

# Stage V renal failure : a plea for home dialysis

(La Maladie Rénale Chronique au stade V : un plaidoyer pour la Dialyse à Domicile )

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#### Summary

Overall, home dialysis (DAH) remains underutilized in much of the world. It is only in some parts of the world, such as Hong Kong, Mexico, Thailand, the Netherlands, Finland, Denmark, Iceland, Australia, Canada and New Zealand, that home dialysis is used for more than 20% of the dialysis population. It is observed that in most high- and middle-income countries, home dialysis is generally more economical than center-based dialysis.

According to the results of the REIN 2020 registry, the share of out-of-center dialysis in France has been increasing since 2012. This is mainly due to the increase in the number of patients treated in low medicalized dialysis units (LMDUs) (+7.3% per year between 2012 and 2016, then +3.8% between 2016 and 2020). In contrast, the proportion of patients treated at home has changed little. The percentage of patients on peritoneal dialysis is decreasing (-1.8% per year). Home hemodiaysis HDD is increasing (+10.3% per year) but remains very marginal (1% of dialysis patients). Finally, the advanced age of dialysis patients, which is constantly increasing, cannot be ignored. The proportion of these very old patients has increased from 10.5% in 2012 to 12.5% in 2020. However, during the COVID-19 epidemic, several articles in the literature have demonstrated the protective effect of home dialysis in all its forms (peritoneal dialysis and home hemodialysis) against SARS-CoV-2 infection.

We report on the status of home dialysis in France, its advantages and proposals for its development, as presented at the Home Dialysis Day (DIADOM) of University Seminars of Nephrology (SUN) in Paris in January 2022.

**Key words** : Cost; COVID-19; Out of center dialysis; Elderly patients; Home dialysis; Peritoneal dialysis.

### Résumé

Globalement, la dialyse à domicile (DAD) demeure peu employée dans le monde. Elle n'est largement utilisée que dans certaines régions du monde telles que Hong Kong, le Mexique, la Thaïlande, les Pays-Bas, la Finlande, le Danemark, l'Islande, l'Australie, le Canada et la Nouvelle Zélande, où la DAD concerne plus de 20% de la population dialysée. On observe que dans la plupart des pays à revenu élevé et moyen, la DAD est généralement plus économique que la dialyse en centre.

En France, selon les résultats du registre Réseau Epidémiologique et Information en Néphrologie (REIN) 2020, la part de la dialyse hors centre augmente depuis 2012. Elle est le fait essentiellement de l'augmentation du nombre de patients pris en charge dans les unités de dialyse médicalisées (UDM) (+7,3% par an entre 2012 et 2016, puis +3,8% entre 2016 et 2020). En revanche, la proportion de patients traités à domicile a peu évolué. Le pourcentage de patients en dialyse péritonéale est en baisse (-1,8% par an). L'hémodialyse à domicile (HDD) est en augmentation (+10,3% par an) mais reste très marginale (1% des patients dialysés). Enfin, on ne peut occulter l'âge avancé des patients dialysés qui ne cesse d'augmenter. La proportion de ces patients très âgés est ainsi passée de 10,5% en 2012 à 12,5% en 2020. Cependant, lors de l'épidémie de coronavirus 2019 (COVID-19), plusieurs articles publiés dans la littérature ont démontré l'effet protecteur de la DAD sous toutes ces formes (Dialyse péritonéale et Hémodialyse à domicile) contre l'infection SARS-CoV-2.

Nous rapportons l'état de la dialyse à domicile en France, ses avantages, les propositions pour la développer, tels qu'ils ont été présentés lors de la journée dialyse à domicile des Séminaires Universitaires de Néphrologie à Paris en janvier 2022.

**Mots clés** : Coût ; Dialyse à domicile ; Dialyse péritonéale ; Covid-19 ; Dialyse hors centre ; sujets âgés.

# ABREVIATIONS

ARS Agence régionale de santé	HHD Home hemodialysis
CNAM Caisse nationale d'assurance maladie	LMDUs Low medicalized dialysis units
CKD Chronic kidney disease	LNHD Long nocturnal hemodialysis
COVID-19 Coronavirus disease 2019	OECD Organisation for Economic Cooperation
DAH Home dialysis	and Development
DHH Daily home hemodialysis	PD Peritoneal dialysis
DPM-PD DOPPS Practice Monitor-Peritoneal	REIN Réseau Epidémiologique et Information en
Dialysis	Néphrologie
DOPPS = Dialysis Outcomes and Practice Patterns	SARS-CoV-2 Severe Acute Respiratory Syndrome
Study	Coronavirus 2
ESRD End-stage renal disease	SFNDT Société Francophone de Néphrologie
ESPIC Établissement de santé privé d'intérêt	Dialyse et Transplantation
collectif	SUN Séminaires Universitaires de Néphrologie
HD hémodialyse	WHO World Health Organization

#### Introduction

Over the past 30 years, the number of dialysis patients has increased dramatically worldwide. In 2010, the number of dialysis patients was over 2 million, and modeling data suggests that the number will more than double by 2030 [1]. Several factors have contributed to this increase: improved survival in the general population, reduced mortality in dialysis patients, increased incidence of chronic kidney disease, expanded eligibility criteria for renal replacement therapies, and better access to chronic dialysis in low- and middle-income countries [2]. Finally, since home dialysis (DAH) has been associated with a lower cost than in-center dialysis, better socio-professional quality of life and lower mortality, several centers have opted for DAH as first-line treatment. Overall, the DAH remains very underutilized. Its use is limited to certain regions, such as Hong Kong, Thailand, Mexico, Canada (20%), Holland, Iceland, Finland, Denmark, Australia (29%) and New Zealand (52%) [2, 3]. The prevalence of home hemodialysis (HHD) in New Zealand, Australia, Denmark, Finland, Sweden, the Netherlands, and the United Kingdom is 15.6%, 9.4%, 4.6%, 4%, 2.8%, 2.4% and 2.1%, respectively [4]. In recent years, many scholarly organizations worldwide that study kidney disease have mobilized in favor of a change in policies and practices in order to increase the accessibility and adoption of DAH [2]. In France, chronic renal failure is a major public health problem, affecting nearly 3 million patients. At the so-called terminal stage of chronic kidney disease (CKD), which affects more than 83,000 patients, renal function replacement therapy becomes necessary. If approximately 40,000 patients benefit from a kidney transplant, nearly 50,000 patients are treated by dialysis [5]. In France, according to data from the REIN registry, 93% of these patients are treated by the hemodialysis technique in care units (either in dialysis centers or in low medicalized dialysis units (LMDUs)) or by self-dialysis [6]. There is an alternative to hemodialysis in a center or LMDU: home dialysis. It can currently be carried out according to two treatment methods: peritoneal dialysis (PD) and home hemodialysis (HHD).

Widely adopted in many countries around the world, where 20% of dialysis patients suffer from end-stage CKD [4, 7], home dialysis is struggling to progress in France, and is currently used for only 7% of dialysis patients (6% in PD and 1% in HHD) [6]. Unfortunately, DAH which peaked in 2003 at 10.5% (PD: 8.7%, HHD 1.8%) [8], giving some people a glimpse of the possibility of reaching the ambitious figure of 15% of French dialysis patients being able to receive treatment at home in 2010 [6], has actually slowly and inexorably declined, and stagnated at the current low levels since 2008 [6]. The current national figure, a low of 6% of PD patients, in fact conceals

significant regional disparities. However, the desired objective (10 to 15% of patients treated with PD), which we announced in a 2006 editorial published in Nephrology and Therapeutics [9], is far from being achieved. Should we resign ourselves to this situation, or should we ask ourselves the right questions to move forward? The objective of this editorial, advocacy for DAH, is not to convince the nephrology community, but to persuade regional health agencies, political powers and patient associations of the medical and financial benefits of the different modalities of DAH as quality renal replacement therapy.

#### Home dialysis as the optimal method for remote residential areas.

The network of dialysis centers allowed by the Kouchner law at the end of the 1990s allowed the significant shortage of dialysis stations in France to be overcome. It has not spread to remote residential areas once again popular with younger generations, particularly following confinement during the first wave of COVID-19 and the large-scale implementation of teleworking [10]. It would be regrettable to pursue a policy of setting up new dialysis centers on these new, very large outskirts of towns. For future patients with end-stage renal disease (ESRD) from these remote locations, DAH (in particular HHD and PD) seems the most rational response given their level of education, their involvement in telework, the adequacy of their accommodation and their desire for autonomy. Many will be "ideal" candidates for kidney transplantation (because of their young age). Nevertheless, we can unfortunately fear that with the perpetuation of the COVID-19 pandemic, these patients will at best have a transplant waiting time identical to that in the period preceding this pandemic, and at worst a longer dialysis time due to the deleterious impact of the pandemic on the organization of transplantation in France. This therefore presupposes a high quality of extra-renal purification currently permitted by the various techniques of home dialysis.

#### Anticipating and ensuring dialysis in old age

The current pandemic has allowed a focus on the extreme fragility of age (with an "early" cutoff threshold at 65), which is a major risk factor for death from this virus and one that is found consistently, across countries. It also revealed an unexpected societal solidarity between generations, expressed by the choice of generalized confinement with heavy economic consequences, while highlighting the deep flaws in the organizations and funding of establishments for dependent elderly people in the different countries of the Organization for Economic Cooperation and Development (OECD) [11]. This pandemic has paradoxically also contributed to raising awareness of the challenges of longevity, giving meaning to the creation of a «fifth risk» provided by social security, which is intended to cover the loss of autonomy and allow our elders to age at home. Many elected officials, intellectuals, union leaders and care and dependency professionals have recently encouraged us to rethink generational links and to take up the demographic challenge of old age. We must anticipate that from the year 2025, a massive number of Baby Boomers, then aged 80 years, will come to join the many nonagenarians in good shape [11]. French teams practicing DAH now have significant and positive experience in empowering certain couples of dynamic octogenarians to perform autonomous PD at home. In addition, the experience of DAH teams in the Toronto region of Ontario, Canada shows the possibility of having HHD provided to elderly patients either by compensated family caregivers or by caregivers paid by healthcare networks [12]. In France, according to data from the REIN register, the number of patients for the age group greater than or equal to 85 years has increased, and the percentage of all dialysis patients has increased from 10.5% in 2012 to 12.5% in 2020 [6]. The factors underlying the use

of DAH are complex, and include those related to a patient, and their caregivers, the care team, the healthcare system, geography, and culture. Better systems for patient information, shared decision-making and patient involvement in their own care can potentially be used to improve and evaluate a change in practice [13].

In France, during the first wave of the COVID-19 pandemic, the infection rate was 3.3% among dialysis patients [14, 15], i.e. 14 times higher than that of the general French population.

Conversely, recent French data [16, 17] corroborated by Italian data [18] clearly show that dialysis patients treated at home by PD were much less infected by SARS-CoV-2 with a reduction in the risk of contracting COVID-19 disease by at least a factor of 2: of 3,014 French-speaking patients treated by PD in 156 centers, 59 contracted COVID-19 disease, i.e. 1.9% [14].

However, it is surprising that the number of PD patients in France did not change in the 2020-2021 period. More surprisingly, the number of transfers from PD to HHD increased. If the number of PD patients remained relatively stable, it was due to a decrease in the number of transplants. This observation, which goes against the recommendations and experience of other countries, is not clearly explained at the time of writing [19].

A protective effect of PD compared to hemodilaysis (HD) in a center, by a factor of 3 against the risk of contracting SARS-CoV-2, has even been demonstrated in Canada and England. In the latter country, where a particularly intense first epidemic wave raged, 9% of hemodialysis patients in centers contracted SARS-CoV-2, compared to only 2.9% of patients treated in PD [20]. In April 2020, the Italian Ministry of Health published a recommendation asking health professionals to put in place measures aimed at increasing the use of HHD and PD through an adapted therapeutic education course in order to minimize the risk of contracting COVID-19 for the population of Italian dialysis patients [21]. Similar recommendations have been made in urgent pleas in both the journal of the American Society of Nephrology [20] and in the journal of the Italian Society of Nephrology. This population-based preventive strategy appears all the more logical since mathematical modeling carried out by a team of epidemiologists from Harvard and published in the journal Science raises fears of the persistence of this pandemic for several more years with significant epidemic peaks until 2024, despite the arrival of vaccines [22]. The risk of the COVID-19 pandemic continuing for more than a decade has even recently been considered by the World Health Organization (WHO). Thus, in view of these current convergent scientific data, it is appropriate to develop DAH, a modality of extra-renal purification that appears to be very protective against contamination by SARS-CoV-2.

#### What are the reasons for the underuse of the DAH in France?

The obstacles to the progress of home care for patients with renal insufficiency in our country have been known for a long time, without any real progress having been made for more than 15 years [13].

**For HHD,** let us cite in particular unfavorable pricing that makes the directors of public and private health establishments and the managers of associations reluctant to practice a technique whose profitability amounts to at best ten euros per session. This is associated to a lack of homogeneity of valuation of the act of weekly monitoring for nephrologists between techniques,

making HHD the only modality of chronic extra-renal purification without medical fees (for the associative world and the private sector). This double economic limitation is aggravated by the obsolete obligation for the presence of a third party, disputed by both nephrologists and all the patient associations, as well as by the regulatory and tariff-related impossibility (apart from certain derogatory experiments put in place by some some regional health agencies (ARS)) to have a nurse intervene at home to assist certain patients who are reluctant or unskilled in having their fistula punctured.

**For assisted PD**, one of the main obstacles is the current absence of tariff valuation of the nurse's visit to the home for the performance of peritoneal exchanges and catheter care. The second obstacle is the economic undervaluation of the surgical act of inserting the PD catheter.

Unfortunately, there are many other obstacles to the development of DAH: the training of young nephrologists in PD is often still limited and very unequal depending on the region, although the introduction of the University Diploma in Home Dialysis has enabled some nephrologists to benefit from this training. The administrative authorizations for the performance of DAH for health establishments (public or private) are rarely granted by the ARS (except in Ile-de-France), which wish to reserve these techniques for expert centers, and for historical reasons most often attribute them to associations involved in DAH for a very long time. These associations provide 76.5% of PD and 84.5% of HHD in France. In addition, until the very recent implementation (October 2019) of the CKD sectors, the information given to patients with renal insufficiency at an advanced stage of their disease regarding the different methods of renal replacement therapy was not structured objectively and uniformly in France. It is clear that the progression of DAH depends on health professionals' (nephrologists and CKD referent nurses) will to assert the need for a course of therapeutic education that grants DAH techniques much more legitimacy than they are currently given.

# Several easily applicable proposals should make it possible to rapidly develop the DAH in our country.

The analysis of the obstacles to the development of DAH shows that it is advisable to work in a pragmatic way on 3 axes of improvement: objective information given to patients on the modalities of renal replacement, the implementation of home techniques in a greater number of dialysis centers, and price increases for these techniques. A CKD sector package for health establishments (public, private, and ESPICs) was set up by the Ministry of Health at the end of 2019. Its objectives are to stabilize less advanced CKD patients (CKD stage 3) and to provide the most objective information to those more advanced (CKD stage 4 and 5) with regard to the various replacement techniques, including grafting and DAH, thus allowing patients a real, informed choice.

Thus the CKD system, when it is fully deployed, seems able both to break the not very virtuous circle of self-sustaining networks in dialysis centers and to allow the many emergency dialysis patients outside the healthcare system (currently 30% of dialysis patients in France and in OECD countries) to benefit from objective information shifted over time and an informed choice of possible DAH. It is appropriate for health establishments, especially in these troubled times of the COVID-19 pandemic, to implement the development of their CKD sector in close consultation with the regional delegations of the ARS. Currently, agreements between health establishments and expert centers remain underused, and often even theoretical. The lack of implementation of home techniques in dialysis centers devalues these techniques in the eyes of patients and nursing

staff. Ultimately, the democratization and distribution of DAH authorizations to all voluntary health establishments, without status restrictions imposed by the regional delegations of the ARS, can be a powerful lever for the revival of home techniques in our country.

At the same time, tariff valuations appear necessary to promote the development of DAH techniques, as highlighted by the SFNDT white paper [3] discussing HHD session packages that are currently undervalued, the creation of a medical package weekly monitoring of HHD (identical to that which has existed for several years in PD), the creation of a nursing act at home for puncture of the fistula and connection to the dialysis generator, and the repeal of the need of a third person present during the DAH session. Similarly, the upgrading of nursing acts carried out in the homes of non-autonomous patients in the context of assisted PD is a prerequisite for the significant extension of this technique, which will allow the management of the future generational shock of the elderly associated with the upgrading of the surgical act of inserting the PD catheter, which is currently undervalued.

Finally, we could also, as imagined by the white paper of the SFNDT [3], consider specific funding for health car institutions (regardless of their status) to enable the effective implementation of a large-scale healthcare true policy that would strongly favour autonomy in dialysis.

A large-scale international project coordinated by the University of Michigan in the US was initiated in 2013 and published in 2016 in The American Journal of Kidney Disease [23]. The primary objective of this project, called DPM-PD (DOPPS Practice Monitor-Peritoneal Dialysis), is to analyze the results of PD in different countries. Together with the data collected, the study will be an invaluable research resource for PD and provide a means to better understand inter-regional variations in clinical practices and PD outcomes. This, in turn, will enable practitioners to identify optimal practices and ultimately intends to improve these results. Following the recent meeting on PD at the Academy of Medicine, this moral and scientific institution, in a press release that appeared in the doctors' daily newspaper and in Agence France-Presse (AFP), called for developing DAH and in particular PD after the finding that only 6% of the 50,500 dialysis patients use PD in France. This rate is half the average for OECD countries, according to the Academy of Medicine, which is calling for the development of this treatment for the management of ESRD [24, 25]. Finally, we cannot hide or forget the testimonials of patients, which are essential to information about the different dialysis techniques.

A survey carried out by the patients' association (RENALOO) in February 2016 revealed that: one patient in three felt that they had little or no involvement in the choice of their treatment; more than one in two (55%) felt that they had been badly or not informed about the possibility of being transplanted without going through dialysis; one in two felt that they were poorly or not informed about the possibility of HHD; and finally, more than 40% felt that they were poorly or not informed about PD [26]. These are results that raise questions about the credibility of the medical information given to our patients. Very recently, a patient expert, Fabrice Huré, prepared, in collaboration with a committee of experts, a 3-part study to shed light on the efficiency of long nocturnal hemodialysis (LNHD) in center or at home. The study incorporated a medico-economic component cross-referencing the REIN and CNAM databases on the cost of LNHD, PD and HD in the center; a questionnaire on the quality of life in LNHD and the interaction with social and professional life; and an analysis of the cost, obstacles and levers that can be used in the deployment of LNHD. Their observation was that daily home hemodialysis (DHH) is financially valued at 30% more than LNHD in a center, with a cost close to the modality in a heavy center. This study, which has been worked on for several months, will open and elevate the debate on proposal number 8 in the DAH white paper, which is to increase the price of home hemodialysis. It is also very surprising that the SFNDT here confuses the rarely applied conventional home hemodialysis (HHD), which is performed 3 times/week for 4 h, with DHH, which is performed 5 times/week for 2.5 h each or 6 times/week for 2 h (Testimony of a patient expert, Fabrice Huré). They observed in this study that the "home" indicator no longer means efficient and less costly modality. It is therefore necessary to have complete transparency on this subject with learned societies and patient associations.

# Promoting DAH does not mean denying and impoverishing the modalities of dialysis in the center.

Promoting and developing autonomy for patients, in collaboration with the patients themselves and their associations, will create the possibility for some of them to become patient experts. This effort will only affect a fraction of dialysis patients (with the hope of ideally reaching the figure of 20% for home techniques).

The current COVID-19 epidemic has also cast a harsh light on the social and ethnic divide inscribed in the geography of the suburbs of Ile-de-France (as in the department of Seine-Saint-Denis (93) and in certain suburbs of regional metropolises where this modern form of "ghettoization" makes the development of home techniques illusory. This point had already been raised in 2006 in an editorial published in Nephrology and Therapeutics [9]. Unfortunately, the problem has only increased over time. The price reductions suffered by private health establishments and associations (ESPICs) since 2014, correspond to a loss of 17.6% in euros, assuming a constant value of the technical package for dialysis sessions in a center, and -9.8% in LMDUs [27]. These price reductions were significant but less drastic for public establishments. They did not have the restructuring effect expected by the supervisory authorities with regard to DAH, but have, on the contrary, contributed to a real beginning of impoverishment of the dialysis centers and the LMDUs. Such impoverishment is aggravated at present by the expense of the implementation of strict protective measures for the personnel and the dialysis patients for SARS-CoV-2 infection. There is also an undeniable loss of sense of their profession for many parametics and dialysis doctors in France and in many OECD countries, with a real risk of a shortage of dialysis caregivers in the near future.

Ultimately, it would seem extremely imprudent to us to reduce the number of places in dialysis centers and LMDUs on the grounds of the development of home techniques, because there is an annual structural growth in dialysis patients linked to the aging of the French population and the diabetes epidemic (apart from the massive arrival of baby boomers in 2025). At the same time, nephrologists are likely to have to take care of a large number of patients who have presented very symptomatic forms of diabetes in the near future. A publication in the Journal of the American Society of Nephrology having analyzed the outcomes of 3,993 patients (without pre-existing kidney disease), hospitalized in hospitals in the New York area for COVID-19, showed that 46% presented with acute renal failure which required transient use of dialysis in 19% of them; 35% of patients had acute renal failure (having or not requiring dialysis) and, having survived, had significant renal sequelae capable of leading them to dialysis in the short or medium term [28]. A probable scenario is therefore the onset of staggered and progressive sequelae of chronic renal

failure for many of these severely disabled COVID-19 survivors, which may co-occur with frequent motor sequelae (post-resuscitation syndrome), pulmonary (restrictive syndrome and fibrosis) and cardiac (heart failure, coronary disease and arrhythmias), and leave them with treatment in a dialysis center as their only option.

# Conclusion

Center-based HD continues to dominate renal replacement therapy internationally, with few exceptions. This dominance suggests that most patients around the world do not have much choice when it comes to selecting their dialysis treatment modality. However, patient autonomy, cost control, quality of life and satisfactory clinical results are strong arguments in favor of DAH. In addition, our approach is clearly an extension of the Ségur de la Santé. We hope that our reflections, born from the COVID-19 pandemic and our proposals on home dialysis resulting from it, will fuel a constructive and pragmatic dialogue between the supervisory authorities, our learned societies, the various unions of nephrologists and patient associations. They must quickly contribute to decisions taken in the field, capable of enabling a new boom in home dialysis techniques in France. We would like to go beyond the current observation that despite the voluntarism shown by the health authorities and the few ministerial decrees published in favor of the development of DAH, the number of incident patients for home techniques in France remains marginal.

#### **Conflicts of interest**

The authors declare no conflict of interest with this paper.

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