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HOME DIALYSIS : WHERE ARE THE BARRIERS ? a national survey of French nephrologists.

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Résumé

La dialyse à domicile, représentée par l'hémodialyse et la dialyse péritonéale, peut apporter de nombreux bénéfices aux patients atteints d'insuffisance rénale chronique terminale, particulièrement en termes de confort, de qualité de vie et d'autonomie. Cependant son utilisation reste marginale en France, avec une répartition inhomogène sur le territoire. Nous avons réalisé une enquête nationale française auprès des néphrologues pour évaluer les freins au développement de la dialyse à domicile. Après analyse des réponses des 230 néphrologues ayant participé à l'étude, les principaux obstacles au développement des deux techniques ont été identifiés et classés selon leur taux de déclaration. Les freins majeurs qui ressortent de l'enquête sont : le manque de médiatisation auprès du grand public, un défaut de reconnaissance des infirmières spécialisées dans ces techniques, le nombre limité de structures pratiquant la dialyse à domicile, et les difficultés relatives à l'information pré-dialyse. Les freins spécifiques à la dialyse péritonéale déclarés sont : les difficultés de prise en charge en Soins de suite et de réadaptation (SSR), la crainte d'une épuration insuffisante et les difficultés liées à l'abord de dialyse. Concernant l'hémodialyse à domicile (HDD), les freins portent sur la peur de l'autoponction et la nécessité d'une tierce personne. Cette étude permet d'identifier les représentations des néphrologues sur les freins majeurs au développement de la dialyse à domicile pour développer des pistes de réflexion pour sa promotion, tant sur le plan de la formation, de la reconnaissance institutionnelle, que de la nécessaire évolution réglementaire.

Mots clés : hémodialyse à domicile, dialyse péritonéale

Abstract

Home dialysis, which includes peritoneal dialysis and home hemodialysis, offers many benefits to patients with Chronic Kidney Disease, including comfort, quality of life and autonomy. However, its use is marginal in France, with an inhomogeneous distribution on the territory. We conducted a French national survey of nephrologists to assess barriers to the development of home dialysis. After analyzing the responses of the 230 participating nephrologists, the main barriers to the development of both techniques were identified and ranked according to their reporting rate. The main obstacles that emerged from the survey were: the lack of information of the general public, the lack of acknowledgement of the nurses specialized in these techniques, the limited number of structures practicing home dialysis and the difficulties about dialysis techniques information process. Specific difficulties reported with peritoneal dialysis include: difficulties for patients to access to rehabilitation care units, fear of inadequate dialysis dose and difficulties related to the dialysis catheter. Concerning home hemodialysis, the barriers concern the fear of self-cannulation and the need for another person at home. This study helps to identify the perceptions of nephrologists on the main barriers to the development of home dialysis in order to show the best ways to promote it, both in terms of training, institutional acknowledgement and necessary regulatory changes.

Keywords : home hemodialysis, peritoneal dialysis



INTRODUCTION

In France, the treatment of end-stage renal disease is based on a diversified offer whose central focus is kidney transplantation. Nevertheless, the shortage of organs makes pre-emptive transplantation uncertain and many patients have contraindications, necessitating dialysis treatment. We can schematically oppose in center dialysis with home dialysis. This last includes two distinct techniques, peritoneal dialysis (PD) and home hemodialysis (HHD). Different modalities have been developed for each of these techniques in order to offer a wide and flexible range according to each patient's aptitudes and way of life. PD can be used in a continuous ambulatory (CAPD) or automated (APD) mode. Hemodialysis can be prescribed according to conventional, nocturnal and / or daily procedures. Despite this large panel and recognized strengths in terms of quality of life (1-5), the use of home dialysis remains limited in France, as evidenced by the latest annual report of the Epidemiological and Information Network in Nephrology (REIN) 2016. Among the prevalent dialysis patients, 6.3% are on PD and only 0.8% are in HHD. However, studies comparing these techniques with conventional hemodialysis, have confirmed their safety(7), their effectiveness (8-9) and their benefit on quality of life (10-12). The orientation towards home dialysis and its implementation require individualized support by the nephrologist and the healthcare team. Thus, the promotion of home dialysis requires a strong involvement of medical and para-medical actors, in order to make treatment accessible to patients (13). The prerequisites are on the one hand the training of specialized nurses (14-15) and doctors and, on the other hand, the development of a pre-dialysis information program, the quality of which has a major impact on the orientation of patients towards the one or other of the dialysis modalities proposed (16-18).

Many barriers can be at the origin of the weak development of home dialysis in France, but the heterogeneity of use of these techniques on the territory shows that these barriers can be attenuated (6,19,20). This is the case for example in Franche-Comté, where PD represents 19.9% of dialysis patients. The identification of home dialysis barriers is not a new approach (21-23), but faced with the inertia, it seems necessary to better identify and prioritize them to guide future actions. Thus, with the help of the Francophone Society of Nephrology Dialysis and Transplantation (SFNDT) and the French Peritoneal Dialysis Dialysis Registry (RDPLF), the Young Nephrologists' Club (CJN) conducted a national survey of nephrologists to identify factors that they think associated with the lesser use of home dialysis techniques in France.

METHODS

We conducted a survey of nephrologists practices working in France. A group of members of the CJN designed a questionnaire, which explored different axes of potential barriers: the barriers related to the mastery and the perception of the techniques, the psychosocial and patient barriers, the barriers related to the approach of dialysis and organizational barriers related to infrastructure and logistics.

The questionnaire was available on the CJN website, and was sent via the CJN, RDPLF and SFNDT mailing lists, as well as via social networks. Some centers also received paper copies to complete. The investigation took place between January 22nd and March 26th, 2019.

Only the responses of certified nephrologists were taken into account. Responses were stratified into 2 groups, based on the respondent's reported level of expertise for home-based skills.

Qualitative variables were described by their frequency and percentage. Quantitative variables were described by their mean and standard deviation.

RESULTS

Responding nephrologists

We received 230 responses, 55% of the participating nephrologists were women. The median age was 42 ± 11 years old. The majority of respondent nephrologists worked in a general hospital (Figure 1A). All statutes were represented: 40% were hospital practitioners, 7% university hospital practitioners, 9% in post-internship, the remaining 44% were associative or liberal nephro-

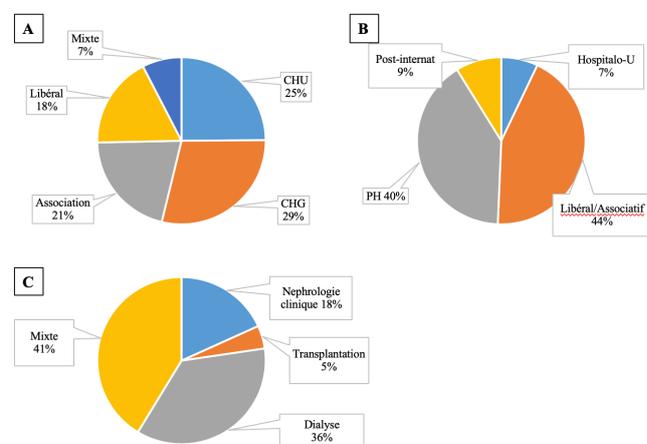


Figure 1: Distribution of respondents according to their mode of practice (A), their status (B), and their area of activity (C).

gists (Figure 1B). The exercise conditions were preferentially centered on dialysis in 36% of cases, on renal transplantation for 5% of cases, and clinical nephrology in 18% of cases (Figure 1C). The remaining 41% considered themselves to have a mixed activity. The answers to the questionnaire came from all over the country, with a fairly homogeneous distribution.

The majority of the responding nephrologists rated themselves as PD competent (62%), contrasting with HHD (34%) (Figure 2A). The vast majority of nephrologists who responded to the questionnaire had access to both home dialysis techniques, with PD being more frequently available than HDD (83% versus 68%) (Figure 2B), but only a minority benefited from adequate initial training (22%), while 72% said they needed additional training to follow dialysis patients at home. For a large majority of nephrologists who participated, both home dialysis techniques are routinely offered to patients during their pre-dialysis orientation course (97% for PD and 80% for the HDD). PD as well as HHD, enjoys

strong confidence from the nephrologists interviewed, as evidenced by the scales of evaluation of the effectiveness (average score of 8.6 / 10 for the DP and 9.1 / 10 for the HDD), security (average score of 9/10 for the RFP and 8.2 / 10 for HDD) and the service provided to patients (average score of 9/10 for the RFP and 8.9 / 10 for HDD) (Figure 3).

The barriers

Among the factors common to both techniques and associated with less development of home dialysis, most nephrologists highlight the lack of awareness of home dialysis by the general public (82%), the lack of recognition of the role of home dialysis nurses (67%), the limited number of structures (63%) and patient refusal of autonomy (58%). The lack of standardization of orientation programs is underlined by 55% of respondents, and 51% consider the difficulty of transferring patients to an empowered structure as problematic (Figure 4).

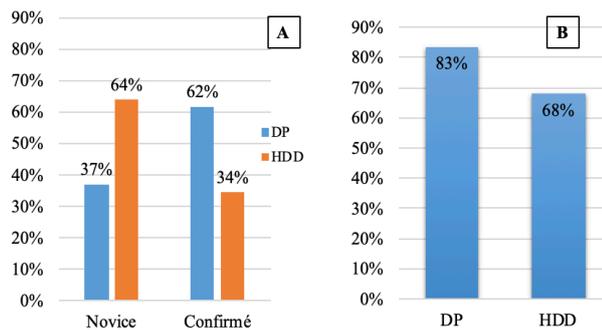


Figure 2: A / Distribution of respondents according to their expertise in home dialysis (self-assessment).
 B / Availability of both home care techniques for nephrologists participating in the questionnaire.

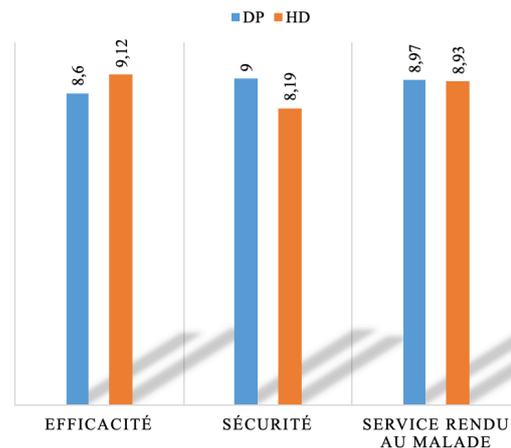


Figure 3: Average confidence level in home techniques, in terms of efficiency, safety and service to the patient.

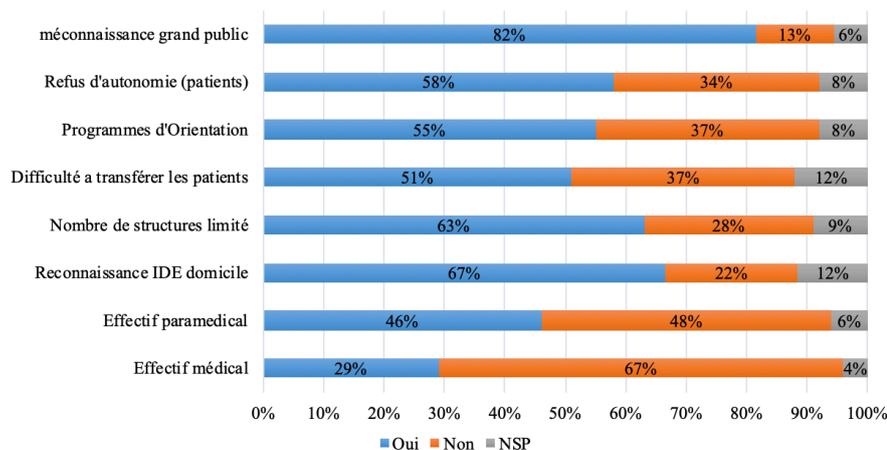


Figure 4: Barriers common to both home techniques

The main obstacles related to the mastery and perception of PD and HHD techniques reported by nephrologists were physician anxiety for out of medical environment treatment (PD = 13%, HHD = 28%), heavy load for carers (DP = 38%, HDD = 40%) and insufficient medical training (DP = 30%, HDD = 43%). The lack of recommendations on which to rely seems to be a specific constraint on HHD (HDHD = 27%, PD = 11%), while the risk of under-dialysis is considered to be an obstacle mainly for PD (PD = 28%, HHD = 10%) (Figure 5).

For 73% of respondents, obstacles to the development of the home dialysis are : the refusal of PD or HHD by the patient and / or his entourage, as well as the lo-

gistical problems of implementation. In HHD, the lack of autonomy (84%) and the fear of puncture (76%) are particularly highlighted. The difficulty of treating these patients treated with HHD or PD in follow-up and rehabilitation care is also problematic for the majority of the nephrologists who responded (PD = 71%, HHD = 52%) (Figure 6).

The management of the dialysis access (catheter or fistula) may also become an obstacle, mainly in the context of PD, regarding the involvement of surgeon who implants the catheter-based (31%), the training of the surgeon (31%), the delay of creation of vascular access (28%) and the difficulties related to anesthesia (27%). Bathing restrictions are also a barrier to PD

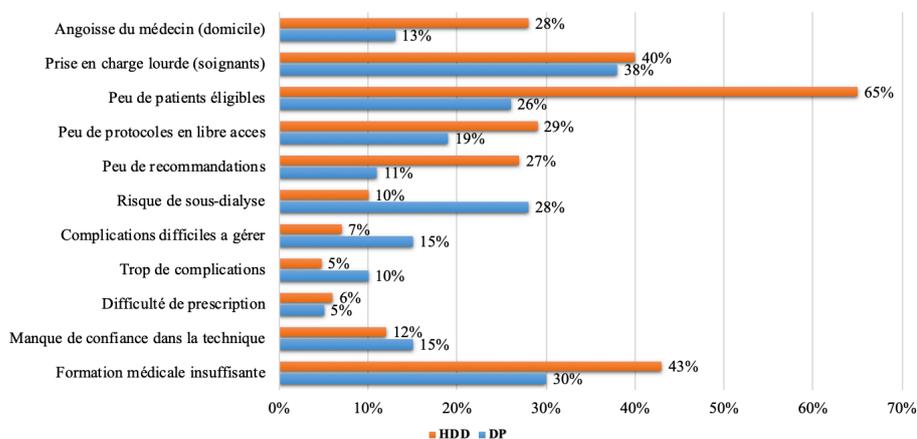


Figure 5: Barriers related to mastering and perception of techniques

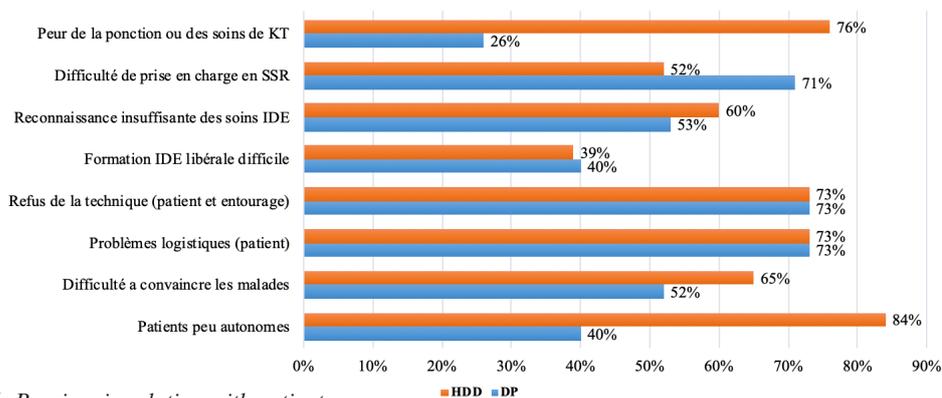


Figure 6: Barriers in relation with patients

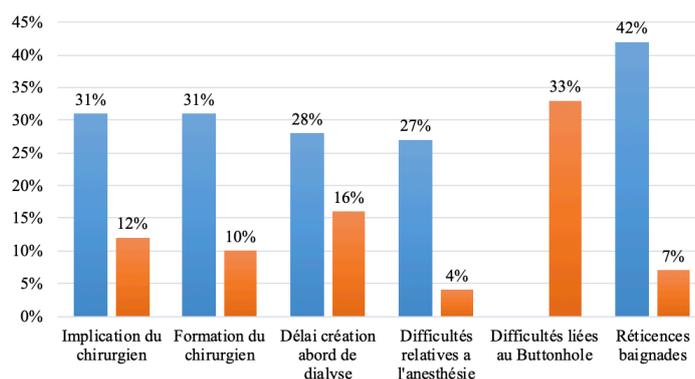


Figure 7: Barriers in relation with fistula of catheter

orientation for 42% of nephrologists surveyed. The use of the «Buttonhole», supposed to facilitate and secure the self-puncture, is however not the ideal solution for the HHD, it is even designated as problematic by 33% of the respondents (Figure 7).

Eventually, with respect to infrastructure and logistics factors, the need to have a third party for each HHD session (in France) is a barrier for 79% of nephrologists. The financial aspect does not seem to be a factor limiting the development of home dialysis, for both the nephrologist and the health care institutions (Figure 8).

The opposition of the results obtained with the doctors practicing or not the dialysis at home brings out differences of perception on certain barriers. For non-practicing nephrologists, the low number of structures, the lack of training and the difficulties related to the management of emergency situations are felt to be much more penalizing (Figure 9).

DISCUSSION

In this work, we sought to provide the opportunity for nephrologists, regardless of their modalities of exercise, to speak about the obstacles encountered to guide patients with renal failure to home dialysis. Indeed, these dialysis methods are underutilized in France, compared to other countries (19) (15 to 21% of prevalence in Denmark, Norway, United Kingdom ...), despite multiple benefits. This first objective is achieved, since all types of structures and modalities of exercise are represented, and the geographical distribution of respondents is fairly homogeneous. There is, however, a probable center-effect, since the accessibility announced by respondents to home-based techniques contrasts sharply with the prevalence of home dialysis patients at the national level. The main limitations of this work are related to the format, namely a free participation survey and disseminated via the internet. On the one hand, this method of dissemination may have led to a selection bias according to the age of respondents, our seniors may sometimes be less comfortable

with the computer tool, which seems corroborated by the median age of 42 years among respondents. On the other hand, free participation has clearly had both a center effect and probably a selection of nephrologists by their affinity for these techniques, according to the information and home orientation figures. Nevertheless, one can imagine that it is precisely these nephrologists who have the best knowledge of the field and the obstacles related to home dialysis orientation. Finally, the questionnaire posed closed questions, on a defined list of potential obstacles, with the risk of ignoring other obstacles.

The barriers reported in this study are numerous, and may vary depending on the technique. One of the objectives of this work is to prioritize the barriers, in order to identify the most problematic in the eyes of nephrologists and allow reflection on relevant answers. It is therefore essential to identify modifiable factors. Thus, we can identify a base of barriers to home dialysis common to both techniques (PD and HHD). These are the lack of media coverage among the general public, the lack of recognition of nurses specializing in these techniques, the limited number of structures, and the difficulties relating to pre-dialysis information. There are also specific barriers to PD, such as the difficulties of management in follow-up and rehabilitation care, the fear of inadequate purification and difficulties related to the dialysis access. Regarding the HHD, we mainly underline the fear of self-puncture and the need for an accompanying person in France, involving significant disponibility and probably responsible for the lack of eligible patients. These barriers are well known to nephrologists, and here we can take stock of the problem they represent. Regarding the fear of self-puncture, it would be interesting to measure its true prevalence in patients. Nephrologists must not censor the HHD proposal to patients by projecting their own fears ; they must implement the necessary conditions to reassure patients because complications related to self-punctures are rare in the literature (24,25). The reported difficulties with the use of the «buttonhole» technique, however, are well described in the literature, including an increased risk of infectious complications, and unchanged mechanical complications (26). It should

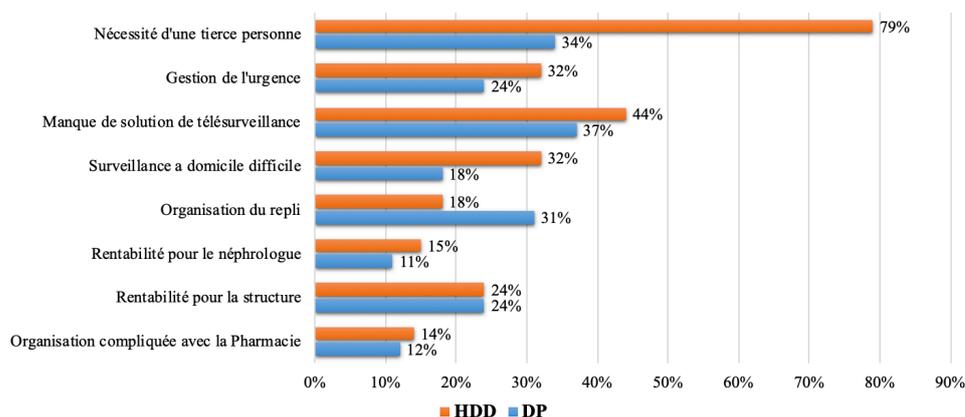


Figure 8: Barriers in relation with institution or organization

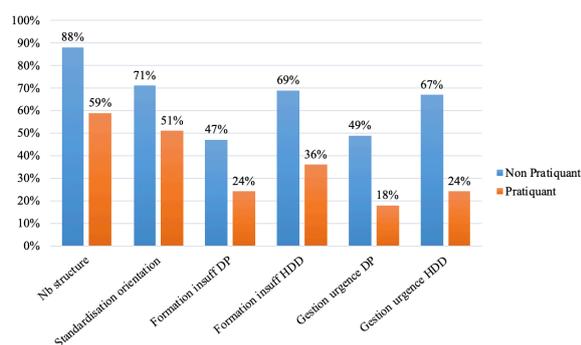


Figure 9: Main differences in perception of barriers between nephrologists with and without home dialysis practice

also be noted that there are specific training needs for nephrologists who do not practice dialysis at home. On the other hand, this survey also brings positive elements, such as the confidence placed by nephrologists in both home techniques in terms of safety and efficiency.

A particular remark must be made on the refusal issued by the patients or their close relative. It is difficult to draw conclusions here, but these answers invite us to wonder about the way in which pre-dialysis information programs are built, the actors of these programs, the people who benefit from them (patients, family ...), and the level of assistance that can be offered to patients (16,27,28). Cooperative work with patient organizations could help to adapt the discourse and develop tools to value and promote home dialysis. Many assets are indeed to be put forward, such as the flexibility of dialysis, the possibility of night dialysis, the reduction or absence of transport time, the reduction of post-dialysis recovery time, and the improvement overall quality of life (29,30). The difficulties of access to follow-up and rehabilitation care, related to the care burden in these structures, are also an obstacle to the continuity of care for these patients, especially when they are treated with peritoneal dialysis. The creation of a sector with these care structures could help to guarantee the continuity of dialysis, by training and raising the awareness of staff and institution administrators. Another way could be the regulatory adaptation to allow the intervention of liberal nurses in follow-up and rehabilitation care, like what was set up for nursing homes in our country. These various points have recently been the subject of concrete proposals to the tutorships, via the white paper of home dialysis proposed by the SFNDT (31).

CONCLUSION

This survey shows that many modifiable obstacles still prevent access to home dialysis, regardless of the technique considered. The information of the general public, but also the early information of the patients and their entourage are crucial elements to favor the choice of

these therapeutic solutions, together with the programs of accompaniment towards the transplantation. The specific skills of nurses involved in home-based dialysis orientation and training programs need to be recognized and valued in order to improve their quality. Regulatory obstacles (obligation of accompanying person, fistula puncture by liberal nurses,..) must also be removed.

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DISCLAIMERS

CJN is a partner of Baxter, Physidia, Theradial and Fresenius. However, they have never intervened in the design of the questionnaire, nor in the writing or the review of this article.

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