialysis [4]. Hence, it is imperative to prioritize education and information dissemination to promote the expansion of home dialysis, notably by engaging nurses and patients alongside physicians, allocating ample and recurrent contact time, and utilizing patient-centered tools such as face-to-face discussions, group sessions and informative home visits.

To gauge satisfaction regarding the information process, independent entities such as patient organizations or regulatory bodies may develop objective patient satisfaction surveys. These surveys could yield results that are independently published allowing for objective and transparent comparisons among different centers.

Next to the traditional person-to-person strategies, telehealth and telemedicine have gained momentum, particularly due to the COVID-19 pandemic, and have been implemented in various clinical scenarios [5]. Specifically in the realm of home dialysis, they facilitate the delivery of general information, remote monitoring, advice from a distance and troubleshooting for acute complications. Moreover, many websites of dialysis equipment manufacturers offer valuable information on home dialysis options. An independent platform provided by the International Home Dialysis Resource Center hosts a repository of documents and publications regarding home dialysis [6], with the intention to support initiatives pertaining to home dialysis.

Education initiatives should not only focus on patients but should also reach out to accomplished medical and nursing professionals as well as to students. By targeting these groups, support can be provided in delivering accurate information and making sound therapeutic decisions. The scope of the target audience should not be limited to nephrology, but should encompass all healthcare professionals who may interact with individuals suffering from chronic kidney disease (CKD) and who may share a stronger trust relationship with patients than the nephrologists due to earlier or more frequent interactions. This broader group includes general practitioners, as well as cardiologists, diabetologists and vascular surgeons.

Although most nephrology educational curricula likely contain courses on home dialysis, nephrology training endpoints should also include predefined exposure periods to home dialysis clinics. For accomplished nephrologists, calls to action like the 2023 Kidney Disease: Improving Global Outcomes (KDIGO) controversies position statement may function as an eyeopener facilitating a change of paradigm [7].

## NOBODY EXCLUDED

Ethnic minorities and individuals with lower income or education levels face a heightened risk of being overlooked for home dialysis initiatives [8]. Tailored communication methods are essential for reaching out to these demographic groups, including concise videos or cartoons presented in their native languages and/or by community members, capitalizing on social media and internal community networks. Guidance from pedagogical and communication experts is indispensable. Geographically, particular emphasis should be placed on specific strategies for lower-income countries and Eastern Europe, where the adoption of home dialysis and satisfaction with information provision are notably low [4].

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**Table 1**: Ranking of European countries with regards to uptake of home dialysis strategies vs all dialysis.

	% home D/all D	% PD/all D	% home HD/all D
Denmark	26.7	20.3	6.4
Norway	25.2	22.3	2.9
Sweden	24.9	22.1	2.7
Cyprus	23.3	23.3	0
Finland	21.5	15.6	5.9
Latvia	20.3	20.3	0
The Netherlands	20.1	15.7	4.4
Iceland	19.8	19.8	0
UK	18.0	13.4	4.6
Estonia	14.5	14.5	0
Hungary	12.4	12.4	0
Spain	12.2	10.9	1.3
Italy	12.2	11.9	0.3
Serbia	10.9	10.3	0.6
Switzerland	9.6	8.1	1.5
Belgium	9.2	6.8	2.4
Russian Federation	8.8	8.8	0
Ukraine	8.7	8.7	0
France	7.5	6.1	1.4
Austria	7.2	7.2	<0.1
Belarus	7.2	7.2	0
Portugal	6.6	6.6	NM
Croatia	6.5	6.5	0
Czech Republic	5.3	4.5	0.8
Romania	5.1	5.1	0
Greece	5.0	5.0	0
Lithuania	4.4	4.4	0
Poland	4.2	4.2	0
Bosnia & Herzegovina	3.7	3.7	0
Albania	2.8	2.8	0
Slovakia	1.8	1.8	0
North Macedonia	1.0	0.9	0.1
Montenegro	0	0	0
Kosovo	0	0	0
OVERALL	9.9	8.6	1.3

All dialysis: home hemodialysis, peritoneal dialysis and in-center hemodialysis; all home dialysis: home hemodialysis plus peritoneal dialysis.

Based on the ERA Registry 2023 (covering the year 2021) [2]. Data for some countries (e.g. Cyprus, Germany, Ireland, Luxembourg, Malta, Moldova, Russia and Slovenia, and small European states like Andorra) are missing in the ERA registry and for other countries data is incomplete (France 27 of 28 regions, Italy 7 of 20 regions). For Portugal, no figures on home hemodialysis were made available. Belgium, Spain and UK: composite figures for 2, 16 and 4 regions, respectively. Tunisia (Sfax region), Turkey and Israel are reported by the ERA registry but are not included here. Data for Cyprus and Russia extrapolated from [3] (data referring to 1 January 2016).

D: dialysis; HD: hemodialysis; NM: not mentioned.

On-line approaches pose accessibility challenges for individuals lacking computer access or skills, a circumstance frequently associated with poverty, marginalization, health illiteracy and older age, but also with inadequate access to quality healthcare, rendering them more vulnerable to kidney disease development and faster progression of kidney dysfunction [8]. Therefore, the implementation of telehealth for all requires tailored educational approaches. Should this appear unfeasible, alternative more traditional approaches should be explored following consultation with the affected populations.

#### SHARED DECISION-MAKING

Efficient information provision also hinges on patient empowerment. Patients and their families must feel empowered to

articulate their preferences and engage in discussion with medical professionals on equal footing.

Shared decision-making serves as a potent yet underutilized method to provide balanced information to patients throughout the decision-making journey. This approach mitigates the risk of professionals imposing personal opinions, and yields superior satisfaction, adherence and overall health outcomes [9]. Surveys indicate that patients undergoing in-center hemodialysis assign a lower weight to their own role in the decision-making process and a greater involvement of their physician than people dialyzed at home [4], pointing to the utility of shared decisionmaking in promoting home-based dialysis options. Unbiased information delivery can be facilitated by adopting Dialysis Decision Aids [10].

One crucial aspect to consider in the communication process is the cognitive impairment often present in individuals with advanced CKD, potentially hindering information assimilation. Entreating nurses with a primary informative role can mitigate this challenge. The reduced hierarchic and emotional distance compared with physicians fosters enhanced understanding and trust among patients and their families. Also, peer support from individuals already receiving home hemodialysis informing those considering it may significantly increase uptake.

# PRACTICAL ORGANIZATION

Drawing inspiration from successful transplantation programs, such as those in Spain, the implementation of a pyramidal organizational structure to foster home dialysis, spanning from national to regional down to local hospital levels, warrants consideration. The exchange of best practices can catalyze a positive momentum for units and countries experiencing challenges. Within each unit, a minimum of one nurse and one physician should be designated to organize and advocate for the home dialysis program, ideally with substitutes and contingency plans in place to prevent disruptions in case of drop-outs.

Particularly for home hemodialysis, the establishment of small self-care units where individuals can administer self-treatment in the confines of a center with prompt assistance in case of complications, or permitting brief returns to in-center care, termed "home dialysis holidays," could prove beneficial in preventing patient and caregiver burn-out.

For individuals unable to autonomously perform the procedure and lacking support from their immediate vicinity, assisted home dialysis should be championed by authorities. However, if assisted home dialysis is available and supported financially, the practice should also effectively be implemented by caregivers, which is not always the case [11]. In addition, assisted home dialysis should not be limited to PD, and should also encompass home hemodialysis.

The uptake of home dialysis could be facilitated by simplifying the available equipment, particularly that for home hemodialysis, to make it as user-friendly as possible.

#### **FINANCIAL INCENTIVES**

Around 2010, the US authorities opted to standardize reimbursement rate for all dialysis modalities to an equal amount per week, which was followed by an increase in home dialysis options, particularly PD. However, taking a global view reveals that most countries incentivizing PD financially, tend to experience lower PD uptake compared with those applying PD first policies, despite investing significantly more funds [12]. These findings imply that financial incentives alone often fall short and advocate for a multifaceted approach to enhance home dialysis (see below).

National regulators may take initiatives to avoid disincentives to home dialysis, such as providing financial support based on the percentage of people on kidney replacement therapy in a unit not treated by in-center dialysis.

# A HOLISTIC APPROACH

A comprehensive approach is implemented in Scandinavian countries, where the prevalence of home dialysis stands out as one of the highest in Europe. Notably, their financial framework emphasizes reimbursement of real costs, which deviates from a blanket reimbursement policy as implemented in the US, but also discourages opting for the financially more rewarding strategy, which typically is in-center hemodialysis in many nations. Hence, such financial disincentives may prove more effective than overreimbursement of home dialysis or equal reimbursement for all strategies. However, real-cost coverage constitutes just one facet of a considerably broader strategic approach encompassing informational campaigns, educational courses, meetings and debates on home dialysis, and multicenter studies aiming at familiarizing professionals with home dialysis practices. Moreover, reimbursement is provided for assisted home dialysis, and benchmarking with transparent reporting of dialysis practices per center allows for public comparison. Such databases could contribute to a European registry, potentially accelerating awareness and growth of home dialysis.

However, the most effective solutions may vary across countries, necessitating tailored adaptations based on specific local contexts.

# **POLICY ACTION**

Advocacy aimed at persuading both the public opinion and policymakers regarding the burden of kidney diseases is a crucial yet underutilized avenue for instigating the necessary paradigm shift in kidney care. Collaboration between patients and professionals is imperative across international, national and regional levels to compel governments to implement measures facilitating home dialysis, as a component of a comprehensive strategy to reduce kidney disease and its repercussions. Key advocacy campaigns should address pressing contemporary concerns including the living conditions of children and the elderly, environmental sustainability, enhancement of quality of life, healthcare workforce shortage and cost-effectiveness. Employing a diverse range of tools, such as position statements, publications, meetings and press and social media campaigns, and enlisting persuasive and credible patient ambassadors, are essential strategies for this endeavor.

Given the European Union's low competence in health matters, actions should include not only European top-down initiatives but also national bottom-up approaches. This necessitates a comprehensive strategy guided by a step-by-step roadmap such as the one currently elaborated by EuroPD with input from several patients and experts.

## CONCLUSIONS

In Europe, many advantages of home dialysis often go unrecognized, leading to unfortunate underutilization. Significant segments of both the medical and the political spheres overlook the prevailing societal and environmental circumstances that could be remedied by prioritizing home dialysis [1]. Alongside more traditional perspectives, this text also proposes less considered specific approaches, such as the education of students and nurses, tailored educational methods for minorities and for those who are health and computer illiterate, consideration of cognitive impairment in people with CKD, and the need for a pyramidal organizational structure and a holistic approach. Additionally, we highlight several focal points that we believe will capture the interest of policymakers. International and local organizations dedicated to kidney care ought to ensure a central coordinating role in addressing this issue, setting out a blueprint for action that incorporates enhanced patient education, empowerment and shared decision-making. Advocacy must serve as pivotal catalyst by all stakeholders involved.

# CONFLICT OF INTEREST STATEMENT

R.V. is advisor to AstraZeneca, Glaxo Smith Kline, Fresenius Kabi, Novartis, Baxter, Nipro, Fresenius Medical Care and Nextkidney.

S.D. has previously received lecture fees from Baxter Health-Care and Fresenius Medical Care, and is on the advisory board for Ellen Medical. His Home Dialysis research is funded by the National Institute for Health and Care Research Health Services Health and Social Care Delivery Research programme.

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The other authors have nothing to declare.

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