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Feedback from two patients treated with daily home hemodialysis with autonomous water treatment

(Retour d'expérience de deux patients traités par Hémodialyse quotidienne à domicile (HDQ) avec traitement d'eau autonome)

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Pour citer :

Summary

Our hospital has long offered peritoneal dialysis (PD) to enable patients to maintain their independence while continuing with their daily activities. Recently, we introduced daily home hemodialysis (DHH) with the NxStage® cyclor and the Pureflow® system, a new system for preparing dialysate from running water, making it easier to manage the necessary equipment. This initiative began in October 2023 with the training of two patients, who then began their treatment at home.

The impact of this change was assessed by interviews based on a quality-of-life evaluation grid, gathering the patients' experiences. We report the testimonies of the first two patients, Mr. J and Mrs. S, who shared their positive experiences, noting an improvement in their fatigue and sleep as well as better integration into their family and social lives. Mrs. S was able to adapt her dialysis sessions to her family's schedule, while Mr. J regained a certain degree of autonomy and improved his physical condition despite some challenges linked to his daily dialysis routine.

These testimonials highlight the improvement in patients' quality of life thanks to home dialysis, particularly in terms of reduced fatigue, improved sleep, and reduced pain. The transition to daily home hemodialysis (DHH) has been well accepted, with patients appreciating the flexibility and adaptability of dialysis to their home environment. This positive experience encourages our department to continue offering DHH as an advantageous alternative for the management of renal failure, emphasizing the importance of quality of life in the choice of dialysis techniques.

Keywords : Daily hemodialysis, home dialysis

Résumé

Notre hôpital propose depuis longtemps la Dialyse Péritonéale (DP) pour permettre aux patients de maintenir leur autonomie tout en poursuivant leurs activités quotidiennes. Récemment, nous avons introduit l'hémodialyse à domicile quotidienne (HDQ) avec le système Pureflow® un nouveau système permettant de préparer le dialysat à partir de l'eau courante, facilitant ainsi la gestion du matériel nécessaire. Cette initiative a débuté en octobre 2023 avec la formation de deux patients, qui ont ensuite commencé leur traitement à domicile.

L'impact de ce changement a été évalué par des entretiens basés sur une grille d'évaluation de qualité de vie, recueillant les expériences vécues par les patients. Nous rapportons les témoignages de ces deux premiers patients, Mr J. et Mme S., ont partagé leurs expériences positives, notant une amélioration de leur fatigue, de leur sommeil, et une meilleure intégration dans leur vie familiale et sociale. Mme S. a pu adapter ses séances de dialyse à son emploi du temps familial, tandis que Mr J. a retrouvé une certaine autonomie et a amélioré sa condition physique, malgré quelques défis liés à sa routine de dialyse quotidienne.

Ces témoignages soulignent l'amélioration de la qualité de vie des patients grâce à la dialyse à domicile, notamment en termes de réduction de la fatigue, d'amélioration du sommeil et de diminution de la douleur. La transition vers l'HDQ a été bien acceptée, les patients appréciant la flexibilité et l'adaptation de la dialyse à leur environnement familial. Cette expérience positive encourage notre service à continuer de proposer l'HDQ comme alternative avantageuse pour la gestion de l'insuffisance rénale, mettant en avant l'importance de la qualité de vie dans le choix des techniques de dialyse.

Mots-clés : Hémodialyse quotidienne, HDQ, dialyse à domicile



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TESTIMONIALS

For many years, our university hospital has been offering peritoneal dialysis (PD), a home-based technique for patients who wish to maintain their autonomy and pursue their social and daily activities.

For several years now, we have been keen to expand our range of home hemodialysis services. The availability of a system for preparing dialysate from running water (the Pureflow® system) (which reduces the storage of equipment often prohibitive for our patients) has enabled us to offer this technique. Our daily home hemodialysis (DHH) activity began in October 2023 with the training of two patients, who have since been installed at home.

We wanted to find out what impact this change in technique had had on our patients by asking them about their experiences and feelings. We listened actively to what they had to say, using a quality-of-life evaluation grid (based on the PROMIS 29 questionnaire validated beforehand by our quality department).

Our 1st patient, Mr. J, is 38 years old. He was treated with PD for 3 years before being transferred to hemodialysis (HD) for clinical reasons. He is single and had a professional reconversion project that had been abandoned since the start of HD. HD was adapted to his lifestyle, which led him to spontaneously accept our proposal to switch to DHH.

Mrs. S is 40 years old and has 3 children, and her husband is only present on weekends. She was forced to quit her job as it was not compatible with her dialysis schedule. She immediately expressed her wish to switch to home hemodialysis, with a view to resuming her professional activity.

Both have been on dialysis for 3 years in a dialysis center, 3 times a week for 4 hours. They have been transferred to DHH for 2 hours and 30 minutes, 6 days a week. They have benefited from 5 weeks' training and puncture themselves their arterio venous fistula using the buttonhole technique. Each of them is waiting for a kidney transplant.

The interviews were conducted 1 month after the patient had been placed in DHH by one of our 3 referent nurses. The interviews were open-ended, but we sought responses in each domain assessed by our grid: physical capacity, emotional state, ability to participate in social roles and activities, sleep disturbance, burden of illness, pain interference, and the patient's satisfaction with their care.

Mr. J and Mrs. S both report feeling "better" and less tired. This notion of fatigue was expressed at the very start of the interviews. They spontaneously report an improvement in their sleep. Mrs. S used to take unrefreshing naps every day and was constantly weary, even on weekends, when her husband was present, which prevented her from taking part in family activities; she felt constantly out of step with the other members of her family. This affected her morale. Home hemodialysis enabled her to regain a place in her family and in her relationship, which greatly improved her morale. Mrs. S also reports having regained a libido and sexual complicity that she had lost through exhaustion.

Both of them quickly got organized at home. Mrs. S prepares her cyclor in the morning while her children are getting ready; then she does her 2.5-hour session once her children are at school. She sometimes dialyzes in the evening while watching television with her family. Her children, a little apprehensive at first, have gotten used to this routine.

Mr. J appreciates having regained his autonomy and freedom but reports that it's "not for free": he puts himself under "pressure" to adhere to this daily discipline, sometimes feeling overwhelmed, but today he has achieved an "efficient routine."

Physically, Mrs. S enjoys looking "better." Mr. J no longer suffers from dyspnea; he walks and no longer feels the "lull between 2 dialyses." He has not yet resumed all of his activities; his AVF prevents him from carrying weight, and a "circulation problem" in his fingers prevents him from playing the guitar again. He likes to puncture his fistula with "buttonhole" access, "which reduces the pain," as "in a natural way, it touches the nerves less." He no longer feels pain at the puncture points during the session and feels less obliged to immobilize.

Mrs. S concludes with the pleasure of the time she has freed up, enabling her to look after her family and resume manual activities. The absence of transport and the distance from the center where she struggled to "find her place among elderly patients" give her renewed energy. Now she can dialyze "at any time, when she wants."

Our first two patients are satisfied with this change of technique; education, puncture, and discharge were all carried out with ease. Dialysis has once again become routine but adapted to a familiar environment. The reduction in fatigue, insomnia, and pain (for Mr. J) has enabled them to regain their personal and social equilibrium.

We look forward to equally positive feedback from our next two patients, who are currently in training. We are convinced that quality of life is an important factor to consider when choosing a renal replacement technique.

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